Dr. Louis Jacques, M.D.
Director, Coverage and Analysis Group
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Re: National Coverage Analysis (NCA) for Beta Amyloid Positron Emission Tomography in Dementia and Neurodegenerative Disease (CAG-00431N)

Dear Dr. Jacques,

The Alzheimer’s Association is the leading voluntary health organization in Alzheimer care, support and research. We appreciate the opportunity to comment on the Center for Medicare & Medicaid Services (CMS) draft determination on coverage of positron emission tomography (PET) amyloid-beta (Aß) imaging for individuals with dementia or neurodegenerative disease. The Association is disappointed with the proposed determination of Coverage with Evidence Development (CED) given the sufficient evidence and corresponding clear, scientific consensus recommendations provided to CMS by the Association and the Society for Nuclear Medicine and Molecular Imaging (SNMMI) regarding appropriate, limited coverage, only in specific populations.

We would like to submit for the record 923 comments from members of the Alzheimer's community from around the country who shared their first-hand experience on the difficulties of receiving an accurate Alzheimer's diagnosis.

If you have any questions, please contact Rachel Conant, Director of Federal Affairs at 202-638-7121 or rconant@alz.org.

Sincerely,

Robert Egge

Vice President, Public Policy

Alzheimer’s Association

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My wife was diagnosed at age 59 with early onset Alzheimer’s dementia. It was through the use of PET scans and MRI as well as cerebral spinal fluid analysis that we knew for sure it was AD and not a viral, fungal, autoimmune or other condition. This knowledge allowed our physicians to prescribe the state of the art medical therapy, allowed me to make the necessary family law plans, allow my wife to receive disability and allow me to qualify for FMLA. Because of her young age the certainty of her diagnosis has made her life safer and more healthy, less of a burden to the healthcare industry. I have also left my full time employment to be her full time, unpaid, care giver, again avoiding burdening Medicare.

I cannot tell you how vital imaging was to our personal situation and how important it is to those who may have the diagnosis. I know for a fact an accurate diagnosis has allowed my family to better plan and manage the disease.

[PHI Redacted]

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I am a 71 year old working female. I am a hearing healthcare provider that sees patients daily for hearing evaluations and hearing aid fittings.

I began to notice that I was having difficulty remembering how to drive to familiar destinations without using my GPS. At work I was having to concentrate harder to remember certain task I do on a daily basis.

I was fortunate to be enrolled in a memory research program. I have had MRI's and PET scans that found beta amyloid in my frontal center and temporal area of the brain.

Not good news, but the early information allows my family and I to prepare better for future care and treatment. This is invaluable information, to know now that we need to be more conservative financially for future healthcare expenses and make plans.

I urge you to reconsider the test called brain amyloid imaging so that other families can start early treatment and be more prepared for what the future holds for their loved one.

[PHI Redacted]

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The availability of brain amyloid imaging has made a huge difference in my mother's life. My mother is 70 years old and had retired within the past year. We began noticing that she seemed to "drift away" and appeared depressed and were concerned about her memory. My siblings and I talked about it but had concerns about bringing up the subject with her. One of my sisters works for LSUHSC and told me they had a few vouchers for Amyvid. That availability prompted us to talk with my mother, who was immediately very relieved, as she was concerned about increasing problems with her memory, and jumped at the chance at a diagnosis. We were able to obtain the amyloid imaging study, which confirmed a probably diagnosis of Alzheimer’s. Although a scary diagnosis, we now felt we had more "control" over what was occurring with my mother. We scheduled an appointment with a primary care physician (her first ever) and started her on Aricept and then added Namenda. She also began walking one mile on a daily basis. The diagnosis and treatment has made a tremendous impact on her quality of life. Even her physician has been amazed. Because my mother has always been fairly high functioning, I don't think these symptoms would have been picked up as easily as they were subtle. We firmly credit the availability of this test with beginning my mother's path to a much higher quality of life than would have been possible without it.

[PHI Redacted]

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My mother was diagnosed by her VA doctor after she was already showing signs of Alzheimer's. Even though it was not as early as we would have wished, she was able to live independently with the aid of medication for another four years. An earlier diagnosis would have enabled her to live independently even longer. That would have conserved some of her savings and kept her off of Medicaid. The cost of the disease is the heart breaking loss over time of my cherished mother, the use of all of her savings for assisted living and several years on Medicaid in a nursing home. Finding a cure is paramount but early detection can relieve the finances of the individual and Medicaid. It is short sighted not to have early detection when the benefits to the individual and the system are so great.

[PHI Redacted]

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My name is **[PHI Redacted]** and I am 47 years old and reside in Scituate, MA and am a lifelong resident of Massachusetts. On June 7, 2013, I was diagnosed with Early Onset Alzheimer's disease which was catastrophic day in my wife's, kids and extended family and friends. Upon that diagnosis, we found out that I was not eligible for new trial drugs give I was too young!

For over 25 years I have been working in the Financial Services industry and contributing significant dollars the health care system. I am also an active participant in volunteering in my community in order to assist families less fortunate that us and we continue to do so.

While working with my neurologist on testing, he recommended that we do a PET Scan as it is required that I have a positive PET to get into new trials...that is crazy, especially since I ended up with a positive (meaning I have amyloid protein in my brain which leads to Alzheimer's and dementia). To top it off, insurance does not yet cover the PET so we had to pay $3,000 out of pocket!

The current number of ALZ diagnoses continues to grow and there are no survivors...if you don't die from it, you die with it.

In 2013, an estimate 450,000 people in the USA will die from ALZ or another dementia, meaning they will die after developing the disease.

As a comparison to other diseases from 2000-2010, breast cancer has decreased (-2%), Prostate cancer (-8%), Heart disease (-16%), Stroke (-23%), HIV (-42%) while ALZ has increased a whopping 68%!

We look to our government officials to spot issues that impact a wide range our communities and there is no cure. Alzheimer's is the only cause of death among the 10 in America without a way to cure it or even slow its progression. Many thanks for your consideration as our elected officials as we need you focus on ALZ to stop this potential epidemic in our future.

[PHI Redacted]

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My husband and I had to travel from Colorado to the Mayo Clinic in MN for a week of testing after having failed to get a diagnosis in Colorado. Our primary care physician did not understand the disease nor did he take the time to truly understand the symptoms. He sent us to a neurologist who sent us to a neurosurgeon who sent us to a neurooncologist and he was even the subject of a review by University of Colorado physicians but for 5 years Bill went untreated and undiagnosed. We struggled with the frustration, depression and anxiety about what was really wrong with him. Please help other families avoid the heartache and additional out of pocket expense of having to travel out of state to find help to identify his disease and get what little treatment could help him. If he had been prescribed treatment medications in the early stages, we may both have managed to avoid those difficult first few years.

We need a change to the current reimbursements for physicians so diagnoses can happen with the doctors who know us best and in the community where we live and within the structure of our existing medical insurance, Medicare or Medicaid. Please!

[PHI Redacted]

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My husband, a retired pharmacist and construction company owner, has early onset Alzheimer's. He did not believe he had Alzheimer's until he had a PET scan which gave a concrete diagnosis. For 6 years the health care professionals just kept giving him more medication and put him on anti-depressants, bi-polar meds, and more. The very first doctor he complained to about his memory said he was just getting older...my husband at this time was 57! Actually what he needed was a diagnosis of AD and people trained in taking care of AD patients to work with us in how to alter our communication skills with each other. AD is not just about losing your keys or growing old; it is much more than that. For my husband, the effects of AD have taken a very intelligent man and choked off his ability to communicate, think orderly, and have a normal perception of physical matter not to mention remembering. Had we had the PET diagnosis up front, we would have been able to prepare for the decline. Now, as he is in the middle stages, I am trying to take a crash course in how to deal with everyday life challenges such as taking the keys away (rather late), finances, physical adjustments in our home, care giver help, and how to better care for him when he gets a normal sickness. Lastly, if we would have had this accurate diagnosis to share with family and friends, we would have had an established support system. Instead, we had people saying all the wrong things and supporting his negative behavior towards me and his children. The diagnosing years, for my husband, were extremely frustrating and that frustration was taken out on me and his children. It is hard for the children and I to heal emotionally from the affects of those years, put a smile on your face and deal with a debilitating disease. We are still walking on egg shells...I would like to prevent someone else from traveling this very rocky road.

[PHI Redacted]

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My husband was diagnosed symptomatically and through neuropsychological testing with possible frontotemporal dementia (FTD). We chose to pay $1500 out of pocket (a reduced fee because we agreed to out of pocket payment) for a PET scan to in order to have a definitive diagnosis. I thought having this scan would speed up receiving SS Disability benefits as well as opening our long term care insurance claim. I was wrong. I still had to submit this documentation twice to SS and three times to our long term care insurer.

What this scan gave to me was courage and perseverance to withstand the onslaught of paperwork to be completed and to respond to the denials all the while adjusting to a new way of thinking about life, personal responsibilities and the future.

I had the test results in hand. The radiologist said it was FTD; the neurologist concurred. I'm not sure if I could have mentally and emotionally been able to do what I needed to do without the confidence a clear diagnosis provided.

[PHI Redacted]

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My wife was diagnosed with Alzheimer's thirteen years ago, in the most early stages. We support the earliest diagnosis for several reasons. It allows time for the one with the disease to be involved in planning for the future, to have her say, to be a part of the process. It allows for her family and friends to become acclimated to the situation and learn how to deal without. Knowing is more comforting than not knowing for both the patient and the caregiver, family, and friends.

[PHI Redacted]

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My wife **[PHI Redacted]** was diagnosed with Alzheimer's in July of 2010. This was after living with obvious decline and in her cognitive capacities over several years. We had two very different diagnostic sequences to finally get the proper findings and to be able to respond to it. The first sequence was highly disappointing because the physician, while having had an MRI done and read by a neurologist, had a listing of the cognitive issues she was dealing with, and a neuro-psych exam done, did not really provide a conclusive diagnosis and suggested she take some anti-depressants and see how things went. We feel, in hindsight that this was a result of the lack of knowledge of diseases of cognitive impairment and diagnosing Alzheimer's and other related dementias.

Being unsatisfied with that outcome, we consulted a geriatric specialist, who has been the physician for my mother during the last 8 months of her life, and was familiar with dementia. After looking the MRI and reading the neuro-psych exam results, she suggested that there may well be consideration of Alzheimer's and recommended a neurologist. The neurologist, upon reviewing the material, immediately set up an appointment with the Alzheimer's Imaging Center at the Neurology Clinic at the University of Utah.

At the Center, we were able to receive a comprehensive, sequential assessment of Beverly's condition, culminating in a PET scan that resulted in the diagnosis of having Alzheimer's. What was important about this was that with the diagnosis, a set of events occurred that was important to adjusting to the disease and to move forward with our lives. Not only did the physician go over a myriad of issues on addressing the disease, what medications were available and recommended, and how one could live their lives, but we were given appointments with a Health Care Educator and a Health Care Social Worker. It was a comprehensive package that dealt with the medical issues, knowledge of the disease and how to respond to it, how family could adjust to the new conditions and get necessary information, and how to plan for the future both emotionally, physically, and financially. We truly felt we were not alone in dealing with the disease and continue today to enjoy the services of the Center. We feel quite fortunate in having this form of support base from our medical provider.

We are quite aware that not everyone receiving a diagnosis of Alzheimer's or related dementia has this level of care or assistance. And in looking back over the several years before our diagnostic process began, if we and our physician at the time were more aware of the symptoms of Alzheimer’s the diagnostic process might have been completed several years earlier. While an earlier diagnosis would not necessarily change the trajectory of Beverly's disease, it would have emotionally, physically and psychologically assisted our family in addressing the cognitive decline we were seeing and experiencing in our family member and allowed Beverly to know what was happening to her and how to begin to address it.

It seems to us that several things are evident. First, that physician education and knowledge of issues surround cognitive impairment and the possibility of dementia are an essential part of any annual check-up or wellness visit. This needs to be an essential part of any preventative health care program. Second, that testing and assessment options are essential to diagnosis of the disease this includes MRI's, neuro-psych exams, and PET scans. Without comprehensive and complete testing patients are not receiving the medical assessment they deserve and need. And lastly, the educational component of how to live with this disease and how to plan for the future with it is an essential part of the diagnostic process. Individuals cannot be left to fend for themselves.

In summation, while there is yet to be a cure for Alzheimer’s, there is no reason for not having comprehensive assessment and support services available for individuals and their families. If we cannot cure it, we can at least make living with this deadly disease a manageable process.

[PHI Redacted]

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Eight months agoI was diagnosed with Alzheimer's disease. I had been concerned that I sometimes could not recall words, had problems with spatial relationships, math, and depression. Fortunately, I expressed my concerns to my children and they were able to get me into a trial/research study of Amyvid, which determined my diagnosis.

It was a relief for me to know what was happening to me at an early stage in the disease, and a blessing to be able to start treatment (Namenda and Donepezil) to forestall its progression. I'm doing very well and am still able to do all of my normal activities, including walking a mile most days, cooking, housework, shopping, and most of all, spending time with my children and grandchildren.

I have benefited first hand from the Amyvid study and hope, anyone with this same need would have the same opportunity as was given me!

[PHI Redacted]

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Early diagnosis is vital in providing and planning for the future of individuals suffering from dementia related illnesses most likely from Alzheimer’s disease. Families are able to financially plan, build a medical team, seek legal counsel, and build the support that is needed for an unpredictably long journey for everyone involved with the care and well-being of the person diagnosed. Please support the need for funding early detection and early interventions. Millions of individuals are being mistreated, neglected, and forgotten due to a lack of understanding of the plight of dementia. Education is key for all walks of life to create a compassionate awareness in helping others through their journey.

Thank you for your support in addressing this growing epidemic.

Sincerely,

Mrs. Debra Mittelbach

[PHI Redacted]

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I strongly protest the draft recommendation of the CMS concerning brain amyloid imaging. To not include this as a tool covered by Medicare when the scientific community is showing a strong consensus that this test is valuable and justified is simply wrong and makes one wonder just what does it take to get some support and exactly what are the motivations for these decisions?

My father died of Alzheimer’s 2 years ago. It was a gut-wrenching process especially early on as we tried to get a clear diagnosis of what was happening. Had he been able to get an earlier diagnosis our care for him would have been better and less stressful for everyone concerned.

The CMS and its processes MUST do a better job of keeping pace with the speed of innovation in Alzheimer’s research and treatment. Those of us who have been and will be so damaged by this horrible disease are depending on you to see that it does!

[PHI Redacted]

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My father has had Alzheimer’s for 5 years but only was officially diagnosed 2 years ago. He was incorrectly diagnosed with vascular dementia originally and lost valuable time to slow down the progress of Alzheimer’s if he had been taking different medication. Today, my father is not able to keep up with normal conversation and gets confused/lost in thought easily even for the simplest of topics. I wonder how life would be different today if he was diagnosed accurately at first.

[PHI Redacted]

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My mother's dementia was not diagnosed as early as it could have been and we were delayed in planning and decision-making as a result. Please give patients and their families every possible tool in their fight against this terrible disease.

[PHI Redacted]

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I was distressed to see that Centers for Medicare and Medicaid Services (CMS) made a decision against coverage for brain amyloid imaging. While this test may not change outcomes, it gives people important information to be able to plan their futures.

My mother has Alzheimer’s. There have been NO other family members in my mother's large family who have had Alzheimer’s. Is this a genetic mutation that occurred after I was born? Did the mutation occur before I was born? Could I or my siblings inherit it?

I am an active, working 64 year old who intends to continue working for at least another 4 years, maybe more. I need to know if minor memory things such as not being able to remember a word, forgetting where I put something are just normal aging or are early signs of Alzheimer’s. I don't have a husband to take care of me should this be in my future and I need as early a diagnosis as possible. At some point I will have to stop working and will necessarily be relying upon Medicare and a Medicare supplement policy.

In addition, early diagnosis allows the ongoing medical study of people as they progress and the effectiveness of current and future medical and other interventions. At the moment there are medications that can slow the progression, but if people don't have a diagnosis, they won't be taking those medications. While current medications may not change the ultimate outcome, they slow the pace, allow people to plan, reduce the incredible stress on families.

Please reconsider this decision.

[PHI Redacted]

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In 1998 my mom had a tentative diagnosis of dementia, possibly Alzheimer after CT scans and X-Rays showed no other causes for her bizarre behavior. There is no family history of dementia and/or Alzheimer’s. We next visited a neurologist after begging the internal medicine physician for a referral as the neurologists would not schedule an appointment without this referral. As the years progressed, mom became more and more mentally and physically debilitated so as soon a new drug would hit the market, we were first in line at the neurologist's for a prescription, if possible. From the beginning, I begged the neurologist for a PET scan but I could never convince him as we were having to justify why mom required Namenda and Aricept for insurance coverage purposes. Several times I would pay for the drugs until we could get her new prescription authorized. Neurologist said that PET scan results could cause mom's insurance to stop coverage of prescriptions. This scared me to death as the Namenda was a life saver, and all the drugs were extremely expensive without insurance. I continued requesting the PET scan testing until mom became so debilitated that testing was no longer a physical possibility for her.

Today mom lives in a nursing home, totally bed fast, unable to feed herself, unable to speak, and no longer on any medications after enduring three visits to geriatric psyche units at three different locations. Physical mom is a vegetable; however her internal organs are in excellent shape. She was recently removed from her antidepressant due to the extended period of her taking the prescription. I was upset; however she is now on Medicaid which has some type of requirement for this. I was adamant that once the antidepressant was discontinued she was not to be placed back on the drug. It took too many years to get her off the drugs the geriatric psych units had placed her on while knowing that these drugs placed her at greater risk of death if she had Alzheimer’s. May be that was the rationale, i.e. an early death.

Mom did have the foresight to take care of future medical and financial decisions along with estate planning when she first heard of a possible Alzheimer diagnosis. This planning in 1998 armed me with a durable power of attorney and a living will which I continue to utilize when continually asked to place her on a feeding tube, or take some other medical path that will only scare her. I am frustrated with the Hospice issue, as she has been placed on Hospice at my request, then removed without my request because she is getting "better". Do people with Alzheimer's get better? And recently I was approached about placing her back on Hospice due to her decline which I did after ignoring my feelings that I was once again giving up on her. [I never saw the new and improved mom.]

All of this to say, I still do not know if my mom has Alzheimer's. I wonder each day if I did/do all that I could have done / can do as we look back over 15.5 years. I have requested an autopsy when my mom passes, maybe then I will have peace with my actions. Of course I have had to promise to pay the autopsy costs. Please allow the PET scans to be part of the treatment diagnosis.

[PHI Redacted]

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If we had had this test when my mother became afflicted, we might not have had to spend 15 years caring for her and watching her dwindle away...to death.

Don't dally with something as important as this test!

[PHI Redacted]

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My grandfather, [PHI Redacted], had been the publisher for the newspaper in Attleboro, Massachusetts. He developed Alzheimer's - before the disease was even thusly named - and he went downhill mentally over the course of several years. He became unaware of who anyone around him was, nor was he aware of any events outside of his immediate vicinity. He certainly could no longer follow current events.

I lived with this man - in his house - while I was growing up in the late 1960's. I saw firsthand what damage this disease can do, and also the undue burden which it puts upon the family members. This disease and the conquest of it should definitely be a national priority!

[PHI Redacted]

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Early diagnosis and help is essential to the patient as well as to the caregivers. I had the privilege of staying with my mother for a week while my father was in the hospital. Due to my hearing problem I decided it would be best if I slept with her. She woke me up 4 times every night because she needed to use the bathroom. I would tell her where it was and she would go. On one trip she did not use the toilet, she used the waste basket. I was in my early 50's, Dad was 80. He said she usually gets him up 3 to 4 times every night. I was exhausted after one week; I don't know how he did it all the time. He had motion detectors installed at the front and back doors as well as on the stairs. She managed to go down stairs to the bathroom, and back again, and he slept through the detector going off twice. He knew she was up because she left all the lights on. We finally convinced Dad that a home was the best place for Mom. After she went in the home, Dad said he slept constantly for 2 - 3 weeks.

Help is truly needed to help diagnosis the disease and find a cure. If you have never had a loved one with Alzheimer's you cannot fully understand how it affects everyone involved.

[PHI Redacted]

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I am the father and primary caregiver for my 54 year old Down syndrome son who has been diagnosed with Early Alzheimer's. The initial diagnosis was from the family doctor based on input from me noticing a difference in my son's behavior. He would ask me the same question more than once. This happened many times before taking him to the doctor. The doctor said he thought it was Early Alzheimer's and put him on a 24 hour Exelon patch. The patch was increased to 9.5mg sometime later and I began to get involved with the Alzheimer's association locally, learning more about this illness. I decided another opinion was needed and once the family doctor agreed and approved it, an MRI was done at the Neurology Lab. It concluded he did have Early Alzheimer's, and we then saw the Neurology doctor who added Namenda 10mg in addition to the Exelon Patch. The Neurology doctor now sees my son every few months for a checkup. It has been very difficult to obtain information about someone with Down syndrome and Alzheimer's together to assist me in the caregiver process. My son is still working - however, he has been transferred from a multiple task job to a single task job, which is all he candle handle successfully. I believe there is a much needed improvement in diagnosis and treatment of someone who is Down syndrome with Early Alzheimer's, sometimes I think we are the very first case?

[PHI Redacted]

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Fluorodeoxy glucose is already approved as an imaging test for Alzheimer's disease, however it has very low sensitivity and specificity. Scientists have developed a new test, based on amyloid imaging that is far more sensitive and can DEFINITIVELY rule out Alzheimer's disease.

CMS recently disallowed reimbursement for the amyloid imaging test. This is neither sensible nor cost effective. CMS should give doctors the choice to choose EITHER fluorodexy glucose or amyloid imaging. Disallowing this choice does a tremendous disservice to patients with Alzheimer’s disease, as well as to those who receive inaccurate diagnoses of Alzheimer’s disease.

Sincerely,

Dr. Benjamin Wolozin

[PHI Redacted]

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In my experience as a clinical social worker it can be life changing for individuals with dementia and their family caregivers to determine exactly what kind of dementia they have- be it Alzheimer’s or another form. According to the Alzheimer’s Association's task force, Amyloid Imaging is recommended for certain situations. I urge you to support the funding of this testing when it can make a critical difference in people's lives.

Sincerely,

Ms. Mary Stehle

[PHI Redacted]

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My mother at 67 has early onset Alzheimer’s in stage 2. It took a couple years to be able to get a definitive diagnosis of what we knew to be the case. She was even lost a couple of years ago and we were not able to get a Silver Alert issued because the lack of a definitive diagnosis. Though this may not help her at this point I would not like to see anyone go through the difficulty we had in this process.

[PHI Redacted]

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Early diagnosis is a very important step.

Sincerely,

Ms. Camilla Farrell

[PHI Redacted]

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I believe that an early and accurate Alzheimer’s diagnosis is very important.

I was the sole caregiver for my mother who suffered from Alzheimer’s. Her mother (my maternal grandmother) also suffered from this disease.

When my mother first started showings of Alzheimer’s, I sought advice from the Alzheimer’s Association. The Association representative suggested that I immediately make an appointment with a neurologist who specialized in the treatment of Alzheimer’s. After administering a short test, the neurologist diagnosed her and set up a plan of action for her treatment and care.

By having an early and accurate diagnosis, I was able to take control of the situation in the early stages and plan accordingly.

[PHI Redacted]

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Early diagnosis is crucial! We cannot allow cuts in early detection to happen. Alzheimer’s is not going anywhere. It's the 6th leading cause of death and the only one without a cure, prevention or the ability to slow it down!

Sincerely,

Mrs. Jamie Guay

[PHI Redacted]

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I am participating in the Minnesota Memory Project in St. Paul, MN. Since my parents and two older siblings had dementia when they died, I consider myself at risk. If the Memory Project shows that my cognition is declining, I would certainly want any appropriate diagnostic test to be covered by Medicare.

Thank you for your attention to this.

[PHI Redacted]

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My father died from dementia related diseases.

[PHI Redacted]

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My wife was diagnosed right before her 53rd birthday, that was four years ago. No one should have to go through this, please find a cure.

[PHI Redacted]

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Having experienced the untimely beginning of Alzheimer’s in my mother’s case at age 50. It was never truly diagnosed and was called something else. Yet she lived for 17 years diminished and she had all the effects of classical Alzheimer’s disease. I hope you will see how important allowing Medicare to cover diagnosis testing.

[PHI Redacted]

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Please make early diagnosis of Alzheimer’s disease easier, not harder. An early diagnosis can improve treatment and care for the victim of the disease and improve the ability of the family to cope.

Sincerely,

Ms. Sarah Propst

[PHI Redacted]

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Both my maternal grandmother and my mother had Alzheimer’s and it would have been handled differently had we known their early "forgetfulness" was the precursor for Early Onset Alzheimer’s. My own sons and husband deserve to know what to expect and make plans if/when I fall into the same pattern as my mother and grandmother. Please allow the pretesting diagnosis like Cancer and Heart Disease have in place.

[PHI Redacted]

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My mother just passed away at age 76 from Alzheimer’s disease. She had told me for over 20 years what she wanted or didn't want when she died but we never imagined this disease and how it takes over your brain so quickly after being treated for depression for years then finally getting the diagnosis of dementia. After that there was no way of getting any answers to questions about what or how she wanted to live her life after she could no longer do simple things like dial a phone or get a drink. This is only one a very small example from a daughter who took care of her mother until her last days when she was laying on her side, nothing but skin on bone while all her bodily fluids drained out of mouth and nose. Wait until someone close to you gets the diagnoses of dementia (what they have to call Alzheimer’s disease in the beginning) has to go through it. Then you'll understand completely.

[PHI Redacted]

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My mother died from Alzheimer’s. I have as well as my wife has noticed a significant loss of memory function. I have difficult remembering phone numbers and where I have laid items in the house. Early diagnosis as well as appropriate meds to defeat or slow down this disease is critical to many of us like myself. Let's move forward.

[PHI Redacted]

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My husband was diagnosed early with this test .Three and a half years later with proper medication from the beginning he is still at home and functioning with minor help.

[PHI Redacted]

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My now 63 year old husband was diagnosed with early onset Alzheimer's Disease at age 55 via a PET scan after undergoing numerous MRIs, CT scans, EEGs, and numerous other tests for three years. He had to leave his job of 24 years and go on disability. While I still worked in RI Superior Court for another few years, he was still driving. When I couldn't reach him on his cell phone or our home phone, I decided I also needed to retire early. We lived in a wooded area with no street lights and he would suddenly disappear if I left the room momentarily. Thankfully I had registered him with the local police department. His inability to speak was one of the first signs. We thought it was anxiety, stress, depression. He was much too young to have AD! Even the neurologist couldn't pinpoint the problem. Finally he sent him to Lahey Clinic and they sent him to Mass. General Hospital where the PET scan was done. The diagnosis allowed us to prepare as best we could emotionally and financially for our future. Our only child was still in high school at the time. She is heartbroken about her dad. He will never walk her down the aisle!

This disease has been the most devastating, all-consuming earth-shattering experience of our lives. He is now in a Veterans Nursing Home and rapidly declining. I urge you to vote for Medicare, Medicaid coverage of ALL diagnostic tools available for AD. Please don't allow people to experience the gut-wrenching stress of not knowing what's wrong because they can't afford a test!!!

[PHI Redacted]

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This is so depressing watching my mom with this disease. Please do anything you can to help with its cure and/or diagnosis or prevention.

[PHI Redacted]

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I urge you to make available this important and valuable diagnostic imaging tool and have Medicare cover it to improve the quality of care for persons with dementia. This tool can help dementia experts understand whether a decline in memory is due to Alzheimer’s or some other perhaps preventable cause.

Sincerely,

Ms. Colleen Reilly

[PHI Redacted]

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My dad suffered from this for so long before passing away from it after about 8 years. It was such a sad thing to watch him progress further with this disease, until he was nothing more than a vegetative human being who didn't respond too much. He ended up being confined to his bed for about the last year of his life hardly ever opening his eyes, and when he did, there was no "life" in them.

My dad was a man who was a great finish carpenter and could fix anything. His whole identity was with being able to provide for his family and indeed fix anything for us. It was sad to believe the man that I knew as Dad was no longer there when we would visit. He just sat staring ahead for many years with not much communication.

He knew the hell he was condemned to live because he had a cousin die of the same thing. He was angry and rightfully so. Our government throws so much money around to the lobbyists of different companies, please throw some of this money to the doctors and researchers who can actually do some good for the millions of people who end up being diagnosed with this disease such as getting an early and accurate diagnosis!

I would like to know that in my lifetime, we have come up with a cure, so as we age, we don't end up in the same boat as my dad and countless others!

Thank you!

[PHI Redacted]

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I have seen my grandmother and mother go through and die from this tragic disease. It would be irresponsible not to approve of early diagnosis tests to help those who develop the disease receive better, early care and have a better quality of life. The alternative can be horrible.

[PHI Redacted]

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My dad was diagnosed with dementia and his spiraling downward proceeded rather rapidly. This downward spiral, which was biologically inevitable, was exacerbated and aggravated by an exponential downward spiral that was preventable- the abysmal care that he received due to an absence of a public facility that afforded dignity to one who had lost all dignity.

My dad worked for 57 years, with his weekly schedule vacillating between 60-70 hours. During this vocational period, he never lamented his fate and his faith in what is right and wrong never wavered. During the nursing home care at the tail -end of his life, he was warehoused like an inanimate commodity and treated like a feral animal.

The repercussions of his care reverberate during my waking hours and his pained face haunt and dominate my nighttime meanderings. Sleep and I have become enemies instead of friends and Dad's pleading visage still shares space with me every evening as I try, once again, to erase images that are not eradicable.

May my eviscerating experience not be the harbinger of recurring and relentless nightmares for those whose family members are on the cusp of dementia. Our humanity, and theirs, hangs, like a Sword of Damocles, in the balance.

[PHI Redacted]

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In our case I believe it was caused by the debilitating effects of her sleep apnea...Once we realize our mother was suffering from this (she had been widowed and slept a lone for 30yrs.) We began noticing as we stayed with her. I begged her doctor for many years to treat her for this. Their plan was a take home kit. Unless you are really able to hook up all the wires, you really should be in a clinical setting. Again after going to heads with her doctors that would not listen and also the Neuro department in Roseville, after it was too late they finally agreed to schedule her for an overnight sleep study lab. The tech asked why we waiting so long! I was floored. I told her I had been begging for that past 3 yrs. During this period the news media and medical journals were beginning to connect sleep apnea as one of the causes of dementia. Way too late for Betty so we hope and pray that others get better care and acknowledgement. Yes in some cases preventable or at least treatable...

[PHI Redacted]

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My personal experience with Alzheimer's dementia with my wife being diagnosed with the disease is she fell and broke her hip. After surgery and approx. 7-10 days later, the doctor from the hospital called at 7 AM to tell me my wife crawled out of bed to the nurses' station to look for her purse, he asked is this normal behavior for her, of course I said absolutely not, so he recommended we have a neurologist examine her. After his exam he concluded a problem exists so he recommended an MRI. The MRI showed some determined there is plaque build-up on her brain causing her this memory problem, which in turn she began taking Aricept. This all accrued in 1996. By 1998 her neurologist changed her medication from Aricept to Namenda, she is still on this med. Month by month she became worse as far as memory and anxiety goes. In 2011 she again was hospitalized with pneumonia and also had several T.I.A.'s. She rapidly went downhill to the point of not being able to feed herself, speak coherently nor dress herself . Our family doctor and her neurologist suggested I would not be able to care for at home, (which I had been doing for approx. the past 5 yrs.), no longer. She is now in a nursing care facility since. Tough decision to make !!!

[PHI Redacted]

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We have been battling Alzheimer's disease with my dear mother, [PHI Redacted], for the last 12 years. At first, she just kept saying her memory was getting bad, but we saw that she was still competent to live her life. On subsequent visits, however, we gradually noticed that she was really slipping, and within a two-year period, we realized we had to start medication and get her into safe housing immediately.

Mom was on Aricept for about 8 years. We added Namenda to the mix when it was new (around 2005) and that seemed to help her maintain a "status quo"" for a couple of years.

After a number of falls, we were forced to place her in nursing care, where the doctor suggested that Alzheimer's meds were not needed or helpful past a couple years' use. At the time, it was hard for me to imagine Mom getting any worse, but now, 4 years later, although still alive, she can no longer speak intelligibly, and cannot walk at all. She has to be fed her special pureed diet, sits in her soft recliner chair and does not seem to understand anything that is said to her.

It may have been a coincidence, but Mom stopped calling me by name right after we stopped the Alzheimer's meds.

Although I am adopted, and don't have an immediate fear of this disease, I know that Alzheimer's may overtake my generation in a few years time, and that the burden placed on our children will be enormous, as it has been for me.

When my mother received an initial diagnosis of "Minimal Brain Shrinkage", I asked her doctor if that meant she had Alzheimer's and he said "Oh, probably, but who knows"?!! That hapless diagnosis was made in 2001...have we come a long way since then?

12 years and counting,

[PHI Redacted]

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If Alzheimer's can be diagnosed earlier, we could save so many people from this heartbreaking disease.

Sincerely,

Mrs. Sarah Podrasky

[PHI Redacted]

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My father and mother-in-law both died from Alzheimer's. It's a terrible, debilitating disease, leaving the patient without cognition and finally having to be attended to for every need. Please help.

We all face the possibility of someone in our lives having Alzheimer's. An early, accurate diagnosis is one of our only hopes.

[PHI Redacted]

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C'mon! How much more evidence is needed to make it clear that Alzheimer’s is real and that it impacts families and their resources to the extreme. Anyone can get it . . . including you and yours. Wouldn't you want the best care for your friends and family (and yourself) without having to hit the poverty level, or already being in poverty - or close to it - and being able to get the care that is needed?

Sincerely,

Ms. Carol Pendleton

[PHI Redacted]

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Alzheimer’s runs in my family. With the baby boomer generation on the precipice of getting this disease, showing the first signs of it, this testing is so important. It will save money and lives for our country, We must have it!

Sincerely,

Mrs. Valerie Overstreet

[PHI Redacted]

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Alzheimer’s needs to be stopped!! Too many people are being affected by this terrible disease!?!

Sincerely,

Ms. Erin Flatley

[PHI Redacted]

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My wife died with Alzheimer’s disease at the age of 69. She had it for five years. Maybe with proper testing and whatever else is out there she might've lived longer. If you ever experience one on one like I did you would not think of cuts. You would think of improving the program and putting as much money as possible into it. It is the most sickening disease that I've ever experienced.

[PHI Redacted]

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We need early diagnosis. This would prevent things like coming home and finding my mother had turned on all the gas pilot lights, at an attempt to cook. Upon my arrival, the house was full of natural gas. Had I had any indication of what was happening to her I could have taken steps to child proof the house. Just one of my experiences with my beloved mother. Had we know earlier we could have prevented her from unintentionally trying to hurt herself, myself or our neighbors. If you haven't had a relative with Alzheimer’s consider yourself very lucky. This is the most cruel and heart stabbing disease and the caregiver and Alzheimer’s patient go through challenges that no one should have to endeavor. It’s so painful to see a loved one in pain. Please I urge all government agencies to give us all a fighting chance with Early Diagnosis. PLEASE

[PHI Redacted]

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In addition to providing confirmation of an Alzheimer’s diagnosis, amyloid imaging allows for earlier detection of Alzheimer’s disease. While effective drug treatments preventing the progression of AD may not yet exist, early diagnosis gives both the family and the individual time to prepare and adjust to their upcoming challenges. Allowing time to establish proper family and caregiver support systems in advance of the disease may help to improve quality of life for the individual and their family.

Sincerely,

Ms. Michelle Farrell

[PHI Redacted]

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By receiving an early and accurate diagnosis for my mother, we were able to get Hospice intervention and mom was able to get on the medication immediately. It is very important to the family, who usually end up to be the caregivers, to receive an accurate and early diagnosis so they can receive this support that is so greatly needed and to prepare the family emotionally to know what the diagnosis is as soon as possible.

[PHI Redacted]

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I am the fourth member of my extended family to be formally diagnosed with Alzheimer’s disease, my mother had it. Her brother had it. His son had it. And now, I have it.

Because I was aware of the possibility that I might have inherited the disease, I was able to get a diagnosis and enter a treatment regimen at a very early stage in the progress of the disease.

Because I was reasonably well off, I was able to obtain excellent medical advice and treatment. As a result my disease has progressed more slowly than the average patient.

These "lucky" circumstances should not be restricted to a minority of the people suffering from the disease. The opportunities that I had should be available to everyone.

[PHI Redacted]

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This is important.

Sincerely,

Ms. Brehan Fitzgerald

[PHI Redacted]

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My wife now age 65 has early onset Alzheimer’s . Her neurologist ordered an MRI and PET/CT scan. She had the MRI which doesn't show much info, but Medicare did not pre-approve the PET/CT scan which is needed because the secondary insurance Emblem health GHI which only has to pay 20% of Medicare would not approve it which doesn't make sense.

[PHI Redacted]

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This is very important.

Sincerely,

Mrs. Felicitas Blackburn

[PHI Redacted]

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Please do not eliminate any test that might delineate differences between Alzheimer's and possible diagnoses. Without funding for such tests, patients may unnecessarily suffer from preventable conditions which could be identified. It seems likely that rather than saving taxpayer money, poor diagnosis could lead to more expensive care of more serious conditions. I urge you to retain accurate diagnostic tests.

Sincerely,

Ms. Marilyn Hackett

[PHI Redacted]

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My wife has early Alzheimer's disease and would have been better aided had she been sooner diagnosed.

[PHI Redacted]

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Please make early detection and accurate Alzheimer's diagnosis a priority by approving healthcare providers the ability to perform needed tests and funding to pay for the test through Medicare.

My precious father, [PHI Redacted], of Spartanburg, SC, died in 2008 at 75 years old, after a 5 year battle with Alzheimer's. He left behind a wife, 7 children and 10 grandchildren - 2 of which he never had the opportunity to meet.

I fear that one day another relative will be diagnosed with this terrible disease and the process will start all over again. I am surrounded by friends who have parents with the disease and I empathize because I know firsthand the toll it takes on the family.

Please take every measure possible to fund research, early detection, diagnosis, and treatment to help people live a long and productive/quality life - for the benefit of the entire family and the community as a whole. This isn't a singular disease - it doesn't belong just to the person diagnosed - it is the disease of the entire community. Alzheimer’s has a ripple effect on those surrounding the person diagnosed and the earlier it is diagnosed the better for everyone! Please make wise choices in Washington for us all. I pray you and yours aren't touched by this terrible disease!

[PHI Redacted]

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My husband, age 82, has dementia but it has not been determined what type or types he has as he seems to have symptoms which are conflicting as to the type of dementia. Without additional imaging being covered by Medicare we may never know the type and may be wasting money on medications which will not help his condition

[PHI Redacted]

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An early diagnosis can provide direction for the patient and the family. It will save money in the long run and provide the best possible care for the person with Alzheimer’s diagnosis. It will also prevent accidents that can be life-threatening to not only the patient, but also to those around them...less chance of driving impaired, leaving the home unattended / wandering at night, etc.

Sincerely,

Mrs. Melissa Fairbanks

[PHI Redacted]

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I personally believe that if my mother had been diagnosed much earlier that the current drugs available on the market would have extended her life. Had we known early on, we could have helped her enjoy more of her life before succumbing to this HORRIBLE disease.

[PHI Redacted]

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Please vote to increase government support for research into our understanding of the causes and potential treatments for Alzheimer’s disease.

Sincerely,

Mr. Jay Atkinson

[PHI Redacted]

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My two aunts have passed away from Alzheimer’s. It is a disease that sounds gentle but in reality is horribly brutal leaving those with it feeling completely confused, scared, anxious and depressed. The caretakers don't fare much better.

My father is now a victim of the disease and I see him changing every day. We need to do everything we can to figure out this destructive disease.

The importance of an early and accurate Alzheimer’s diagnosis is the first step to better understanding and treating the disease. Please allow all the tests necessary to make the treatment of Alzheimer’s as good as can be.

[PHI Redacted]

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When you have to treat your parent as a child, the emotions are extremely difficult. If you have to "guess" at diagnoses, it makes it even that more difficult. This is an important disease to cure to give us back our parents and their dignity.

[PHI Redacted]

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My sister was showing signs of memory loss but doctors did not properly diagnose her and actually claimed she did NOT have Alzheimer's disease, that was 5 years ago. As a result she was asked to resign her job and went on disability. This resulted in no healthcare coverage for two years due to the high cost of COBRA. Once she was on Medicare and able to be seen at Cleveland Clinic was she diagnosed with Alzheimer's, the doctor seemed shocked that we had never been given that diagnosis before. By that time she was totally unable to care for herself and another problem arose, not being able to afford proper care for her. Today in only 2 years since the correct diagnosis Beverly is in a nursing home and does not recognize any of us. She is just 65 years old.

[PHI Redacted]

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My husband, Richard, started displaying changes in his personality in 2007. It was almost as if had two different personalities. He would get angry and his eyes would look different, full of rage. Constant yelling and slamming doors if he didn't get his way. I thought he had bi polar disorder and psychiatrists really didn't know either. They treated him for bi polar. His systems slowly became worse. He became withdrawn, disoriented and consumed with picking up trash from the road, sorting tools, collecting worthless junk, hoarding beyond belief. He didn't want to take baths and seldom slept. I noticed his gait become shuffling and his posture stooped. Gradually, he lost his ability to remember language (except profanity) and you had to guess what he was trying to tell you. He was frustrated and knew something was different. He would drive and get lost on dirt roads in the middle of nowhere. He started digging a hole for oil in the backyard and was going to build a bridge across our pond. This list goes on and on of the bizarre changes he was going through. Never really knew night from day or what day it was. Doctors were never much help and I felt they had no clue with what to do with him. He was even barred from going into one of the clinics that used to treat him due to his aggressive behavior. Finally, he couldn't be kept at home and would wander daily away from home. We divorced because he hit me out of a rage fit he had over nothing. I couldn't help him and his family took over. He was given an MRI and diagnosed with Fronto Temporal Dementia. They had him admitted to several facilities from which he always either escaped from or was kicked out of. He was placed in North Florida Regional Hospital for three months and kept sedated so he would not get out of bed. Things went from bad to worse. He was transferred to a skilled nursing facility where he died two weeks later. At that time, he could not speak or feed himself. He would respond only to me. I miss him very much. He was my first love and my last. He was 68 years old. I hate dementia.

[PHI Redacted]

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I'm terrified of this disease and you should be too! What could be worse than losing your mind? Or having your mother forget who you are? We should be doing everything we can do combat this.

[PHI Redacted]

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Half of the more than 5 million Americans with Alzheimer’s have never received a formal diagnosis. We know that an early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer’s and their families. Yet the federal government is moving to put up a barrier to those benefits.

The Alzheimer’s Association convened the Amyloid Imaging Taskforce, a group of leading experts in the field, who recommended that for certain situations amyloid imaging should be covered by Medicare immediately to improve the quality of care. One of those situations is when a dementia expert is unsure whether a decline in memory is due to Alzheimer’s or some other perhaps preventable cause.

Those who have lived with Alzheimer’s or related dementias know an early and accurate diagnosis allows individuals with the disease and their caregivers to better manage medications and other chronic conditions, receive counseling, engage in financial and long-term care planning, and consider all medical and non-medical treatments and supports including participation in appropriate clinical trials. These benefits improve the quality of life for those fighting Alzheimer’s and can lead to significant cost savings, both for individuals and our nation.

We can't afford to postpone for years important tools that are ready to help doctors provide better Alzheimer’s care today.

Sincerely,

Ms. Erif Thunen

[PHI Redacted]

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My mother, a vibrant 78 year old, was finally diagnosed with Alzheimer's, too late to allow her any quality of life. Let's help others get the diagnosis early on, so they don't have to suffer as our family did!

[PHI Redacted]

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As staff for the Alzheimer's Association, I hear all the time about how an earlier diagnosis of Alzheimer's would have helped them. Often services aren't available to people without a diagnosis, even if they clearly have dementia. Often they don't realize they needed to deal with financial matters until they get to the point of having to go through much more complicated and expensive legal procedures once their family member is incapacitated. And I hear about families who had to go to several doctors before they got a diagnosis, which is time consuming, expensive, and frustrating. Some simple policy changes could dramatically improve this situation OR make it worse. Please do the right thing for these families. Thank you.

Sincerely,

Mr. Jon Bartholomew

[PHI Redacted]

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The importance of early diagnosis and intervention may prevent watching your loved one waste away over years of confusion, humiliation, and ultimately the slow process of losing all one's ability to maintain human dignity before dying. I took care of my mother for many years, trying to get help from neurologists but my mother would not agree to medication, by that point the disease started taking over her thought process. I had to take a loan out against her home to keep her there with a live in and when the money was exhausted I then had to place her in a nursing facility [the proceeds of the sale of her home went to the state] and virtually lived there most every day to make sure that proper care was given her. I also had an elderly father to take care of who was suffering from severe depression due to losing his wife as his partner, two young children and a husband, a physician with his own every day stresses taking care of his patients. Of course I think about if I am diagnosed in later years with Alzheimer's and hope in the near future some kind of medical intervention will be available.

[PHI Redacted]

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My dad, 4 brothers and I are slowly but surely losing my mother to Alzheimer's. My grandmother died from the disease in 2008, Please help us. This terrible disease is crippling our family. EVERY major disease now receives in the billions for funding. Alzheimer's receives in the millions and Alzheimer's is the only disease with increasing mortality over the last decade. EVERY other disease has decreased. Alzheimer's has increased 69%. Please I'm begging you. I love my mother. Please help her.

[PHI Redacted]

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My husband's beautiful, funny, and intelligent mother showed signs of Alzheimer's for at least 7 years, steadily declining until her death at age 69, in 2003. She was cared for at home, and no formal diagnosis was made. If this was Alzheimer's, and early onset as well, the ramifications for her 4 children are frightening. Without the diagnosis, her adult children live with some fear and uncertainty that they could be at risk. Ten years later, advances have been made that may help us either allay our fears, or help us plan for and manage our lives as they will be affected by Alzheimer's. Knowledge is power. Please let's use it.

[PHI Redacted]

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Please keep up research and diagnose accurately. Don't ruin lives for the usual reasons and greed and poor judgment.

Sincerely,

Dr. Marilyn Stachenfeld

[PHI Redacted]

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Our family was very fortunate to learn of our mother's early diagnosis of Alzheimer's. It allowed us to plan and manage the 16 year long journey.

[PHI Redacted]

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My husband was diagnosed early with an MRI with vascular dementia, and because of expensive medications his progress was PROBABLY slowed and he was able to enjoy spending more time in his own home

[PHI Redacted]

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With the knowledge that there are forms of dementia that are reversible, it is important for every American worried about their personal cognitive decline to have a fast, accurate diagnosis. How unfortunate it would be for someone with a form of reversible dementia to live untreated thus raising their health care costs as a result. I sure wouldn't want to be that person and I expect you would not either. Please support legislation that provides for a good diagnosis and, if need be, decent, affordable dementia care. Thank you.

Sincerely,

Mrs. Erna Colborn

[PHI Redacted]

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As with all medical/health issues, the earlier you diagnose, the earlier measures can be taken to treat the issue. Please push harder for early and accurate diagnoses. You never know, you may personally be affected by this issue in the future....and you will be grateful if you acted quickly. Thanks!

Sincerely,

Ms. Maria Teresa Miguel

[PHI Redacted]

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Our family has had 5 members pass with this horrible disease, which includes my grandmother, her daughter, my mother, an uncle, an aunt on my father's side and his brother in law. My cousin her children, grandchildren and so on as well as mine have a greater chance at getting this disease. Early detection is vital to everyone that would have the slightest chance of having Alzheimer’s, large possibility for my family. For those in government and government agencies that do not want to provide this is appalling. You don't give our family much of a chance to be able to remember what our lives could be or to be able to understand why we are not important.

Those of us that want have a productive life in our later years deserve this test. We have given to others so they could have, we do not deserve any less.

Please, please make the right chose.

[PHI Redacted]

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We are very thankful that we have health insurance that helps us to seek and receive an early diagnosis, and that we have the service and advice of a qualified neurologist to monitor the Alzheimer’s disease, and to prescribe necessary pharmaceutical therapies. We are also thankful that we have the Medicare Advantage coverage to help provide the necessary pharmacy required to combat this rapidly progressive disease. But, we are paying substantial premiums and copays for this coverage by our health insurance company now for at least two years. And, we understand that a patient who has this progressive disease, who is in otherwise good health, may live several years requiring current and additional memory care, which is extremely costly. Our health insurance does not cover in-patient care in a memory loss facility for patients with a diagnosis of Alzheimer’s disease. Thus, we are not currently able, at the ages of 83 and 87 years, both on very limited retirement and SSA incomes, to afford the long term care required by our loved one suffering this greatly dreaded and costly debilitating disease. My wife is the patient, and I am the primary caregiver.

[PHI Redacted]

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My mother developed Alzheimer’s in her 70's, my maternal grandmother developed dementia (hardening of the arteries) in her 70's. My mother is now 93, is in fairly good health, happy and living in a nursing home because she is no longer able to care for herself. She is fed pureed food, gets around in a wheelchair, recognizes us but no longer knows our names. She says very little and usually in response to something we've said. My grandmother had similar symptoms and lived her last 8-10 years in a nursing home. She, however, lost her ability to speak; we knew she understood what we were saying at times, but tears were her response. Since my mother and previously, grandmother, were well cared for, I know full well this is NOT something they would have chosen for their last years. My mother was a very energetic, helpful, caring woman who was very active in her church. She is now a shell of who she was. My sister and I are very thankful she has such wonderful care and is so happy. It's very hard for us to see her this way but it's something we've accepted as "the way it is." My sister is 63 and I am 66 so our "70's" aren't so far off. We are very hopeful that research will find some answers so that we don't have to suffer the same fate! My husband and I are raising our 10-year old grandson, who we adopted when he was 18 months old. He has Sensory Integrative Disorder with some Autistic tendencies. He is a great joy and we enjoy him so much as well as our other grandchildren and great granddaughter. My sister has younger grandchildren as well. We are so hopeful that we will be able to be able to remember our children and grandchildren in our late 70's and 80's and possibly 90's. We pray for solutions to this terrible disease that robs a person of their memory and ability to care for themselves. There is no greater hardship!!!

[PHI Redacted]

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I think it is very important to come to an early diagnosis of dementia and Alzheimer's! My mom was diagnosed 5 years ago with fronto-temporal dementia. Perhaps if we would have recognized the symptoms sooner we could have gotten help earlier. I'm not sure if my mom had this test but she was diagnosed within a reasonable amount of time after we discovered that maybe it wasn't just getting older and forgetting a few things. She did begin medication which perhaps did extend her life, and or quality of life, for a little while longer. The disease progressed over the years and eventually the disease claimed her and she passed away in Nov. of 2012. My sister and I are terrified that perhaps we have inherited whatever causes this disease. Early detection with any tests available is certainly a valuable tool in fighting this horrible disease. We believe my mom actually began with symptoms up to 10 years before she was actually diagnosed and unfortunately we didn't realize that all of the early smaller symptoms specific to fronto-temporal dementia were symptoms. We were very lucky that she had the forethought to get her affairs in order to make it easier for us to care for her and she made us aware of her end of life wishes before she was diagnosed. Early detection would greatly assist in planning for care. My mom's disease was a horrible thing, she had always been very proud and self sufficient and this disease stole those things from her as well as her ability to talk, write, walk, comprehend, etc. It is not easy to care for Alzheimer/dementia patients! If there is a test available to detect early symptoms it should definitely be made available and covered by insurance companies so that patients may better prepare for life with the disease and relay their wishes for care. Thank you.

[PHI Redacted]

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My late wife suspected she was getting Alzheimer’s long before anyone else but her doctor was unable to diagnose her case for several more years. Surely an earlier diagnosis would have meant many positive things to her in her last years. Please help in getting early diagnosis to suspected cases. Please.

[PHI Redacted]

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My daddy lives in a nursing home now. He is only 71 years old. Although he has had Alzheimer’s for almost two years, he never really received an official diagnosis... his doctor simply referred to it as a 'memory disease'. Just this past Christmas, before having to go live in a nursing home, he and my mom were here to celebrate the holiday with our family. They only live one town away, so when dad needed to get home, it was just a matter of minutes until he was home. Three hours later, I received a frantic call from my mom...dad had gone missing when she fell asleep in a chair. He just walked out...no coat or jacket, and went for a walk...something he always loved to do. We live in the country, so there was little traffic. Dad took ONE left turn...and got lost. A quarter of a mile down that road, he slipped on the ice and fell, striking his head on the pavement, breaking his glasses and cutting his forehead. He spent the rest of Christmas night in the hospital.

He became more and more confused after that, even forgetting what my mom was to him (they've been married for 53 years), calling my mother names that he NEVER would have used before, saying she was trying to kill him, refusing to use the toilet, peeing on the floor. But he was her husband, and my dad, and we vowed to keep him out of the nursing home as long as possible. Well, we were only able to hang on until February, which is when he started falling. My mom was not able to get him up by herself, so she would call us to help. Thank God these calls usually came on the weekends, when my husband was home. After another fall which resulted in some minor injuries, I convinced mom that it was no longer safe for him to remain at home.

Please, please lend your support to early detection of this mother-father-grandparent-aunt-uncle-stealing disease. I miss my dad, my aunt and my grandma, all of whom were taken or will be taken by this insidious disease. Please help those who cannot help themselves any longer. Before you have to find out what it’s like to lose a loved-one to Alzheimer’s.

Thank you for taking the time to read this missive.

[PHI Redacted]

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My mom was diagnosed with dementia in 2010 at the age of 83. Once diagnosed, she was prescribed the Exelon patch, which really helped her think more clearly and have fewer episodes of panic and frustration. I wish she could have been diagnosed a lot sooner. She struggled for several years before the diagnosis and we did, too. Besides wandering off at any hour, she had terrible nightmares that haunted her long after she was awake. She found it impossible to tell the difference between a dream and reality. One morning she insisted a black monkey was hiding in her bed and that he was there as a sign of death. Despite our trying to convince her it was a bad dream she had and our going into the bedroom with her to prove there was no monkey, mom insisted she was going to die that day. She was so fearful of death. Another time, she hallucinated that "someone was hiding down the hallway - don't you see him??" among other things. She knew there was something wrong with her. I remember a few years before she was diagnosed, how excited she was when she and dad bought one of those fancy organs at a yard sale while they were in Florida. She loved playing music on the organ for hours. When she began to have "memory problems" , (as the doctors would say), dad and mom had to come back home to Massachusetts as it was getting too difficult for dad to care for mom alone. We rented a U-Haul and managed to get that organ back home so she could continue to play. She gradually lost interest in the organ, then, stopped all together last year when she sat down at the organ and cried because she realized she couldn't remember how to play. She knew there was something wrong with her, but we didn't know how to tell her. Mom passed away 2 1/2 weeks ago on July 1, 2013 at the age of 86. Thinking of all of her struggles she went through, I wish she had been diagnosed far sooner. If she had been on that Exelon patch earlier, she would not have suffered as much the way she did. Please seriously consider funding for any diagnostic testing which can diagnose Alzheimer's and dementia earlier. This is a terrible disease that can occur at any age and should be treated with as much urgency as heart, kidney, and lung diseases.

[PHI Redacted]

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My husband was diagnosed with Alzheimer's at age 59 following a series of job losses when he could not learn new material that he had known for many years. It was so early, the neurologist wasn't sure if it was mini strokes to the brain or early Alzheimer's so he treated for both. Within a year, it was confirmed as Alzheimer's through behavior, and spinal fluid. He was started on medications immediately at initial diagnosis. As a result, he had 8 fairly good years and only started deteriorating badly this year. I am a firm believer in early diagnosis and treatment for the patient and the family's sake.

[PHI Redacted]

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A close friend has just been diagnosed with Alzheimer's. Her doctor sent her to a Neuro doc for an MRI in order to confirm that there was not something else causing her dementia. He was not 100% sure of the test results but was reasonably sure it was Alzheimer's. Had my friend been able to have the Amyloid test, perhaps we could have had a definite diagnosis. Her son who lives in Turkey has now come back to the starts to help her find an assisted living situation that is required now in order to fit her needs and dementia progression.

Sincerely,

Ms. Laura Sutherland

[PHI Redacted]

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No one knew what was wrong with my father in the late 1960s except that his memory seemed to be unraveling. No one knew about Alzheimer's in those days so there was no diagnosis. There was no support group for my mother or my siblings. There was no treatment except the doctor would hospitalize him for a week when my mother became too exhausted to care for him. His memory unraveled until he did not know his children, then he did not know my mother then he began to think that we were his parents and his sister. Then he knew nothing. He died at age 72 in 1970.

[PHI Redacted]

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My father has Alzheimer's. This disease has changed our family in ways that is difficult to put into words. My dad has always be the most outgoing, happy, loving, caring person you could ever meet. He has been my mentor my entire life. Suddenly he became someone else. Of course my mother was in denial which I know is very common. My three siblings and I discussed the things that we noticed that was going on with our dad with our mother and his PCP as we all go to the same MD. I did not feel that the proper testing was given along with the proper diagnosis for quite several years. So, in the interim life went on for my dad as if nothing was wrong while he could have been treated earlier and his disease could have been managed so much better, not just giving him vitamins!

Why is it so difficult for patients with his horrible disease seem to be put on the back burner so to speak? Can't they get the help they so desperately need and deserve? They can't speak for themselves, they can't be their own advocate, it is just wrong that patients suffering with dementia have to endure such travesty to get the proper help and when they do it sometimes is just too late.

Every time I see my dad I wonder what he is thinking and if he wonders why he didn't get help sooner. Every now and then it seems as if is brain "opens up" and he will remember something and ask "why do I have to sit in this chair like this" - do you have any idea how heartbreaking that is? Anyone that has a family member suffering from this does. You look into their eyes and all you see is an empty space.

Let's take some action and do something about this. Let our voices be heard!

[PHI Redacted]

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My friend's husband had 5 years of changes in personality, speech, relationships, etc. before the condition was diagnosed as early onset Alzheimer’s disease. He died last year at age 65. It was devastating for all who knew him.

Any tests that can help with early diagnosis and possible control of symptoms of Alzheimer’s disease are too important to ignore. If you have never experienced early onset of the disease in a friend or family member, count yourself lucky. YOU or I could be the next one diagnosed. Of course, we would want every test or trial medication to diagnose and help slow the illness.

Trust that medical professional will use the Medicare benefit wisely. If they don't prosecute and get them out of the way of professionals with integrity.

Please help the many who are suffering now and the many more who will soon be diagnosed. It's not just the elderly being affected. You and I may need this help someday. Vote responsibly so the people affected and their families can have hope.

Sincerely,

Ms. Joanne Boyd

[PHI Redacted]

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My mother has dementia. The problem we are facing is getting any type of help from her primary care doctor. He has not spoken to my mom about her memory loss and why he gave her a simple test in his office to check out her impairment. We have asked him to help us in getting my mom to an appointment with a neurologist since she will not listen to any of us. We have found a group of neurologists that specialize in dementia/Alzheimer that can give us an expert diagnosis but we need him to talk with my mom and tell her directly how this would be her next step in getting her the support she needs. I feel like he is ignoring us and doesn't want to get involved but just won't say so.

Primary doctors need to get educated on the importance of an early diagnosis for the patient and families who are just starting an unimaginable journey.

[PHI Redacted]

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There are many forms of dementia, some of which are treatable and preventable. Using the Brain Amyloid Imaging test can definitely provide a test result which helps doctors successfully determine whether dementia is, in fact, Alzheimer’s.

Please reconsider your decision not to cover the costs of this test, which could help some lead richer and more productive lives as they age.

Sincerely,

Mrs. Deborah Jaquith

[PHI Redacted]

-

Don't allow the government to stand in the way of doctors providing an early and accurate diagnosis.

Sincerely,

Ms. Gwynne Rowe

[PHI Redacted]

-

Dementia/Alzheimer’s is at epidemic status in my community. The cost of treating the symptoms of this disease is becoming more expensive to taxpayers every year. Don't be misled by selfish conservatives, who can afford to have the best insurance in the country. They don't care about the working class of baby boomers who are reaching retirement every day. It is extremely important to reach that class of new seniors ASAP. Don't let the cost of this disease bankrupt this country. We need early detection very seriously.

Sincerely,

Mr. Leon Wallace

[PHI Redacted]

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My mom just turned 57 years old in April 2013. She has early onset Alzheimer’s disease and has for 6 years now. I am her only child and I was 16 when she started showing symptoms. As you can imagine, the last thing we expected was dementia. In only 6 years, she has become 100% dependent on us. Her husband, only 52 years old has changed his entire life to care for her but he cannot stay home to care for her, he still has to go to work, over an hour away from our home. My mom had to retire early from a career of 35 years because of this disease which has severely crippled their ability to afford proper care for my mom. My mom now suffers from seizures, which means we need more help, more care. My only wish as a 23 year old woman is to have my mom back. Though I know that isn't possible, it would help us all sleep better at night if we knew she could get the care she needs and deserves.

[PHI Redacted]

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I lost my wonderful mother in April 2013 to this awful disease. If you have had a loved one that you have watched deteriorate with this disease you wouldn't have to even think about it, it would be first on my list!

My mother went from a beautiful, mother, grandmother, great grandmother, wife, aunt, etc. to a baby in a fetal position starving to death within 4 years! It is awful as a daughter to watch and I plead with all my government to FIND the CAUSE not just to prolong this disease.

[PHI Redacted]

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My father was diagnosed with Alzheimer’s in 2005, a month after my mother died. I was the only caregiver to my 60 year-old brother with mental disability and now for my dad. He did not act like he had Alzheimer’s, but dementia. He shook so bad he couldn't hold a glass or fork, talked very low and his skin was turning purple. I took him to multiple doctors, and he was put on patches that made him mean. After I lost my leg and was in a wheelchair they took him and put him in a home, which I had promised to never do. When they kept putting him on antibiotics for lung infection they finally found out he had mesothelioma and Parkinson’s, which he could of had treatment for. He died the next day, never having had Alzheimer’s to begin with, just Parkinson’s. We need better trained doctors and better tests so this never happens again. I lost my dad at 74, way too young. Please understand and act.

[PHI Redacted]

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I was primary care giver for my mother. Early detection is very important. This should be obvious. A person need not have a personal experience in order to recognize the terrors of this disease.

[PHI Redacted]

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Please work towards making this happen.. Both my grandmother and grandfather suffered with this disease for a total of 22 years. Please help.

[PHI Redacted]

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My maternal uncle was diagnosed as having Alzheimer’s when he died 2 years ago. My mother, now going on 100 years old, has short-term dementia, but she has never gotten a proper diagnosis. It would make all the difference in planning her care (and my own) if we could get an accurate diagnosis for us.

[PHI Redacted]

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My dad passed away 10 months ago at age 79. He had early-onset Alzheimer’s starting in his mid-late 60s. It would help people to have an idea of their family's circumstances as it takes a lot of planning to deal with and set up care for someone with this disease.

[PHI Redacted]

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My wife obtained a degree in teaching and an advanced degree in guidance counseling to follow her life's work ambition. She stayed home and raised 3 wonderful children before starting her career. After about 7 years of teaching and 8 years in her dream job as a junior high school guidance counselor, she lost her job due to early onset mild cognitive impairment, which we now believe to be a precursor to Alzheimer’s. It is very discouraging to me to see the woman I love slowly disappear in front of my eyes. The ambition to achieve is gone; even doing little things, like meal planning, completely escape her. More and more of the responsibility of our marriage is falling on me - which is OK, but I am going to have to take early retirement to stay home with her. This disease has cost we 2 professionals our careers, stolen our financial security and is leading to a shorter life for both. When you multiply this by the millions who have this or an associated disease, the impact on society is staggering, but that does not measure the impact on the family - something that can't be measured yet takes away from those whose lives are close to the person suffering this debilitating disease. This was not a disease caused by risky behavior; nor was it caused by a reckless lifestyle. This disease needs to be stopped no less than AIDS/HIV, drug abuse/addiction or many of the other programs society deems worthy of our time, research and most earnest efforts. To fail to find a cure is to relegate millions of people who once were useful, productive people to the trash heap of society. We cannot afford to fail in this endeavor!

[PHI Redacted]

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Please hear us. My mother has experienced this and we need accurate diagnosis to plan and manage the disease better!

[PHI Redacted]

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My mother is almost 80 years old. At 75 years of age, she was the owner/office manager of a wholesale optical business with my father. She recognized that she was getting more confused while using the computer to input sales and returns. She saw a neurologist in 2008 and was diagnosed with mild cognitive impairment. Three years later, she was unable to perform her job at the office and decided she had to quit working. She also decided she was no longer comfortable driving. Since that time, she has continued to decline in her cognitive abilities as well as her long and short-term memory. She now has been diagnosed with dementia but the neurologist cannot tell us if she has Alzheimer’s. She began taking Exelon and Namenda but her memory continues to deteriorate as well as her functional life skills. She is totally dependent on a caregiver to help with her daily living skills: bathing, dressing, and preparing food. She now has characteristics of Parkinson’s but the doctor does not know if she has Parkinson’s. He put her on Sementet which has helped with her walking gait. I urge the legislature to pass a bill that makes Medicare cover the screening in the early stages with the new imaging available to detect the presence of Alzheimer’s, such a devastating disease. It is hard to watch a loved one lose all his or her independence. He or she becomes a different person, both in personality and functioning. An earlier screening could have prevented the rapid decline I see in my mother. Please don't let Medicare disallow coverage of this new imaging diagnostic tool to detect the presence of Alzheimer’s earlier in a person's life so that measures can be taken to help keep Alzheimer’s at bay.

[PHI Redacted]

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My mother is in the end stage of dementia. She was once a vibrant, intelligent person who is now a shell of her former self. For the past two years she has been living in a skilled nursing facility funded by Medi-Cal. It would have been so important to our family for my mother to have been diagnosed and treated earlier. The cost to my mother and our family is immeasurable. The cost to the government (through Medi-Cal) is quantifiable and could have been potentially delayed or maybe even avoided. I urge you to reconsider your decision.

[PHI Redacted]

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In 2007 one of the most challenging things to deal with in my mother’s sudden decline in health was "is it Alzheimer’s, dementia or some other ailment.” An accurate and timely diagnosis could have prevented misspent time and money, a better and more accurate planning for the future and confusion on prognosis. Please support the best and most early diagnosis for Alzheimer’s and dementia related diseases.

[PHI Redacted]

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Alzheimer’s disease is a heartbreaking illness for the victims and their families! I hope we can find a cure for it! We may not live forever but we can still have longer lives and be happy with those we love, that's what God himself would want!

Sincerely,

Mr. Darius Mazaheri

[PHI Redacted]

-

It's too late for my mother, but she had 7 children, who also have children, who could benefit from the right decision. Please consider this legislation very carefully, as this disease will be the most expensive to this country, and whatever we can do to diagnose and treat sooner and better, the better for all concerned. Thank you for your attention to this matter.

[PHI Redacted]

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My mother died of Alzheimer’s. It’s a tragic and debilitating disease and funds should be provided to do as much research as possible for early diagnosis and prevention.

[PHI Redacted]

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Fortunately, I don't personally know someone with this diagnosis but I certainly do understand the devastation it can cause to the person and to their family and friends.

Sincerely,

Mrs. Rainny Truscott

[PHI Redacted]

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Because of dementia, my grandmother, who we called Nana, suffered and ultimately died because of this disease. Before all of this she was one of the nicest and kindest people you could ever meet. She volunteered at Plimoth Plantation constantly. She died at 87. Age had very little or no factor in her passing. She was and still is greatly missed. Thank you for reading.

[PHI Redacted]

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This should be done!!!

Sincerely,

Ms. Ann Jenkins

[PHI Redacted]

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Due to increasing memory problems my husband was tested by a neuropsychologist in March 2012. The diagnosis was Mild Cognitive Impairment. The referring neurologist did not feel it warranted putting my husband on Aricept or other dementia related drug. All the doctors (internist, cardiologist, neurologist) felt his other medical conditions and/or prescription medications may have added to/helped affect the memory problems. His mother did have some type of dementia in her 70s-80s.

He was re-tested by the neuropsychologist in March 2013 with some improvement in certain areas, possibly due to not being on a pain medication, but more decline in other cognitive areas. Still the neurologist will not prescribe anything which might help with the increasing memory decline/dementia.

I wish there were some medical location where we could go which would analyze all his health problems at the same time so that a definite diagnosis could be made with better treatment. It is so difficult to watch this mental decline in another loved one and to feel there is not much help for the patient or the care giver.

[PHI Redacted]

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My father in law and four of his siblings have been diagnosed or died from this disease. Its effect on the ill is devastating, financially, emotionally, and physically. My father in law slowly degenerated to the point that he no longer could chew, walk, talk, or do anything. The emotional toll on his family was great, day after day tears are shed, regrets of time not spent together or time wasted arguing filed a lot of minds. He passes March 14, 2012, after chocking on liquid food, leading him to cardiac arrest, he was rushed to the hospital, where for 4 days we slept, ate, and prayed, a few times hope was given than stolen. He passed as it was deemed he could not live on his own functioning. We watched his last breath, his color change, and heard he was officially dead. Dead at 69, sick for 5 years. I urge you to permit testing to find an accurate diagnosis, nor only are there diseases which simulate Alzheimer's, but more and more research has concluded that early diagnosis is vital. I thank you for time.

[PHI Redacted]

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It is vital that you support early detection and treatment by allowing this type of diagnostic test to be covered by insurance.

Sincerely,

Mrs. Katherine Patrykus

[PHI Redacted]

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I helped to care for both of my parents who suffered from Alzheimer's disease before they passed away. One of my biggest fears is that one of my siblings or myself will also have the disease and I believe that it would benefit us to have diagnostic procedures if we begin experiencing symptoms of dementia.

[PHI Redacted]

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Each day I work for the Alzheimer's Association, I get to see just how devastating this disease is to those affected. Knowing that early diagnosis can be the difference in how fast the disease affect someone, I urge you to support any policy that can help a person, their family and caregivers live a rich life for as long as possible prior to the disease taking over their life.

Sincerely,

Mr. Peter Cowley

[PHI Redacted]

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My father died from Alzheimer’s, as did at least 4 of his 9 older siblings, At least a dozen of my first and second cousins have either died or are currently suffering from the disease. While I only know of one instance where the Alzheimer’s was in the early onset form, nonetheless this scourge greatly impacts my family, me and the lives of everyone connected with us.

Those of us who are approaching our later years, including me, are stricken with great anxiety and fear about our potential for having this horrible disease, which takes such a horrendous toll on everyone it touches.

My family is not alone in this.

Any means by which we and others like us can get a jump on a diagnosis is so crucial. Not just for us, but for all caring people. The huge costs and burdens it inflicts will affect everyone in this country as the years march on.

[PHI Redacted]

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My mother-in-law of 34 years is in the early stages of Alzheimer’s disease, and we are watching her slowly fade away into someone who barely resembles the sharp minded woman she's always been. We cherish every moment we get to spend with her, and try to make sure that no one makes her feel bad for not remembering that she just had a big dinner, or realize that she's wearing the same clothes she put on the day before. We are showing her the care and respect that she deserves, and wish that everyone in her position had people surrounding them who would do the same. I am very concerned that my husband and two adult children may inherit this awful disease and hope that everything that can be done is being done in order to prevent it. I hope that in the very near future there will be a cure for this sad disease but in the meanwhile, I am using coconut oil in every food I prepare for my family in hopes that will help stave it off and reverse the symptoms in my dear, sweet mother-in-law.

Thank you for reading my thoughts.

[PHI Redacted]

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I have a family history of Alzheimer’s, my father, his mother and his sister, who was recently diagnosis, my mother, her mother and great grandmother. I have been experiencing memory issues for myself and I just turned 60. The memory issues are those that are related just to me and how I have seen changing. My mother and father both have passed away from Alzheimer’s and I took care of them both. I want to know if I’m going in that direction in order to be prepared. I only have one son and don’t believe he should be responsible for my welfare. Therefore, I want to know so that I can plan for the future and enjoy today without worry of the burden I might put on my family in the future. If was able to have a scan that was covered by my insurance it would be fantastic.

[PHI Redacted]

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My beloved mother was diagnosed with early onset Alzheimer’s disease when she was 55 years old. I was 18 years old at the time and my brother was 15 years old. I just turned 50 last fall. Mom passed away in December, 2011 after a very courageous life. My dad cared for her until his stroke and death in 2006. At that point, we had to have skilled care for mom. My brother and I helped our parents out all we could. Through it all, though, our mom was determined that we kids have a normal life. We attended college, have been working in our chosen occupations, married, and had children. She really did wonderful, all things considered.

I can't begin to tell you how devastating an Alzheimer’s diagnosis It impacts the entire family. While my brother and I would make the same efforts that we did on our parents' behalf all over again, caring for a loved one with Alzheimer’s is an exhausting experience.

I am very disappointed that our government continues to abandon the American people. Alzheimer’s patients are people....their families are people. Patients are wonderful people who have led interesting, productive lives. Let's not leave them and their families all alone.

P.S. We all need to remember that all of us could be affected by Alzheimer’s ourselves one day. Wouldn't you want help, too????? Please reconsider this decision. Thank you.

[PHI Redacted]

-

Although she is still alive my mother’s quality of life is forever changed 10 years into this terrible disease. She never got to know her two grandchildren, both girls that she wanted more than anything else in this world. She used to paint, teach, travel and all of that is gone so soon and so young. Please support funding an awareness for this terrible disease.

[PHI Redacted]

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People with Alzheimer’s need all the help they can get!

Sincerely,

Mr. Ken Thomas

[PHI Redacted]

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My mom was diagnosed with Alzheimer’s well after she had the first symptoms of dementia. Her symptoms started around 1999, I noticed a distinct change in her, but my dad refused to see it. Both of my sons noticed it also.

She started "taking" items from my house and putting them under her bed at her house. I also noticed a change in her demeanor. Her personality was getting sarcastic, quick-tempered and withdrawn. This was NOT the mother I knew. She was a professional piano player, and always was the life of the party. She was a beautiful woman. Always with a smile on her face. Especially when someone requested "Piano Man", she loved to play that song!

Her doctor diagnosed her as "just getting older". I disagreed, but, she was adamant about going to another doctor. I watched her deteriorate rapidly. She became extremely withdrawn, hearing voices at night, talking to people when no one was there, sarcasm to me, her daughter, was unreal. My son and I lived with my parents to take care of them. My mom had a brain tumor, which was benign. The doctors said no relation to dementia.

Her balance was off terribly, she fell quite a number of times at the house, one fall being exceptionally serious. By this time it was 2004. Her doctor said it would be wise to put her in a nursing home. I was beside myself. Well, she did end up in one, and seemed to enjoy herself, not really knowing where she was, and thinking she was going home again. My heart was breaking.

It was only then that her doctor put her on meds for Alzheimer's. She seemed to pick up a little bit, and even was allowed to play the piano in the dining room! She was always happiest sitting at the piano. Well, that soon came to an end, as her disease progressed. She stayed in her room, and rarely talked to her lady friends, saying "they were mean to her", which was far from the truth. I was there with her every day.

She passed away in 2007 at the nursing home. I do believe that if her doctor had gotten another opinion, or at least listened to me when I would call her and relate incidents to her that I thought were strange, maybe her life could have been extended.

I miss her piano playing, she also had a beautiful singing voice, thank God I have tapes of her.

No one I know seems to be taking this horrendous disease seriously. It robs you of your life, your personality, your mental capabilities, and leaves the ones caring for you in a quandary. All cases are different, but I miss the mom I used to know. She became a hollow shell of a beautiful woman who loved life, and I was helpless.

[PHI Redacted]

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I am very concerned that our country is not taking high interest in addressing some health care conditions that remain very high and ongoing in our populations. One of them is Alzheimer's which is a horrible illness affecting all of us. Most, if not all, Americans know those who have been affected by this condition.

On a personal note, my mother was diagnosed with the disease about ten years ago. She has since passed but her mind declined significantly and she just was not living as she knew it at the end. She had always been so active; I and my siblings found it hard to keep up with her before becoming tired. She loved life and experienced each moment with all it shared.

I have known many cases of it and become aware of more cases in our community and country more frequently, it seems.

I am urging you, as a leader of this country, to address this illness. We need to find answers to why it is present. There is a reason for it and we should know that reason! We need some quality medications and healthcare to stop it! That will require focused research and some quality researchers. Thanks for your full support on this national issue of health.

[PHI Redacted]

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Please help us!

[PHI Redacted]

-

Half of the more than 5 million Americans with Alzheimer's have never received a formal diagnosis. We know that an early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. One excellent way for Congress to help in the diagnosis of this terrible disease is Amyloid Imaging. It has been determined that the amyloid PET would be appropriate only in those [MCI] individuals who the dementia expert has concluded would benefit from greater certainty of the underlying pathology and whose clinical management would change as a result of this greater certainty. (Alzheimer's and dementia, The Journal of the Alzheimer's disease, July 2013). Other patients who would benefit from the test are individuals meeting tests for possible Alzheimer's, but who are unusual in their clinical presentation and individuals with progressive dementia and atypically early age of onset (before age 65).

I personally have seen the ravages of Alzheimer's in members of my family, and want to spare other patients and family members the heartache it causes. Please see that CMS covers PET Amyloid Imaging. Early treatment would keep these patients productive, thus reducing medical costs. As a result, both Medicare and the patient would come ahead financially. Therefore I urge you to vote to authorize Medicare to Amyloid Imaging.

Thank you.

Sincerely,

Mrs. Micheline Rotblut

[PHI Redacted]

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I would like to be able to possibly reverse a diagnosis by early detection.

Sincerely,

Ms. Cindy Dalton

[PHI Redacted]

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Half of the more than 5 million Americans with Alzheimer's have never received a formal diagnosis. We know that an early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. One excellent way for Congress to help in the diagnosis of this terrible disease is Amyloid Imaging. It has been determined that the amyloid PET would be appropriate only in those [MCI] individuals who the dementia expert has concluded would benefit from greater certainty of the underlying pathology and whose clinical management would change as a result of this greater certainty. (Alzheimer's and dementia, The Journal of the Alzheimer's disease, July 2013). Other patients who would benefit from the test are individuals meeting tests for possible Alzheimer's, but who are unusual in their clinical presentation and individuals with progressive dementia and atypically early age of onset (before age 65).

I personally have seen the ravages of Alzheimer's in members of my family, and want to spare other patients and family members the heartache it causes. Please see that CMS covers PET Amyloid Imaging. Early treatment would keep these patients productive, thus reducing medical costs. As a result, both Medicare and the patient would come ahead financially. Therefore I urge you to vote to authorize Medicare to Amyloid Imaging.

Thank you.

Sincerely,

Mr. George Rotblut

[PHI Redacted]

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My Husband has been diagnosed..but much later that it might have been if we had started serious work on the problem

[PHI Redacted]

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I was at the height of my career, working in the Healthcare field, when I began having memory issues. I became my own Advocate and needed answers to the issues I was having. At the age of 58 years, I was diagnosis with Mild Early-Onset Alzheimer's. I believe it is extremely important that people get the earliest of diagnosis if they are experiencing cognitive issues so that a Neurologist can assist them in an accurate diagnosis and begin treatment.

[PHI Redacted]

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I have experience with two parents, my father and my mother-in-law, who have experienced Alzheimer's at different ages and in different ways. With my father, we did not know whether he had Alzheimer's until it was confirmed by autopsy. With my mother-in-law, who is in an Alzheimer's care unit, we now struggle with whether some of the drugs she has been taking continue to be necessary - or whether the disease has progressed to the point where they are not.

I cannot speak to the relative cost of continuing pharmaceutical care vis-à-vis the efficacy / cost of any particular test. However, surely, it must be the case that appropriate guidelines can be established to empower the physician to make these decisions as and when appropriate.

[PHI Redacted]

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First my mother, then my mother-in-law, and now my 64-year-old sister-in-law. It would be so nice if they could have had early diagnoses.

[PHI Redacted]

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Please support early detection practices for Alzheimer's.

Sincerely,

Mr. Adam Wall

[PHI Redacted]

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My mother-in-law has definitely benefited from early diagnosis, I cannot imagine how it would have been if she hadn't been able to get the help that she needed, and the medications early on. This is critical, so many care-givers have years of care and if their loved one can have a few more years of quality of life before they go into their own world, what a gift that would be.

[PHI Redacted]

-

Been There ::: Done That.

Information is key to everyone enduring Alzheimer's. The earlier and the more accurate, the better. Followed by real practical support without biases from others.

Sincerely,

Mr. Fred Bichl

[PHI Redacted]

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My husband was 54 when diagnosed with what we thought was Alzheimer’s disease . At that time there weren't specific tests that could determine his exact illness. Now almost 10 years later we have tests for FTD and the amyloid test for Alzheimer’s. We cannot give the best treatment for these illnesses unless we have accurate diagnosis. Please approve this test for all patients in the early stages of diagnosis.

[PHI Redacted]

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Please take action to help cure this to help so many people.

Sincerely,

Mr. Steven Lefkow

[PHI Redacted]

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Please do what you can. Rarely detection is so important.

Sincerely,

Mrs. Lou Chamberlin

[PHI Redacted]

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My grandmother was a victim and now my uncle was recently diagnosed with the disease...it is sad to see the deterioration.

[PHI Redacted]

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At 77, my mother went through an exhaustive day of diagnostic evaluations with the area Alzheimer's MDs. Barring autopsy, they cannot verify that she does have Alzheimer's with absolute certainty. She has other factors, thyroidectomy, para thyroidectomy, peripheral vascular disease, and osteoporosis. She is being treated with Aricept as though she has Alzheimer's . She has always been a lean 110 lbs at 5'6" with a life of exercise and very healthy eating. Now at 80, she weighs 93 lbs, and has had an unexplained decline. As a Clinical Laboratory Scientist, I believe more information is needed. I find it distressing, that we may have mistreated her due to lack of information.

[PHI Redacted]

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I am very sad and will try to express my feelings, my dad has had this disease since 2000 two weeks ago the police had to be call because he became violent, my mom is also sick so he was taken to a hospital that specializes in this disease he was in the hospital for seven days we brought him home, not even an hour pass he had to go back so I think he's in the very bad stage now, we have tried so hard to keep him home but cant any longer. Now we are having a hard time finding a place that will help him, because my dad is called a sundowner, when it's between 4:00 to 6:00 he wants to leave and it's hard to stop him. My dad a good father and husband my protector my strength is No longer there, he was a very good provider and watching over all of us I have two sisters and a brother and I'm the youngest as my dad always says his baby, I don't have enough words to tell you the pain that I feel but can't even express because I have to be strong for my mom, stop the arguing and wasting time let the help continue, families need the help and compassion, help us.

[PHI Redacted]

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My family has been impacted by misdiagnosis of Alzheimer's disease of my mother, as Mild Cognitive Decline. She was taken off the current standard regime of medications for AD, due to this misdiagnosis. There is no way to assess clinically how this impacted the progression of her AD, but it was frustrating for her family and she lost years due to this mistake. I understand how hard it is to definitively diagnose AD. I work in this field of cognitive decline in older adults. So I support early testing and diagnosis, even though there is no cure for AD. Early testing is known to delay the progression of this debilitating disease and that's what we lost.

[PHI Redacted]

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My husband Ron has been stricken with early onset Alzheimer’s disease. Our health care providers didn't look for Alzheimer’s disease so getting an accurate diagnosis of early onset Alzheimer’s was a long and frustrating process. His symptoms were incorrectly attributed to stress and depression. He is the first in his family to be diagnosed with this disease. By the time the diagnosis was made he (age 64) was already at the moderate stage. If there is a test that could be given that would have diagnosed his illness earlier he could have been on the medications in the early stage and perhaps the meds would have given him a longer period of time with a higher quality of life. Please spend time researching this cause. It can strike anyone.

[PHI Redacted]

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Caring for an individual with Alzheimer’s can be extremely tough. No one knows that better than my memere. To my knowledge, my pepere was never officially diagnosed with Alzheimer’s before he passed, but most in our immediate family knew he was suffering from this terrible disease. In many ways, we were lucky that he passed before he progressed further along. At the time of his passing, he still remembered who we all were and who he was, but he would often forget information he was told within a short span of time. I think perhaps it was tricky for the doctors to tell if he was suffering from this disease because he would often use humor to brush off his forgetfulness. This was incredibly difficult struggle for my memere. It took a monumental amount of patience for her to deal and in many ways affected her own health.

I feel that it is important for such a terrible disease to be diagnosed early, especially when it is a disease that "runs" in the family. My mother, who is in her mid fifties, now worries that she may have the genes that causes Alzheimer’s since several elder members on my pepere's side (my mother’s father) of the family have been diagnosed with Alzheimer’s or some form of dementia. Perhaps, if she and others like her could get an early diagnosis they could better prevent the onset or slow down the effects with the current medications out there.

[PHI Redacted]

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My mother had dementia though not Alzheimer’s and getting an early diagnosis was hard for her but not getting a diagnosis would have made dealing with it even harder.

[PHI Redacted]

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Specific medicine is essential for treating Alzheimer's vs. dementia. With an accurate diagnosis correct medicine can make a difference with the quality of life for the patient. Even though some medications are used for both an accurate diagnosis can make the difference for families facing life changing decisions for their loved ones. Also, if correctly diagnosed Insurance companies would save money by using accurate treatments for specific problems.

Sincerely,

Ms. Anna Marr

[PHI Redacted]

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This disease has been affecting me since my mother was diagnosed in 2006. From my journey with my mother I noticed some of the same problems in my husband. I was the person that pushed to get a diagnosis early. That diagnosis came in October of 2011. He did not start any treatment until February of 2012. This was due to the VA scheduling and appointments. He is now on the right medication but due to doctors. Changing it is very difficult to get the medication prescribed and filled for him.

There are enough things to worry about and handle as far as this disease is concerned. Medications and accurate diagnosis should not be something the caregivers have to worry about. Individuals with this disease will not see new doctors. If their family doctors won't diagnose; by telling them and treatment the family/caregivers are between a rock and a hard place. This is wrong!

[PHI Redacted]

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My husband has Lewy Body Dementia.

[PHI Redacted]

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Both my parents showed symptoms of Alzheimer’s. I'm 62. I might be said to have an interest in reducing my own likelihood.

[PHI Redacted]

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I lost my mother to Alzheimer’s, and she could have lived longer if the Gov. would provide funds for research. A lot of money can be saved if they hurry up and find ways to cure or slow down Alzheimer.

[PHI Redacted]

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My father is dying of cancer and Alzheimer’s. His two brothers both died in similar circumstances. He had two sisters, both dying afflicted with dementia. This is very personal for me and my children. This disease is neither faceless nor pleasant. It is time for our policy-makers to start acting like it.

[PHI Redacted]

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There is not a doctor in the world who can treat an illness unless they know exactly what that illness is. And if it is your loved one that gains a few more years of knowing who you are, you cannot put a price on that.

Sincerely,

Mr. Robert Mortenson

[PHI Redacted]

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Make your voice heard

Sincerely,

Mr. Paul Smith

[PHI Redacted]

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With an earlier detection we might have had more time with mom before her memory faded and she became this new person who is both fearful and combative.

Without earlier detection and better treatments these changes come quickly forcing a family to lose their loved one twice - quickly at first when they no longer know who you are which is unbelievably painful and then finally, once the disease that robs them of life finally takes theirs.

Please - please take action to bring about earlier diagnosis, better treatment and eventually a cure.

Thank you.

[PHI Redacted]

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My grandfather suffered from this terrible disease. He wasn’t the same guy I knew growing up who taught my brother and I how to hit a baseball, play cards and all the fun things grandfathers do. I urge you to fund more research so that steps can be taken to cure this disease.

[PHI Redacted]

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This devastating disease is facing so many in our population and needs to be dealt with promptly so it doesn't end up bankrupting our social services as well as our families.

Sincerely,

Ms. Susanne Hesse and Doug Dyer

[PHI Redacted]

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My oldest sister, now age 60, was diagnosed in her mid-fifties with early on-set Alzheimer’s. She is now in a rapid decline but for several years she was holding steady due to her early diagnosis. This is a devastating disease for the patient and everyone connected with the patient. Early detection is key to giving a patient quality of life for as long as possible. Currently, there is no reversal of this insidious disease- but hopefully a slowing of its debilitating progression through early detection! It is so incredibly sad and frustrating to watch a healthy, vibrant, loved one become a mere shell of a person. Please help all affected obtain an early diagnosis.

[PHI Redacted]

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When my husband at the age of 59 should symptoms that were beyond forgetfulness, I knew that it was important to act. Some forms of dementia can be alleviated (especially those due to medications, poor circulation or diet, and brain rumors). We needed to know what we were facing and what possibilities the future held. Unfortunately for us, the diagnostic process provided the information that they were 95% certain that it was early onset Alzheimer’s. Believe it or not, even though we realized that meant the situation was terminal, at least we knew what we were dealing with! It allowed us to seek information, support, coping mechanisms and medications that could enhance the quality of life even if they provided no cure.

As a spouse in my 50's, I was overwhelmed by all the changes that needed to happen...my husband had to retire from his career as a real estate agent... we had to apply for disability...I had to plan for eventual residential care... and I had to find a way to eventually say goodbye to my marriage, my husband, my best friend, and the life I thought I would have in my later years.

Having an early diagnosis allowed us to focus on enjoying the moments as much as possible...and allowed me to maintain my sanity over a process that was intensely emotional. My husband passed as a result of the Alzheimer’s on January 24 of 2013.

The numbers of families living with dementia are ever increasing. The stresses that this form of illness places on the person with dementia are many...but the pressures encountered by their caregivers are endless! Please don't add to those pressures by removing the aspects of early diagnosis that can actually help to lend support at a time when it seems the foundations of life are crumbling.

[PHI Redacted]

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After you watch a loved one succumb to this slow and cruel disease, you find yourself questioning your faith and your purpose on this planet. There is nothing more heartbreaking than watching a formerly vivacious, intelligent, happy person wither into the vegetable that Alzheimer's has left them. And while you watch this person you dearly love slowly wither, you pray to god that science will find a cure for this horrific disease before you find yourself in that same bed.

Sincerely,

Ms. Jennifer Rhoads

[PHI Redacted]

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My great-uncle suffered from Alzheimer's.

During a family reunion Uncle Howard left to buy a phone card so we could call great-grandma, and hours later he had still not returned. It was a terrifying experience, one no one had foreseen or was anticipating because he had not yet been diagnosed, although early warning signs were there.

Luckily my uncle was returned to us safely. However, it could have easily ended badly. If only he had been diagnosed early on the entire experience could have been avoided.

[PHI Redacted]

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I am a 55 year old with early onset dementia. The cognitive and short term memory issues for me forced me to retire early from Walt Disney World with 24 years of service. My pension won't sustain my finances and it has defiantly put a burden on my family. Research is showing 20 years before symptoms show up they can tell from gene testing who has the probability of getting the disease sometime in their life. I have some of those genes and makes it hereditary in my case. Therefore we should continue to move forward with all aspects of getting a grip on this devastating disease. The diagnosis is the beginning of a depressing future and removing obstacles and stress is so important. A lot of people dismiss symptoms or right it off to other things when they should be getting help and medication to at least slow the progression of the beginning symptoms. Getting a diagnosis when you think you are having problems is very important. My mom passed away at 75 and her father had dementia. I am in tuned to the possibilities of me and my siblings also getting Alzheimer’s disease. That was the reason I was tested when I started thinking I was forgetting more than I was remembering.

Please don't' put up barriers so that doctors can't provide people with early and accurate diagnosis, it's hard enough for families to care for a loved one.

[PHI Redacted]

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I have recently been diagnosed with early Alzheimer’s. The medications available are not effective at this stage. I'm thin, fit, active, and involved in my work as a registered dietitian. I'm a singer, a dancer, an F-horn player and an avid hiker. I'm re-learning Spanish and write blog articles on nutrition topics for our website. This is not in my family. I don't have bad cholesterol levels. Why in the world did I get this, and what can I do? I haven't gotten the CT scan yet. I need more, better research to find out the best next move. Please support more research.

[PHI Redacted]

-

Many members of my family have had Alzheimer’s. I anticipate getting it as well, but not having a clear diagnosis drives all sorts of crazy thoughts, and may itself progress the symptoms. This is a national crisis, and should be addressed with the same fervor that we address other epidemics.

Please support funding for more research into cures and prevention of Alzheimer’s, as well as funding for early diagnosis

. Sincerely,

Ms. Camille von Eberstein

[PHI Redacted]

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My dad had Alzheimer’s.

[PHI Redacted]

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We received our diagnosis for mom very late making it impossible to enroll mom into clinical trials for new medicine. If there was an accurate way to diagnose-it would help the Alzheimer’s patient and their families be further ahead and allow them to enroll in trials and manage the disease better-all around. This would be better for the patients, better for their families and better for the healthcare system in general.

[PHI Redacted]

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When my mother was diagnosed with Alzheimer’s, much of the information and many of the tests that are available today were not available. With better information and diagnostic choices, mom might have been diagnosed earlier, had more options for the years ahead and we could have had more and better years with her. The Alzheimer’s Foundation and news sources have provided much more information, so people are more aware of Alzheimer’s and other forms of dementia and can take action sooner. It is so important that all diagnostic and medical options are available to our senior citizens, and that usually means through Medicare. Please, please don't take away our hope and the possibility of earlier and more accurate diagnosis.

[PHI Redacted]

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Degeneration! I can put a bunch of words on here, but if found early (like brain tumors) we may have a chance at this! Thank you.

Sincerely,

Ms. Elisa Farley

[PHI Redacted]

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I am at a point in my life where I am forgetting names of people and forgetting names of things. I know that people eventually do this, and, so far, those are the only symptoms I have. I believe people who are at this stage in their lives should be able to have a brain scan to determine the amount of amyloid plaque buildup in the arteries in the brain. This would determine whether that person should start medications that would help them with cognitive mental health loss. Please keep this scan as one of the brain scans that Medicare covers. I'm 74 years old and hope to be able to maintain cognitive skills for a long time. I do tests, puzzles, etc. to keep my cognitive skills from decreasing.

Thank you for your consideration of this matter!

[PHI Redacted]

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Please listen to the experts. Doesn't it stand to reason that early diagnosis and treatment will save money over the years?

Sincerely,

Ms. Shari Hamilton

[PHI Redacted]

-

Two of my family members have suffered Alzheimer’s dementia—one gone, one going.

Please act to sharpen the diagnostic knife which addresses this baffling condition.

Sincerely,

Dr. John Peck

[PHI Redacted]

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My mother suffered for years with Alzheimer’s. It forced my dad into being a caregiver and his health suffered greatly: dying before his wife. Their retirement years were ruined by this disease. I now worry about getting Alzheimer’s.

[PHI Redacted]

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This test should be more main stream with aging Americans increasing and early detection enabling measures to slow down progression and huge expenses of care.

Sincerely,

Ms. Jennifer Goode

[PHI Redacted]

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As a caregiver for my father, I cannot emphasize the importance of early detection of this devastating and costly disease. My father is suffering from early onset, and as a result of early detection in 2003, is alive and functioning today. We are lucky in that we had the means to aggressively treat this disease, but many are not as lucky. Until we find a cure, early detection is the best proactive treatment we have. It slows down the progression, and actually saves the healthcare system thousands of dollars in care.

We, my father and I, were able to embark on numerous experimental treatments because of our economic status. I am convinced, one of these procedures slowed the course of this disease or my father would not be alive and ambulatory today.

It is imperative that whatever means are available for an accurate diagnosis are utilized. I think the savings in medical care with early detection should encourage people to cover this important test. We could also utilize this data for further research.

Let's face it, this will be an epidemic before long, and we must act proactively. Think of the longer term savings in care, versus the short term goal of not reimbursing this test.

[PHI Redacted]

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My mother had Alzheimer’s disease..... Her mother had Alzheimer’s disease.... My 2 sisters and I wonder which one of us (or all of us!) will get Alzheimer’s disease. It is not a nice way to live. Every time I forget someone's name, or who I gave information to, my 4 daughters say “you already told me that”, or “you never told me that”, I wonder.... “Is it me???? Am I the one???? Am I going to burden my children with this awful disease? Am I going to forget who my 4 beautiful daughters are!?!” (One of whom is working in neuroscience at the NIH... I am sure because of her grandmother!).

Life is never easy after a diagnosis of Alzheimer’s disease... I won't bore you with the day to day details of living with my dear mom's Alzheimer’s. Suffice to say that my 4 young children suffered as much as I did. I am a Master's prepared RN, but nothing I ever did, including telling parents that their child was not going to make it out of open heart surgery alive, compares with the stress, anxiety and deep sadness of Alzheimer’s.

All I can say is please, please make Alzheimer’s a priority! You cannot understand the horror until, you live it, and I would not wish that on anyone.

[PHI Redacted]

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My first experience with Alzheimer’s was with my Uncle Fred. How devastating to have a loved one not know who you are. This was back in the late 80's. Since this time I have worked as a care giver for many others with this disease. More needs to be done to find a way to stop this disease! This affects everyone!

[PHI Redacted]

-

In 2009 I lost my mother after several years battling with Alzheimer’s disease. I want to feel that the best means of early diagnosis will be found and also effective means of treatment will be developed so that I stand the best chance of not ending in the same way.

For her, diagnosis came too late for any treatment to slow the progress of the disease. Although we were able to provide her with good nursing care and in the end with good palliative care, the cost of such care is beyond the means of most people who suffer from this terrible disease.

[PHI Redacted]

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I am personally at risk for Alzheimer’s; my father, who died with AD, started showing serious symptoms at just about my present age of 80-plus; his mother also died in serious dementia in her mid-80s, and the two cousins to whom I was closest in childhood, both slightly younger but of opposite sexes and one each from my mother's side and my father's, also are diagnosed with dementias, one confirmed as AD. As you perhaps can imagine, by now, if I didn't keep busy, I would be spending my days and nights in fear.

Circumstances alter individual cases, I know. But if I did show symptoms, I would want every test in the techno/medical armory to be available, so that my children and I could have every bit of head start in planning that was humanly possible.

Please reconsider banning any particular test from coverage.

[PHI Redacted]

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There are now drugs that can significantly delay Alzheimer’s. Early diagnosis is essential to getting these drugs in time.

Please, please do what you can to help folks get these necessary drugs.

Sincerely,

Mr. Rick Clemenzi

[PHI Redacted]

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To everyone who may read this message, I thank you.

Wife Betty, a retired educator with advance Degrees, developed Alzheimer's in 2005 and I, husband, became her sole caregiver throughout this terrible journey until she died May 28, 2013 at age 68.

You have already read the many stories effecting families dealing with Alzheimer's. Betty was still mobile until a few days as I watch her passed in the Marmet Center. While I kept Betty at home as long as possible could not get help for my needs; doctor's, dentist's appointments and etc. No one would sit with a mobile Alzheimer's person and the many agencies displayed enormous fees.

You are probably bored with this outcry for help and hardship caused by the Alzheimer's disease but PEOPLE it is real and you cannot swept it under a rug!!

When I discovered where my donated dollars were being spent I learned only two cents out of one dollar goes to research this disease, I am asking WHY such a small amount?!!

I am asking you please add a larger amount of the dollar for research so everyone's aware of AD. We need RESEARCH not so much PR work Again I Thank You.

[PHI Redacted]

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Since my wife's diagnosis EOAD, our life has improved. She knew that something was wrong but could not express what it was in words or thoughts.

I have found out that highly educated and intelligent folks are much better at covering up the problems they are experiencing.

She no longer is able to work as a R.N., but was fired and no one knew that her diagnosis was what was causing her failure to continue in her field after 25 years.

[PHI Redacted]

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If we could have known more about the progression of Alzheimer’s, we might have been able to keep my mother in her home (with assistance) for another two years. Also, many facilities don't understand the special needs of Alzheimer’s patients so they don't always receive adequate care.

[PHI Redacted]

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My husband was finally diagnosed with Alzheimer’s in 2008. He has been diagnosed as having early onset and had to go to a nursing home in 2011 when he didn't know me and wouldn't let me help him with his insulin and blood sugar testing. He can no longer feed himself or walk by himself or do any personal care. He can talk but he doesn't make sense and sleeps more and more. He was able to be on Aricept and later Namenda once he got his diagnosis. It is very important to know what one is dealing with and to provide proper care.

My husband retired at the end of 2004 and I realized something was going on in 2006 and he himself had talked to his primary care doctor about maybe having Alzheimer’s and was told he didn't have Alzheimer’s. Proper diagnosis is important. The first neurologist who examined him didn't realize it because she went to Ohio State University and so did my husband and they talked about that and he covered well. His diabetes doctor was influential in getting him in to see another neurologist who was able to correctly diagnose that he had Alzheimer’s.

[PHI Redacted]

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Alzheimer’s will become a national crisis if we do not address proper care now.

Sincerely,

Mr. Alex Oshiro

[PHI Redacted]

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Today I went to see my mother's neurologist and he emphasized how important early diagnosis is with Alzheimer's, the earlier it is treated the better the outcome, this is what makes it possible for family to keep their loved ones home for an extended time. The later the diagnosis comes the sooner the person needs to go to an extended care facility. This point alone should be reason to diagnosis as soon as possible. ECF costs are skyrocketing and Medicare/Medicaid will not be able to keep up. The importance of keeping these people home with their families should be#1. I also would like to know why Alzheimer's is not treated the same as cancer, who would tell us we could not use these scans to diagnosis cancer, Alzheimer's must be put on the front burner it is and will affect all of us.

[PHI Redacted]

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My husband has early Alzheimer's and is now 84. He has served his country with honor during the Korean War and also spent 20 years in service after that.

He deserves the best care we can provide for him, not only because he answered the call in Korea, but because he is a human being deserving of all that can be done for him.

To delay, put obstacles in the way of accurate, beneficial care is an insult to the intelligence of all seniors and their spouses as well as those who have served.

I urge you and your friends in Congress to do everything possible to make this care assessable and available to all who need it now and in the future.

[PHI Redacted]

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As part of my work, I became very familiar with the symptoms of Alzheimer's disease. One of my subordinates began developing the symptoms around age 50. Since there is no definitive way to diagnose early Alzheimer's, I was faced with the problem of either ignoring her performance issues or having to fire her.

If there had been a test, combined with a medical opinion, she may have received benefits from her group medical plan and, perhaps from her group disability income plan.

Instead, when I retired she was dismissed and her husband had to quit work to care for her. When she was disabled for over a year, Medicare paid for her care. The diagnosis was a surprise when it came. Since there was no time to plan, the emotional and financial effect was devastating.

I would strongly urge you to allow the Amyloid Imaging test for diagnosis of Early Alzheimer's disease. This would allow for a fast approval of Social Security benefits. It may also provide the incentive for private insurers to also cover the test and provide benefits before government programs become the last resort.

Sincerely,

Mrs. Cheryl McNamara

[PHI Redacted]

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My dad, [PHI Redacted], died from his 11 year struggle with Alzheimer's disease in 2004. Our dad slipped away from us over many years. He was always our "go to guy" when any of us needed help. And in the end, there was nothing we could do to stop the terrible progression of Alzheimer's. We loved him dearly but could do nothing to make it go away.

I'm not sure how many families are able to deal with this disease. It seems to consume everyone related to it. It nearly ruined my mother's health who was his main caregiver for 9 of the 11 years. For the last 2 years, he lived in an Alzheimer's Unit of a Nursing home. They were reasonably good to him but it was NOT what our family wanted for him. Faced with needing to have care for him 24 hours a day, we simply had no choice because it was impossible for 1 or 2 people to care for him. I personally developed interstitial cystitis due to the stress of managing his care and being his advocate throughout his years as a patient as well as my mother's deteriorating health.

It is important for families to know as soon as possible of an Alzheimer's diagnosis because there are so many financial decisions that need to made so those who are left behind have funds to live on. There are so many decisions that need to be made regarding who will care for the person, how they will be cared for, where they will be cared for. The decisions never end.

[PHI Redacted]

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My mother recently passed away and dementia had set in a couple of years prior to her death. Her primary physician knew of her dementia and asked her if she would like to take medicine for it. Mother declined due to the risk of unpleasant side effects.

It is my hope that there is a cure for this terrible memory destroying disease of the brain. Early detection and diagnosis is important since new medicine just might be the cure one day.

[PHI Redacted]

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Simply put...Because of the lack of adequate diagnostic tools, my mother was not diagnosed until she was late mid stage/early late stage Alzheimer’s. It was a year after the first cognitive testing that the decline was significant enough to declare it Alzheimer’s. This was at a Research Memory Clinic. At that time there were no Amyloid PET Scans. From experience, I can attest....If there is a scan that could give an earlier diagnosis it would be better for the patient and the family. We wasted over a year not knowing! A year of chaos, inadequate care for my mom, confusion in the family, and distress on the part of all involved not knowing. Please include early diagnostic procedures in your considerations please!

[PHI Redacted]

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My mom is an extraordinary woman who is afflicted with Alzheimer’s. I have said goodbye to the once vibrant woman I knew who was and continues to be my inspiration and role model. Luckily she is still with me however she is now further away and with each season retreats more and more into her world. I love her with all my heart but miss the many conversations we once shared.

We had no help. We struggled and fumbled at the beginning. And if it weren't for my tight knit family I do not know where we would be today. We have chosen to keep her home with me rather than place her in a facility. It is a sacrifice but one I was willing to make after much soul searching. I was fortunate to have an extremely supportive partner and with my family we pooled together our financial resources in order to pay for two caregivers. It is our reality now but we know we made the right choice for our family. Fortunately for us, my mom has held on and still recognizes us and responds to the constant love and affection given to her. It has made all the difference in the world for her and us.

[PHI Redacted]

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[PHI Redacted]

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Having personally dealt with my [PHI Redacted] who lived just short of 100, I know how devastating this illness is. She went from a vibrant contributing member of society into her early 90's to a rapid declining person who was aware that she was dealing with this disease until, it finally took her mind and being. Allowing people to not receive a proper and early diagnosis is unfair to families and caretakers. It forces people to be housed and live with a condition for many years that is tolling on all concerned. We must address this problem and get this disease under control ASAP!

Sincerely,

Ms. Susan Gordon

[PHI Redacted]

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My husband is 58 years old. He is in a nursing home with early onset of Alzheimer’s disease. My husband is a Professor with two Masters Degrees and a PhD.

I have known for as far back as ten years ago that something was wrong with my husband. I rationalized the changes with stress, with mid-life crisis, that he was just being an "ars." Jealousy appeared, paranoia, he was making notes and posting them everywhere.

One day he called me. He was in another state and he was lost. Not lost like which highway do I take. Lost like oh my God, how will I find him? Help me Lord. What do I do.

It took me ten years to find a diagnosis for my husband. For ten years all I wanted was to know what was wrong. If I knew what was wrong, then I could deal with it.

One more thing: we have a son named Jack who is 18. He is at a 50/50 risk of acquiring this diagnosis as early as in his thirties... If we can detect this early in his life, then maybe, just maybe we can start treatment early and stunt this ugly disease? Please? Will you do this for us

? [PHI Redacted]

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Hi. My name is Therese and I take care of my mother full time in our home. She was diagnosed with vascular dementia and Alzheimer’s disease at the Mayo Clinic only 3 years ago. She has had these diseases for many, many years but without the proper tests, the doctor felt she was depressed and rationalized her decline as such. I didn't know how to help her and she became dangerous on the roads and in her own home. She would put metal in the microwave, touch an outlet with wet hands, and not notice she was doing anything wrong. Her spending became out of control and she couldn't remember to pay her bills. She became $60,000 in debt in a matter of a couple of years and was going to have to file for bankruptcy.

Early detection of the dementia would have meant early intervention. I took over all of my mother's finances and paid off every single bill/ person she owed. Early diagnosis is imperative. We could have made better decisions and my mother's quality of life would have been significantly better had testing been done to diagnose my mother sooner.

This disease has torn apart our family. It isolates and tries to destroy not only the person with the disease but the primary caregiver too. Please don't look away. There is no other disease out there like it; one that will thoroughly destroy an entire family but will do it painstakingly and slowly. Help us defeat this disease.

[PHI Redacted]

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This is an awful disease and too many people are living longer and need some help in battling this disease. Please, don't push Alzheimer’s help aside.

Sincerely,

Mrs. Rhonda Lawford

[PHI Redacted]

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It is important for an early diagnosis for this disease. It took 2 years to get my late wife diagnosed with early on-set Alzheimer's, due to her only being 53. We went through change of life, menopause, and even being told that she was a hypochondriac. By the time we got her diagnosed (2 years later), she had permanently lost a lot of brain cells, and the disease was progressing. She died at age 62. Her medical bills and medications destroyed us financially. Social security disability was denied twice, and luckily finally approved the day before we started legal proceedings. This approval provided Medicare, which kept us from losing our house and car. So yes, early diagnosis is of the utmost important for starting of early treatment, financial, and extended care options, as well as end of life preparations.

[PHI Redacted]

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My little mother died in 2002 after suffering the ravages of dementia. I cared her for the last seven years of her life what turned out to be the best seven years of my life. At that time, her doctor said that IF the Aricept slowed the progress of her disease, it would be an indication that her dementia was related to and/or combined with Alzheimer's disease. Fortunately for us, it did, but one can only wonder how much the quality of her life would have been increased had the diagnosis come earlier.

The lives of our seniors are precious. They are worth preserving. The choice lies in your hands.

[PHI Redacted]

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As a mother of four adults, three of which have been diagnosed with Alzheimer's, and a husband who was also diagnosed with AD, I have hands on experience of the importance of early detection and accurate Alzheimer diagnosis. My husband was diagnosed at 42 and passed away at 52 years. My eldest daughter was diagnosed at age 44 and died last year at age 48. My youngest daughter was diagnosed last year at age at 38 and my son of 44 was just diagnosed this year with AD. This horrible disease robs your loved ones of all they have accomplished in their few years of life. Early detection can provide whatever medication is available sooner in addition to qualifying for services needed. Please don't set back any funding or testing necessary to treat this illness. We need help and as a caregiver and a senior citizen, I need all the help I can get. Thank you.

[PHI Redacted]

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My dad has severe memory issues as well as general physical degeneration at age 88. We do not have a diagnosis. We didn't know there was a way to find out for sure if it was Alzheimer’s. He did not receive any specialized treatment for Alzheimer’s, and his condition has been deteriorating for 8 years. For his sake, as well as for family members of the subsequent generations to perhaps avoid the illness if they know it is in the family, we need access to the test. It is just as important as treatment of cancer or heart conditions.

[PHI Redacted]

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Time to give this disease the recognition it deserves as a looming epidemic for successive generations.

Sincerely,

Mr. Brandon Chavez

[PHI Redacted]

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If you have had a family member go through the totally debilitating, demoralizing, and dehumanizing ordeal of Alzheimer’s you would understand the desperate need for accurate early diagnosis in cases where there is hope that another, treatable disease may be the culprit. This test, given when appropriate, can also save millions in medical treatment and care of advanced dementia patients, and frequently the added expense of treatment and care for family members whose own health is degraded through the stress and exhaustion of that very trying, often years-long ordeal of care giving for patients of these dreadful diseases.

Sincerely, Ms. Paula Jordan

[PHI Redacted]

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My husband Tom has dementia and I his wife am his sole caregiver. We have had numerous diagnosis and treatments all with differing diagnosis and treatment. If we had known earlier what we know now we could have implemented certain treatments in the earlier stages which would have slowed the progression of his disease. First diagnosis cerebritis and on prednisone x l yr. at Ohio State Univ. which ended up be more detrimental his condition. Second Cleveland Clinic conferred with OSU. Third was Mayo Clinic diagnosis Alzheimer’s. Most other physicians do not agree with this diagnosis stating that his is vascular in nature and he has shown mercury and lead poisoning which can give similar symptoms. So I am trying to say that an early and accurate Alzheimer’s diagnosis is essential.

[PHI Redacted]

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My grandpa passed away from Alzheimer’s in 2010. It's devastating to see your loved one go through a discussing illness they changes your life forever. We need a cure, we need to come together as a nation to find a cute for the future generations.

[PHI Redacted]

-

This is an extreme hardship on families to have someone u love going backwards is so heartbreaking my father can't tell you what he had for a few weeks to eat! Can't read a book or watch a TV show as he can't remember the beginning was about so he can't put it together. My parents just celebrated 65th anniversary he 88 thinks he's 58 or younger. I'm 58. Had to sell my home to move in and help them. Had to quit working. Which will affect my retirement situation. Needs to be cured. Too many affected.

[PHI Redacted]

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I am a 39-year-old Psychologist with Posterior Cortical Atrophy. I still work full-time but am making preparations for that to change in the future. I work with dementia and aging patients as my specialty area. The ability to utilize tests such as brain amyloid imaging is highly important. Even though I am a psychologist, it took almost a year to advocate to physicians to conduct the necessary tests to confirm the presence of a degenerative neurocognitive disease for myself. Many are unable to advocate for themselves and relationships, finances, and families suffer before the individual is diagnosed accurately with dementia.

Brain amyloid imaging is good science and should be funded in Medicare reimbursements to assist in earlier and improved diagnoses that allow for more efficient use of medical treatments and preparatory planning. Dementia has the potential to be reversed in some conditions and differential diagnoses through such advanced neuroimaging techniques are necessary. Would we not want to do the same for testing procedures that allow for differential diagnosis of cancer types?

[PHI Redacted]

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My mother died of vascular dementia. My father died of Alzheimer 's disease. My 2nd husband died of Alzheimer's disease, diagnosed by a geriatric psychiatrist. The last year of his life, his internist diagnosed him as having PTSD left over from his combat experience in WWII.

My heredity leads me to believe I have a better than average chance of coming down with Alzheimer's disease, sometime in the next 10 years. My father was diagnosed by his behavior. My husband was diagnosed by psychological testing and an MRI. We need to improve on the testing for Alzheimer's disease beyond the generalized testing we have now.

[PHI Redacted]

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This would make their lives better. My father had this following a small stroke.

[PHI Redacted]

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My father died of Alzheimer's disease, and I know I need to have a test to determine if I also have Alzheimer's. I frequently forget details to the point of no longer trusting my own memory. I am begging you to allow me to find out early enough to treat my possible illness.

[PHI Redacted]

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Please insist that any doctor that makes a diagnosis also reports to DMV. I am a daughter of a mother with early onset, age 60 when diagnosed, she continued to drive and with my sister in the car went 2 miles down wrong side of road. I have been a private caregiver of Alzheimer’s for 5 years, plus cared for my father who also had it for 3 years until his death. In all of these cases, and 3 others I have worked for, none of them should have been driving even with early diagnosis. This is a very serious issue to me, and my children have all been instructed to take my keys and license if I develop the disease. I have had DNA testing and do carry two of the markers, have tried on several occasions to be a part of studies to see if I develop it, but have had no luck at all in receiving any input on this.

[PHI Redacted]

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Please. This is so important for so many reasons. And you know it.

Sincerely,

Ms. Melinda Stephan

[PHI Redacted]

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My mother has dementia (possibly Alzheimer’s) and it has been a painful journey for my entire family as with so many families. An early diagnosis would have meant that my family could have made more effective choices about her care in the earlier stages. Some of my family members would have been more sensitive through awareness rather than judgmental about her "forgetfulness" and mood changes. An earlier diagnosis would have enabled us to join together as a unit to respond to her needs in a more humane and beneficial way.

[PHI Redacted]

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My brother-in-law has Alzheimer’s which started more than 5 years ago. Now he is at a stage where he cannot do anything for himself. He has been bounced from hospitals to nursing homes and back home again.

My sister has become a nervous wreck dealing with all of this because she is constantly hounded by agencies who are suppose to help her get him placed and provide food when he is at home. They give wrong information and it takes too long to get it corrected. Nursing homes send bills for expenses which Medicare is supposed to pay and providers take too long to deliver food when he's at home(he has to be fed through a syringe). Some aides are not dependable (coming in the mornings when they are supposed to come in the afternoon and one or two did not know how to care for him).

Something should be done to improve agencies' responsibilities as well as early diagnoses.

[PHI Redacted]

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I feel the brain amyloid imaging allows for an accurate diagnosis of Alzheimer’s versus other forms of dementia. My mom was recently hospitalized for heart problems and exhibited dementia symptoms while there. She had terrible memory loss prior to the visit. When I questioned the doctor, he told us he "thinks" it is mild dementia. After leaving the hospital, we had no idea what that diagnosis meant. Does she have Alzheimer’s or is this from the heart condition (AFib can cause memory loss, as well as her meds). Without the brain amyloid imaging test, we will never know. According to that doctor, she should see her Primary physician to take a "question and answer" quiz to tell if she has Alzheimer’s. Well, that won't tell us if it came from the heart condition, Alzheimer’s, stroke, or what -important information before she starts taking Alzheimer’s drugs for a condition she may not have!

[PHI Redacted]

-

My mother suffered from Alzheimer’s ... one of the most devastating diseases that you can experience. I always wonder if my mother knew at the beginning what was happening ... in a way, I hope she didn't. I hope she didn't realize the horror of what she was going to go through. It was heart-breaking for her four daughters. I still cry about losing my mother too soon ... at the age of 38 years, I should have been enjoying time with my mother and my toddler and newborn ... My two daughters will never know their grandmother and I will never experience parenthood with my mother here. I can only hope that my two daughters do not have to go through the same tragedy with me. Please help us find a cure for this devastating disease.

[PHI Redacted]

-

The more information that people have about Alzheimer's the better they can make informed and timely decisions for themselves and their loved ones.

Sincerely,

Ms. Annette Bryant

[PHI Redacted]

-

I work with veterans who have dementia every day in my position at VA Puget Sound Health Care System. It is a costly and crippling disease which affects not only the patient, but the whole family as well. Please consider support and research for early diagnostics in order to direct the patient and their family to medical and community support to delay costly institutionalization as long as possible. Thank you.

Sincerely,

Mrs. Barbara Reuter

[PHI Redacted]

-

My mother was diagnosed with dementia in 2001 and died in 2010. We were thankfully able to obtain kind caring people in a setting which cared for her like family! The medications took a while to stabilize for her care. Some less invasive ways of determining the type of dementia patients have will help others to give appropriate care to our loved ones. Allow the others less pain than those who have gone before, please.

[PHI Redacted]

-

My mother and her sister have Alzheimer’s. It is a devastating disease. I am an only child my mother has had Alzheimer’s for 9 years now. She is in her last stages it is breaking my heart to see this happening to her! We need to find out earlier in life and be able to get an accurate diagnosis. The only way to get this done if there are the funds available for research! So, I urge you to allow this to take place for all the baby boomers out there!!!!

[PHI Redacted]

-

Alzheimer’s is a horrendous disease for the victim and a painful disease for the loved ones of the victim. I watched my mother suffer with Alzheimer’s for 10 years and I took care of my aunt (her sister) for 7 years who also had this disease. I am so scared that if I get this, my children will have to go through what I went through with my mother and aunt. Please we need to money and resources into finding a cure. We can do it.

[PHI Redacted]

-

My mother died this last February of Alzheimer’s disease and heart failure. She was never "formally" diagnosed but was given Aricept. The doctor said she had dementia/Alzheimer’s but never talked to my mother or me about treatment options etc. He never did any tests.

I believe that an earlier diagnosis, information and options would have been a great help to my mother and me.

[PHI Redacted]

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My mother was showing signs of Alzheimer’s at least 10 years before her diagnosis.

[PHI Redacted]

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Please support funding for Alzheimer’s disease. God Bless.

Sincerely,

Mr. Dave Mattozzi

[PHI Redacted]

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This is an ever increasing health issue that needs to be addressed, funded and researched. It has hit my family as well as many others. Thankfully we are able to keep my mom at home. I believe in my heart that being surrounded by her family has slowed the progression of this condition.

Please help!

[PHI Redacted]

-

My maternal grandfather died of AD at the age of 67 and so did my mother at 67 and my aunt in her seventies. My grandfather was not diagnosed with the disease, but, my mother and my aunt were, and the symptoms were almost identical.

I have tried to find ways to get into an early detection program; but, have been unable to find a clinical group in my area. Government assistance would be appreciated.

[PHI Redacted]

-

I am 15 years old and helping my grandmother that was diagnosed last year with severe dementia. My mom and I want to get her retested because we have seen her memory worsen and we need more help with her. But it's going to cost us so we need your help to get her retested. Please help us help her.

[PHI Redacted]

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Fund this preventative program.

Sincerely,

Mr. Jason Husby

[PHI Redacted]

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My mother has Alzheimer's; I have seen the devastation that this disease can do to those who suffer and to all who love them. Our country needs to do all that it can to fight this tragic disease.

[PHI Redacted]

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My wife was diagnosed with Alzheimer's over six years ago. The progression of the disease has been slow and difficult to determine. We have visited 8 or more Neurologists. Two have diagnosed her with Alzheimer's, five have not made definitive diagnoses, and one has said she definitely does not have Alzheimer's. We are still working with Dr. Gregory Jicha, Sanders-Brown Center for Aging at the University of KY. He has my wife in a research program. We have visited the Mayo Clinics in Jacksonville FL and Rochester, MN seeking answers. Diagnosis of Alzheimer's is still pretty much a guessing game and is very expensive. Being able to map the brain using CT's would take a lot of guesswork out of a diagnosis, and would save a considerable amount of money in Medicare costs. I am not alone in seeking every possible clue to identify what is going on in my loved one's brain. I can not rest until I know for certain her diagnosis and can be expected to continue to search until I have the hard evidence that a brain scan will show me. I beg you to approve this test. You may consider me irrational, but put yourself in my shoes - wouldn't you search to find an answer, if your wife was diagnosed with Alzheimer's?

[PHI Redacted]

-

My husband had 3 vehicle accidents and could not remember any of them. He began getting lost could not find his way home. Medicare and MediCal did not give him any tests, just told me he may have dementia or Alzheimer's, plus I am disabled and it took a long time to get him in a home after his stroke.

He had both Alzheimer’s and a stroke. It would help to have a test before so you know he has a serious problem.

[PHI Redacted]

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I am 56 years old, with a father, paternal Aunt and paternal grandmother all having fallen to dementia/Alzheimer’s as they advanced in age.

2 of my paternal aunt's daughter, hence my 1st cousins, have been diagnosed with dementia/Alzheimer', one in her mid 50s (i.e. early onset) and the other in her mid 60s; they are both in their 60s now and living in institutions already.

I have been trying for several years to enter a longitudinal trial but have yet failed. I may have hope with the R.I. Hospital this month. I believe research and funding are our only hope. It is critical for families like ours, and for the population in general, that research be upped and the early detection and hopefully treatment be designed at once to fight this epidemic.

Thank You for doing just that as a legislator.

[PHI Redacted]

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My mother died of Alzheimer’s disease in 2010 only two years after a very late diagnosis. She was able to mask her growing confusion due to her very high intellect, but suffered in silence without our love and support. Instead, not knowing, we lost patience with her occasionally revealed lapses and gradual retreat from our family life. Please don't allow other families to live with this regret.

Only with early diagnosis can we get an accurate picture of the growing percentage of our elderly suffering with this insidious disease, and then direct the appropriate amount of research dollars to a cure. Please support early diagnosis.

[PHI Redacted]

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I dealt with a doctor my mother chose who did nothing. He saw her on her return visits and wouldn't even listen to what I had to tell her as a primary care person in my mother's life.

She lived in my house telling me she would pay for her care but kept sending money to my brother who did nothing to help her. And gave me nothing of her money to care for her. She constantly told me and others that I was stealing from her when she would find what I was suppose to have stolen she would never say she was sorry. She kept thinking she was 20 years old and walked around naked at home and peed and pooped all over the house constantly.

But all I would hear from the doctor was she was his patient I was not. And he could not discuss her care with me. I was livid.

This not only cost me all my savings. But it caused me great stress and my problems with my family were vast and very problematic. A standardized test may not fix the problem unless everyone can be given any kind of test that is made up for Alzheimer's. And official status is given to family members who care for parents or others for care and can talk to the doctor about what a parent is doing and the doctor needs to listen to the care person.

[PHI Redacted]

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It took us almost 2 years to get the most devastating diagnosis that my husband, at age 59, had Early Onset dementia. There were tests out there but we were not entitled to them because the doctors insisted he was simply depressed. My husband was never depressed his entire life. He was the proudest and most wonderful police officer for our local police force for 30years. Yet the neurologists kept saying that he was not eligible for the "million dollar tests". A simple CT scan or MRI would have helped to determine his condition. There are more tests out there and we all deserve to have them to better our lives and those that we love and live with. Early diagnosis is so crucial to us all, please work to get these tests provided for us now. Alzheimer's is the most misdiagnosed and undiagnosed disease out there, please help now!

[PHI Redacted]

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My mother had this terrible disease beginning in her 40's. It was devastating.

[PHI Redacted]

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I am writing to share my story. Both my paternal and maternal grandfathers passed from complications of Alzheimer's disease. At the age of 55 my father began to show similar signs of the disease and after a long battle, died at the age of 67. We donated his brain for research hoping for some insight, hope and even more so, a cure. All three men in my family led the most comfortable path we could provide during their decline. There were numerous incidences along the way that we feel could have been avoided had there been an earlier diagnosis and thus, appropriate care of support planned out. The challenges we faced were life altering and ongoing for decades. Thankfully my parents planned out their finances, and although we still incurred years of untangling bills and paying them off for the eventual necessity for in home care and then hospitalization for over a year with my father - we felt that the ground work of diagnosing our family members should be been in place at the very least. Please support the ever growing number of families touched by this disease. Help diagnose, treat, and provide the care necessary for these human beings who are helpless to this fatal disease. My father was a Harvard professor. He did not smoke. He did not drink. He was a healthy weight and exercised every day. By the age of 60 - he stared at me blankly referring to me as "little girl" before finally not knowing who I was or even being able to formulate words by the age of 63. By 64 I was showering him, brushing his teeth and changing his diapers. Our lives were put on hold - gladly to serve our father - but the support we needed was not there. Please help. You have the power to put energy and money into assisting the victims and families of Alzheimer's disease. Please make it a priority to fight for the things we need.

[PHI Redacted]

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My mother died after suffering from Alzheimer's for maybe 10 years. We don't know how long she had the disease. Had she been diagnosed early on we may have had her company and memories for more than 5 years.

[PHI Redacted]

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I have been working with this population for over 13 years. It is necessary for the caregivers and the patients to have an early diagnosis, as it assists with preparation for care.

Sincerely,

Ms. Evelyn Mannino

[PHI Redacted]

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My mother suffered with Alzheimer’s for 7 or more years. She had to undergo grueling testing by answering numerous questions on two occasions. The test was very frustrating for my mom. If an MRI was available she wouldn't of had to suffer unnecessary agony.

[PHI Redacted]

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Please consider approving the test to differentiate types of dementia and providing a way to diagnose Alzheimer’s as early as possible. The experts think that the blood test they are advocating has a good track record. As so many Americans are learning their diagnosis later, it would be advantageous to insurance and MC companies to families to know the diagnosis earlier to provide more cost effective treatment for all.

Sincerely,

Mrs. Lois Heckart

[PHI Redacted]

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I cared for my mother in the last decade of her life as dementia crippled her relationship with the world about her. She lost recognition of family members who rarely saw her even as she retained knowledge of my family with whom she lived. But she was never offered a formal diagnosis of cognitive decline nor the services that would have reduced the burden upon me in the last year-and-a-half when she was in full-blown dementia and at times combative. I did not have the support of my male siblings as I was the sole female and, culturally, the burden fell upon me. I lost years of my life as a professional person and my mother was denied the support of services through Medicare that might have ameliorated the difficult situation in which we both found ourselves.

It was a decade ago that my mother died after I devoted over a decade of my prime earning years to her. I never recovered financially. I did learn the valuable lesson of living my life to avoid her tragic end-of-life experience. Diagnostic and treatment protocols for cognitive decline in the elder years are an imperative. I am a few years short of qualifying for Medicare. I provide valuable community service to the needy in my rural area medical services that support my cognitive health are an imperative.

[PHI Redacted]

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In working with many people who are in the early stages of memory related disorders, I understand the importance of getting an accurate diagnosis.

Being able to use Brain Amyloid Imaging in specified cases would help to reduce the amount of "second" or "third" medical assessments and opinions that are costly especially in the Medicare system.

Also, there is increased tension and stress in families in which the diagnosis is not confirmed. Symptoms are present and the families often suffer from stress related conditions, using Medicare dollars for their own care. Meanwhile, they are in "limbo."

The other reason to support this Imaging tool is to encourage participation in clinical trials so that research dollars are used more efficiently. Since we know the current impact of Alzheimer's disease and related dementia's on those affected and we anticipate numbers growing, deterring use of diagnostic tools to assist in accurate diagnosis only prohibits participation in the much needed research for adequate treatments for all dementia.

In those specified cases, people often struggle with what to do next as they are unable to get medical direction as to the cause of their cognitive symptoms and they also cannot get treatment.

Since Alzheimer's disease and related dementia's have been identified as a primary public health issue, it only is logical to support Medicare coverage for the use of Brain Amyloid Imaging as outlined by experts who convened as the Amyloid Imaging Task force.

Please reconsider support of this diagnostic tool to support better care and treatment for those who are struggling with the reasons for their cognitive symptoms.

Sincerely,

Ms. Julie Thomas

[PHI Redacted]

-

Alzheimer's disease is horrible, mostly for the caregivers. Please support significant funding for research and awareness. It is going to cost the U.S. government astronomical amounts of money through Medicare and Medicaid if money is not devoted to finding a cure or a way of slowing it down now.

Sincerely,

Ms. Vicki Winner

[PHI Redacted]

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I hope that you will see that in certain situations amyloid imaging should be covered by Medicare immediately to improve the quality of care. I only wish that this type of testing were available when my mom had Alzheimer's. Early detection can help improve the quality of care for the patient as well as help family and other caregivers when caring for a person with Alzheimer's.

Thank you for your time.

[PHI Redacted]

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Don't let our seniors get lost.

Sincerely,

Ms. Betsy Holway

[PHI Redacted]

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I watched my grandmother over the course of 13 years decline and eventually die from Alzheimer’s disease.

During her last years of life, my husband and I noticed changes in his father that were concerning.

His father went to his primary care doctor who ran the appropriate/covered tests to r/o other causes of dementia. She referred him to a geriatric psychiatrist who ran the battery of cognitive testing. He explained to us that Alzheimer’s disease at this point is diagnosed truly after death with a brain biopsy. Currently we can only diagnose by ruling out other causes of dementia.

My father in law chose the approach of denial. He would not take his Namenda - because he did not have Alzheimer’s disease. He progressed to the point that now he has difficulty speaking, reading and comprehending what other's are saying. He doesn't like to take a bath or change in to clean clothes. Imagine July in Kentucky with that approach!

Finally, he became fearful and started to take the medication. He has lost so much of who he is and is losing his independence. He is living at home right now. The medication has provided some improvement and has slowed the progress of the disease - a little.

His wife has vascular dementia. Again, there is no cure. She knows who we are but cannot remember what happened five minutes ago. She is living in a personal care facility - not quite skilled care.

This cost $5000 per month. Right now, us children are providing the care needed for my father in law. We are exhausted and will need to hire someone to help us soon. Their funds will be depleted over the next 3-4 years. At that point, I am sure they will have to move into skilled care and utilize the Medicaid system.

Our health is taking a hit. The stress level in our own homes is out the roof. Do you know what stress levels due to the level of beta amyloid in the cerebral spine fluid? It rises. A lot.

Please consider the amyloid imaging for early detection of Alzheimer ’s disease. You will help with earlier, definitive diagnosis which will provide earlier intervention and planning. You will keep people out of the financial spiral that forces them into the Medicaid system and into skilled care. Compare the cost of even 6 months of skilled care to a dozen imaging fees.

Now compare the cost of the average 2.1 adult children who go on to develop Alzheimer’s disease due to high stress levels and poor diet and exercise. (Have you ever tried to eat healthy and get exercise while caring for a dementia patient and working fulltime?).

[PHI Redacted]

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My grandma had this and I want to help prevent other families from having to deal with it if possible.

[PHI Redacted]

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Please don't leave the public behind with this terrible illness! It can happen to anyone.

Thank you,

Sincerely,

Ms. Lisa Graham

[PHI Redacted]

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Half of the more than 5 million Americans with Alzheimer’s have never received a formal diagnosis. We know that an early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer’s and their families. Yet the federal government is moving to put up a barrier to those benefits. I urge you to improve care and provide an accurate diagnosis.

Sincerely,

Mrs. Donna McGowan

[PHI Redacted]

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To All Those Concerned: I caregave for nearly 16 years for my mother who was afflicted with Alzheimer’s disease. As a healthcare provider, I had the skills and knowledge and insisted that my mom's primary care physician run some tests and do further testing to confirm the diagnosis. I had to convince the doctor to do this. This is because I followed and monitored my mother's changes every day and began noting even the most miniscule deterioration. Most cases aren't like this. If this diagnostic tool would be approved and utilized early on, an individual faced with Alzheimer’s could have those crucial options and make those necessary decisions early on before their life is dramatically changed with no possible, advanced planning. Please help to ensure this dementia diagnostic tool be made available to this population. Wouldn't you want to know and be afforded the opportunity to plan your future before becoming cognitively impaired?

[PHI Redacted]

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One of my most vivid memories of my mother's last lucid days was "Honey, I've lost my life." She was slowly losing her memory and ability to care for herself. She forgot her children's names, and was eventually unable to live alone and had to be put into nursing care because she needed 24/7 attention. She never wanted to have to go to a nursing home, she wanted to die of natural causes, in her own home, in her own bed ... Alzheimer’s took her remaining years away from her and her family!

This is a terrible disease that takes away a patient's life! The women in my mother's family lived to their late 90's, early 100's. My mom began to lose life at 84 when she was diagnosed with Alzheimer’s. She survived another 6 years until she died after a fall in a nursing home when she fell and fractured her hip. She never recovered, and died after a very painful 5 days in the hospital. The fall killed her, Alzheimer’s took away her remaining years of life.

PLEASE, we desperately need to increase research into prevention and cure of this horrible disease! The number of people who are getting this disease is going to vastly impact our medical system, and loving families more and more as we grow older!!

[PHI Redacted]

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I'm from a small town called Roseto, PA. Naturally, it's not easy to find a physician with expertise in Alzheimer's. Fortunately, we have a good family doctor who correctly diagnosed my grandmother. However, once we had a diagnosis, there was no plan of action. She was in and out of the hospital with related complications and given meds for psychosis. Some of them worked, some of them didn't. Currently, she's in a personal care home living out her last years. There's nothing more that we can do. Trying to access a good geriatric psychiatrist has resulted in not being able to find anyone local with any availability.

[PHI Redacted]

-

Half of the more than 5 million Americans with Alzheimer's have never received a formal diagnosis. We know that an early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. Yet the federal government is moving to put up a barrier to those benefits.

Sincerely,

Mrs. Donna McGowan

[PHI Redacted]

-

Thanks to an early diagnosis of Alzheimer's, my husband has received early treatment and has enjoyed a relative enjoyable life for the last 11 years. I would like to see others receive a diagnosis as early as possible and believe that the amyloid imaging will provide that. I hope you will not vote to prevent that diagnostic tool from Medicare recipients. Thank you for your consideration of this request.

[PHI Redacted]

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My mother received a "rule out" diagnosis of Alzheimer's disease after a wide battery of evaluations at the University of Michigan Hospital in late 1997. At that time, the rule out approach was the only option available. Ultimately, however, the doctors stated that there was also significant evidence of mini-strokes, and they shared that it was impossible to determine the extent to which either was affecting her decline.

How helpful the amyloid scan would have been in anticipating her challenges and in providing insight to my brother and myself to plan for what may lie ahead for us.

[PHI Redacted]

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Given the nature of the disease and the increasing numbers that are projected to develop Alzheimer's, I urge Congress to support research and treatment efforts for this disease.

Sincerely,

Dr. Martha Ellison

[PHI Redacted]

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My mother was an intelligent, active individual who watched her mother decline with dementia in the early 1960's (when you only whispered the word behind closed doors). In 1993, I was promoted to a job that required my working long hours keeping me away from home until late in the evening, and often on weekends. My mother lived with me, and took care of our home. I began to notice changes in her behavior, mood, and memory in 1995. It took from 1995 to 1998 to get a diagnosis a diagnosis that was derived from asking her a few questions and learning that her mother had had dementia and then, we were told that "it was just the dementia" as if dementia were a common, everyday occurrence about which I should already be fully informed. When I asked what the prognosis was, what to expect as the disease progressed, and what I could do to help her, the doctor replied "nothing," and warned me that soon she would need full-time supervision that soon she would go to the mailbox and forget how to get back home. That is exactly what happened one day while I was at work. I received a phone call from a neighbor two doors up, telling me about mom's confusion when he waved to her, she went up to speak with him, then he had to walk her back home and get her safely inside, then call me.

We had been to the doctor several times, and no one had told us anything other than it was just her getting older no one had mentioned dementia, and certainly not that it would be progressive, irreversible, and fatal. doctor after doctor told me to just let her go, it was normal aging...but it wasn't. We lost several good years because we could not get a diagnosis to get the care that she needed, to get the medication that could help with the behaviors, and to get the community services supports that she needed. From the treatment she received, and the fighting that I had to do with the medical community to get her any care, I certainly appeared to me that the medical community had simply "written her off," that she was somehow not worthy of a diagnosis or care.

At one point, she was given Haldol to help with her "sundowning." In less than 48 hours, she went from a very active, inquisitive, healthy person to having to use a wheelchair, drooling, and unable to communicate. The interaction of Haldol with medications she was already taking and the fact that although Haldol is contraindicated for those with Alzheimer's, it was still prescribed for her put her in the hospital. The doctor told me that she needed a feeding tube, because she had curled into a fetal position and he assumed that it was the normal disease progression. When I asked what would happen when, due to her dementia, she pulled the tube out, he told me that I would just have to let her go she had lived a good life (she was only 78). I declined the feeding tube because I strongly felt that it was either a medication interaction or an over-dosage of Haldol (at the time, I was unaware that Haldol was not appropriate). As they discharged her from the hospital, and I wondered how I was going to continue to work and care for her, the nurses assisted her from her bed to the wheelchair and she promptly became nauseated and threw up. The nurse took one look and me, and immediately went to call the doctor she finally agreed with me that it was a medication interaction and too much Haldol. They kept her one additional night, sent her home without a prescription for Haldol, but for a new medication. Within 48 hours she was able to walk, talk, and was getting mentally clearer with no more drooling. From that point on, I paid much closer attention to her doctors, and had to strongly advocate for her every step of the way. She had a nephrologist, a cardiologist, and a family physician and they did not communicate with each other. So, for each doctor visit, I got a copy of the additions to her files, and began carrying a catalogue case with me with all of her medical records, to share with each physician what the other had charted and then began asking them to have a conversation with each other because the nephrologist would give her medication to absorb fluids, while the cardiologist would give her medication to expel fluids and that was hurting her physically because they were not communicating. It took until 1998 to get a definitive diagnosis, and to get her the care that she needed she remained at home with me until she had to go to the nursing home for medical care that I could not provide at home. She had another hospital visit due to a urinary tract infection that did not present the normal symptoms and she went from the hospital to a nursing home for "rehab." When they realized that she would only improve as the dementia fog lifted due to curbing the infection, they withheld her physical therapy because there was no hope of her getting better only progressing through the various stages until the end. Though she was fully ambulatory, the nursing home confined her to a wheelchair strapped her in so that she could not get out to help control her wandering over my protests. Six months after her admission to the the nursing home funded by nursing home Medicaid (because we had exhausted her and my resources trying to care for her at home and get a diagnosis), she developed a skin tear that went untreated until I found it and brought it to their attention. It still was not properly treated, and she developed sepsis and was dead within 36 hours.

Individuals with Alzheimer's and other dementias deserve to have as good a quality of life as possible, with good medical care that contributes to their thriving as much as they can and to not be written off as unworthy because their condition is progressive, irreversible, and terminal. If diagnosed early, and provided proper care, they can live a good quality of life longer, and in good physical health longer in the community surrounded by family and friends.

Only one social worker who assisted us while my mother was in the hospital ever mentioned the Alzheimer’s Association, or adult day care, or the fact that she would soon need to be placed in a nursing home, or apprised me of what to expect with the disease process no physician was ever open and honest and none of them seemed in the least concerned that I might need to know about resources that might help us in spite of my questions. When I called the Association, they had huge waiting lists, so could not offer financial assistance, but they did provide care, concern, and guidance in helping me to learn how to care for her, what to expect with the disease process, how to handle behaviors and provided empathy and patience on the other end of the phone at 3:00 in the morning when I couldn't sleep because I was at my wit's end after battling mom's behaviors, the doctors, and others who would have me "just let her go because she had already lived a good life."

Earlier diagnosis and the determination that it was "dementia of the Alzheimer’s type," and doctors who understood the desperation that families have in trying to find out what is wrong so that they can make the best of the worst possible situation would have made the journey better mom would have received better, more compassionate care she could have been referred to a neurologist, or a geriatrician, or Wesley Woods for a full evaluation and diagnosis many years earlier especially with the history of dementia in her family...and I would have been better equipped to seek out resources to learn about the disease, the behaviors and non-pharmacological management of those behaviors, the nutritional needs, the contraindicated medications to allow me to be a better caregiver and a better daughter but more importantly, allowed her to retain her dignity and a better quality of life for much longer.

I felt that I had to battle the healthcare system to get her the care she needed not that the healthcare system was supportive of getting her the care she needed.

Early, accurate diagnosis along with receiving counseling to become aware of the disease process and community resources is crucial in supporting families who are facing the journey.

Please, had she been directed to the right type of physicians for the proper screening when we first started trying to find out what was medically wrong with her such as the brain imaging I would have known years earlier, and been able to learn about the disease so that I could access the proper community resources and care to provide her the care and quality of life she deserved. Please, living with the disease and caring for loved ones who have it is already hard enough don't throw up just one more barrier to an individual or family already having to fight to find out what is happening to them or their loved one.

[PHI Redacted]

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The methods to detect/diagnose dementia must be improved upon. My mother was diagnosed with dementia only after she was taken to ER by police. At least 2 years prior to this horrendous experience we had begged her family doctor to treat her for signs of dementia. The 'test' that her family doctor conducted consisted of him talking to my mother when she was at her annual exam. He told me that based on his conversation with her he did not see signs of dementia and would not diagnose. He also would not conduct any other tests to back up his diagnosis and simply disregarded the signs and symptoms that my family relayed to him.

The literal hell that we went thru - as well as the trauma that my mother endured - in order to get a diagnosis and have her declared incompetent - is something that I pray to god no other family ever has to go thru.

The diagnosis eventually was obtained after a doctor conducted a 15 minute conversation with my mother and the police officer that had responded to the incident that led to her being forcefully taken to the ER.

Even after my mother was admitted to assisted living and eventually skilled nursing, her treatment was based on heresay (what one nurse vs. another told one of the 2 resident physicians). Due to limited space here I won't even go into the 3 years we went thru that consisted of multiple treatment plans that included up to3- 7 narcotic ('black box') prescriptions at 1 time.

Educating the healthcare industry is imperative. Establishing objective methods of detection is critically important. At this point I believe just about any method of testing that goes beyond a 15 minute conversation with the patient is an improvement.

[PHI Redacted]

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People with Alzheimer’s and the family members who take care of them need all the help they can get. My mother had been declining in cognitive ability for at least ten years. Finally, after totally messing up her bank account and getting lost while driving in the small city where she had lived for 30 years, she was diagnosed with "probable Alzheimer’s" in 1998. Her cognitive decline accelerated over the next 2 and 1/2 years, especially during the last 6 months, and ended in her death in 2000.

She wanted to remain in her home and not go into a facility. So I stayed with her and took care of her for those last years of her life. The very last year, I had to have live-in help in order to manage. We "spent down" my mother's assets, which were only modest, taking care of her and paying the ladies that came in to help provide care for her. Looking back, it was a very dark, lonely, and painful time. Subsequently, I have heard that there are multiple services - such as respite care and financial compensation for a family caretaker - but I don't know if they existed at that time. My mother and I did not have the benefit of any of them. I suffered from stress-related illness, post-traumatic stress syndrome, and multiple health issues in the last part of my mother's life and subsequently, some of which undoubtedly were related to dealing with my mother's illness and 24-hour, 7-day/week need for care. So I know firsthand how important it is to provide resources to battle this terrible disease and the demands it places on its victims.

[PHI Redacted]

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Without the determination of whether the cognitive decline is due to dementia it is a big guessing game as to what is really going on. This then subjects people to unnecessary tests, procedures, medications and hospitalizations.

With early and accurate dementia diagnosis families will be able to better plan for their loved one. The patient will also be able to help in the decision making process. It is hard enough for dementia patients to have everything slip away from them. It can help them to feel like they are in control if they are part of the planning.

Sincerely,

Ms. Roberta Miller

[PHI Redacted]

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I saw a gradual change in my mother's behavior after my step-father died. I assumed it was a form of grieving, but eating, wandering, purchasing items she already had were a symptom of her early dementia. As soon as she had difficulty with her monthly bills I knew something was wrong.

My mother paid her rent three times in one month not having the finances to pay her other utilities. My mother had never received a late notice and she was worried about her bills. She would not share these concerns so I had my daughter assist with her checking account which she then placed her on her account.

I called in authorities to evaluate but they saw nothing wrong. I then started to visit and stay with her more frequently as I live in Florida and she in New York. My guess was right about her. She was needing help and did not want to bother her family.

My brothers thought I was over reacting. They now see it my way. We moved her to a partial adult independent assisted living residency. We then sought help from Managed Care to help with 24/7 attendants as she progressed in her condition.

She is quite aware of the changes but has surrendered to the situation and we monitor it daily. She has not gotten worse by the grace of God. She has developed other conditions and we are more concerned with those because her nutrition and eating can cause lack of energy and constant sleeping and bed sores.

I hope that all families and or neighbors of these afflicted with dementia take notice early on and act on the situation while decisions for their care can be made.

I am very happy that my mother had enough trust and did not resist my intervention.

[PHI Redacted]

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My mother was diagnosed with early-onset Alzheimer’s disease a few years ago. Because she was only in her early 50s, the doctors didn't believe at first that it was Alzheimer’s disease; they were looking at a number of other possibilities before diagnosing her. I remember quite clearly that the brain amyloid imaging test was one of the most important diagnostic tests that the doctors performed. This test allowed her to receive her diagnosis much earlier than she otherwise would've, and begin treatment for Alzheimer’s disease. I can only imagine how much harder it would have been if we had to wait even longer for a diagnosis.

Please consider this when making your decision about how to vote on this legislation.

Thank you.

[PHI Redacted]

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I would like to talk about my dad, [PHI Redacted]. He is now retired from the fire department. He was lieutenant for hazardous materials and was in charge of running the fire department in [PHI Redacted]. My father was 50 at the time they diagnosed him! He had quite a few lapses before he was diagnosed. Had he been diagnosed sooner, he would have left the fire department earlier. Luckily no one suffered from his lapses at the fire department, however it could have been much worse! He is responsible for countless lives in a job like that! They need to run early diagnoses not just to the elderly, but to people who may suffer from shift work disorder. I strongly believe this contributed to my dad's early onset dementia! Think of how many lives can be saved if we do the proper tests for diagnosis!! Thank you for your time.

[PHI Redacted]

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My mother-in -law was diagnosed with Alzheimer's but too late. Still miss her and curse the needless death.

[PHI Redacted]

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The care and treatment of AZ is difficult to understand, diagnosis is not always clear. They just say it is dementia or mild cognitive impairment, which are "symptoms". No clear diagnosis = no disease, no medicine and no coverage!!!!

How can you cure something that you can't diagnose??

Please help with the cost of AZ and research to find medicines, or a cure that works. Right, now there is nothing to a) help with the disease currently or b) prevent it for future generations.

Need medicine that works!!!! Aricept is not a cure!!!!! Please help!!!!!! Alzheimer's is the new heart disease! Thank you.

Sincerely,

Ms. Mary McDonough

[PHI Redacted]

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I've read too many stories of the devastating effects of the disease. And, it can go on for years and years.

Sincerely,

Mrs. Mary Jo Banks

[PHI Redacted]

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Alzheimer's is a cruel and savage disease. In the early stages, you KNOW you are losing your mind. The person with the disease suffers in terror. Everyone who cares for the afflicted person suffers by watching the loved one die over and over again each day!

Early detection can help. Doctors need all available tools NOW to help provide better care.

Amyloid imaging should be covered by Medicare immediately to improve the quality of care. One of those situations is when a dementia expert is unsure whether a decline in memory is due to Alzheimer's or some other cause.

Sincerely,

Ms. Marilynn Willits

[PHI Redacted]

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My mother’s early diagnosis in 2001 has given her a good quality of life much longer than expected all do to a scan that showed the onset of dementia.

[PHI Redacted]

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Jul 19, 2013

CMS Docket

Subject: Importance of Early Diagnosis of Alzheimer’s disease

Dear CMS Docket,

My husband, John, received a diagnosis early in 2010 that he did not have Alzheimer’s disease. Then after several more issues and wondering again exactly what was wrong with him we were referred to a different neurologist. In September of 2010 he was diagnosed with Alzheimer’s disease at the age of 58. He was put immediately on medication (Aricept) along with the depression medicine he was already on. John stopped working in September 2010, and has been on Social Security Disability Income since December 2010. It has been an interesting and challenging journey. I am sure that getting an early diagnosis has helped immensely. I know the medication has been helping to hold him steady although I am beginning to see a little more rapid pace in the progression of the disease. Going once every 6 months for his neurology appointment is also most helpful. I attend 2 different support groups (through the Alzheimer’s Association), and I cannot say enough about the help and support I have received by doing that. I cannot imagine this journey without the help of his neurologist and the Alzheimer’s Association. Please do whatever you have to do to help folks get an early diagnosis. I think it is key. Thank you!

[PHI Redacted]

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My maternal grandmother eventually died of Alzheimer's related complications, but at that time there was little treatment. She was originally diagnosed with "Hardening of the Arteries."

My mother, 77, is now beginning to exhibit disturbing signs - not being able to think of a word or name, forgetting that she just told you this story 20 minutes ago, looking at photographs and not remembering who the people are.

Finding care for her in East Texas was nearly impossible. She has recently moved to Oklahoma City with my sister, and we are hopeful the medical care will be better and more accessible, but everything must be done to diagnose this disease correctly and begin early treatment before she, and others like her, reach the point my grandmother reached where she forgot how to feed herself.

[PHI Redacted]

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As a daughter of both parents who suffered from Alzheimer's, I know firsthand of the pain of seeing what were active, loving parents. Watching them wither away to bedridden people who were unaware of whom I was, crushed me beyond words.

Also as a daughter of Alzheimer's parents, I am terrified as to developing the disease myself and having my two sons go through the pain that I went though!

So I am pleading with you to continue the funding for research for this horrible disease.

[PHI Redacted]

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I had a father die from Alzheimer's, my mother had dementia and it runs in our family. It has become an epidemic in this country. Please provide the funds for research and care for those who are afflicted and/or may be one day.

[PHI Redacted]

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I am a clinical neuropsychologist running an Alzheimer's clinic in the Dallas area. Early and accurate diagnosis is critical in the care of dementia patients, and planning disposition issues for family and caretakers.

Sincerely,

Dr. Eric Smernoff

[PHI Redacted]

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Because my mother was not diagnosed early, we did not have access to treatments which might have slowed the progression and made life easier for her.

[PHI Redacted]

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Please consider support funding for Amyloid Imaging tests under Medicare, when the need for a differential diagnosis exists. Early diagnosis of Alzheimer's can help to manage the financial impacts of the growing frequency of Alzheimer's across the aging American population. As unsustainable as the current Healthcare cost trajectory is for the American (and international) Health care system, I believe that substantial rises in incidence of Alzheimer's is likely to be the single largest driver of Healthcare costs as we move further into the 21st century

Sincerely,

Mr. John Sullivan

[PHI Redacted]

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This test was very important to the doctors that care for my mother. Please do the right thing and cover the test cost.

[PHI Redacted]

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Hello. My Great Aunt Patty has Alzheimer’s disease. She is turning 80 years old this November. For her safety and the safety of others, we had to take her car away from her and we had to move her out of her home and into a living facility. She is very resentful toward two of my Aunts and does not understand why "they" or "we" are treating her this way, even though everything we have done for her is for her safety and well-being.

She was diagnosed with Alzheimer’s in the Winter of 2011. She is still in denial and does not believe anything is wrong, or that she has any type of disease or impairment. I am a big advocate for early diagnosis.

For some of my family members, hearing that diagnosis from the physician was a turning point. Even though we had seen signs and symptoms for a couple years, that diagnosis got the ball rolling and pushed our family to make some difficult, but necessary decisions for my Great Aunt's safety.

Alzheimer’s is NOT an "old persons" disease. It is NOT a "normal" facet to aging or old age. Alzheimer’s is a DISEASE, a devastating, expensive, non-curable disease. Please join me in this fight and push for early, accurate diagnosis. It makes a huge difference.

[PHI Redacted]

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Both my mom and my Aunt (my mom's sister) were diagnosed with Alzheimer’s. My mom was diagnosed with early onset in her early 60's. My aunt was diagnosed in her early 70's.

I cannot tell you how important it was to us that my mom received a diagnosis. The diagnosis was instrumental in our family getting my mom the medical care she needed and providing her support. Not to mention how much it helped my dad, her caregiver, to accept that mom was no longer able to function in life as she previously had. It was only with the diagnosis that my dad was able to accept the fact that my mom had Alzheimer’s and that she needed extra care and medical attention. It is so easy to go along acting as if the memory issues are just a sign of getting older when it is, in fact, so much more serious than that.

My mom's diagnosis allowed my dad to take my mom to an Adult Daycare while he worked part-time, alerted his children to the fact that he couldn't take care of mom alone, gave the family the opportunity to find additional financial resources and gave us all peace of mind in the knowing that mom was not "going crazy" as she so often thought. It is hard to hear someone you love has Alzheimer’s, very hard, but yet the not knowing is worse and more devastating.

Myself, my two sisters and brother live with the fact that we may have Alzheimer’s one day. Possibly in the not too distant future for myself and my older sister (we are 50 and 51 years old). It is so important to me that if that happens to myself or my loved ones, we receive the diagnosis we deserve.

Everyone deserves to know what is happening to them. Loved ones and caregivers deserve to know as well so they can provide the best care possible for their loved ones.

[PHI Redacted]

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My family struggled for nearly two years with my late aunt's doctor to provide an early diagnosis. After giving away nearly 100,000 dollars and mounting debt etc. did she finally receive a diagnosis of AD. She was soon reduced to public assistance and placement in a supervised environment. A earlier diagnosis would have allowed us t better plan for her care, kept her in her home and delayed applying for public assistance.

[PHI Redacted]

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No one knows how devastating this disease is until you experience it yourself or go through it with a loved one. We need to do everything we can to prevent anyone from having to go through the horrors of Alzheimer’s.

Sincerely,

Ms. Sharon Koenig

[PHI Redacted]

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Please help the people you serve by making sure that we are able to establish the preventative measures that have been set forth.

Sincerely,

Mr. Haze Harrison III

[PHI Redacted]

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Our mother was diagnosed with dementia 8 years ago. She was placed on medications and has been able to be in her home with assistance, due to early diagnosis and treatment, until this month. Early diagnosis is vital in keeping Alzheimer type dementia patients functioning at their best ability. Our mother's treatment has slowed the advancement of this disease and gave her several years to be in her own home.

[PHI Redacted]

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I watched my mother lose a little bit of herself everyday for 8 years. I am a registered nurse and took care of mom at home as long as I could thinking and telling her I would never put her in a facility. mom started having seizures and it became difficult to keep her at home. mom could still walk and talk in words, but she needed constant attention. I loved my mom with all my heart, she was my best friend, my cheerleader, my confidant. She was my rock. As time went on I became like the parent and mom became more childlike. At times is was neat to see how my mom was as a child, she became more outgoing and adventurous With all that said it was still HELL watching a brilliant, vibrant woman who played six musical instruments, was the church organist and pianist since nine years of age struggle with wondering why she couldn't remember things, why she couldn't remember I was her daughter, why she had Alzheimer’s as we had to tell her because she obviously would forget and then we would have to see her cry and struggle with it over and over again. I BEG you to increase funding and research for this horrific disease. It will be a wonderful thing when a person and a family doesn't have to go through this dreaded process. I spent all of my 30's working with my mom and dealing with this with her. I was 40 when she died. I would do it all again in a heartbeat. Please make it so others do not have to go through this patient or family, please make places available for people to educate themselves in this, and please make longterm care and assisted living more affordable for people. As a nurse I worked homecare for along time and saw many people I the same situation I was in, it is heartbreaking as many families have no alternative, it is even more heartbreaking how many people out there live alone with this disease and have no one to care for them. Please fund programs for this devastating killing disease!!!!!!

[PHI Redacted]

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My father was diagnosed with dementia back in the mid-1990s when diagnostic methods weren't as keen as they are now. Because of that many of his brain functions were lost.

Had this occurred now, he would have been diagnosed earlier and would have been able to have been treated with drugs which would have slowed the onset of the ravages of this disease.

I would not want anyone else to go through what my family experienced. As we all know dealing with a disease early may help stem its advance so early detection is imperative.

I hope that my story will keep early detection available for others

[PHI Redacted]

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My father was diagnosed with Alzheimer's several years before his passing. Although he attempted to set things in order early enough to make sure his extended family would benefit from his good planning before he died, he did not plan on being unable to follow through with those plans due to dementia. The repercussions from the years he lost reverberate through our family still as we spend thousands of dollars in legal fees and tax problems that have resulted from his inability to remember to continue his intended good planning for his family. Not only am I left, as second successor trustee, with the problems that developed subsequently, I am very concerned about the possibility of having the same thing happen to me. I would never want the challenges that I, as trustee, and my father's other beneficiaries have had to endure, to happen to my children. I want there to be a way to prevent this disease for my children and for all others and their families who have this disease in their genetic heritage as well.

[PHI Redacted]

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My mother was 48 when she started having significant issues with her cognitive functions. I had seen evidence of it for a few years before that but I thought it was stress. We knew something was wrong but didn't know where to start. Eventually we found our way to a neurologist. Many tests were run to determine what was causing all the confusion and memory loss. Over a year later she was diagnosed with early onset Alzheimer Disease. The doctors were very hesitant to even diagnose her at such a young age but because we were able to run these tests we were able to research and prepare for the inevitable. Having seen the devastating effects of Alzheimer Disease, I know firsthand that it takes a toll on the victim as well as the family. Don't take away a test that can give answers to patients and families. This disease is hard enough when you know what to expect, but not being able to get the answers you need for your family member because an important test such as brain amyloid imaging is no longer available is just unacceptable. We need MORE tests and preventative measures not less. Please consider the importance of this test and put yourself in the patient or family member's shoes. With this disease you lose so much, please don't take away potential answers

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My mother passed away last year at age 57.

[PHI Redacted]

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My father had Alzheimer’s and so did his father. My father was about 78 when he was diagnosed, but he had early onset Alzheimer’s earlier. While he was still working he began having trouble getting his e-mail at work, having simple computer problems and more forgetful. We all mentioned it to mom and she claimed there was nothing wrong. She didn't ask his doctor and by the time she had convinced herself, it was too late to help him. He retired at 76 and died at 81. He had no time to enjoy his retirement.

I often wonder how long he may have lived if his doctor and my mother had paid attention. Early diagnosis is key in helping a patient with Alzheimer’s.

Please help.

Thank you.

[PHI Redacted]

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Alzheimer’s has been a word I understood from an early age. My grandmother suffered with this horrible disease. I remember when I was around age 10 and would watch my mother worry day in and day out about how best to care for her mother. My grandmother had to be put in a nursing home after her care became too much for my mom to handle. My mom went back to school so she could work at this facility to be with her mother daily. For years my mom would tell me that if she got sick, don't give up my life for her. The fear was there daily for my mother that she too would follow in her mom's steps. When her brother started this horrible journey, mom's fears got worse. My uncle passed away in his early 60's. At age 63 my mom's worse fears became reality. I moved my mother in with me and became her caregiver. I watched her slip away day by day. She died at the age of 69 years old. Alzheimer’s has been a word mentioned too many times in my family. I just turned 50 years old on June 6, 2013 and I am determined that I will enjoy my years I have left and not walk the same path so many in my family have had too.

I believe every day a cure for this cancer of the brain will be found. Thanks and God Bless for all you do.

[PHI Redacted]

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Please help.

Sincerely,

Mr. Nathaniel Russell

[PHI Redacted]

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"...Those who have lived with Alzheimer’s or related dementias know an early and accurate diagnosis allows individuals with the disease and their caregivers to better manage medications and other chronic conditions, receive counseling, engage in financial and long-term care planning, and consider all medical and non-medical treatments and supports including participation in appropriate clinical trials. These benefits improve the quality of life for those fighting Alzheimer’s and can lead to significant cost savings, both for individuals and our nation.

We can't afford to postpone for years important tools that are ready to help doctors provide better Alzheimer’s care today."

Sincerely,

Ms. Alesha Oliverlane

[PHI Redacted]

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As a medical provider, and a daughter of parents both with AZ disease- I cannot stress the importance of allowing ALL patients who need a confirming diagnosis to have amyloid imaging.

Not only can this initiate cognitive saving therapy but also allows for caretakers of these patients to make a plan for the future of their loved ones and also for how the progression of AZ will impact their own lives.

Until you experience this disease either yourself or within your family, you will never understand the absolutely devastating impact it has on the patient and the family.

Dealing with both parents at the same time with AZ disease was the hardest and most challenging care my family has ever had to take on. I fear for my own future and that of my siblings and extended family due to the familial tendencies AZ has to inherit the disease. PLEASE consider this important next step to aid in a more rapid diagnosis for these patients as it will touch your life too - you can be sure.

[PHI Redacted]

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I can personally attest to having the correct tools to early diagnosis of Alzheimer's disease. My first wife died from the disease and she was not diagnosed until late stages of the disease. Therefore she was not able to get into any of drug trials at that time. I remarried and now my second wife has been diagnosed with Alzheimer's disease mainly due to my experience with my knowledge of the disease. She is in a drug trial study because her early diagnosis. The biggest problem I aware of with getting people in the study is the early detection of the disease. We need every tool to detect the disease with the proper controls get Alzheimer's patients into the drug studies to cure this disease. Please include the PET scan test as a tool to achieve early detection of this disease.

[PHI Redacted]

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My 2 sisters and I are stumbling our way through dementia with my father. There is some support, but it is very difficult to get accurate diagnosis and the few 'treatments' are ineffective for him. I think it is terrible that the USA has not focused more attention to this huge epidemic disease. It is very depressing for the patient and very difficult for the caregivers as there seems to be little assistance out in the public.

[PHI Redacted]

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I lost my mother one year ago to this awful disease. As I look back over the course of her beginning stages all the way through until her passing, I realize now that we really weren't educated in what was happening or what to expect for our mom. My mom's Dr. just kept saying that you can't really diagnose Alzheimer’s. It is all under a big bubble called dementia. I was thrust into this unfamiliar position of now parent to my parent, caregiver and I just did the best I could. I have regrets now that I could have added to my mom's quality of life and care, if I would have only knowen. I would love to see early diagnosis for patients and education for the patient and family/caregivers. As I look back on my mom's journey through this I realize that I could have helped her is so many different ways that I didn't realize at the time. So now I have to fear for my own future and what it might hold. I saw everything my mother went through and quite frankly, it scares the hell out me. I would love the opportunity to find out early enough in the process to really make a difference in my care, if that is my future. I believe with all of my heart that this is an area that we can't afford to miss the boat on. Please do whatever you can to make this a top priority.

Thank you for your time!!

[PHI Redacted]

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In 2010 both of my parents ages 85 and 86, suddenly exhibited strange delusions and my father died of Lewy Body dementia the following year. His condition was misdiagnosed as Alzheimer’s and so he was given Risperdone which caused violent behavior in people with Lewy Body. After I researched online, I realized what was wrong and we took him off Risperdone, which instantly improved his behavior to the mild mannered person he always was. I had to put him in a locked facility because he was escaping the house. Meanwhile, my mother began saying that the food and water in her home was poisoned nightly by people who got in the windows, and other weird beliefs. Her condition turned into extreme anxiety and she also had to go to an assisted living and was put on a cocktail of psychiatric drugs which ultimately harmed her brain, destroying pathways of dopamine, causing Parkinson's-like symptoms. Dad died in 2011, still misdiagnosed, and mom has survived the harmful anxiety drugs although she still has memory and thinking problems. Her neurologist is treating her as if she had Parkinson's and she has improved greatly. He took her off Namenda which she does not need, yet took for a year. The misdiagnoses of both their conditions was directly due to the lack of proper tests for Alzheimer's and other related dementias. It is imperative that this be corrected by new research, better tests, and that it is covered by insurance and Medicare to avoid the harm that is done while the doctors only have clinical diagnoses at their disposal. Mistakes are being made with our elderly on a daily basis. This has got to be addressed as a serious disservice to our elderly.

[PHI Redacted]

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I am caring for my mom with Alzheimer's, it is very difficult since I am the only member of the family left. I am trying not to lose my job at the same time, help is too expensive at home.

[PHI Redacted]

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Every day I see firsthand how an early diagnosis has made a difference in the lives of the person diagnosed and the people that support them.

Sincerely,

Mrs. Annie Murphy

[PHI Redacted]

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I am from a high risk family with a history of Alzheimer's. This is extremely important to myself and many family members of mine

Sincerely,

Ms. Nancy Broussard

[PHI Redacted]

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My mother and maternal grandmother died from Alzheimer's. The devastation and chaos it created is not describable. No one should have to have this happen to them. However, I was 15 years old when my mother, age 43, was diagnosed. Failure to cover a diagnostic test that could assist doctors and patients to pursue early treatment options is irresponsible and heartless. Please cover diagnostic testing!

[PHI Redacted]

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I think that any time a person is forewarned, it makes it easier to accept and try to prepare, no matter what the case. I am in a situation that involves my mom, and my aunt,(her twin)who both have the disease. They share a room in a rehab nursing home and for the most part, are just "surviving". Both of their parents had it and now hopefully me, my sisters and cousins can try to learn how to prevent getting it or if we do, try to prepare to manage it better. If there's a way to diagnose it early, maybe early treatment can help people live symptom free longer.

[PHI Redacted]

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Please improve care for an earlier diagnosis. We had to go to many doctors and wait many months to find out my mother had Alzheimer's.

[PHI Redacted]

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I have worked for five years with dementia and Alzheimer's patients and now care for my 88 year old grandfather was developed dementia.

[PHI Redacted]

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Diagnosis came pretty quickly. The issue is with care for people with Alzheimer's. My mother has Alzheimer's disease and since her diagnosis 5 years ago, we have struggled with finding care. She was in a day center for 4 years and it was only one in the area until a year ago. I live in the 4th largest city in USA, Houston with one of the biggest and most renowned medical centers in the world. Yet, there are very little resources for anyone suffering or dealing with Alzheimer's.

Since the family member who mom lived with had to move, she would be too far to attend this day care so we were forced to put her into a nursing home. Her money will only last a year in the nursing home and then will have to apply for Medicaid. We don't know what we'll do once that happens because she will not be able to stay.

If there had been more day centers in Houston, we could've prolonged the need to put mom in a nursing home. Also in-home help is so expensive and not covered at all by Medicare which would be both financially and health wise beneficial to those with Alzheimer 's disease.

This disease affects those who have it, those who take care of family members with the disease, and, in turn affects those who employ the family members. This disease affects the whole of the country and the economy!

[PHI Redacted]

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If someone you loved was told they MIGHT have breast (or any other kind of) cancer, would you want them to be tossed aside and find out the truth later, when it might be too late? Or would you want the chance to have one more definitive test done so everyone could prepare for the future? Not everyone is going to need further testing in regards to Alzheimer's and dementia diagnosis. However, when in doubt, tests should be provided and covered. This disease is real, and it does kill.

Knowing that a test is available, but the patient can't afford the full cost, can be as harmful as not even being offered the information regarding the test.

I implore you to use your brain before you let a few dollars take away ours.

Sincerely,

Miss Nancy Middendorf

[PHI Redacted]

-

My mother currently resides in a nursing home. I accept that she has a percentage of dementia. We have been told she has Alzheimer’s disease. We were told one can only be certain if that person is deceased. I thought only a brain scan can show plaque build-up on the brain is the

Only true method of diagnosis. What is the truth?

[PHI Redacted]

-

My father was diagnosed with Alzheimer’s on June 1, 2012. It has been devastating for us. He is failing fast. If you have never dealt with anyone with Alzheimer’s on a personal level, then you have no idea the trauma and stress everyone goes through, even the patient themselves. Your life is totally changed when you have to treat your father as your child and your mother has to treat her husband as her child. Everyone should be working diligently to erase this disease from the world. I read where they were coming up with a new drug to maybe reverse Alzheimer’s but would be 2 years before it could be used for human trial. Both drugs are already FDA approved as individual drugs and i understand the process to a point but would have my dad go for human trials today if they would ok it. Time is so important with this disease. I could tell you all kinds of stories since my dad has been diagnosed but don't have enough room. Just know that something needs to be done immediately so other families, including mine doesn't have to go through this anymore. Lawmakers need to be considerate and compassionate when it comes to issues on this disease. God forbid any of their family go through this. So please do not block any testing or early and accurate diagnosis processes for Alzheimer’s!!!!

[PHI Redacted]

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I encourage support for early and accurate diagnosis of Alzheimer’s and other dementias to improve future quality of life.

Sincerely,

Mr. Richard Adrian Nelson, Jr.

[PHI Redacted]

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Without an early and accurate Alzheimer's diagnosis, the care that is needed for my mother would be more difficult to help manage this dreadful disease. This disease hits so many thousands of people.

I have lived with Alzheimer's/dementia and I know an early and accurate diagnosis allows individuals with the disease and their caregivers to better manage medications and other chronic conditions, receive counseling, engaging in financial and long-term care planning, and considering all medical and non-medical treatments and supports including participation in appropriate clinical trials. These benefits improve the quality of life for those fighting Alzheimer's and can lead to significant cost savings, both for individuals and our nation.

Please do not cut this very important diagnostic test called brain amyloid imaging. We need to do everything possible to help with this dreadful disease and to one day eradicate it!

[PHI Redacted]

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My aunt was misdiagnosed several times and received medication that was not appropriate for her condition. I believe these misdiagnosis caused a delay in the appropriate medication and she may have retained more of her cognitive abilities if she had been on the correct medication. I urge you to consider if your mother or father had cognitive impairment and you did not know why or how to help them, what would you do? It is devastating to watch a loved one decline: look, act, behave like a different person and be given hope and medication only to watch them decline more and told that it was a misdiagnosis. Wasting time trying yet another medication with other side effects and hopes dashed again. Meanwhile your loved one is needing more tests, more meds, more care that you cannot afford. Please help these people keep as much dignity and cognition for as long as it is possible. It will save the government so much money in the long run.

[PHI Redacted]

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My mother’s husband received a half baked diagnosis at the Mountain Home Air Force Base clinic in 1998. The doctor told my mother, he has Alzheimer’s, you'll just have to take him home.

No support, no medications, no HOPE. My mom is 5 ft 2 inches tall and weighs 110 lbs. Her spouse was closer to 6 ft tall weighed over 200 lbs. She waited on him hand and foot for almost 3 years. I have no idea how they got by. I don't believe there was any consistent medical care or management of the disease via further doctor visits.

He took a drive to Nevada chasing UFO's and had an accident. He was gone for 2-3 days, mother ,not knowing where he had gone... Rolled his pickup and may have been having hallucinations and fascination with Area 51.

On December 31rst, around midnight, he nearly killed her. He went after her with a phone cord screaming he was going to kill her. mother was able to get away from him, call 911, unlock the front door and hide under the kitchen table with a portable phone.

Meanwhile 911 dispatch was recording his screams and threats and mothers screams of terror, 911 EMT's arrived to save her life and tie him to a gurney for transport and admission to Canyon View , which is a mental health facility in Twin Falls, Idaho.

Another few minutes and my mother would have been killed in a domestic violence/dementia related murder. This story is tragic.

The lack of appropriate medical attention, medications, routine doctor visits, respite support for caregiver spouse......Not only civilian doctors need education but military physicians needs to be better versed in early detection and treatment.

[PHI Redacted]

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My mother was alone and living in Florida for many years. Because she had always had various "issues", I didn't realize she had developed Alzheimer’s until I received a call from Social Services. The bank manager she knew for years had made an anonymous report because her landlord was escorting her to the bank each month and demanding higher and higher monthly rent. After I was contacted and then moved her to NC with me, I was able to finally get professional help and some medications to make her last four years happier and safer. I can't even begin to describe the conditions she was living under because she had never had a correct diagnosis and the two years it took me and my family to make appropriate decisions and take proper steps to ensure her well being.

[PHI Redacted]

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My husband first contacted his doctor with concerns about his memory in 2004, but it was not until 2005 that he was seen by a psychiatrist who finally confirmed the diagnosis in 2007. It is now known that the available drugs are most effective in the early stages of Alzheimer's. It is important that patients have access to early diagnosis by the most appropriate means. I urge you to support the coverage of such techniques by Medicare where they are appropriate.

[PHI Redacted]

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My dad was afflicted by two strokes and had Alzheimer's. It is difficult to remember which was worse: his inability to use his right hand and struggle to eat, or the aphasia that prevented him (a very intelligent and brilliant man) from speaking. If we had caught the Alzheimer's in the early stages, it might have made recovery from his two strokes easier. Recovery from the first stroke took two years, many months in a recovery center plus speech therapy. The second was worse and he was completely in his own world. What part of this was Alzheimer's and what part was the strokes? Who can say? But perhaps he wouldn't have made the final decision, the one that killed him, if his Alzheimer's had been diagnosed and he had been given the proper medication. He died painfully of a broken hip after deciding in the middle of a snowstorm to shovel a path to the garage and fell. Had he been in his right mind, he simply would have asked me or my brother to do the shoveling and would have lived a much more painless life.

[PHI Redacted]

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It's a heartbreaking thing to watch.

Sincerely,

Mrs. Joyce Filauri

[PHI Redacted]

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My mother is a 72 year old widow of ten years. She started showing marked memory issues about 3years ago. I accompanied her to her PCP who completed a mini-mental test which she scored fairly well on. He dismissed her memory issues as related to her high level of anxiety. I knew differently. I know my mother. I pushed on and brought her to Johns Hopkins Anxiety Disorders Clinic where she was carefully interviewed and assessed. At the end of the day, she and I were referred to the Memory Disorders Clinic at Johns Hopkins Bayview. None of these clinics were covered by MC or her primary insurance, Aetna. When the memory clinic recommended neuropsych testing, a CT scan and potentially a PET scan, we knew she was in for some heavy copays if not just plain bills. Neuropsych testing cost $900 out of pocket. CT scan was $1200. Insurance paid none of it. She was diagnosed with MCI (mild cognitive impairment), which I continue to argue is a BS diagnosis they give people to prepare them for the prospect of what's to come. Two years and another neuropsychiatrist later, mom was diagnosed with early stage Alzheimer's. I am in the medical field. My mother has some private funds. We struggled through this process. When all is said and done she began to have difficulty dealing with being alone in her home of 44 years and moved to a retirement community shortly after her official diagnosis. It is absolutely essential we help families in the future to have immediate, insurance covered access to the best medical interventions surrounding Alzheimer's disease. This disease is going to become a crippling thorn in our society's side if we do not act now, proactively to provide early, comprehensive care to peoples memory.

[PHI Redacted]

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The government should not stand in the way of doctors providing an early and accurate diagnosis of Alzheimer's. My mother had a stroke and showed dementia signs. We were desperate to understand what was happening and how to deal with it. Half of the more than 5 million Americans with Alzheimer's have never received a formal diagnosis.

We know that an early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. Yet the federal government is moving to put up a barrier to those benefits. I urge you to improve care and provide an accurate diagnosis.

On July 3rd, Centers for Medicare and Medicaid Services (CMS) the agency that controls many aspects of the Medicare services you receive issued a disappointing draft decision on coverage for a particular type of diagnostic test called brain amyloid imaging (read more). CMS stated they believe there is insufficient evidence that use of this test improves health outcomes for Medicare beneficiaries with dementia or neurodegenerative disease in specific populations.

I oppose this decision.

[PHI Redacted]

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My grandpa passed away from Alzheimer's in 2010, was the most difficult time in all our families life. This disease is so hurtful to anyone that has it, dealt with it or has ever encountered anyone who suffers from Alzheimer's. We must unite as a nation and help find a cure for our future generation.

[PHI Redacted]

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My mother, [PHI Redacted], died on Christmas Day 2011 of Alzheimer's Syndrome, Pneumonia and Parkinson's disease, in that order. She had Alzheimer's for 12 years, and during that time we watched her descend from a vibrant, talented, musically astute, Bible teacher and member of the local Toastmster's chapter, to a silent, vacant woman who eventually gave up walking and speaking. In 2006, her sister [PHI Redacted] died of Alzheimer's in Ohio, and was ill with it for about 12 years also. My father cared for my mother at home up until he died in 2009 - partly from being overworked by seeing to my mother's needs 24/7. He had very little help because of the cost of in-home care. After his death, I placed her in Skilled Nursing at the Inland Christian Home in Ontario, California, where she lived out the next two years in excellent care. This was paid for with my dad's retirement and MediCal. Medicare was doing a poor job of covering her prescriptions, because she kept "Falling into the Gap" to the tune of $600. a month. I was able to get her on Blue Cross which had no "Gaps" and no membership fees, and scrapped Medicare. Any additional fees, like hair trims, clothing, sundries, came out of my pocket.

This disease is most terrible and distressing, because it robs its victims of who they are, long before the physical body fails. There is presently no cure. It is a guaranteed death sentence. It shows no evidence of slowing down or going away, and the aging "Baby Boomer" population is at the highest risk, much more needs to be done in the areas of prevention, research, affordable in-home help, and more facilities like the Inland Christian Home in all communities.

[PHI Redacted]

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Without an early diagnosis, my mom, who suffered 12 years with this disease, would have missed the opportunity to make plans for her family's future. It would be very cruel to deny these families a chance to get their lives in order before their brains are ravaged by Alzheimer’s disease. Please do all you can to make this early diagnosis tool available to anyone who can benefit from it.

Thank you.

[PHI Redacted]

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It is important to follow diagnosis and help family and professionals plan.

Sincerely,

Mrs. Judy Kaplan

[PHI Redacted]

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We have an abundance of screening tools for cancer, why not for Alzheimer’s? Treating Alzheimer’s will soon reach epidemic proportions and will greatly impact our overworked health care systems. Please use your influence for us all.

Sincerely,

Ms. Kathie Faulkner

[PHI Redacted]

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My family having suffered from my mother's 13 year struggle with Alzheimer’s, I am offering a strong voice for early diagnosis and improved care of dementia patients. Not all families can afford adequate care for this devastating disease and the financial ramifications of long term care can be devastating. Please support better early detection and care for dementia patients.

[PHI Redacted]

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I am writing to share how an early diagnosis of Alzheimer's disease was helpful to us.

My husband, Dale, began to show possible signs in his late 60s. Both his father and brother died from the disease. We decided to get an evaluation at Emory Alzheimer's disease Research Center, where his brother had been evaluated and treated. After an extensive evaluation cognitive testing, medical history/testing, an MRI of the head to rule out stroke/tumor the neurologist concluded that Dale had Mild Cognitive Impairment, perhaps caused by Early Alzheimer's disease. One final test of cerebrospinal fluid enabled the doctor to conclude that the cause of the cognitive changes was indeed Alzheimer's disease.

That early diagnosis helped us in the following ways: 1) Dale was able to enter a clinical trial right away, which, if it doesn't help him, will surely aid the research efforts; 2) Dale made the decision to stop driving; 3) We got all of our financial and legal matters in order; 4) We moved into a continuing care retirement community, where we both will get the support we will need as his disease progresses.

I hear horror stories in my support group of the difficulties in getting an accurate diagnosis. Not everyone can afford to travel out of town to an Alzheimer's disease Research Center like we did. I believe that the people who might be put off by the idea of a spinal tap might opt for the less-invasive PET scan if it were readily available and covered by Medicare. Because I can see in our own lives the advantages of an early diagnosis, I urge you to reconsider the reimbursement policy for any test that would enable an accurate diagnosis of this disease.

[PHI Redacted]

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Some of them staring run away from their care givers. others make sure they eat their meal. Look after them. It's hard on their family members and friends see them go through this. Watch their pain and suffer.

Sincerely,

Ms. Miriam Woodhead

[PHI Redacted]

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My grandmother got Alzheimer’s when she was 80. My mother worked hard to find care for her when she was no longer safe being on her own. She lived to the age of 86. My cousin has early onset Alzheimer’s and she lost her home, and her job, as a result.

I have 2 people in my family with Alzheimer’s. I expect there are millions of people who have been diagnosed with this disease. I urge you to do whatever you can to help.

[PHI Redacted]

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Please support research into early recognition and prevention of Alzheimer’s.

Sincerely,

Ms. Lindsey Johnston

[PHI Redacted]

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The need for early diagnosis is crucial. The general public needs to be made more aware of symptoms. My husband was diagnosed too late. My Dr. got him into a treatment program and all the testing was too late as were the prescribed drugs. !!! The "team' at the Center did all they could but he faced several years of decline before he passed away Christmas afternoon of 2012. Maybe an early on test could have been given and the meds might have prolonged his life but since there is no cure there is no hope..More people in your neighborhood have been diagnosed with this awful disease. Just ask around and you will be very surprised...I do not like being a widow!!!!!

[PHI Redacted]

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My mother Elizabeth died without receiving a medical diagnosis of Alzheimer’s disease. At that time definitive testing while she was alive didn't exist...you had to die before was a diagnosis could be positively made.

Her doctor said it was pretty sure she did have Alzheimer’s, but by that time her conditions had progressed that she could not make the important decisions a person makes before they die, and medical treatment could have begun much earlier..

If mother were alive today and could be tested, life and the life of her family caregivers would be much easier, and she could participate in the decisions medical, financial, and personal that a person without Alzheimer’s takes for granted.

My sister and I are now 69 and 74. I do brain exercises in order to keep a healthy brain and my doctor and I are following my overall health, which so far appears to be normal. Every time we forget a word or wherever we put our phone or keys we are constantly tormented by the question of "Do I have early stage Alzheimer’s, or are these "senior moments" normal for someone our ages.” Being able to have testing done so we can make to make an informed plan of attack, or be able not to worry all the time would help us both so much

I'm sure there are many many Alzheimer "orphans" who wonder like we do, whether our lives are about to be shattered by the disease that took our parents

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Please support Medicare funding for these tests.

[PHI Redacted]

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My father passed away in 2008 when he was 90 years old. However, at least around 10-15 years before he passed away, his character changed and the capability taking care of himself was getting worse since he's living alone. We don't have as much knowledge on Alzheimer’s as today but actually it's still very limited. If I could have more help on an early and accurate Alzheimer’s diagnosis for my father, we could better take care of him and understand why his character changed before he passed away.

More importantly, I'm suspecting myself, as his son, I may also inherit his Alzheimer’s. I may be the 4th generation as far as I know potentially to have Alzheimer’s from my father family tree history. That's another reason it's importance of an early and accurate Alzheimer’s diagnosis.

I was forced to retire early in 43 years old since I feel my capability to handle my job was going downhill which include my memory even on some very simple vocabulary or spelling on words, my communication skills with people. Sometimes I have hard time to structure my sentences to express myself. All these may be the symptoms of early Alzheimer’s after we have more study on it. We can find out more if we can have early and accurate diagnosis.

[PHI Redacted]

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We were "lucky" that our father had a seizure that sent him to the hospital. Being told that he had Alzheimer’s was a difficult thing to hear, but it helped us to be able to care for him better and to understand that his memory problems were only the beginning. Have an accurate diagnosis was what we needed to start planning and facing his long-term care with the most knowledge possible. The care that he has received since then has been invaluable in managing his disease and keeping his quality of life at the highest it can be. Not only the medical services available because of his diagnosis, but the resources available in our community to help us take care of him at home as long as we can. I only wish that doctors would have had the ability to diagnose him earlier.

[PHI Redacted]

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An important part of the process in assuring that my mother get the right medicines and the best care was obtaining the diagnosis. Without an accurate diagnosis, her doctors and I wouldn't have been able to help her as much as we've been able to. I urge you to consider allowing Medicare to pay for diagnoses of Alzheimer’s. The huge expense of caring for my mother, who is still at home with me, is made bearable only by her coverage from Medicare. Don't make my life even harder than it already is. Thanks!

[PHI Redacted]

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Jul 19, 2013

CMS Docket

Subject: Fighting for Joe.....my sweet daddy

Dear CMS Docket,

My name is [PHI Redacted]. I lost my dad to Alzheimer’s on January 29, 2012. He was 78. While I am grateful that my dad lived a beautiful life, I am still horrified by how it ended. My dad lost his ability to walk and talk. He could not do anything in the last year of his life. It was like he was in a coma with his eyes open. It broke my heart. He had a mind that was sharp. He was always working, reading and thinking. He began working since he was a little boy in South Philadelphia. He could not have been more active. This disgusting disease robbed him of every memory he had. He no longer remembered his children, wife and grandchildren. I can't even imagine not remembering my life. That is what scared me the most about watching my dad suffer. It was like he never existed. How could this be? How could you not know who you are? How do you forget your own flesh and blood? Your wife of 45 years? I could go on or hours about the poor medical treatment he received when his disease got so bad. My family and I were at the mercy of the doctors and other caregivers who told us what was best. Most of the time they were wrong. You know why? Because they don't know how to treat this disease. No one does. There is no treatment. It get progressively worse. The cost of care is astronomical. We were fortunate enough to pay for "better treatment" but we never got it. My dad was dropped twice and developed a stage four bedsore that almost took his life. It was pathetic to watch. I never want another family to experience what mine did. Please help us. I just found out I am going to be a mother. I don't want to forget my child as my dad did me.

[PHI Redacted]

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I urge you to consider all tools, test and regimes to detect Alzheimer’s early on. My mother died at the age of 72 and if she had tests available for early detection her horrid last ten years may have been avoided and treatment /diagnosis in her 50;s or 40's could have been a profound help in her quality of life.

I am turning sixty soon and would hope that I live to see the day where there is coverage for early testing for dementia and Alzheimer's. I personally do not have any medical coverage and would like to get tested as this runs in my family.

[PHI Redacted]

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My mom died of Alzheimer's and never had it diagnosed until she was in a nursing home. Her family doctor should've known more about screening, and it was possible to give her medications to help her before she was too far gone. She did not even remember her husband of over 65 years or her children or family. Too said and a very "long goodbye."

We need better screening early on and aid or this scourge will bankrupt America and lead to loss of productivity as families struggle to care for their loved one for years! I had to take a part time low level support job although I had a Master's Degree and had been a human resources manager for the Medical College of Wisconsin and an Asst. Director at a state university in Illinois. What a waste of talent and the loss of income has affected our retirement security as well.

[PHI Redacted]

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My mother and siblings are dead and Alzheimer's was the cause. There is no good way to plan or manage this disease. It ultimately leads to a total loss of quality of life and ultimately death. The devastation for those family members still alive is immeasurable.

[PHI Redacted]

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My day's father was diagnosed with Alzheimer's at 84. My dad was diagnosed at 73. I am 49. Am I going to be next, and if so, when? It's almost impossible not to worry about it all the time, and I wonder how my family and I will cope with the challenges we could face. Your action is critical to us and to millions like us. Please make this the priority it should be.

[PHI Redacted]

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Alice was a wonderful person, then her daughter began to notice a strange form of behavior in her mother she shared that with me mom would go to the kitchen and eat go back up stairs forgetting she had already had her meal she would return to the kitchen again this behavior prompted her daughter to seek help for her mother. Alice was admitted to the Nursing home, her condition continued to decline her conversation was of things of the pass. Before she died she no longer recognized her family and friends.

Ruth was a wonderful woman she didn't behave like a person with dementia, we was able to have great conversations we went for walks in Memory Garden I took her to the Cafeteria for coffee and snacks she loved going to the garden. Then her memory began to fail she would tell me staff was taking her money that she didn't have money for coffee, I reminded her that she didn't need money because I would get her coffee. We solved the money problem I found her money and put it a safe place.

Sincerely,

Ms. Rosia Johnson

[PHI Redacted]

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My mother who is 71 has late stages Alzheimer's disease. My mom was diagnosed at 65 years of age been told that she had it since she was 62 early onset. My parents had 4 children and all 4 of us are at the risk of having Alzheimer's since our mom was diagnosed early onset. Believe me none of us are want Alzheimer's after seeing firsthand what it has done to our mom. My mom has never been put into a nursing home between my sister and I we take care of her at home.

[PHI Redacted]

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I am currently the caregiver of my mom who was diagnosed with Alzheimer's in 2005. It took me awhile to find the right doctor and I was fortunate to have been referred to health care team that specialized in dementia related illness. This team included social workers, psychologists, as well of course the physician who happened to be an osteopathic physician (very holistic in her practice). Many people are highly misinformed about this disease as most people think it only involves forgetting names, faces or places; that's just the tip of the iceberg. The social worker gave me a book entitled "The 36-hour Day," a must read for all families who have a loved one with this disease. It prepared me for all the changes I would observe in my mother and how to deal with them. This team provided an excellent support system for me; this is extremely important for the caregiver.

It has been a long hard road but early diagnosis is essential as well as treatment, As I reflect on my mother's behavior, I can pinpoint tell-tale signs that I noticed years ago that something wasn't quite right. But I attributed this to natural aging. Please.....at the first instant you recognize strange behavior, get your loved one to an experienced doctor.....the earlier, the better.

[PHI Redacted]

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Millions of Americans can live longer, happier, more productive lives if improved, affordable early detection becomes available to them. Medications than can retard memory loss already account for a tremendous amount of relief for victims of Alzheimer’s disease and their Caretakers and all who love them. This is urgently and critically needed!

Sincerely,

Ms. Jan Jackson

[PHI Redacted]

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An early diagnosis of Alzheimer’s or other dementia can help the patients family make the best care decisions for their loved one. My husband had a problem getting a diagnosis of Alzheimer’s. Once he had a diagnosis I was able to obtain the information I needed to properly care for him. It made our lives so much easier in so many ways. Early detection is so important! For medical treatment and for the best informed care of the patient.

[PHI Redacted]

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America's elderly deserve to be treated in a much more humane manner.

Sincerely,

Mr. Jason Kaler

[PHI Redacted]

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Please help us and allow the diagnostic test using Amyloid Imaging. The Alzheimer’s Association convened the Amyloid Imaging Taskforce, a group of leading experts in the field, who recommended that for certain situations amyloid imaging should be covered by Medicare immediately to improve the quality of care. One of those situations is when a dementia expert is unsure whether a decline in memory is due to Alzheimer’s or some other perhaps preventable cause. This is an epidemic and the citizens of this country need all the help they can get.

We're counting on you.

Sincerely,

Ms. Ana Garrido

[PHI Redacted]

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Before my mother was diagnose I notice her change of behavior, I told my oldest daughter and my youngest sister but they won't want to believe she was sick after 5 years finally my sister took her to a doctor who confirm what I was telling them, because my sister was in charge her decision took all those years and it was too late. The Alzheimer’s was real advance and complicated with dementia. Is being like 4 years since the illness has been taking her memory and herself, she didn't know who I am since 3 years ago at first she was thinking I was my oldest sister but only took a year to erase that too. Don't wait until is too late check this site no matter you don't needed you can help another person closer to get help before is too late. Now I been notice around me, people with signals of their behavior and helping the families to inform about Alzheimer’s, also given the site address to learn about this. Is easy to make a difference just read and learn about it.

Thanks for your time to read this.

God Bless you all

[PHI Redacted]

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We must do everything within our power to detect even a slight possibility of having this horrible disease ... The earlier; the better ... We must exhaust all tests to provide as much diagnostic information as possible.... Please readdress the laws and allow these invaluable tests to be covered benefits.

Sincerely,

Ms. Elsa Herrera

[PHI Redacted]

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When my father did my mother went into a serious depression. She began then doing things like leaving the stove burners turned on. She was eating mostly sweet things.

Eventually, we had to do something with all her collectibles and art works and move her into assisted living where she did fairly well until the morning check found her unconscious on the floor. She was moved to an Alzheimer's facility. She sustained a shoulder injury that left her arm partially frozen in place. I know she was hurt every time they dressed and undressed her. but she could not tell them. You could, however, plainly see the fear in her eyes She died there.

We never had a diagnosis that seemed based on solid testing. Perhaps her last years would have been very different if we had had an accurate diagnosis similar to amyloid testing.

[PHI Redacted]

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My mom had the benefit of an early diagnosis of Alzheimer's. Although the diagnosis was devastating to our family; looking back I can see that this early diagnosis allowed us to plan and to make the most of every moment with my mom.

We put my mom on Aricept right away which I believe slowed the progression, we took some vacations together and prepared for the future.

Think about what it is like to lose someone so close to you and whether you wouldn't want to have a little extra time to prepare and plan. I will be forever grateful for the time I had with my mom. Soon after my moms diagnosis I had a baby and I am grateful that my daughter and my mom did know each other. Without this early diagnosis I do not think this would have been possible.

[PHI Redacted]

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My father started having memory issues at age 58. He did not get an accurate diagnosis until age 81. My mother cared for him for the last 10 years if his life until he finally died of a massive stroke at age 88. He was on Aricept, but it did not really help.

My mother was a very stressed caregiver and ended up having a stroke herself after dad died. Dad's Alzheimer's was a very stressful situation for our whole family.

[PHI Redacted]

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People over profits! It is time for the Congress to fully support Alzheimer's research, if, for no other reason, it could help save their lives and the lives of those they love.

Sincerely,

Mr. Joshua McKain

[PHI Redacted]

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Since Alzheimer's disease runs in my family and my husband's, it is important for us to get early detection and treatment. My mother (91), her sister (80) and her brother (87) all are diagnosed with dementia/Alzheimer's and still living. That's 3 out of 3 children on my side. On my husband's side, his mother and her brother both died of the disease in their 70's.

We are in our middle 60's and early detection will help us plan for our health and financial needs now and in the future should the need arise.

Early detection is key for us and others as well.

Thank you for listening.

[PHI Redacted]

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This October, I am going the distance with the Alzheimer's Association by running the Marine Corps Marathon in Washington, D.C. as an ALZ Star! The Alzheimer's Association mission is to advance the care, support and research efforts of the Association.

As I am sure you are aware, there are currently more than 5 million Americans suffering with Alzheimer's disease. This number is expected to grow to as many as 16 million by 2050. Additionally, 1 out of 3 Americans over the age of 65 dies either with or of Alzheimer's. Even with this astounding statistic, medical research is severely underfunded. Currently, there is no cure or treatment. It is the only disease that takes so many lives that we have NOT made any advancements in prevention or treatment.

Until we are able to prevent this disease, early diagnosis is critical. Alzheimer's Association strongly supports early and accurate diagnosis of Alzheimer's disease. An early diagnosis has been found to lead to better outcomes and higher quality of life for people living with the disease and their families by: enabling earlier access to appropriate treatments, allowing the family to build a care team and seek out education and support services, enabling enrollment in Alzheimer's/dementia clinical trials, and providing an opportunity for the development of advance directives and financial planning.

This cause has deep personal meaning to me. Alzheimer's disease robbed me of both my parents in the past decade. Current treatment could not help slow the disease process, nor could it bring them peace in the final stages of their illness...

I strongly support the Alzheimer's Association mission to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Please support policy to allow Medicare to cover Amyloid Imaging testing when indicated to improve the quality of care!

Your support of appreciated.

[PHI Redacted]

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My mother was diagnosed with Alzheimer's years after the onset of signs, which were assumed to be normal age-related forgetfulness, absentmindedness, and loss of hearing. The latter was not hearing loss, but simply her inability to understand or follow a conversation. Once she was diagnosed she was prescribed Aricept, then anti-depressants, then anti-anxiety meds, none of which helped, and in retrospect probably made her physical condition worse. We cared for her in our home for several years, which was the hardest thing I have ever done, having 2 teenagers, both my husband and I working full-time, and no other family or community support, except, thankfully, a dear friend and neighbor who gave us some respite. The toll on our family was enormous, with long-lasting effects. When it became impossible to care for her at home, we had to apply for Medicaid and find a nursing home that would accept her and frankly, was not awful, which took months. We found one that was a nearly 2-hour drive from our home, but it was the best (clean, kind) and made the drives to visit regularly worth the time. She lived there for 8 years before this horrific disease took her. There was no family history of Alzheimer's in her long-lived relatives, and I believe if we had had an earlier diagnosis, we may have been able to better plan for her, and our, future. If not a cure, then an early diagnosis at least!

[PHI Redacted]

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We are all afraid to admit there is something wrong with our loved one but know there is a problem. I for one let it go on for a few years. It was after I was diagnosed with cancer that I could no longer ignore the obvious.

This was a hereditary problem that affected both his mom and his sister who died at age 54. It scares not only me but my adult children.

We need programs that help to give our loved ones the opportunity to get involved with brain stimulus. This would be a variety of repetition of math, reading, and other brain exercises. I try to do this every day with my husband but sometimes it is impossible with all of life's trials.

With the statistics that are out there for Alzheimer's disease the President and all our other government officials should be worried about our future.

I sincerely hope we can find a cure. I do not want to see my children or anyone else have to face this diagnosis.

I just paid $423.00 for a 3 month supply of the Exelon patches. The Namenda will have to be refilled next and I shudder to see the cost.

It is definitely the long goodbye but also it is heartbreaking to all of us who have to watch.

[PHI Redacted]

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Alzheimer's is a terrible and heartbreaking disease for both the patient, the family and friends. Watching my mother see herself deteriorating and the associated depression was heartbreaking. Early detection and medications to help patients slow the symptoms not only help them but those caring for them.

From a financial standpoint it also makes sense. The cost of caring for patients is enormous and keeping symptoms at bay for as long as possible can only save the insurance companies money. The mind goes way before the body.

Thank you in advance for ensuring that the insurance companies support the new procedures and medications to help manage this disease.

[PHI Redacted]

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My partner is experiencing what could be termed cognitive impairment! I am on disability and barely able to take care of myself. Hence I feel I must leave this situation before I become what I fear would become a full time care giving situation. If this happened Joy (her name) would become incapacitated and I would have to quit my job.

Bear with me...if this amyloid screening were allowed by CMS we could determine if Joys condition were not in fact permanent thus saving our relationship and a heretofore happy household.

[PHI Redacted]

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My grandmother and mother both have suffered from Alzheimer’s prior to the age of 60. I feel like early diagnosis is important so you can make preparations and work to financially take care of your family. I know that we are suffering both financially and mentally because of the early age of Alzheimer disease occurring in our family.

Please take steps to help with this horrible and disregarded disease!

[PHI Redacted]

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My dad died at age 58 because of complications related to early onset Alzheimer’s. Advances in treatment and diagnosis are necessary and critical for the health of our country.

[PHI Redacted]

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After 7 years, I do not know whether my wife has Alzheimer’s disease or vascular dementia. The available tools for determination are very imprecise. Much more needs to be done in determination as well as both prevention and treatment. Vastly increased research funds and top human talent needs to be devoted to this area of medicine.

[PHI Redacted]

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My mom has been diagnosed with Alzheimer’s and my sisters and I are concerned about whether or not we will end up being diagnosed with it also. We need to ability to ask for testing to make sure if we have early signs we get the treatment that we need.

[PHI Redacted]

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I am helping care for my mom who has Alzheimer’s. My father is her primary care giver and it is an exhausting job. There needs to be more research for early detection and medications to stop this horrible disease! It's heartbreaking!!!

[PHI Redacted]

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Early detection is the key to stopping this diseas

e. Sincerely,

Mr. Kassi Ydris

[PHI Redacted]

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I have had and continue to have care from Dr. Allan Levy, a renowned Neurologist and Alzheimer’s Researcher. My care and testing over the past few years have helped me stabilize my memory problem. One of my medications have been cut in half and will be discontinued in a month if my condition remains stable. I need this care to continue under coverage for Medicare.

[PHI Redacted]

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My mom is currently in stage 7 (final stage) of this horrible demoralizing disease! We have to continue to fight this disease as well as continuing research toward reversing it and ultimately preventing it completely! My oldest brother seems headed in the same direction as my mom and with better test for diagnosis we would know for sure and in the future be able to stop it from destroying his mind!!! The fact that we are having to fight for this is sad! It makes me wonder if any of the elected leaders have loved ones that are suffering with this disease.

Do what's right and help stop this disease!!!

[PHI Redacted]

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My grandmother had Alzheimer’s. She died in 1998 . Had she had this test, I believe that her quality of life would have been better longer.

[PHI Redacted]

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I was a former sole caregiver for my mother who suffered from Alzheimer’s. She died in 1997. I was very fortunate in receiving an early diagnosis from a board certified neurologist who specialized in Alzheimer’s. This early diagnosis enabled me to develop a plan of action. I immediately enrolled my mother in an adult day care center where she received excellent care from a staff of highly trained specialists. These specialists counseled me on the type of care that my mother should receive. When it became necessary to place my mother in a nursing home, the staff also assisted me and guided me in the proper direction.

With an early and accurate Alzheimer’s diagnosis, I was able to develop a plan of action for my mother which alleviated some of the stress of care giving.

Thank you.

[PHI Redacted]

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In 2007 I accompanied my mother to see a neurologist. My sisters and I had begun to notice changes in her memory and ability to use cognitive processes. We did not know if these were part of the normal aging process or symptoms of the onset of dementia. My mother scored fairly high on the standard Alzheimer's questionnaire, but the doctor felt that it would be advisable to do a CT scan of her brain. The results showed that it was likely my mother had Alzheimer's, which was in the early stages. The neurologist prescribed Aricept which my mother took until her death six years later from a fall. The progression of Alzheimer's in my mother was very gradual and when she died in early 2013 (from injuries she suffered in a fall) she was entering the later stages of the disease but could still recognize me. This is in marked contrast to her younger sister who did not take Aricept and was never diagnosed until she was in the late stage of Alzheimer's. It appears that her dementia was much more accelerated than my mom's.

Obviously with a family history of Alzheimer's, I am at risk. I hope that if I begin to exhibit symptoms, I will be able to take advantage of the most current diagnostic technology and that it will be covered by Medicare. Given the prevalence of the disease and its toll on caretakers and society, it is vitally important to identify and begin to treat it as soon as early as possible. I am concerned that if diagnostic testing is not covered by Medicare, many people will continue to go undiagnosed and treated.

[PHI Redacted]

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Now is not the time to be unilaterally ruling out any diagnostic that stands to benefit even a portion of the dementia-afflicted community.

If there's a chance that brain amyloid imaging can distinguish between patients with treatable and non-treatable cognitive decline, there needs to be mechanisms in place for patients to have this test covered by their Medicare benefits.

Sincerely,

Mr. Galen Sjostrom

[PHI Redacted]

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The strange tall tales started many years ago and the rest of the family just brushed it off, She kept asking her son and I to move in with her so after 6 times we did, and we are sure glad we did she would have been dead by now. No one was watching over her and we thought the other family that lived near her was, taking closer look at her health, but we were wrong. The house hadn't been cleaned in forever, and she thinks she cleans every week, and gets mad at me when I do. We were able to get her on Namenda and Aricept, and she is so much more active and will go places now with us and it's been 3 years and she is doing very well. These meds have made a huge difference in her life and if she would have started them ten years ago she may not be in stage 4. My husband have had so many memories with her, and the quality of life is so much greater with the help of agency IV and other places who have been able to help us with this horrible change in her life. The other family members just wanted her to go away, and she would have, if we hadn't stepped in and tried to get her some help. Thank You God, please don't stop these funds to help us and others, it makes something so very hard, a lot easier

[PHI Redacted]

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I have been taking care of my mother for 10+ years. Time is slowly stealing her away.

I was calling to her recently and wondered why she wasn't answering me. Then the reality of Alzheimer's shook my existence. My mother did not know she is "mom".

Caring for her is increasingly demanding, and has taken a huge toll on my entire family. She is aspirating more frequently now because she sings the same song over and over, and sings this song while she is eating, then strangles, aspirates, and then gets pneumonia.

I do not want my children to devote their life to taking care of me if I develop this insidious disease. I am 64 now, do I have the stamina to continue this battle? Cost of a care facility is $6,000.00 per month. The government does not help, unless she goes to a filthy horrible home that only collects government checks and warehouses the patients. Help Please!

[PHI Redacted]

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Please Pass ANYTHING that will promote early detection of this terrible disease. Researchers are very close to finding some great treatment and I have even read of a "cure".

My wonderful, dynamic, charming father had owned his own hardware store and worked until he was 71. He had about 8 good years and then started going downhill and died at 91 from aspiration pneumonia. His brain had stopped telling his body to let food go into his stomach and it went into his lungs instead.

I am 57 now and I know I will have this terrible disease in some form, I am steadily going downhill, Today I spent about an hour looking for my car title which is supposed to be in the file labeled car title, I found it on my scanner, I had forgotten I had started to scan it! And I could give you many more instances, I really need early help and have discussed it with my doctor and we have not really come up with anything else except some brain exercises and omega fat vitamins. Also my father took fish oil tablets every day. IF he had not been in such terrific shape he would have died much sooner. The person MOST affected by his disease is my sweet mother. They were married for 63 years at the time he died and she is still recovering from all the stress. I could go on and on please help us win the fight against this catastrophic disease, Thank You.

[PHI Redacted]

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My grandpa had dementia, please continue helping!

[PHI Redacted]

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My husband was diagnosed with Alzheimer’s almost 9 years ago. He still goes to the swimming pool with me to an exercise class. He sings in a retirement choir. He chooses his own clothes and takes care of personal needs. Why?

I believe due to early diagnosis. He was put on both Razadyne and Namenda. But he also participated in clinical research at Georgetown Medical Center. We followed doctor’s advice to eat a diet rich in vegetables and fruits, exercised daily, stayed physically and mentally and socially active.

He is still a joy to our family, thanks largely to early diagnosis and treatment.

Alzheimer’s is a frightening disease but not impossible to live with if given early treatment.

[PHI Redacted]

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My wife was experiencing cognitive decline 5 years ago at age 53. Although we did not have a cause for her impairment, we pursued diagnostic tests and sought medical advice from various medical specialists, most were inconclusive. We continued down this path, until I requested an advanced MRI scan (PET scan). The neurologist reviewed her images and diagnosed the early on-set of Alzheimer’s disease. With a correct diagnosis she began receiving galantamine, which made a significant improvement in her cognitive abilities. Although it does not reverse her disease, it slows the progression and enables her to maintain a more independent life. As her caregiver I realize this is important for her emotional state of mind and gives her a positive outlook as she continues to battle the disease.

I ask all who are in a position to make a difference in the early detection of Alzheimer’s, to do so. It made a difference for my wife.

[PHI Redacted]

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Such a devastating disease for both the patient and the families and loved ones. Please do what you can to help end this.

Sincerely,

Mr. Doug Krause

[PHI Redacted]

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An early diagnosis is necessary so that individuals effected by Alzheimer’s disease and their loved ones can engage early treatment with medication and other therapies. Research has proven time and again that the early stage of this disease is the very best and most effective time for treatment. One must know what dragon they are up against in order to give a good fight against it. My own mom died from this dreadful disease at age 68 after a 17 yr fight with this and we didn't know for sure what she had until her brain biopsy after death. I beg you to support legislature that will support early diagnosis and treatment.

[PHI Redacted]

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Having recently experienced the passing of my father in-law and currently caring for my mother-in-law who also has Alzheimer's, I feel it is imperative to determine early diagnosis of this disease. My husband and his siblings are highly likely to develop this disease and it would be helpful to learn sooner than later in order to set up treatment and care. Why would any medical diagnosis be denied and furthermore, why would we not want to treat early in an attempt to lower the ultimate long term care costs to federal insurances? This disease will become more rampant as our population lives longer.

[PHI Redacted]

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Please assist in this regard.

Sincerely,

Mrs. Lise Susi

[PHI Redacted]

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Please allow any diagnostic testing that could help provide an early diagnosis of Alzheimer's disease to be available to everyone, including individuals who rely on Medicare and Medicaid and other forms of medical financial assistance.

I watched my grandmother decline for many years before she was institutionalized.

I watched my father fear the disease and attempt unsuccessfully to find help to prevent his own decline due to Alzheimer's. My mother and I cared for him as long as we could before we had to put him in a nursing home, and quickly ran out of money for his care.

For the remainder of his life his care was paid for by Medicare. Tens of thousands of dollars, maybe more, could have been saved by the government if he had been diagnosed earlier, in time to be eligible for treatment with some of the drugs available then.

Two of my uncles also died from Alzheimer’s disease. But the one who was able to be diagnosed so that he could receive a new drug was able to stay functional and able to be cared for at home almost until his death.

My three siblings and I also deal with my father's fear of what Alzheimer’s disease could do to each of us and our families.

Please help us to be able to take appropriate and humane care of ourselves without having to rely on government assistance for long term nursing home care. The dollars saved could improve the quality of life for countless people, and allow funds to be available for many other needs.

[PHI Redacted]

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This is a terrible and progressive disease!

More funding is desperately needed - - millions of Americans have it and more will have Alzheimer’s and dementia! The numbers are staggering!

Support increased funding - - we may all fall prey to this debilitating disease!

Thank You!

Sincerely,

Ms. Ruth McDermott

[PHI Redacted]

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Please make sure to include the importance of a brain autopsy (donation of brain can be made at various centers e.g. The Taub Institute at Columbia Presbyterian Hospital).

As of now Alzheimer's is a "rule out" (kitchen sink) diagnosis. If no other dementia (frontal temporal lobe, Lewy-Body, vascular) is detected patients are given the diagnosis of Alzheimer's disease.

Only the dissection of tissue can really give up a proper diagnosis and thus begin the work of finding a cure.

I give you 2 examples of the importance of a biopsy.

1. My husband has been ill with "Alzheimer's" for 8 years. His clinical course has been quite unusual and his neurologist, Dr. Laurence Hongi at the Taub Center is not convinced that he has Alzheimer's but we will not know until her has a brain biopsy..

2. A 2nd example of my personal experience is through breast cancer. A mammogram picked nothing up but I noticed a small lump. My surgeon insisted I have a lumpectomy but having had a first breast cancer at age 40 I did not trust a lumpectomy only. I got the mastectomy and the pathology indicated that there was indeed a second tumor thus highlighting the importance of a biopsy.

We cannot do research without brain autopsies as we will not have proper diagnoses.

[PHI Redacted]

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Please, please, please focus on Alzheimer's, and do what you can to encourage early diagnosis. This will help people deal with this dreaded disease and possibly get treatment to help with the awful impact. I have seen firsthand with both my parents. And I greatly fear that I will get this disease as well. In fact, some current symptoms are a grave concern.

Please do all you can to help patients and their families as well as people who are just noticing symptoms. They don't know what to do and you can help!!!

[PHI Redacted]

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Thank you for taking the time to read this.

My mom was diagnosed with Early Onset Alzheimer’s, last year.

She is young and vibrant, and was not even 60 years old. The disease has no cure and the accuracy of the diagnosis would be supported through the Amyloid testing via imaging which the CMS does not support.

Please help. The only accurate diagnosis is by the imaging.

The only cure for Alzheimer’s at this moment is death.

[PHI Redacted]

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My grandmother was learned to be afflicted by Alzheimer’s only when her condition deteriorated visibly. Had our family the knowledge of what Alzheimer’s was or what it did, we may have been able to slow its progress. However, she was sadly far gone by the time our family realized what was happening to her. Please, educate the children, adults, politicians- whoever could benefit from it on the effects of this disease

. [PHI Redacted]

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Alzheimer’s disease is a life sentence. My family was never sure about my mother's dementia until the symptoms were very advanced. Part of the reason was because my father cared for my mother, and worked hard to cover up her failing memory and changing personality. The other reason is that their family doctor didn't think that a test would accurately diagnose her condition. Such tests do exist! I know for a fact now, that there were medications that could have helped my mother to hang onto the life she knew. If we had possessed the knowledge about her disease we could have advocated for her and my father for a better outcome.

For my mother, the onset of the disease was when she was in her 80's but I know of another friend whose husband was just diagnosed at the age of 55! I have urged her to get all the testing that she can so that they can manage his disease as best they can. Early detection will help them through - Please do everything in your power to enact legislation that will support early and accurate diagnosis. Planning for medical care is the only part of this disease that loved ones can control. Please don't let insurance companies limit early testing.

[PHI Redacted]

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The time to do more research is now!

Sincerely,

Mrs. Anna DelaMonica

[PHI Redacted]

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My father-in-law, [PHI Redacted], lived alone in Florida, and his grown children lived in various locations in Indiana. My father-in-law had been showing symptoms of memory loss, confusion and difficulties with driving for a number of years. Unfortunately, many of his children did not believe that he had any problem or, if they did see a problem, they attributed it to his being very hard of hearing and refused to wear hearing aids. Even more important, his family physician never gave him/us a diagnosis as to the cause for Glenn's memory problems and confusion.

In July of 2002, the Police contacted us because my father-in-law had apparently gotten lost while driving. He was found over 100 miles from his home. The Officer told us that it took them some time to get him pulled over. According to the Police Officer, he questioned Glenn, and Glenn did not know where he was, what happened, the date or even who he was. Because Glenn was so confused, the Police Officer had him taken to the hospital. The Emergency Department called in a Neurologist, and the Neurologist gave Glenn a diagnosis of "dementia, probably of the Alzheimer’s type." We later learned that the Neurologist determined that Glenn should not do any more driving and should not live alone.

Because of the doctor's determinations, we made an emergency trip to Florida to get him and bring him to Indiana. We then made arrangements to sell his home in Florida and bring his belongings to Indiana. He lived with two of his children until he was placed in the dementia unit of a local nursing home.

By the time my father-in law was diagnosed, he had been showing symptoms for at least five years. Because he/his children did not know that he had dementia/Alzheimer’s disease, we were not able to make arrangements for needed care and for his future. In fact, it is a miracle that no one got hurt when Glenn was driving, especially when he got lost in 2002.

I believe that if we had obtained a diagnosis for Glenn in a more timely basis, it would have allowed us to better plan and manage his disease. We would have been able to make decisions, especially taking away his ability to drive.

Please reconsider your decision and cover brain amyloid imaging.This imaging would have allowed an earlier diagnosis if his family physician was unsure whether Glenn's memory declined was due to Alzheimer’s or some other possibly preventable cause

[PHI Redacted]

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Our mother had symptoms of dementia way before we even realized it. so needless to say she didn't start treatment when she could have Been ahead of the disease and its devastating effects, and because we knew something wasn't right with her but I didn't know what, it caused my mom and us a lot of turmoil and frustration that could have been prevented by earlier diagnosis. We would argue and disagree with her because at that time we didn't understand anything about the disease and its stages. Please don’t let this happen to any other family members and loved ones.

[PHI Redacted]

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My father had Alzheimer’s for 15 years. I don't think medication was available when he first exhibited symptoms.

However, several books I have read indicate that medication can be helpful in slowing the progression of Alzheimer's, thus the importance of early and accurate diagnosis.

Also, being able to rule out the diagnosis would be a blessing to anyone lucky enough to not have it.

[PHI Redacted]

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As with more and more of my acquaintances, my parents have come under the nasty specter of ALZ. Yes, it is imperative for all of us affected to have access to early and accurate diagnosis.

[PHI Redacted]

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I have seen numerous friends whose parent(s) have Alzheimer's and within the last several years, my uncle was diagnosed. My uncle was always a very calm, gentle and wonderful human being. Alzheimer's has turned him into a violent person who needs 24-hour care in a facility that can deal with his violent behavior. What a shame that such a gentle person has turned into the complete opposite.

As a writer of health care issues, I am convinced that we have a ability to get to a much better position for prevention of Alzheimer's as well as many other health concerns.

Significantly more emphasis needs to be put into prevention efforts. I am The Prevention Social Worker and I know there is so much we all can learn (including health care providers).

Let's get this right for everyone's well being! Best always,

[PHI Redacted]

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Seven years ago my mother was diagnosed with Alzheimer's. I had taken her to her family physician after I started noticing my mom was becoming more forgetful and confused. He asked her 3 simple questions, her name, date of birth and who was the president. Of course she passed. I was content with the diagnosis but knowing something wasn't right. I decided to find another physician. He gave her a full examine and questions that last about 45 minutes and then end results was dementia with early onset of Alzheimer’s. My mother passed away January 20, 2013 she received wonderful care during her 7 years with the disease. I couldn't have asked for a better physician than Dr. Emmual Yanelli. Although my mother knew something was wrong she never wanted to acknowledge she had the disease. My father was her primary care giver and I was her second. Not only is this disease horrible to the patient but to the families who suffer along with them. Please help in detecting the early onset of this disease for future generations. More studies and drugs need to be available in treating Alzheimer’s.

Thank you

[PHI Redacted]

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My mom had Alzheimer’s but it was not diagnosed until it was in the later part of Stage 3. We lost valuable time in getting possible treatment to slow it down. That was time lost with family and the stress and confusion we all went through not knowing what her problem was. It gave us little time to prepare for what was to come. Early diagnosis is important for many reasons: patient can get treatment to slow process, family has time to research, understand and plan for necessary care, patient has time to get things in order. Please do your part to help. Thanks.

[PHI Redacted]

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My mother has Alzheimer’s and it is a very difficult disease to understand and prepare for. Any help in detecting it early would give families more time to try and find the right care for their loved ones as well as help us know if we have any chances of getting the disease. Please help to get diagnosis and treatment progressed to help current and future generations.

[PHI Redacted]

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My mother-in-law had Alzheimer’s.

[PHI Redacted]

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My wife, now 78 and I, now 75, have incrementally noticing over the years how forgetting is becoming increasingly noticeable. We attribute this to getting older, yet we both have obvious concerns that this might very well have a deep affect on us at some point. If we were able to be diagnosed early on that would give us peace of mind.

[PHI Redacted]

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Dementia and Alzheimer's runs in my family and took the life of one. I urge you to approve early preventative testing. It is imperative to young and old to get early screening for better health and preventative care.

Thank you!

Sincerely,

Miss Jeanne K. Hampton

[PHI Redacted]

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My mother was diagnosed with Alzheimer's at the age of 64, after we'd apparently missed the many symptoms she seemed to be displaying for a few years. My mom was still working, for the company she'd be at for over 25 years. Her employer asked my father to suggest that she retire. I didn't know this at the time. What I did notice was that she repeated stories. I thought she was just being "mom," making sure we heard her or understood what lesson she was trying to impart on us. Then, one day she misplaced something thing right after she used it and another day she just "forgot" about a medical appointment. This was not at all like my mom. On the other hand, (as far as we could tell) she was completely "functional," in her daily routine, driving, cooking, interacting with us, and so on. She remembered where things were on a regular basis. We didn't have any reason to suspect that she needed to be evaluated until it was her turn to drive on my parents' cross-country trip. My dad told me she "freaked out." Once they got onto the highway, she became overly anxious about missing her exit. In other words...this disease was already working on her long before we even thought she needed any kind of evaluation. So, by the time she was diagnosed, she had already passed the point of being able to have an objective discussion with us about her options, about the disease itself. Getting the word out (to both the general public and the medical community) about what symptoms to be alert for and ways of diagnosing Alzheimer’s at the earliest age possible are so greatly needed. I'm grateful my father is still fully functioning, still able to care for her. I wonder how many people are out there, living alone, and thinking that they're fine, too, because there has been no "proof" that they have a disease. I wonder how many families are going through what we went through in the "beginning," just thinking that their loved one is simply "being a nag," repeating themselves. I hope that those who are doing the valuable research, developing ways to combat the effects of Alzheimer’s, and searching for a cure know that they are making incredibly valuable difference in my life and in the lives of millions of others. I also hope that those in a position to continue these efforts and to make additional progress will keep fighting for everyone, especially for those like my mother who never got to speak for themselves. Thank you for reading.

[PHI Redacted]

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I work with families all the time who are completely in the dark not knowing exactly what is going on with their family member who is suffering from some kind of memory loss. My first suggestion is to ask their primary doctor for a referral to a neurologist and have the full testing done. Since there are different types of dementia, not alway Alzheimer’s, it's important for family members to get the full diagnosis so they have an idea of what they will be dealing now and in the future.

Sincerely,

Ms. Cindy Adams

[PHI Redacted]

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An early and accurate diagnosis of my dad's dementia could have added years to his life.

[PHI Redacted]

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I'm self employed and have been a house painter for 40 years plus. I have seen so many of my customers who became my friends come down with Alzheimer's. It is alarming because at first they have no idea of what is happening to them. They just think they are getting old and forget things. After a while they become much worst and then require much more care from friends and family. After that, friends drop off and family really receives the full problem of care. Costs and quality time spent with these folks becomes harder. Then what can we do to help them becomes lost. After the money is gone from the families ability to pay the burden falls on Government and charity organizations. There has to be a better way to find the cause of this disease and slow the progression. If something seems to be working, then those entering a program for a cure should increase the numbers. If we continue to wait the numbers will grow and the costs will also grow. I'm sure those with the disease knowing they are dying would willingly help to find a cure. This is why I believe an earlier diagnosis would help us all understand the progression of this disease and find a cure much faster. Once you lose your mind what is left to live for?

Sincerely,

Mr. Richard Luczyski

[PHI Redacted].

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My father was diagnosed with Alzheimer's disease several years ago. Even though he still recognizes me and my daughters, he is not the same person that he was and, for the most part, lives inside his head a good deal of the time. I miss my father and often feel that, due to Alzheimer's disease, I am saying goodbye to him in increments. Please continue research for this disabling disease that robs people of what little they have left in old age: their memories.

Thank you.

[PHI Redacted]

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There is a definite probability that I will develop Alzheimer's disease within the near future, due to family history.

It would have been helpful if there had been more clinical trials available for those of us who knew we were at risk for developing Alzheimer's disease.

Many of the clinical trials are for those individuals aged 65 and above.

We need to start screening at an earlier age [55 and above] if we are to learn how the disease develops.

This will hopefully lead to earlier prevention and treatment of Alzheimer’s disease.

[PHI Redacted].

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My father was not officially diagnosed with Alzheimer’s until the disease had progressed for several years. Although he succumbed to this dreadful disease in 2011, I often wonder if an earlier diagnosis would have given us more quality years with him. This is a disease that demands an early diagnosis for any chance at all in fighting it and the thought that new legislation is taking that chance away is preposterous. We should be running towards a diagnosis and a cure instead of running the opposite way!

Please do not allow new legislation and new healthcare laws to dictate and reduce the care that everyone deserves by eliminating important procedures that could give an early and needed diagnosis of Alzheimer’s. While the new healthcare laws are demanding reductions in cost (and rewarding hospitals and doctors who spend less), we are demanding that necessary procedures and tests for Alzheimer’s not become victim to the bottom line.

Until you've experienced and lived through a loved one fighting this disease, you cannot know the hell they and everyone in the family goes through. Please do NOT allow this to happen!

[PHI Redacted]

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For quite some time I was concerned that my husband was not as he had always been: sharp and on top of things. He was getting forgetful and he was only 69 years old, running a successful business. When we went to the neurologist, he underwent a battery of testing and the only test that gave us a clear but heartbreaking diagnosis was a PET scan.

At this point the doctor prescribed Aricept 10 which is supposed to slow down the progression of this horrible disease. Our lives will never be the same again, but getting an accurate early diagnosis enabled us to get the medication in a timely manner. We are currently fighting our insurer to obtain coverage for the newer Aricept 23. They cover Viagra but not this!!!!!!!!!

This government should have better control over the politics of money hungry drug companies that can make a difference in people’s lives so I don't have to cry myself to sleep every night.

[PHI Redacted]

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In 2001, I noticed that my husband seemed to have trouble understanding a simple statement. He could repeat it to me, but with a questioning expression in his voice as if he didn't understand it. He was a very intelligent man who had been admired for his teaching and his coaching (a state champion-ship), etc. Since he was 70 years old, I was not so concerned about small lapses of memory, but more concerned with his seeming lack of understanding, as if the messages weren't reaching that part of his brain. So I persuaded him to come to see Dr. Richard Gold, a neurologist in Baton Rouge, The doctor said that it could be Alzheimer’s, but if it was, it was very early stages. He prescribed Aricept which my husband has taken ever since. When Dr. Gold retired and we moved back to B.R. in 2003, we went to Dr. Eberly. Dr. Bolter tested my husband and he continued on the Aricept which seems to have delayed the progression for 10 years. He was able to handle 3 OLLI (Lagnaippe) classes per week plus bible study until 2 years ago when he stopped attending these classes because he could no longer enjoy them as a participating student. He was very aware of his condition and hid it from others with his outstanding ability to joke with people As he lost this, I was able to pick it up and joke with him as he had always done with me and others. He enjoys this a great deal and seems to be aware of the fact that I picked it up from him and am "giving it back. He therefore has maintained a good state of pleasantry. We had traveled a great deal until 2009 when we went on a Mediterranean Cruise which included the Pyramids in Egypt and riding a camel. But he is unable to remember the questions and answers that he asked a minute ago, plus al the times that he asked it a few minutes before that. He get no exercise and refuses to use a cane or a rolling walker.(We have both. He still dresses himself, with help for buttoning buttons or buckling a belt, etc. used 4 or more Depends per day and although he can feed himself. His hands tremble (he takes primadone for that) and he has difficulty balancing food on his fork until he gets it to his mouth. His daily routine is to arise between 6 and 8 a.m. watch TV for an hour or so, eat a bowl of cereal and go back to bed for 2 - 3 hrs. He used to read a great deal, bought hundreds of books, but had no interest in reading any more. He sits and watches TV, action movies most often, but can't answer a question if I enter the room and ask about a character or event. Our dog lies on the couch beside him with his head on my husband’s leg or cuddled up to him. He loves the dog that is "almost as good as "Scratch" (who we loved for 16 years when our sons were growing up. We considered moving into a retirement home a few years ago, but decided to stay here as we both love our house (and I love the yard with its trees, shrubs and flowers). That and Water Exercise are my therapy.

[PHI Redacted]

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I am at high risk of having the disease and feel that I should get accurate testing.

[PHI Redacted]

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My father has Alzheimer’s. At the time he had been diagnosed, around 4 years ago, he started receiving treatment. He should have been diagnosed around 7 years ago.

Our family thought it was the stress of mom having a stem cell transplant as treatment for Multiple Myoloma cancer. Maybe with the brain amyloid imaging it could have been diagnosed more quickly. Today, he is living in a memory care unit.

Between mom's cancer and dad's Alzheimer’s, Alzheimer’s is a much more cruel disease. Dad still has clear moments once in awhile and doesn't understand why he can't remember things, especially activities of daily living.

Please consider allowing Medicare to pay for the brain amyloid imaging.

[PHI Redacted]

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My mother began to have memory problems in her late sixties. She was not really aware of it, but she would come home from work angry that her boss had told her she forgot to do something. "I/m going to get a tape recorder." she would say.

She was forced to resign and a number of tests were performed to justify the act but of course Alzheimer’s has no definitive test.

So she was never diagnosed with it at this relatively early stage. It did not affect her at home any that I noticed.

About a year later, she was in a car wreck and had to be hospitalized for about a year. Her memory declined rapidly. But the doctors kept contradicting each other about whether it was Alzheimer’s or not. They even did those 'memory' tests to try and diagnose but decided it wasn’t Alzheimer’s

Well it was, her memory declined rapidly over the next two years until she didn't know who I was (her only child). She couldn't tell the difference between television and reality, once getting upset that there were 'all these boys in my room' when 'Leave It to Beaver' was on. She asked me where all the 'mud' in her underpants came from. She wasn’t put on Aricept until the late stages when it was too late to do any good.

Thankfully, she developed liver cancer and died from that. Cancer is a joy compared to Alzheimer’s. Her sister had Alzheimer’s as well. I am 56 now and looking down the barrel of a loaded gun. I know this thing is in my future. It terrifies me and it angers me. I have quit going to the doctor for anything because I would rather die early of cancer or heart disease than live long enough to get Alzheimer’s.

If there is anything that can be done to diagnose the disease early enough to slow its progression, it should be done. In my mother's case, just putting off the onset of the disease for a mere 5 years would have made all the difference in the world.

It's sad. When Alzheimer’s first gained public recognition, my mom would say "I hope and pray I get anything but that."

I'm glad I no longer believe in God. If he exists he is a cruel monster and I hate him. He should burn in his own hell for what he did to my mother.

Science is our only hope.

[PHI Redacted]

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My mother died from Alzheimer’s in April this year. She may have had it earlier than when we thought but if there was an accurate way of diagnosing the disease, I think we (my sisters and dad) would have been better prepared to give my mom the best care. Instead, the facility that she was placed in didn't know how to treat Alzheimer’s patients. She "fell" according to the aides and of course, no one knew how. After a week, the aids finally decided she was arthritic when in reality, she broke her left femur. Terrible facility. We got her to the hospital. The surgery was extremely risky at her age. Needless to say, mom didn't last much longer after the surgery. Had she been better diagnosed, we would have placed her in a better facility than Signature Pointe.

[PHI Redacted]

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Better choices for early detection for Alzheimer’s, please!

Sincerely,

Ms. Angela Kimbro

[PHI Redacted]

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My mother, Shirley, died of Alzheimer’s related complications in 2007 at the age of 72. Had she been diagnosed earlier she might have been able to live longer with a better quality of life.

We know that an early and accurate diagnosis allows individuals with the disease and their caregivers to better manage medications and other chronic conditions, receive counseling, engage in financial and long-term care planning, and consider all medical and non-medical treatments and supports including participation in appropriate clinical trials. These benefits improve the quality of life for those fighting Alzheimer’s and can lead to significant cost savings, both for individuals and our nation.

We can't afford to postpone for years important tools that are ready to help doctors provide better Alzheimer’s care today.

[PHI Redacted]

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Unfortunately, this county has not begun to confront dementia diagnosis and care in ways that make economic sense and address the many facets of the tragedy of this disease. Early diagnosis, like any kind of advance preparation and planning, can not only ready a family to make the financial preparations and life arrangement decisions that evolve over the long course of dementia care, but can be an important part of lowering the costs of a wide range of other services that Medicare does cover. Assisted Living facilities will use emergency room visits as a treatment plan when there is no real diagnosis. Each time mom got difficult to care for; the facility would send her to the emergency room for a "change in cognitive status." Had we had any real diagnostics at all that could have inspired us to confront the reality of dementia in the early stages, it would have forced earlier conversations of financial planning and long term care options. It would have improved the drug treatment plan as well. Uncertainty is a big part of the anxiety of family members when you start down this rabbit hole. Maintaining a job and a family life in the wake of this tsunami of demands takes a huge toll on the family. Sometimes you feel as a caretaker as though you are dying from the care of this disease. Please help families confront and understand the long journey that may lie ahead.

[PHI Redacted]

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My grandfather recently passed away from Alzheimer’s. The last years of his life were very difficult for our entire family because those vital moments were stolen from us and those precious, priceless memories we had were stolen from him. Earlier diagnosis would have given us all a few more good years with him. But the disease was too far progressed when he was diagnosed for any real delay to have taken place. Moments are fleeting and each minute is precious when it comes to family. Early diagnosis can give each family a little more time with each other, and with constant progress in medicinal science, potentially (hopefully) save more lives. Please consider the struggles of everyone who experiences this disease. It is a cruel disease that leaves more victims than just the patient. And consider that it is easy to ignore when you don't have to witness it. I truly hope you will never have to witness it.

[PHI Redacted]

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When my mother turned 83 she came from the den where she was sitting watching TV to the kitchen. I was in the kitchen and saw her coming in the doorway. She looked dazed and started to fall to the left. I ran to her and caught her from falling and somehow got her in a chair. I took her to the emergency room and they said she had taken her medication wrong or miss taking it. I disagree knowing she had taken it correct. They sent us home so I made an appointment to get her checked. She had a small stroke on the left side of her brain. She recovered from the stroke in the form of using her body and speech was fine. I started to notice she was not remembering things. She had been watch the death of Michael Jackson on TV and had liked his music for years. She asks me who is this "Michael Jackson" they keep talking about. I was very upset and took her for more tests. The Neurologist told me she had dementia in the form of Alzheimer’s. She slowly but progressive got worse and was taking Namenda for treatment. It did not help. After using caregiver to help I quit my job to care for her for 1 1/2 years. My mother passed away on May 1, 2013. At the end she knew me some days but mostly she did not. I notice when her fluid were good she could remember more. She would get urinary tract infection and need IV fluid to get her kidneys back to her normal. She would have one day that she was alert and talked more. Then back to no personality.

It is very sad and depressing to see loved ones that were great people go back to "childlike" state of mind. I just watch her die slowly. I pray they will find a cure for dementia.

[PHI Redacted]

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They say the spouse is the first to KNOW. When my husband was in his fifties, i knew something was wrong with him. His personality was changing....and a once gentle, sweet natured man was becoming obstinate and argumentative about almost everything, yet I discovered, he would forget what he'd said or done the night before..after a good night’s sleep. It wasn't until he began using foul language and became violet..things he had never done in his life. Along with his Diabetes, Retinopothy and Renal Failure, he had one Transient Eskemic Event, yet I had to do research to try to discover what was wrong with my husband. Doctors would give him medication for his eyes, his blood, his kidneys, and one doctor, instead of listening to my plea, had given him an abundance of free samples of Viagra. Had I not continually told his doctors of my concerns about his bizaar behavior, a car accident that he caused..involving 3 vehicles, and repeatedly begged his doctors to find out what was wrong with him, we may never have known. As it was, we did not discover definitively he had Alzheimer’s until he was in his late 60's. We are now in our 70's. A few years ago my husband was finally diagnosed with "early onset Alzheimer’s".

[PHI Redacted]

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My husband first experienced changes when he was 55 years old and he is now 75. The doctors continually reassured me during this time that he was normal. He had two MRI's, several years apart, and we were told they were normal. It was very frustrating because I knew he was not normal as far as his memory was concerned, but not one doctor would listen until I insisted on Aricept about 3 years ago.

We were finally urged to go to the University of Utah Neurology Clinic by our Nephew, who is also a Physician. As it turns out the 2nd MRI showed the Alzheimer's disease, according to the Alzheimer Specialist at the University; sadly, he could have been on meds to help him many years before he was finally diagnosed 2 years ago by this doctor; and unfortunately, too much damage had occurred to his brain now for meds to be beneficial.

It is unfortunate for my husband that the system failed. I would certainly recommend that if Alzheimer's disease is suspected that people get a neurologist that is experienced in Alzheimer's disease and not just anyone who may not know how to correctly read an MRI.

So sorry that I didn't take that road.

[PHI Redacted]

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Support Alzheimer's research.

Sincerely,

Mrs. Gaile Carr

[PHI Redacted]

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My mother had Alzheimer's. She complained of not remembering things but didn't get a diagnosis until well into her disease. Maybe an earlier diagnosis could have given her medicine that would have helped her or at least slow the progress.

[PHI Redacted]

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My grandmother, mother, Aunt and Uncle died with Alzheimer's disease. My oldest brother was diagnosed with early on-set Alzheimer's 2 years ago. Medication has helped to keep slow the progression of Alzheimer's. In fact, we see little change in him since he started taking medication.

Using brain amyloid imaging will help to identify persons who may only be experiencing mild memory problems but medication would slow the disease reducing the cost to both the family and insurance payers. Early diagnosis also allows the patient the opportunity to live with the disease healthier and longer.

[PHI Redacted]

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My husband of over 40 years had Lewey Body dementia. It was several years before he had an accurate diagnosis. His actions were blamed on his age. He was forgetting things, but then he stated 'SEEING" things. I let him drive too long, but thank God he didn't hurt himself or anyone else. But I hated to say you can't drive. Then he did hurt himself, he stood up on the bed in the middle of the night "to fix the light" and fell off the bed, hitting the night stand, and put the corner of it through his eye, he lost that eye. Another time he went out without me and we found him in another part of the neighborhood. I had alarms put on my doors. We finally went to a doctor who said, no it's not his age, and had him tested. He had to be in the hospital a long time, and then I was told, he would have to be in a nursing home, because I wouldn't be able to give him the care he needed. If he had been diagnosed sooner and could have taken medication, I could have had him with me longer.

[PHI Redacted]

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With a MMSE (Mini Mental Status Exam), which is the standard "Memory Test, score of 24/30 mom's primary physician thought all was well. I knew it was not. I ask for a referral and got nothing. I finally took mom to MARS (Memory Assessment Research Service in connection with UNC-Wilmington Psych Department) and received mom's diagnosis after 2 cognitive testing sessions 9 months apart. When symptoms are obvious it should not take a year to get a diagnosis! Some have to wait even longer. If I had not been proactive and persistent it would have taken a lot longer for mom as well. Early and effective diagnostic protocols have to be implemented for this ever growing disease. You wouldn't want to wait a year for a brain tumor diagnosis.... you don't want to wait a year for a dementia diagnosis either!

[PHI Redacted]

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Early diagnosis of Alzheimer’s disease is a must for a family. My husband of 52 years who was a bright, intelligent, well educated man was diagnosed with Alzheimer’s 2 years before he died. I saw things happening to him and was very suspicious that he had some dementia.

It is very difficult to accept the diagnosis but the earlier that is detected the better for the family. There is so much a family has to deal with as the horrible disease progresses concerning future plans, research in how to deal with it and acceptance of it by the family that the sooner it is diagnosed the better. I feel it is the worst disease there is as a person loses his mind, his dignity and forgets everyone he/she knows in his life. There is much preparation the family needs to take as it is such a heart breaker to lose the love of your life and still see his/her body but he/she doesn't know who you are. The more help a family can have at this time the better, so early detection is extremely important.

[PHI Redacted]

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Please allow more than one test to be available, one test is not sufficient to diagnose dementia/Alzheimer’s. My mom went 25 years undetected but was clear after 3 doctors visit and me giving medical history with and a childhood car accident which started it all. Thank-you.

[PHI Redacted]

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Alzheimer’s disease is a terrible disease emotionally, physically and financially. I watched as both of my parents slowly died from Alzheimer’s. They were both Christian, caring loving people who did not deserve to have their lives end in such a sad way.

[PHI Redacted]

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My mom was formally diagnosed with Alzheimer’s in 1993. However, as early as 1988 (perhaps) something began to happen to my mom. She was always so keen, and was the planner in the family: events, birthdays, and got everything in order. She was an immaculate housekeeper. And mom and dad were in their late 70's and were active. They walked a mile each day, and oh my even helped my family/myself move in the 1980's. mom was born 1910, died in 2000. However, she began to become paranoid concerning someone was stealing her mail, and then she would say things like it is frost out there I believe, well, it was July. mom's personality was such you believed her. Of course we did not believe it was frost. We just did not know what was wrong. She was volatile at times in her harsh words. I took her/made appt with Emory University Neuro-Psych department with the best psychiatrists in the world. We checked her in and she spent a week there. Yes, her diagnosis was Alzheimer's. We were devastated. But we lost a lot of ground. We just did not know. My dad insisted upon her staying at home with him for four years. But his health declined. She lived with me and so did my dad, but I worked, and was not well myself. So she went into a wonderful facility in St. Augustine, Florida. However, we went each day. And the staff knew we would be there. I attended every session of evaluation/updates with the staff. This early diagnosis is needed! very much. She became so sweet and even laughed in the different stages. The Dr. said this as unusual. She loved dogs/who came to visit, smile, and birds, and little children, and Reese's cup/candy. She was not a diabetic, she received no meds. Just the Alzheimer's. And that was rare nurse said. The only time she spoke any sort of words would when she saw a baby, child, or pet. She had been a children's coordinator at a church nursery for 35 years. And muchly loved by everyone. You would have loved my mom. She was spirited, and gregarious, and compassionate, and giving, and fun just to be with. And a great cook! smile. Thank you for your consideration. There is a lot of pain just in thinking about all of this. I truly missed my mom way way too soon.. to the final goodbye.

[PHI Redacted]

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I want this test - before it is too late!!

Sincerely,

Mr. Reese Forbes

[PHI Redacted]

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For the past 4 years I have witnessed my father struggle with everyday living. Tasks like buckling his seatbelt to mixing his sugar in his tea. Watching the man that has always been my super hero struggle with such simple task has scared me. This man was known by family and friends as the man that could do or fix anything. Growing up we were the first to have central air in our home. No Sears service man, but my own father, my super hero, installed the unit and ventilation throughout our home. He was a simple pressman for the local newspaper but in my eyes he was a genius.

Today he can't tell you a name of a tool he would use every day - a simple screwdriver, a hammer, a tape measure... And to watch him struggle to find the words kills us. It leaves us hurting for him and lost on what we are to do to help him.

In the last five months I have noticed my mother's memory is worsening. When I brought it to her attention asking her if she wants to go to see dads doctor. She says "no, you won't like what he has to say." Today mom can't tell you what she did just 30 minutes ago.

Today dad is living alone- diagnosed with dementia for the last 4 years. He has been taking Namenda to help him maintain some sort of normal life. Recently they have added an anxiety medication to help him with communication.

Mom has been diagnosed with vascular dementia and is living in a personal care facility. My parents are going on 56 years of marriage. This is the first time they have lived separate. Dad misses his lifelong partner and it hurts him seeing his wife not recognize life any other way but for the way it is today.

I can't help but wonder if the stress of taking care of my father helped speed my mother's condition to where it is today. Research says that high stress, bad diet and little exercise leads to Alzheimer’s. For the 7 months, I live with high stress, little exercise and very poor diet. Working a full time job, being a wife and mom, and being the person that tends to my parents adds to that stress level.

I write to you today asking that you help families like mine. My parents have been too many doctors but not one can say what they really have or help us with what we can do for them. We all want the best. We want their remaining years to be comfortable. But to think that we could have done testing to help get the proper diagnose. Or better yet help them live the last 5 years with the right medication so they could have a normal life for seventy year olds.

My mother relives the death of a sister and son, because she can't remember them passing. My father is angry because he can't communicate, read or do simple everyday tasks.

You have the power to help working families like mine. Please do the right thing and help with early diagnose. I would like the help; I don't want my child to have to go through what I am having to go through with my parents. I want to be tested and if I have the gene I want to get the help that is available. Please make it that our future can have and use the tools out there to help.

[PHI Redacted]

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We talked with our personal general doctor and he finally listened after 3 years of asking him why. An MRI was done and a diagnosis of dementia was given. Years later, due to other changes, my husband needed psy. treatment and meds were prescribed then. We lost almost 6 years if we could have had a better diagnosis and treatment, possibly. After visiting a neurologist we officially got the Alzheimer's diagnosis. My beloved spouse is in a nursing home close to home, and has no short term memory ability. Other things are happening also, and I wonder if there is more I should know. But no one can tell me what to expect, the whys and how long. I have read every available book and all the things the Alzheimer's Association puts out. Something needs to be done, this is a horrible disease. More research, better testing, and availability to all. Not just the ones nearest to research facilities. They (the victims)know it is happening to them and no matter how hard they struggle, they can't win.

[PHI Redacted]

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My mother [PHI Redacted], was diagnosed with Mild Cognitive Disorder 9 years before she passed away this year, in 2013. As the dementia progressed, it was a foregone "conclusion" that it would develop into Alzheimer's disease. Clearly the mid and late stage symptoms indicated that and in the end, the final stage, also suggested Alzheimer's Disease. However, throughout the last 2-3 years of her illness when things were so deteriorated, we never knew for sure, and we never felt sure that we had the proper balance of medications in an attempt to stabilize her condition. In fact, her last 2-3 years were literally a living hell for her as we moved from one type of behavioral related medication to another. Reflecting back, I can't stress enough how significant a more formal diagnosis of Alzheimer's might have contributed to getting mom to a better place and improved quality of life, especially if it had been made and confirmed early enough.

[PHI Redacted]

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I am eternally grateful that I had tools available to be able to receive a diagnosis early in the progression of her disease. My tools came in the form of years of education and a cognitive assessment. mom had worked as a respite nurse for patients with Alzheimer's and dementia. During those years she trained me to recognize signs, to aid implement coping skills and when she began to manifest those signs, I was equipped to respond. I had a vocabulary with which I could communicate to the doctors administering the cognitive test. It was that vocabulary, that alerted the doctor to mom's cognition deterioration and resulted in her diagnosis of early-onset Alzheimer’s in its early to moderate stage.

Early detection was critical for us as a family to be able to include mom in long-range planning of decisions for her care. Early detection allowed us to value the precious time with mom while she was still coherent and to establish patterns and coping mechanisms that permitted her to maintain strong bonds with her grandchildren even now in the severely declining stage. Early detection made mom eligible for certain medications that I credit with delaying her decline. Early detection in short gave me years with my mother that I am certain Alzheimer’s would have taken.

Most families do not have the knowledge and vocabulary my mother gave me. For most families, a test like brain amyloid imaging will fill that knowledge gap and give to them the opportunities I had with my mother.

This is important, for families and for patients.

[PHI Redacted]

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My husband suffers from P.T.S.D., having served as ambulance driver in WWII. Now he is slipping away from Alzheimer’s. I believe there is a connection between his horrific war time experiences and the Alzheimer’s. I believe there is a connection between the two diseases.

[PHI Redacted]

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My husband and I care for his mother, who we *think has Alzheimer’s disease. Why do I say think? Her doctor has never given her the test for Alzheimer’s. In fact, the entire diagnosis was made based on her symptoms alone. We treat her medically as best we can based on this diagnosis, but often feel we may be missing something. Because there are other reasons for dementia, it is possible that other treatments would be better for her. In addition, her whole family worries about their own future. Every forgotten conversation or miss placed set of keys has them wondering if their mind will go next. After watching the sadness and difficulties mom faces, how could they not worry about their own future. Alzheimer’s testing could verify whether mom needs different or additional treatment for her own troubling dementia and help the family either get early treatment or rule out Alzheimer’s as they get older. Alzheimer testing is imperative.

[PHI Redacted]

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I am writing this because I am hoping that better care will be provided to Alzheimer’s patients. My grandmother was diagnosed around 2006 and passed away on September 22nd, 2009.

We had no knowledge of treatments. She was put on Aricept and Namenda. She couldn't sleep. We called her doctor and received no help. We called nursing homes that specialized in Alzheimer’s care. They were the ones who gave s information in which mess to suggest to the doctor. The doctor approved it. When we asked how much she could take - her doctors told us to use our own judgment.

It is as if Alzheimer’s patients are not given as much importance as other patients with other illnesses. No one told us what the side effects were. One medication made her totally bed ridden. She never walked again. I pray no other family has to suffer the same consequences.

[PHI Redacted]

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For about three years now, my mom has been going through a lot of different symptoms..such as forgetting a lot of things, not being able to concentrate, and things like that. First of all, we did not know exactly what it was, but when we discussed whether it was Alzheimer’s or not, we just assumed there was no test in it.

In the three short years since she started showing symptoms, it has progressed too very fast..and she can no longer even be left alone, she cannot even find a rest room in a public place or building, and she forgets all short terms things that she is going through or being told.

If there was a test that we could have taken back then, we could of gotten her on meds a lot faster, and this heartbreaking speedy progression might of slowed down just enough for us to enjoy a little bit longer with the old mom I know and love. All any of us ask really is a chance to have our loved ones last awhile longer being active in our lives as well as their own.

[PHI Redacted]

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It's been approximately 4 years since my mom's mental lapses were first detected by her doctor. We eventually came to realize that her forgetfulness was due to Alzheimer’s. She is now bed ridden, and has been, for the last year. She is on a feeding tube and has a colostomy bag from complications first brought on by colon cancer radiation treatments. Needless to say the last 15 years of my mom's life have not been good. Personally, I have been ready to "release" my mom for quite a while since, to me anyway, her life is a struggle. She always said she didn't want to be kept alive with tubes etc. but that decision was hers to make and she never put anything down in writing. I believe if her illness had been diagnosed sooner (while she still had the capacity to understand) we could have walked her through the process and she could've made her own wishes known to everybody. As it stands now I'm having to send $750.00 a month home to help pay for a provider so she can still be in her own home instead of in a nursing facility. Is this about the money? No! It's about the lives and health of those people who are left behind to take care of a loved one who didn't have the facts regarding a disease which there is no cure for as of yet.

[PHI Redacted]

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I am a nurse practitioner and have worked for the better part of 10 years with elderly clients. I currently work as a geriatric care manager. Many of my clients are suffering from Alzheimer’s disease and other types of dementia. In order to manage dementia properly, it is essential to determine the cause of the dementia. What works with one type of dementia, does not always work for other types. Since all types of dementia are progressive, it is important for early, accurate differentiation of the disease. MRI's and CT scans can help with the diagnosis of some types of dementia but not Alzheimer’s disease. Brain amyloid imaging may help to establish the early diagnosis of Alzheimer’s disease and improve the quality of life for the client and family members. Because of the devastating nature of this disease, any chance of improving the lives of those affected by it should be strongly considered.

Sincerely,

Mrs. Kim Miller

[PHI Redacted]

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My family and I have been fortunate enough to not have firsthand experience with dementia. However, I have gained an in depth understanding of the obstacles and outcomes facing those with dementia throughout my graduate studies (current Ph.D. candidate) related to Gerontology and Social-Behavioral Psychology. Furthermore, I have worked for over 5 years in the Medical and Scientific Relations department of the Alzheimer's Association, which has provided science-based knowledge regarding the biology and mechanisms of dementia and, more specifically, Alzheimer's disease.

It is this combination of knowledge and expertise that provides a holistic and complete understanding of dementia-related disorders; how they impact individuals and families; the enormous economic impact; and the inevitable outcomes if nothing is changed.

An accurate, early diagnosis is paramount.

This will allow individuals and families to plan better and manage the disease more effectively. In turn, this will likely positively impact Federal and State governments economically (I need not explain the tremendous strain the aging population is placing on our healthcare system today). Earlier, accurate diagnosis will prove beneficial to individuals, families, the U.S. healthcare system, all levels of government, and the economy in the long-term.

Sincerely,

Mrs. Rachel Jantke

[PHI Redacted]

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My mom is suffering. Please help!

[PHI Redacted]

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My mom died ten years ago from complications of Alzheimer's disease. She was diagnosed early with cognitive impairment because she was part of a research program through the University of California-San Diego. However, at the time she was not diagnosed with Alzheimer's disease. Ten years later, we are still struggling with early diagnosis.... It would be wonderful to accurately diagnose Alzheimer's at an early stage when treatment can prove to be most useful.

If you have never experienced first-hand the struggles and challenges of being a caregiver for someone with Alzheimer’s disease, you are very lucky! This disease takes away your loved one, one piece at a time, it is so distressing and horrible to see your loved one disappear to become someone you don't know and the same goes for the person with the disease...

Please make this happen!

[PHI Redacted]

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Just a short note to say that our lives have been significantly altered as a result of Early Onset Alzheimer’s disease. My wife was forced to leave her position as Professor of Mathematics at our local community college. She was nearing retirement but has now lost company paid health insurance. We are fortunate that we can continue to pay for the insurance until Medicare kicks in. As a retiree we were looking forward to travel to visit our six children but travelling is very difficult with someone with AD.

This is a serious disease affecting many, many people and has a decided disruption of normal life activities.

I implore you to consider additional funding for early diagnosis and treatment of this debilitating disease.

[PHI Redacted]

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My loving wife of almost 37 years passed away in April.

She was diagnosed w Early Onset Alzheimer’s 11 years ago at the age of 49.

We cared for her at home, eventually with The Catholic Hospice helping, The last couple of years together were wonderful as I was able to take a sabbatical from work and become a full time caregiver.

She passed with us at her side.

[PHI Redacted]

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My wife was recently diagnosed with Alzheimer’s. In the past few months there has been an obvious and rapid deterioration of her cognitive skills. Who knows what help she might have gotten had she been tested years ago. Not only the fear of being erroneously diagnosed and the cost of testing delayed our decision. It is one thing to care for a loved one with a debilitating and understandable disease. It is not the same as watching a physically healthy and relatively young person loss their mind. This country needs more effort to testing and understanding this horrific disease. Too many vital years are being lost.

[PHI Redacted]

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We were told, when my mother passed away from complications due to dementia (we think it was Alzheimer’s) that the only definitive way to prove that it was Alzheimer’s was to have a cost prohibitive autopsy done. mom was never officially diagnosed but we certainly would have benefited from knowing exactly what she had and what we could do to prepare for the various stages of the disease. We considered having a neuro-psych examine mom, but decided to not put her under that sort of pressure. If there had been something easy like an MRI or scan we would have chosen that. Please help others avoid the confusion we did.

[PHI Redacted]

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My mother, aged 77, and now living in nursing home care has suffered from a her internist's "diagnosis" of Alzheimer’s disease for over 5 years now. My father, age 83, attempted to care for her himself as long as he was able. She is now entering the last stages of the disease, where here speech is impaired, and her mobility almost gone. One of 8 children, at least 3 of them have died, presumably of the same disease. two living sisters have also been diagnosed with Alzheimer’s/dementia. All of their decedents (I am the eldest daughter at 58 of my mother), now live in the shadow of this terrible disease. The lack of an accurate diagnosis certainly made life more difficult for all of us as caregivers. The fact that I cannot put to rest my fears about having the disease makes me question every forgetful moment, or unclear day. Although I still work, have insurance provided through an employer, I cannot afford PET tomography scanning to provide an early diagnosis, or clear my fears... Please, recognize that advanced in research and put them to us helping us prepare for future care needs, and give peace to those of us who want to know. Withholding this now helps no one!

[PHI Redacted]

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My mother passed from vascular dementia in October of last year. She started falling in May, and continued to fall on her head primarily till her death. Hospital scans showed amyloid plaques galore, which the doctors blamed for her dementia. It is horrible to see a strong, healthy woman who has survived a terrible life to lose her life in six short months. The doctors at Mary Immaculate Hospital in Virginia said there was a direct correlation between her falls, her lesions and her dementia. This is becoming an epidemic. How can you not afford to continue with this testing. My mother had 3 children and I know we would all like to know if we are predisposed to this humiliating disease. It would be a national disgrace to discontinue this vital testing to the public!!

[PHI Redacted]

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I think our family has been one of the lucky ones if you can consider having a family member with Alzheimer’s any kind of luck. My father was diagnosed in his early seventies and started on medication. Our experience has been much different than some of the other families that we have spoken to through a support group which has now disbanded for lack of leadership. At times I wonder if his diagnosis was correct because although he has no idea where he is he still is able to recognize me most days and he was 88 in June. I would like to know for sure that it is Alzheimer’s that he has and that we are on the correct treatment plan. What we have been told is that you try to rule out everything else and then go with Alzheimer’s. That is not very comforting.

[PHI Redacted]

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My mother was an intelligent, very well-read, strong woman. She was caring, open, and never met a stranger. She had a wonderful, albeit odd, sense of humor. She loved crossword puzzles and her beautiful flower garden. She loved her pets, whom she treated like family. She beat breast cancer and has been in remission for 25 years. She survived a stroke. Through all of that, she never lost her love for life and her family.

Today, however, she is nothing like the woman she was. She can't speak intelligibly. She can't tell you when she's hungry or has to use the restroom. She can get violent when you have to "change" her, because she doesn't understand what you are doing. She refuses to get into the shower or tub. My father has to sponge bathe her. Yet, portions of her still remain. She still laughs, although we don't always know why. She gets silly every now and then. She knows that she loves us, but she doesn't know why. She still never meets a stranger, frequently walking up to people in the grocery store, restaurant, etc, which results in odd looks and people pulling their children in the opposite direction. People think she's weird, sometimes scary. All because she no longer has control over her mind. Alzheimer’s has control of her. Please, please help put an end to this terrifying, life altering, life destroying disease. Thank you for taking the time to read my letter.

[PHI Redacted]

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To whom it may concern, if you had a love one or friend with this horrible disease, maybe just maybe you would want them to continue the work and stop trying to stop everything they are trying to accomplish, my heart is breaking because my dad does not know me anymore, try to imagine that. Please stop making it harder for them to try to get a handle on this disease.

[PHI Redacted]

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I, personally, waited too long. My "life partner" has been diagnosed and is suffering from denial. Do not wait to request help!!!!!!!

[PHI Redacted]

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I take care of my mother who has early stages of dementia. It is vital to have an early diagnosis. It is also very important to tie the potential link between Diabetes and dementia.

I believe the following should be communicated to ALL individuals, not just Alzheimer's, dementia and diabetic patients.

I've noticed that making the following changes has improved the overall health of my elderly mother and maintained her dementia score.

If possible:

Eat foods with high antioxidant levels every day

Supplement her diet, DAILY, with a nutrient shake (I give her Glucerna) to maintain her weight and provide valuable nutrients

Puzzles (word search, etc) daily

Stay active to maintain muscle tone (even if it means just getting out of bed and taking care of something ie. feed the dog or let the dog out into the yard). Also, assign small chores.

Better management of diabetes actually improves the overall health of my mother (her diabetic / edema in the eye) has stabilized.

The rate of Alzheimer's and dementia is rising. It takes a toll on the family, especially the caregiver. Early diagnosis as well as communication of the above would help the patient and the caregiver.

Please support early and accurate Alzheimer's diagnosis as well as the risk factors that may pre-determine Alzheimer's disease.

[PHI Redacted]

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Up until a year ago my family and I knew very little about Alzheimer's Disease. My mother was a "stay-at-home" mom who raised 3 boys (I am the middle). We've known for a long time there was something wrong, but we couldn't get any of the 15 doctors we went to, to give us the proper label, or to ask for the proper test to be done to help diagnose this. They threw everything at the wall from; empty nester, hi blood sugar, depression, anxiety, etc. Then finally, after finding a doctor in Florida, and doing a spinal tap - they finally arrived at "Moderate/Severe level Alzheimer's disease", at the ripe young age of 56.

My mother is in perfectly good health.....except for her brain, which is the most important thing. My parents did everything right. My father worked around the clock to provide for our family, and to allow my mother to stay at home. They were very conservative, and saved a lot of money, so that when they got to this age, they could travel the country, and live a relaxing and care free lifestyle. But now, my father finds himself working twice as hard as he ever has in his entire life, to make sure his; rock, wife, and best friend is as comfortable as she possibly can be.

This disease is the saddest thing I've ever dealt with. Watching your mother fade away slowly is the most depressing feeling in the world. I have never felt so helpless in my entire life. We spend something like .02 on finding a cure or a way to prevent this disease for every dollar we spend on taking care of those affected. The statistics are terrifying, and the future for Alzheimer's disease doesn't look great. I wouldn't wish this disease on my worst enemy. I hope and pray every night a cure is found for this.

[PHI Redacted]

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If your mom had it you would want to know. My mom did. We didn't know.

[PHI Redacted]

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I am writing to encourage you to continue the broad coverage for Medicare/Medicaid for PET scans for beta amyloid proteins in the brain. As you are aware, early scans allow people to receive some medications at the earliest stages of Alzheimer's to slow the progression of the disease. My oldest brother, Arlin, died at age 69 of Alzheimer's in 2011, as did my oldest sister, also at age 69 this year. Both were diagnosed with early onset Alzheimer's, with my brother's reportedly noticed as early as age 55 or before. With earlier PET scans, perhaps the disease could have been slowed in its progression.

Thank you for your time.

Sincerely

[PHI Redacted]

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My father is in what I believe to be the moderate (middle) stages of the Alzheimer’s form of dementia. He is a retired pathologist whose mother died of Alzheimer’s about 30 years ago. He is a huge phobia against even hearing the word so his PCP, out of respect for my dad, refuses to give him the diagnosis. I have been trying to get me dad to accept the fact that Alzheimer’s needs to be studied further and the main problem in America is the lack of acceptance. IF this exam were available in Pensacola (currently the closest place to get one is Atlanta), then maybe the physician in him would be more likely to come to terms with the fact that he actually has a disease and NOT going through the normal aging process.

[PHI Redacted]

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In October of 2008 my husband was diagnosed with Alzheimer’s disease. As a smart physician he knew something was wrong with his mind so he enlisted his internist to find out the answers. He referred us to a geriatric psychiatrist who gave us the diagnosis. It changed our lives, but in the first year Claude was able to tell me his wishes for his care as the disease progressed, as well as practical matters regarding the care of our home, which he had largely managed since he retired 12 years before I did. Now I know how to change the filter on our water system as well as a myriad of other tasks I never dreamed of having to learn. Our legal documents were also in order so when he could no longer make decisions I could take over as his Power of Attorney. I attend a support group sponsored by the Alzheimer Assoc. and have seen firsthand what happens when a spouse refuses to sign the documents. The financial and legal struggles are heartbreaking and no one would do this to a spouse if they are in their right mind. Early diagnosis and education for the entire family are crucial in this process, even if there is no treatment for this disease at this time. My family has been lucky and smart. The last thing Claude wanted was to be a burden to his family, but in this disease each patient reaches a stage where he no longer thinks anything is wrong with him and this is the highly dangerous stage. Early planning can keep this stage from spiraling out of control for everyone.

[PHI Redacted]

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Being a social worker with the senior population, I can't tell you how many times clients tell me that their physicians brush off their concerns with recent memory lapses. It's just a normal part of "old age" they are told. As they later find out, it is not normal. It is brain failure. It is a terminal disease that will eventually take their lives. My clients spend many precious years thinking their cognitive decline is expected, when they could be spending their limited time doing meaningful things with their families. They could be creating memories for their loved ones that the ravages of this disease won't be able to take. By not allowing these individuals an early and accurate diagnosis early on, they are being robbed twice. Robbed by Alzheimer’s and robbed by limited access to a timely diagnosis. As a society, we owe these individuals who have worked hard, raised families, and created rich lives, to be able to participate in decisions regarding the care for their days to come. Not only for their benefit, but for the benefit of their loved ones left behind struggling with the guilt of making decisions for the one who no longer has a voice. Please help be their voice and advocate on behalf of early diagnosis. Thank you.

Sincerely,

Miss Ashley Olson

[PHI Redacted]

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I suspected my mother had Alzheimer' for six long years. The first time she was tested with the Mini Mental State Test, we were told that she scored high enough that they thought she was just "depressed". It would be another two years before she was diagnosed. By the time she had a diagnosis she was not capable of making intelligent choices about her care and who knows how many ways and times she put herself and possibly others in danger. Maybe an early diagnosis would not have changed the progress of this disease but certainly it would have allowed her to have a true say in her care. My brothers and I are guessing...and sometimes don't agree. How many others are deprived of their voices and choices because effective tests are unavailable?

[PHI Redacted]

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I have a 71 year old mother who was diagnosed with Alzheimer’s 3-4 years ago. Until then, we had no idea why she seemed to be withdrawing from the interaction with others.

We thought it was depression and she was being pumped with a handful of pills until the diagnosis was finally made.

If we had known earlier in the process what her problem was, the quality of her and our lives would have without a doubt been better.

I whole-heartedly believe that with better early-detection procedures in place for Alzheimer’s patients, only good can come from, from both a financial as well as emotional standpoint.

[PHI Redacted]

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This is probably no surprise-there is no cure, no way to slow it or prevent it. However, a small hope is found in an early and accurate diagnosis. Early and better care planning can drastically improve the quality of life for a person with Alzheimer's disease.

Amyloid imaging helps doctors accurately diagnose or rule out Alzheimer's in patients. A family friend had been having memory problems and trouble receiving a diagnosis because imaging wasn't covered for him. He couldn't afford the imaging test, and this caused a lot of trouble confirming an Alzheimer's diagnosis.

When a physician decides that imaging would be appropriate for a patient, I would hope the CMS will provide that diagnostic option. No one should have to prolong their wondering because they can't afford a test and the CMS won't cover it.

Please change your decision, and you will change lives by providing better outcomes and a higher quality of life for the millions of Americans with Alzheimer's and their families.

Sincerely,

Miss Kelly Stone

[PHI Redacted]

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My wife went through the testing early on when we started to notice memory problems. I can tell you that it was a great help and comfort to have the diagnosis early on along the way and the stages of her Alzheimer's decline I have involved myself in as much as a can and learning of the disease as possible as a care giver I have 2 homes one in Tampa Florida and one in Atlanta Georgia I am a member of Alzheimer's support groups in both locations the sharing of information and fellowship has been and will continue to be very helpful and also comforting thank you for this form and allowing me to tell you just a little bit about my daily journey with my wife of 43 years.

[PHI Redacted]

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As I said on Twitter. My uncle has been a preacher longer than I've been alive. Although my Uncle suffers from Dementia there was nothing more scarier to my Aunt Pamela Magee then realizing something was wrong with him when he couldn't remember things he'd preached for years.

That is no way to discover something’s wrong. The heartache to loved ones cannot be undone. To watch the person you love and spent 30, 40 plus years with to mentally disappear.

That is a fate worse than death! My mother in law was diagnosed about a year ago. She's was a nurse. Responsible for others care. Luckily she realized what was going on and took early retirement. But that could easily have gone another way.

My father is another example of why early detection would be important. Although it too is not Alzheimer's if we had known sooner that he was having mental capacity issues I wouldn't be going through this hell right now. Steps and actions could have been taken and it would be such constant battles.

There are consequences for not approving early detection. It doesn't just affect the individual with the disease but others as well. It also leads to the potential to help with so many other issues as well. Is CMS really willing to take those kinds of risks? Is it all about the bottom dollar?

If it is about the bottom dollar consider this early detection of any disease reduces the long term costs of dealing with the complications of the disease. Maybe they get to stay home longer before going to a $6k a month nursing home.

[PHI Redacted]

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Three of my family members (Uncle, Great Grandmother, and Grandfather) all passed due to complications with the disease. It's important to have an accurate diagnosis to seek treatment as to make personal decisions (living arrangements etc). My grandfather was misdiagnosis and was unable to receive important medicine to prolong the effects. Please listen to the thousands of family members who are urging for quicker diagnosis. Thank you

[PHI Redacted]

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Please don't make this more difficult than it already is. We are talking about a deadly disease... that affects entire families, not just the patient. Early diagnosis holds the hope of finding some sort of cure in our time.

[PHI Redacted]

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In the spring of 2004, I was forced onto medical disability due to fatigue. After three months of intensive medical examinations I was given a diagnosis of "mild sleep apnea" as the cause of the fatigue. More than a year later, while still disabled with fatigue, I was battling the insurance company to reverse its denial of my long-term disability claim.

When they suggested I submit neuro-psychological test results to support my assertion of some cognitive issues, I engaged a professional to do the comprehensive tests. The day-long tests showed significant audio and visual short-term memory loss, and recommended visiting a physician to explore the cause. Based on the test results my primary care physician put me on Aricept, ordered a PET scan, and referred me to a neurologist. Based on his examination and review of the PET scan, in late summer 2005, the neurologist concluded that I had "early Alzheimer's disease."

I have been on cholinesterase inhibitors and memantine now for over eight years. I also adopted a range of lifestyle changes known to help prevent Alzheimer's, including exercise, healthy eating, support groups, music.

As a result of my early and persistent treatment including alternative treatment strategies, I continue to live a near normal life in my retirement. While I have to manage my fatigue, I am able to attend my support group, lead my folk singing class, and other such activities.

Without that early diagnosis and medical intervention, I fear that I would not have been so fortunate.

[PHI Redacted]

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Hi, my name is [PHI Redacted] and my Dad has Alzheimer's. Today I am a very active volunteer and advocate for The Alzheimer's Association, and that is because 8 years ago, my Dad began showing obvious signs of dementia. He was only 65 years old. About 4 years later, we finally moved him to a Memory Care Facility, and I began managing medications, doctor's appointments, finances, and his life plan. I am his caregiver. Today my Dad is very advanced in the disease but we have made the most of our journey with him thus far. We make sure to laugh a lot, sing and dance, and when we need to... we cry.

Those first four years were very confusing for my family. It was and still is difficult to get a diagnosis of Alzheimer's, so 8 years ago, the doctors would just use the term dementia. Without that diagnosis, we felt like we were in a holding pattern. We weren't sure what the next steps were. Should we start planning my Dad's future differently? Are there doctor's who specialize in dementia and Alzheimer's? Does he need a caregiver? And also without that diagnosis, it can sometimes be difficult to get specific medications used to treat patients with Alzheimer's. It's possible that we could have had more 'good years' with my Dad if he had started a couple of those medications right away.

I believe that early detection and diagnosis is extremely important for a family dealing with Alzheimer's because it makes the disease more tangible and real. My Dad needed more options for tests that would achieve proper diagnosis and early detection so that instead of sitting in limbo like my family did, we could have treasured our family moments even more, and plan for the future and a time when our loved one may not know who we are. So, please, take steps to increase early diagnosis and awareness!

[PHI Redacted]

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My mother and my grandmother had Alzheimer's and I am concerned about getting it myself. To have an early detection test covered by Medicare would make a great deal of difference to MANY Medicare recipients who don't have the money to pay for the test themselves.

[PHI Redacted]

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My dad died of Alzheimer’s, but his death certificate says cardiac arrest. This is wrong. His heart stopped because of the Alzheimer’s.

He was an amazing man, a WWII Navy veteran who saw action at Normandy and the Murmansk Run. he was born a farmer in Virginia and married mom in New Jersey. With little education, he raised a family, in a beautiful home, he was a good and loving man. Please help this, Alzheimer’s is a disease not a condition.

[PHI Redacted]

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Our neighbor of seven years is suffering from AD and witnessing her rapid deterioration has been very distressing for all member of my family.

Jane (psuedo-nom) is 76 and beyond her failing memory she is in very good health. Her daily emotions fluctuate through joy, anxiety, confusion, denial, anger, and loneliness. I don't know if she is taking medication but she thinks she's getting better. She has three children who live within 10 miles but she lives alone.

The children have taken some steps to prevent her from cooking, driving, mowing, and leave her with no money. We, and other neighbors who have expressed our concern to the children, have been told to 'mind our own business'.

She never knows what day it is, Comes over several times every day to say Hello and doesn't remember she's been there already, Sits out on the porch in all weather waiting for anyone to come home but can't remember our names Dragged her 9 yr old dog around until it died of heat stroke (not exaggerating), then Goes around asking the neighbors if they've seen her dog in moments of near lucidity she thinks she ran over the dog, Forgets to eat, Walks around barefoot in all weather, Loses her key constantly (we've had several made for her), Gets our mail and takes it home, Comes and gets in the car with us if we're going out, and the list goes on...

Given these facts at what point does Adult Protective Services need to get involved? We don't want to cause trouble with her family but we're truly concerned for her welfare, and to be honest my teens are weary of the constant disruptions to our lives. What happens when no-one is around to watch or help? What happens when she locks herself out in 95 degree heat or during a storm?

Early diagnosis won't help her now but it may help other seniors and their families make decisions and adjustments to their lives to prepare for the eventualities of caring for an AD family member.

Concerned Neighbor, Mt. Juliet

Sincerely,

Concerned Neighbor

Mount Juliet, TN

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My wife was showing all the signs of Alzheimer’s that we saw in my mother and her aunt, until they each died from the disease. When we learned that Eli Lilly was conducting a research program for their drug Expedition we were both encouraged to sign up. Earlier we both participated in the clinical study for the shingles drug and we gratified to learn the drug works and is now widely prescribed and is effective in preventing shingles.

When my wife signed up for the Expedition drug she had to undergo MRI's, and with the result of previous testing including an EEG she was accepted into the study on the results of the testing which "indicated results consistent with Alzheimer’s".

My wife is now in a nursing home suffering from the final stages of this hideous disease.

[PHI Redacted]

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My husband suffered many years before diagnosis and treatment. In his late 50's his level of forgetfulness cost him promotions and eventually led to early retirement. His was wrongly diagnosed with depression and anxiety and the treatment only made him sleep all of the time. That was 9 years ago. In 2010 he finally received proper diagnosis and medication, both of which, if given earlier, would have slowed the growth of this horrible disease. Although this topic is very close to home; on a larger scale we as a nation are wholly unprepared for the epidemic coming down the pike. The largest group of aging Americans is also the largest # of Alzheimer's patients. The sooner the disease is slowed, and treated, it buys time for caregivers and family to prepare for the changes that always come.

[PHI Redacted]

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I have been living with Alzheimer's for 4 years now and am doing well. All due to early diagnosis and proper medications. Please help others to help themselves.

To:

From:

Subject:

Date:

[PHI Redacted]

-

My father had dementia and an earlier diagnosis might have helped him lead a better life in his later years.

[PHI Redacted]

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My husband needs this test. Please make it possible under Medicare.

[PHI Redacted]

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My father is 77 and has had Alzheimer's for the last seven years. He takes the combination of Exelon and Namenda and it has significantly slowed his decline. If we were able to diagnose Alzheimer's earlier he could have begun taking these meds sooner and maybe had an even better prognosis. The only hope for delaying symptoms and possible prevention is early diagnosis. Please support early diagnosis. It does help.

[PHI Redacted]

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I have cared for an aunt, my dad, my mom and now my husband who all have had some form of dementia. What kind of dementia is the question. When should they have had dementia medication? Was it just old age? That is what we were told too many times. Knowledge is power. If I had had more information concerning what we were dealing with at the appropriate time our decisions could have been made with facts not some vague comments by the physicians.

Even now with my husband we deal with many questions that with a clear diagnosis might well be handled differently.

[PHI Redacted]

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Early detection and diagnosis allows for more treatment options. Meanwhile, we family members can be educated on how to deal with the behavioral and psychosocial effects on our loved ones so that we are better equipped to provide care.

Thank you.

Sincerely,

Ms. Natalie Kreng

[PHI Redacted]

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My sister and I dealt with my mother's weird changes in behavior a few years after our father died. Only in retrospect can we say it had to do with the beginning of dementia. Of course, at the time, we blamed the occurrences on outside influences. As the years progressed and she continued to decline we were told there's no way to determine if she had Alzheimer’s or not. Then a doctor did supposedly make the diagnosis. My mother went from assisted living, to an Alzheimer’s unit, and ultimately to a nursing home. This was over the course of 15 years. She finally passed away last November at the age of 95. However, had I joined an Alzheimer’s support group (had no idea they existed) if I was positive mom had the disease my sister and I would have been spared many tears, tons of frustration, aggravation, and heartaches. Unfortunately, my sister passed away four years before mom did and I only learned of local support groups after that. Watching my mother's slow decline for years was positively agonizing for me. Regardless of her state of mind I visited her religiously every single week and my heart still tears at the very thoughts. Perhaps all seniors over 65 or 70 should be required to take a test to determine their chance of getting the disease however terrifying that prospect may be...at least it is to me. It's one of my greatest fears.

[PHI Redacted]

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My husband was diagnosed with dementia in 2005. He was having a lot of trouble to get the words. When he started wandering we had to put him in an Assisted Living with Memory Care facility in 2008. None of the Alzheimer’s medications did any good for him. He was asked to leave the first 2 facilities that he was in due to his behavior (there is not enough training for people taking care of these residents, they need training on how to deal with the frustrations these residents are going through). He no longer is able to walk, so is in a wheelchair all the time when he is not in bed. He has since had a health problem which has made it necessary to move to a Skilled Nursing Facility.

[PHI Redacted]

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I am writing to you as the daughter and main care giver of both of my parents who passed away due to complications from Alzheimer’s Disease. My mother died in May of 2011. My father died in March of 2013. We were never given a definitive diagnosis with either of my parents. We were told that Alzheimer’s can only be diagnosed at the time of an autopsy, but they both had the symptoms. All-in-all my parents suffered from the symptoms for twelve years, total. My mother was also blind due to macular degeneration. My father experienced many cardio-vascular issues.

We kept my mother at home until her death. I did not want my father's confusion to escalate if we moved her. Even though we took him to her funeral, he never remembered that she had died. I had planned to keep him home like I had my mom. However after I got him to bed one night he managed to get out of the house and fell, breaking his hip. He was hospitalized for surgery and remained there about a week. He was then transferred to a nursing home that had an Alzheimer’s Unit. He was there for a few months before qualifying to move into a hospice home. He lived there for about 3 weeks until his death.

The financial toll, but more importantly the mental and physical stress on caregivers is unbelievable. I had help with my parents during the day, so that I could continue to work as a speech pathologist in a public school. After working all day, I knew that I had at least 10 hours of work after I got home each day. We had help for 1/2 day on Saturdays. My husband helped as much as possible. In the midst of taking care of them I developed a seizure disorder, which my neurologist feels is stress related.

My father was retired from a chemical company and had a "comfortable" retirement income. My mother had worked as a nurse and had a small retirement income. They lived comfortably. However even with their "comfortable" income, financial difficulties were an issue. We paid $10 per hour for about 50 hours per week. Before mom qualified for hospice care, and because we kept her at home, we had the expense of diapers, special foods, and medications. My father's care in the nursing home was a little more that $200 per day. It did not take long to use my father's monthly income and social security income. His savings account dwindled quickly.

Because both of my parents had Alzheimer’s, two of my mother's sisters had the disease, my paternal grandmother had the disease, and one of my father’s sisters also had it, I know that I probably carry those genes as well. I am 52 and feel like the clock has already begun ticking for me. But, if research can prevent my children or enduring its wrath, I hope that you do all that you can to encourage and support research. Thank you for reading my note.

[PHI Redacted]

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I have lost 3 grandmothers to Alzheimer’s disease and fear for my mother who is getting older. I am already watching for warning signs, so to me a early warning test would mean a lot. In 15-20 years my husband and children will have to keep an eye on me to watch for early signs.

[PHI Redacted]

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Working at the Alzheimer’s Association, you would have thought I had better access to a diagnosis for my husband's dementia. I did probably suspect it earlier than most would, but he resisted my suggestions and was in denial.

If a doctor had screened and talked to my husband, it may have made a difference in his acceptance, treatment and care during his last few years. Instead, there was only the suspected illness, avoidance of any action, and his withdrawal from us.

It played out in a story that was so ugly, I can only describe it as a tragedy. He and our whole family experienced more pain and suffering than was needed.

In the St. Louis area, we have access to highly respected medical researchers who have explained how the diagnostic test called brain amyloid imaging can diagnose Alzheimer’s earlier, and improves health outcomes. In my husband's case and my family's, a reliable, early diagnosis would have made a major difference in our lives.

Please, approve brain amyloid imaging for coverage

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Thank you for consideration of my appeal.

[PHI Redacted]

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My mother has had what we have been calling dementia for 15 years. The progression has been relatively slow but her short term memory is at about 10 seconds at the moment. The doctor has never formally given my mother a diagnosis of Alzheimer’s but it is written on some of her medical charts. My family would like to know, via testing or otherwise, whether she actually has Alzheimer’s or some other condition.

[PHI Redacted]

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My father was a POW in Germany in WWII. Once day I came home from school and he was sitting in the garage looking in an old, green, metal trunk. He was holding an old bent spoon and a chipped ceramic mug. He looked at me and said in a worried voice, "I know these mean something to me, but I don't know what it is".

The mug and the spoon were the only things he had in his prison camp to eat with, for the 18 months he was a prisoner of war. It was then my mother and I knew we had something to worry about.

If we would had known he was having serious memory problems we could have improved his quality of life, and he could have participated in his care. Please support early and accurate detection of Alzheimer's disease.

[PHI Redacted]

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Having a mother with Alzheimer's I've done some research and know that it can be familial. I'm concerned that I may have early onset symptoms but have no way to confirm my suspicions. My memory over the last year and a half has changed drastically to the point where I have to constantly write myself notes.

I would appreciate the chance to be tested but that won't happen unless something changes. I am asking for someone to take a stand for us out there that need access to this testing.

[PHI Redacted]

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I have taken care of my mother with Alzheimer's for 10 years and her sister (my aunt) with Alzheimer's for 7 years. It was a devastating journey in so many ways and very painful for me during the time they had it up to their deaths. We need to address all the horrendous problems for the victims and the victims' loved ones. It can be very lonely.

[PHI Redacted]

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I am a biomedical engineer and have used PET since 1984. I now work for a software company that developed a method for diagnosing Alzheimer's using FDG. FDG monitors lower metabolism due to Alzheimer's. Of course this means that damage has been done. We have also developed software that processes scans with agents that bind to amyloid, a positive detector of a molecule related to Alzheimer's. The difference in detection is the difference in seeing a street light from a plane at night vs seeing a tire on the ground during the day. Hot spot (amyloid) vs. cold spot (FDG). So Amyloid not only provides a better way to detect Alzheimer's disease it also is an agent that is found prior to damage to nerve cells. My mother was being scanned for potential liver cancer with FDG and we were able to get a brain scan in addition. We found early stages of Alzheimer's disease, which was confirmed by a top neurologist, and we were able to start treatment early with Aricept. I am not sure of the time but this was approximately 5 years ago and my mother has progressed very little. Early treatment in my mind will delay the progression even with current drugs and will most likely improve with improved drugs.

[PHI Redacted]

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This is an extremely cruel disease that will affect a larger and larger percentage of our citizens each year. As a society we need to care for each other. And we need make sure that everyone has access to healthcare; early diagnosis and treatment are crucial. We need more healthcare providers who are skilled in dealing with folks living with dementia - so important when people are hospitalized or going through physical or occupational therapies.

Sincerely,

Ms. Jean McMaken

[PHI Redacted]

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Please note the importance of an early diagnosis of Alzheimer's diagnosis. My grandfather passed away from Alzheimer's recently and early detection would have been the key to helping him sustain a longer healthier life. His loss has had great impact on our family and had he lived a little longer he would have been able to see his great granddaughter whom was born a little less than two months after he went off to heaven. Please consider this plea along with the pleas of all the other families who have had similar daunting experiences.

[PHI Redacted]

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Let's beat this disease. It's too late for our family, but it may not be for yours.

Sincerely,

Mr. Harold Renshaw

[PHI Redacted]

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My wife died in Nov. 2012 from Alzheimer's Disease. She had been misdiagnosed with depression, thyroid disease, food deficiencies, and with a mentally ill husband her primary care physician said was making her sick. She finally got the Alzheimer's diagnosis in 2010 after all those other diagnosis. It took several years for that diagnosis to be made, lots of doctors, much extra pain, confusion, may have been prevented by an accurate early detection. .

[PHI Redacted]

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Looking back on it now, what a ninny I was not to have seen his Alzheimer's coming. First, there were the phone calls. So frequent; one on top of another as our old familiar relationship ripened fast into much more than just friendship. I flattered myself that at last I'd found a persistent lover! Although it seemed strange that no sooner would he call about nothing, that he'd call again and again, and again as if he'd forgotten that we'd just talked. Ten, twenty calls a day from him was not unusual. Nothing out of the ordinary for a teenager, but at our ages (70 and 80), definitely odd. And his stories! What total recall he had of years past. So total, some eyes would roll when he'd repeat himself. I remember one of his sons-in-law muttering "If I hear that story again I'll scream." But I thought they were charming tales. Who else could tell about meeting the king and queen of England, playing tennis with the King of Sweden, and having cocktails with Princess Grace and Prince Rainier at their palace in Monaco? Another early warning I did not pick up on was his forgetting a tennis date with his best friend. Now that he was retired, tennis was his major interest. A former champion, his competitive urge had never gone away. He was very picky about his partners. Not showing up for a match, and with his favorite player, yet, was very unlike him. It wasn't until we began living together that certain behaviors stood out. One morning he had a lesson on our new iMac scheduled for 10 o'clock at the Apple store in our town. "Why don't I drop you off and come back later?" I suggested. He agreed. Driving away, I could see him in the rear view mirror about to enter the store. But twenty minutes later my cell phone rang. "Come to the store right away!" urgently cried the manager. Tom had been found wandering around the parking lot in back, shouting "Where is my car? I have a lesson to get to!" A kind soul asked him who she could phone for help. "My wife", he said. Fortunately, he'd remembered my name, so that's how I got the call. Dashing to the store, I found Tom standing out front, arm hooked with his teacher, Jose. Tom was breezily nonchalant; Jose looked worried. "There she is!" Tom caroled, and in we went to have what was left of his lesson. Another day he had a dentist appointment scheduled. "I don't need a passport to go to the dentist, do I?" he asked. "Certainly not, dear, "I answered. "Where do you think we are?" "Aren't we in Mexico?" he asked.

More little things that just seemed amusing at the time: The news of Sir Edmund Hillary's death was in the morning newspaper. Tom's reaction: "What is she doing in Nepal?" (He had Sir Edmund mixed up with Hilary Clinton). At a restaurant one evening, he had a quibble with the bill. "You wait here," he told me. "I'll straighten this out." He was gone a long time. I could see the waitress and he at the back of the dining room, Tom wildly waving a piece of paper, the waitress looking quite perplexed. I finally went to see what was going on. It was not the dinner check Tom was waving; it was his bank statement. A similar thing happened with his stockbroker. Tom came home and told me he'd sold everything. "Well, I kept this and that. Let me show you," he said, opening the thick file he'd taken to the broker. Brokerage statements? Uh-uh. A many-page printout of his personal address book.

Increasingly, numbers baffled him. "What time is it?" he'd ask. I'd tell him. "What day is it?" "What month?" "What year?" And then he'd start all over again. Then he began losing his keys. Where had he put them? In which pocket? What drawer? In the car? It got to be a fetish. Checking the whereabouts of his keys was the last thing he'd do at night, the first thing in the morning, and many times during the day. Next to go astray were his glasses. Like the keys, they were never really lost. One day the fellows at the club played a prank on him. They sat around the card table, pretending to be engrossed in their game, every one of them wearing dark glasses. I confess to being more annoyed with them than helping Tom. "Oh relax, Lee, good old Tom can take a joke" was their reaction. Sure, In the old days he would have laughed. Not now. Their silly joke just made him more frantic. I went to see his doctor. "Isn't there something we can do to help Tom be more normal?" I asked. He's just going through a natural part of aging, I was told. Just humor him. Keep him in touch with reality. We live in a large apartment building. Coming home alone one day, I got off at a wrong floor. So, obviously, had Tom. "Boy! Am I glad to see you!" he said. "I couldn't get my key to open our door." He'd been working his way up and down the hall, trying his key at each apartment, oblivious to the fact that it wasn't our floor. Luckily, no one was home to be alarmed. I finally came to my senses one Halloween Eve. I was upstairs putting together a track-or-treat bowl. There was to be a party in the lobby for the children at 6. At 5:30, my phone rang. It was the manager, saying in a deathly calm voice, “Come to the lobby. Right now." There I found Tom at the wheel of our Honda, a startled expression on his face. He'd mistaken the front entrance for the garage; jumped the curb, driven across the sidewalk and up the entry nearly as far as the glass doors. He'd been halted just an instant before crashing into the lobby. "Oh, honey," I remember saying, "Move over. Let me back out." That near disaster was the impetus for our finding another doctor, a neurologist this time, and getting Tom evaluated, diagnosed, and into a treatment plan. We were soon swept into an alphabet soup of MRIs, CT scans, EKGs, P-Ts, AAA, DMV, TIA, UTI and B-12. Somewhere along the line I was handed a sheet of paper from the Alzheimer’s Association. It listed their Ten Warning Signs for Early Detection. Tom had nine of them.

[PHI Redacted]

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While there is no cure at this time for Alzheimer’s disease, it is useful to have a diagnosis as early on as possible in order to try to slow the progression of the disease in any given person. My mother-in-law suffered severe dementia, but it was probably not Alzheimer’s disease, but rather TIA's. We gave her very expensive medication prescribed by her physician which gave her very unpleasant side effects. We would not have done that if we had had a more specific diagnosis. Please make it possible to use testing for early Alzheimer's by the use of brain amyloid imaging. Thank you.

[PHI Redacted]

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My father has been suffering from severe cognitive deficits and speech issues for three years and only recently was admitted to a nursing home. Without an accurate diagnostic test it took many hospitalizations, ER calls and near fatal instances before he could be admitted. My 80year old mother risked her own life repeatedly trying to care for him at home. I have had cognitive changes and without my dad's diagnosis am left with little information on my own future. Please allow and cover this important research and the tests necessary.

[PHI Redacted]

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My wife was first diagnosed with Normal Pressure Hydrocephalus and had a shunt inserted but never got any better.

Later in her illness she participated in the PET study in question and the autopsy agreed with the test by showing strong evidence of Alzheimer's. An earlier diagnosis would have helped to prepare for her rapid decline and she may have avoided the brain surgery.

[PHI Redacted]

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I currently care for my mother who was diagnosed with Alzheimer's two years ago. I have seen the decline in my mother's health and it continues to worsen day to day. I believe that funds need to be allocated to doctors and researchers to continue to find a cure for this awful disease, at the federal level of our government. We need to understand that the baby-boomers are nearing the age of contracting more chronic illnesses as they age, so it is imperative that a cure is found. If funds are not available to find a cure, who will care for the people that is afflicted with this disease, It is a fact that there will be a shortage of medical personnel to care for record number of Alzheimer's patients.

[PHI Redacted]

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Both my father and uncle have Alzheimer’s. I live with fear that I might develop / have this cruel disease as well. Coming from friends and family, I have learned of exercises and activities that can improve mental function, i.e. diet, exercise, brain teasers, crossword puzzles etc. Interesting enough, my own physician, who is aware of my family history and personal concerns has not made any lifestyle recommendations.

I believe screening, in populations with a family history of Alzheimer’s would be helpful.

1. Physicians will become more proactive and responsible - making patients aware of what they can do through lifestyle changes to delay the onset / progression of the disease.

2. Greater awareness, will increase the flow of information, and enhance research activities focused on diagnosis, prevention and treatment.

3. Screening will identify a pool - population at risk. So, when a cure or treatment becomes available, the population at risk can easily be contacted.

4. And with increase visibility - commercialism will do what it always does - speed progress and the development of tools to fight back - because there will be money to be made (i.e. marketing new combined physical and mental exercise programs, puzzles and of course and most important research for a cure and treatment.

Thank you for taking the time to read my message.

[PHI Redacted].

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You can't understand the need to know one way or another is it Alzheimer’s or not. The only thing presently available to us is the PET scan that measures the amyloid plaques in the brain. We have to wait until the one we are a caregiver to die and have their brain put onto slides and analyzed. I can't wait I need to know now one way or the other. If one has a lump they get a biopsy. Yes they can be treated with chemo or radiation or both. How do you expect the scientists to continue in their search for something's ng to fight Alzheimer's unless they know who has the plaques or not. New meds have to be tested and don't you think more people would volunteer to try a new drug; if they knew they actually had the canal d plaques. This test needs to be authorized maybe for those who seem to have Alzheimer's before the age of 75 or some other age limit.

Sincerely,

Mrs. Peggy Hernandez

[PHI Redacted]

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Thankfully we could be a part of a research with Exelon, that we had that diagnosis, and could plan for our future, both financially, emotionally. We then knew what things we needed to have in place to deal with this dreaded disease in the care of my husband, who died in a nursing home, when I could no longer care for him. Thankfully too, we were blessed by people who came to help with showers, and in home health care, respite for him to give me a break, and then with Day care. Without that diagnosis, none of this would have been possible.

[PHI Redacted]

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My mother, who is in a nursing home now, told us a lot of information that we didn't pay any attention to. We noticed a lot of changes and basically did nothing for quite some time, until it was too late! There were episodes of her getting lost and my mother would have to depend on strangers to guide her home, we found out from other people, my mother wouldn't tell us if something was wrong. My mother raised eight children without a husband, (that's another story). Then my mother took in two grandchildren, raised them and not very well, because by then my mother was tired and still my mother raised her first Great Granddaughter until she was almost six years old. Then we realized that mom would constantly fold clothes constantly, mom wouldn't stay off of her feet because they would swell and we wanted her to be well, by then we had to take over her checking account, I had been paying her bills for quite some time and it didn't dawn on me that Alzheimer’s was her problem, mom said she had head problems because a mirror fell from the wall and hurt her head...We took mom to the hospital and they took tests & more tests, until my sister sent my mother from the hospital, mom was in the hospital because of the leg swelling, to the nursing home where mom still asks please take her home. I have an aunt who is my mom's younger sister, who just lost her husband and my Aunt keeps telling my mother that she should pray to be with her Bubca, grandmother in Polish, and her two dead brothers and other dead relatives, needless to say I told my Aunt No, don't talk to my mother like this, but she still does and now my mother says she has to go to be with her brothers and Bubca and her mother and father, my Grandparents. The nursing home my mom is in is having problems with Legionaires Disease in the water and it is being treated, I'm worried sick because I don't think they ever give her enough liquid to be hydrated and when my sister took my mom's little refrigerator out of her room and gave it to her son, mom doesn't have access to asking or getting something from her own refrigerator. I talked to one of the seven to eleven nurses about the water situation and Kathleen said to me that she personally gave my mother four doses of medication that day and that was sufficient enough to keep her hydrated! I called her Supervisor and this nurse will be told what is needed, as far as hydration for a patient. I actually wrote to our Health Dept. and they sent me a letter saying that they spoke to my mother's peers (Alzheimer’s patients) and they said they were fine and they all got enough to drink. I hit the roof and every time I walk into the nursing home...people scatter and I don't care, someone has to take care of my mother and the others who have no one! Thank you for listening, I am doing my best and I get very little help from seven younger brothers and sisters, including the POA sister!

[PHI Redacted]

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My husband was diagnosed with mild cognitive impairment about 18 months ago. He has taken Alzheimer's medicine since then and we feel that his progression into dementia has been slowed because of them. It is important to both of us to have this time to make plans and get our affairs in order.

[PHI Redacted]

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I have been diagnosed with Minimal Cognitive Impairment, which may lead to Alzheimer's. At the moment I have difficulty with my memory in all areas of life. It is most distressing because there is no drug available to help.

My father and three of his sisters had Alzheimer's. One of my cousin's wives now has dementia and it is horrible for her and her family with no effective help for out of control behavior. Please consider funding the vital studies and tests that could help people with this awful disease.

[PHI Redacted]

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My story is of three generations. My grandmother, my father and my brother were inflicted with Alzheimer's disease. My grandmother was in her 80's when she passed in the early eighties. My father was diagnosed in his 60's and passed when he was 70 in 1997, and my brother just lost his life two weeks ago from this disease. We started noticing my father's behavior changing when he was in his late 50's. My mother would call his doctor and explain his symptoms, his doctor diagnosed him with depression. It wasn't until very late in the game that he was put on Aricept but it was too far advanced to have made much of a difference. My brother had to leave his job due to Alzheimer's symptoms and was unable to do his job. He lost his insurance and was not able to get disability coverage until late in his disease. He was not able to receive Medicare because he was only in his 50's at the time he was forced to retire early from his career. Located in Birmingham, Al., they tried to get diagnosed and help with his care but to no prevail until he was admitted to the hospital, having his hip break, surgery, forgetting how to swallow, feeding tube put in, tube getting infected, repertory complications all in three weeks, death at age 61. Help to those that don't have the resources, insurance, knowledge, or at least knowing who to turn to. There is no help out there for family or caregivers or for the Alzheimer's person to turn to.

[PHI Redacted]

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I have been dating a 56 year old man for a year now, of whom I could tell on the first date that he might have Alzheimer's, because my mother had it and I recognized the early signs. After doing some digging I found out that he had been diagnosed with it, only after his oldest daughter took him to several doctors. The last, a neurologist in Chicago, at first diagnosed him with mild dementia, but changed it to Alzheimer's, apparently so that he could participate in a clinical trial of a new drug and receive a pet scan that was more accurate than the approved one. His daughter signed him up, but he was on a placebo for 8 months, then on the drug. I don't feel it made any difference, so I took him for a second opinion. The neurologist diagnosed him with mild dementia, but that was only with an MRI and other tests. We found out that coincidentally Ely Lily is offering the new PET scan free of charge because insurance doesn't cover it, but only through July, so that is what we're doing. It turns out that that is ultimately why his daughter signed him up for the trial; the PET scan would have been unaffordable. I feel he has wasted a precious 1 1/2 years because of this, and especially at such a young age for this disease. I think ANY improvements in the diagnosis and treatment of dementia is sorely needed, especially with the aging of the Baby Boomers upon us. Thanks for time on this so very important subject.

[PHI Redacted]

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My story will be short. My father died from end stage Alzheimer disease April 7th, 2011. His symptoms began in his early 70's and he was 82 years old when He died form this sad disease that takes away a persons mind, body and spirit. I am 58 years old. I already have problems with short-term memory loss. It is difficult to remember numbers and names. Not all the time but often enough to have concern- do I have this disease? I have a son and daughter and their spouses and two wonderful grandsons I want to be healthy for and live to see them make many milestones in their lives.

Please listen to my voice before I can't remember what to speak.

Thank you

[PHI Redacted]

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I had an aunt who died from Alzheimer's disease. Before passing she resisted help and died because she could take care of herself and resisted help for any medical assistance. She lost everything, because she didn't trust the family to help her prepare her affairs.

If this disease was diagnosed early family members can help get medical help to prevent or delay the outcome of total dependence because of loss of their mental status.

[PHI Redacted]

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On July 6, 2013 I lost my grandmother to Alzheimer's. This is a woman who has been in my life since I was born and raised me at the age of two. She was a strong, willed woman, who worked for everything she had. She was diagnosed with early Alzheimer's in June of 2010 and slowly we watched her decline. Not only did this horrible disease affect her, but my family as well. I watched my grandfather decline physically and mentally as well. We were fortunate enough to keep her at home until her passing, but all due to the great Hosperaus program. We could not seek any other help because either she didn't meet a skill or the nursing home would take all they had ever worked for. I feel it is vital that everyone should be able to receive an early detection of this disease, to help prolong life. I am one voice, but share it with many who have had the same experience. I feel I have the right as well as my family to prolong my life with early detection and feel the government should be all for helping to support this cause in finding a cure. I shall continue to voice my opinion about this disease to honor my mom and to some how help another family from having to deal with my experience.

[PHI Redacted]

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I am 74 years old and especially for the past 6 months I have a problem of remembering where I set something down or more often walk into a room and forget what I was going to do.

I have told my VA doctor several times over the past couple of years of my memory problem but she says its old age and there is really none thing that can be none to cure the problem.

[PHI Redacted]

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I [PHI Redacted] found out in 2007 when I was being treated for heavy mold ingestion which gives you some of the same symptoms of short term memory loss. The discovered thru test MRI and other one, but never had a amyloid test that I had the onset of Alzheimer’s by a qualified neurologist.

[PHI Redacted]

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It is very difficult to make decision regarding the care of a loved one when you do not know exactly what their diagnosis is. If you know for sure they have Alzheimer’s, you can give them the medication, which is very expensive, and choose not to give it if they have been tested and do not show Alzheimer’s. This diagnosis would also have kept me from having certain tests done on my mother and wasting her time and Medicare's money.

[PHI Redacted]

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My mother had Alzheimer’s it appears one of my brothers may be in the early stages of Alzheimer’s.

Any accurate and early diagnosis not only can reduce the time of family stress for caregiving It gives the Medical Profession the opportunity for health measures that can prolong the period that the victim can function on his or her own.

Also, with a positive diagnosis it would seem that it would enhance any studies or new programs that the victim could take advantage of.

It is a terrible thing to loose a mind I watched my mother and I really believe that even though in her late stage, medically she was supposed to be with out cognitive function or memory or the ability to relate there were many incidences where I watched her react to things that I knew were part of her earlier life. What must the thoughts in her head have been? How much did she understand?

For you as a decision maker, you must be concerned about the overwhelming cost of this disease? It would seem prudent that aggressive diagnosis and research for a cure should be uppermost in your mind.

[PHI Redacted]

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I managed the care of my mother who was diagnosed with probable Alzheimer's disease. She was told in 1981 that she might have the disease but of course there was no tool to confirm that. We could only react to her needs rather than be proactive. Fortunately she was accepted into a study as an inpatient at NIH and followed for several years. We learned much more through that program than most people had benefit of.

I am now 66 nearing the age my mother was when she began having memory problems. I live alone. It will be critical to me to have as much ability to determine a diagnosis to enable me to make plans in a timely manner.

All of us who have lived with the disease in our family strongly recommend that study be expedited to provide one of the only clinical tools available to verify a diagnosis of Alzheimer's disease. This would enable earlier use of medications to slow the progress of the illness as well as expedite care planning.

[PHI Redacted]

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My husband slowly lost his abilities. When did it start? 10 years, at least, before his death. During the first 6 years he/we managed. He didn't get lost too often, he tried to control his emotions, he tried to take care of himself. But, the last 4 years were just one deterioration after another.

However, let me tell you, he could fool the best of them. Ray was very intelligent and when he started talking people were mesmerized by his knowledge of history and aviation. "What a wonderful mind he has." was the reply from friends, co-workers at the Air and Space Museum, and even the medical community.

What they didn't know was that I was covering for Ray. I was the one who made sure he was presentable, he got to appointments on time (I did all the driving after he wrapped his car around a pole), and knew that when he came forth with some profound facts and statements that it was wrong - but they didn't know that.

This continued for 3 years until he could no longer cope. The last year was pure Hell for him and for me. My husband was gone, but people still said, "He has such a marvelous mind." Didn't matter that all he was saying was all mixed up - they didn't know and he said it with such authority.

Do I wish there could have been a test to see if what was happening was Alzheimer's or just "dementia" which is what his diagnosis was. Absolutely! But, alas, he rarely was tested other than being asked simple questions that he practiced before seeing the doctor.

I know that Medicare wants to save money. But we did have a good supplement but they followed what Medicare said. Sure we could have gone outside and paid for the tests, but money was getting tighter paying for help to take care of him. The money we went through - several different walkers, a lightweight wheelchair so I could lift it in and out of the car (I am a polio survivor and Ray was given a wheelchair I could not lift - why is there so little help?) Then there was the permanent catheter so no daycare would take him - "they weren't licensed for that."

Ray died September 24, 2012 with never having a diagnosis and I am angry about it. Why would it have helped? Perhaps then people would not have judged me so harshly. Perhaps the end could have been more peaceful. Perhaps our last year together could have been less dramatic and confusing. Perhaps.....

It has nearly been a year since Ray passed. I try to get involved with the community and move on, but....The guilt, the anguish is still there. Dementia, what is that, what does it mean? There are several types of dementia and Alzheimer's is the most common but still I am left with this term dementia.

I must say that the medical community was not helpful and I think it has to do with the fact that they cannot diagnose Alzheimer's because of the ramifications and that Medicare doesn't give any help for it. What a mess, how many caregivers are taken down because of lack of help?

It has gotten so bad that I have given up on the system and that includes the political system. Doesn't seem like there is a system for Alzheimer's in the late stages anyway - there are things for people in early and middle but then when late stage comes, all you hear is "everyone is different" and there is no help.

Well, do what you will, or will not with this, but one day you or your family may be faced with dealing with this and there probably won't be help for you either unless you are incredibly wealthy.

I hope that you read this and will consider making it easier to make a diagnosis of Alzheimer's.

[PHI Redacted]

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We need to setup honest care for the future that will see more Alzheimer’s patients.

Sincerely,

Mr. Alex Oshiro

[PHI Redacted]

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My maternal grandmother and now my mother and the third sister have Alzheimer’s. I live in another state approximately 22 hours away. My only sibling that lived near my parents died two years ago, although he did not provide much assistance to them anyway. I just returned from a trip after staying with them for 8 1/2 months since September last year, I have a family in Colorado and have responsibilities here as well. Any help my dad and I try to get into the house, irritates my mom and then she starts being angry at my dad. This situation is killing him and he really wants to live. Is there a way we can find out if he can get some additional benefits for him so he keeps what little he does still have? I would like some one to help me get an appointment at the Veteran's Affairs Office in Des Moines, Iowa. We have done a lot, but hope there is still more out there that we don't know about. Any help would be appreciated. Thanks.

[PHI Redacted]

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My mother was diagnosed in Nov 2011 but I believe it was closer to 2008 that it began-mild to moderate Alzheimer's had there been some type of testing prior to those three years maybe it wouldn't be as bad as it is now. Please advocate for some type of testing

[PHI Redacted]

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My mother was diagnosed with dementia after undergoing the brain amyloid imaging. She was diagnosed as stage 1 multiple dementia and treated very early 5 years ago. She is still able to live semi-independently and is able to perform many of the basic daily life functions such as bathing, eating, dressing, as the disease is progressing slowly due to the medication that has been controlling the progression of the disease.

[PHI Redacted]

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I am the wife of an Alzheimer patient. He was diagnosed with this horrible debilitating disease 8 years ago. He was under the care of a gerontologist who sent him to have a brain scan and for testing by a psychotherapist, Alzheimer's lesions were apparent on his brain scan and the psychotherapist gave the diagnosis of Alzheimer's disease. The physician started him on a regime of Aricept, Namenda, and Lexapro, indicated for treating Alzheimer's. My husband still recognizes all of his family, can follow some conversation and can enjoy T.V. I attribute his maintained mental state on early diagnosis and the drugs that were started that are indicated for Alzheimer's. We were fortunate to have a doctor that believed in early diagnosis I would think the government would be anxious to support any diagnostic tool used for detection this horrible disease.

[PHI Redacted]

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My grandmother had the disease before I even knew what it was. My mother now has it as well as her two brothers. Please do something before my son, nieces, and nephews have to take of my brothers and I...just to get it themselves one day. My mother wanders constantly and we've been very lucky each time to find her. Sometimes with a police escort. I can't even hold a conversation with her on the phone because what do you talk to someone about who doesn't even remember what they had for lunch 10 minutes ago? If she could've been diagnosed earlier, we possibly could have slowed down this disease.

[PHI Redacted]

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My grandmother started losing her memory after her and my grandfather's house caught on fire. My grandfather was killed instantly when a gas wall heater blew up while he was trying to light it.

My grandmother was in the house when it happened and we think she went into total shock from this terrible experience and we really didn't think she ever had Alzheimer’s, but because she was never tested, my uncle put her in a Alzheimer’s home because she couldn't remember when my grandfather was coming to get her. She never forgot his name the remainder of her life.

My mom's brother was to take care of their mother if anything ever happened to their dad so by him being the executor of their estate, my mother had no choice about him putting her in an Alzheimer’s home. I believe if she had been tested, they would have found that she was still in total shock and never got over the fire and my grandfather's death. If she really had Alzheimer’s disease, she would have eventually lost her memory of all of us, but she never did nor of her husband. She just kept wondering when he was coming to get her. If she had been tested, she probably wouldn't have had to stay the rest of her remaining life in an Alzheimer’s home. This was my mom's parents. She didn't want her there because she knew she didn't have Alzheimer’s, but what could she do. She took her brother to court to get custody of her, but the courts refused her request and she remained in the Alzheimer’s home.

I've been told they didn't think this terrible disease was inherited, but I don't agree. My mom's oldest brother started out with dementia but was not really diagnosed with it, just his wife's diagnosis and later lost all of his memory. His wife brought him to see my mom in the last stage of his life with Alzheimer's and when he saw my mom he had no idea of who my mother was. It broke my mother's heart and my mother cried and heart broken and told them never to bring him to see her again because she couldn't stand to see him this way.

My mom was diagnosed with dementia right after she saw her brother with this terrible disease and then later led into Alzheimer’s for her. She never knew her brother passed away. After being diagnosed with full-blown Alzheimer’s for over a year my dad put her in a nursing home just for Alzheimer’s patients. So, it wouldn't do any good to tell her that her brother passed away. She wouldn't even remember him, so she wouldn't have grieved for him.

I believe this is the worst disease this world has seen. I believe this is so much worse than even cancer. I know cancer is terrible and takes all the life out of a person and they want to die due to the pain they feel and what their family see's them going through. People pray together for God to take them so they won't have to see them suffer any longer.

They lose so much weight, most people won't even know who they are after death when they view the body because the cancer took everything away. Their appearance, weight, everything.

Alzheimer's disease is worse. Your family gets to see a person whom they love so much, forget your name, that you are her daughter, son or husband. When you are visiting with them, which is almost every day, when you walk in they ask who you are. You tell them who you are, and less than 30 seconds, they've forgot who you are. They keep asking is that man down the hall my husband, and he's setting right beside her. It's so bad, my dad can hardly stand to go and see her because it breaks his heart to see her this way. They've been married over 66 years and she doesn't remember him. How do you think you would feel? Now, my mom's youngest brother has dementia and I don't know if he has been diagnosed by a doctor, but this is what my aunt told us. My oldest brother said he wanted to be tested to see if he was going to get it. I don't know if I really want to be tested for this, but if there was something to take to keep me from getting it like my mom has, I think I probably would get the test if the insurance companies would pay for it or something else was in place to stop it, like when the polio shots was given to everyone. Why can't they find something like that to give to everyone to keep people from getting this horrible disease.

I pray something will be done for this devastating disease before it affects so many more lives.

I just want to say this disease is just so demoralizing. You know, when you come into the world, they put a diaper on you and change you when you are dirty. The baby cries when they are wet or with a poopy diaper. They know!!!! The person who has Alzheimer’s doesn't say a word, because they don't know what they've done. They probably lay there some day's all day long wet or with dirty pull ups due to someone not checking them. If someone is mean to them, they can't tell you because they don't remember if they was. I see my mom cover her head with her quilt every time someone who works there comes in. I always think there is still a part of her memory there, but how do you know? If there is someone being mean to these innocent people who are so loving and want attention, I pray that God will give back to them for what they give and do to others.

My mom has been black and blue and they always say she fell or something, but she never remembers what happened, or never remembers there is pain with this black and blue face and a fractured jaw. Man, I would think that would be a lot of pain for me, but I can remember for now. I pray that I will always remember.

So, for all who have to make decisions about the importance of early and accurate diagnosis for this disease, PLEASE help those find a way for the end of this.

I Pray if you are one of the few who hasn’t seen this terrible disease first hand in a family member, you are so lucky. You need to go to an Alzheimer's home and stay as long as you can so you can see first hand how bad this disease is. I bet you won't stay very long, because you won't be able to stand to be around them if you don't know what this does to a person. You will answer the same question 1000 times or more if you are able to stay there with them.

You see we are family and we know all about what they are going to do or say and we go prepared with patience and knowing we are going to have to answer the question 1000 times, but she is our mother even if she doesn't remember us, we remember her, and we love her with all our hearts forever and ever and will keep answering her questions as long as she ask them, and when we have to leave her there, we cry all the way home just thinking about her and how much we love her and wonder what caused this.

Why did it happen to our mom and we pray our children will never have to watch us lose all memory of them and go through this and have the pain we have.

We don't want any family ever to have a mother, father or siblings see them with this horrible disease.

Please allow the importance of an early and accurate Alzheimer's diagnosis for all families, especially the ones who might carry the gene for the disease, but everyone needs it. I pray God will lead you in your decision on this. Thank you for allowing me to tell you about my family...

[PHI Redacted]

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[PHI Redacted]

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My husband is a retired Air Force Major. After retiring, he went to work for a company where he learned a new set of skills, and was able to excel at his new job, so much so that they wanted him to move with the company when they moved to Florida. We didn't move, for personal reasons, and he used his recently acquired computer science degree to land another job quickly. Unfortunately, he was fired from that job after a few months and then two others in succession. This was very unusual for such a smart man. The psychiatrist Tom had been seeing was sure that his depression had just worsened, even after he started forgetting words when talking. Since Tom was so young (51), they didn't want to consider dementia, but they sent us to the memory clinic anyway. After passing their cognition tests, because he was so smart, they said that he didn't have dementia, but started him on Exelon and Namenda, drugs that can delay the progression of Alzheimer's. After trying several antidepressants in a row, the psychiatrist and neurologist finally decided to do a PET scan on Tom. He was scheduled for December 4, 2008, and after the test, we went home, only to receive a phone call from the psychiatrist that Tom did indeed have Alzheimer's. Had there been another test earlier that did not cost as much as a PET scan, Tom could have been diagnosed more than a year earlier, and he might have been able to get into clinical trials before he started on the medicines. Tom is now 57 years old, has been unable to work since August 2007, and doesn't communicate very well. Since all of his jobs relied on good communication skills, this is an especially cruel fate for Tom, as it is for so many people. Please do everything you can to bring such an early test to fruition, so that more people can be included in clinical trials toward a cure or a delay in the effects of this terrible disease. Thank you.

[PHI Redacted]

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My mom was diagnosed with accelerated Alzheimer’s about 4 years ago, mind you she was an LPN. She worked 40 hours a week and loved planting flowers in the spring. She was diagnosed at age 56. She is now 60 years old and my sister, father, grandmother and I take turns watching her so that my dad can have a break and go to work (mind you he is handicapped since birth) . One year after she was diagnosed we had to take her driving away, and now she cannot write, read, and do normal activates. Shopping with her is a challenge as well, she gets easily lost because she likes to wander. She is unable to plant flowers because she doesn't remember how. It breaks my heart to watch her go through this she used to read my kids stories and is no longer able to do that either. The doctors have her on as much medication as they can to help slow down the disease however she is rapidly declining. I know in my heart she only has about a year left, it brings tears to my eyes just to think about it. She was so amazing and outgoing and now she is lucky if she can get to the bathroom on time. I need there to be a cure. I miss my mom, the way she used to be.

[PHI Redacted]

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My poor mother is living in hell from this terrible disease. How much must one person have to endure? And then how much suffering does one family have to watch their loved one go through?

[PHI Redacted]

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What a shock in 5 minutes of a diagnosis my husband Kenny at 53 was told he has Early Onset Alzheimer's. The doctor said you will no longer be able to drive a car or you will have to retire from work. We just sat in shock as we could not grasp how our lives changed in 5 minutes financially and to know just after 9 years of marriage what this disease would take away from us and that is to be able to spent the rest of our lives together. Time is precious and this disease with no cure only to see him declining over the last year. Every day I pray please God don't take my soul mate from me please God let them find the cure. We all that have been put in this situation would like awareness funding and the words we have found a cure or a way to reverse it as I want to spend my life with Kenny.

[PHI Redacted]

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My mom has Alzheimer’s disease. I suspected the disease for about two years before the diagnosis was made. I finally begged the doctor to test my mom for this disease. Sure enough she had the disease; however, it is my belief that if she had started on medications sooner she may have had more days with a clear mental capacity. I am a nurse and I fear this disease. My grandmother had it and now my mom has it. I would like a test to determine if I will be inflicted with this disease.

[PHI Redacted]

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My mother got this horrible disease at the age of 62. She is now 69 and living with this disease. I am devastated. Her mother and grandmother lived to be in their 90's and never got this disease. There is nothing else wrong with her health wise other than Alzheimer's. I am devastated and think it is so cruel and that she did not deserve this. She was a wonderful woman that was an only child just like myself who took care of her sick parents. Now...my father and mother both are sick...my father with aneurysms and I am left to try and take care of them. I am thankful for friends that take care of my mother every day all day long. There are so many that suffer from this disease and it is so cruel and just not fair. I pray that you find a cure and devote the money, time and research on this disease before we all end up with it. I pray for the families that deal with this daily and all the caregivers. Please provide more support medically for this disease as depends and other supplies are very expensive. My parents are on disability and barely able to afford it. Help fund this disease and realize how important early diagnosis is and why we need it.

[PHI Redacted]

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I think that it is very important of early and accurate Alzheimer's diagnosis. My father passed away in 2007, he was diagnosed with Parkinson’s and Alzheimer's. It hit him so fast I had no Idea how to deal with it. I was scared and kept him a promise never to put him in a home. I quit my jobs and moved in with my parents to take care of him. I had to drop everything, not that I am complaining, because I would do it all again if I had to. It was very hard to deal with him because he was not diagnosed until it was to late. He had short-term memory loss, falling down all the time, and mood swings. I took a lot of abuse and he gave me a lot of love. I think I handled it very well because none of my brothers or sisters could handle it. My dad had just retired when he started forgetting and falling down. I took him to doctors they said it was just because he was getting old my father was 62. One time he was so lost at the grocery store he called me crying to come get me. It was heart breaking. It got to the point where he could not ride his horses anymore and that broke his heart. He had trouble walking and my dad was very strong and independent. I’m just saying that if we had known what was happening maybe I could have done a better job of understanding the situation. Maybe there could have been something I could have done. Now I am going through the same thing with my mom, they said she has early signs of Alzheimer's. They gave her pills to slow it down but they made her see things and have bad dreams. She is not taking the medicine for that anymore. I just hope I can do a better job this time.

[PHI Redacted]

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I am writing this with a heavy heart the one nightmare has come true. My dad had to be put in a nursing home for this Alzheimer’s and nursing homes are a nightmare in itself. My dad is and will always be my hero and fighting this disease he is still a hero, the families need your help think about it as if it were your family member, it hurts so much I can't describe the hurt, and my mom is ill also from helping my dad, you have got to get accurate help to take care of Alzheimer's please, it won't help those right now but it could help others and stop the spread of millions of families hurting, I pray that you will do the right thing.

[PHI Redacted]

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Unless you have dealt with a person that has Alzheimer's & Dementia, You have no clue how hard it is for the person and their caregivers. My mother had Alzheimer's and dementia .I cared for her in my home the last 8 years of her life!!

Mom was always a very independent woman. She was always on the go enjoying life. Then to watch her go from a lively woman to a vegetable was the hardest thing, next to losing my Son at the age of 30 years old, that I have ever had to do. I promised mom that she would never go to a nursing home. I kept that promise to her. At times I thought I would end up in a nursing home. . We need more research and definitely need early diagnosis!! The thing that bothers me the most was each time she went to the Doctors was that each time they gave her another pill. That made her harder to deal with. As she didn't understand what was wrong with her. She would cry and apology to me constantly because I had to bathe her, etc. I always told her that she took care of me when I needed it and I was just repaying her for the long years of taking care of me

[PHI Redacted]

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Our family has a history of Alzheimer's disease, and knowing if we will be getting it could help us decide what kind of future we need to plan for.

Sincerely,

Mrs. Karen Marchetto

[PHI Redacted]

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My mother died of Alzheimer’s disease. It took years to get a diagnosis. Please make every means of diagnosis and treatment available to everyone who needs it. To withhold it from those who need it becomes a human rights issue!

[PHI Redacted]

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My daddy never meet a stranger and if he met you once the next time he saw you he remembered your name. I was telling my husband that I never went anywhere with my daddy that there was not someone there that he knew. We were going on a trip and flying out of Memphis. Mom and Daddy lived in a town only 50 miles from Memphis so he took us to the airport. The group we were flying with were grocery store owners. We walked in the door and daddy said well there is ole Jerry Jones. He was at Miss. State with me. He had not seen him since 1942 but he remembered him and this was in 1975. He loved talking to people and he was a wonderful man involved in Farm Bureau (he was a farmer), politics, and church. He worked on several governors’ campaigns. He was a deacon in the church and prayed beautiful prayers. Then one day on a trip he went to order Diet Coke and I noticed that he said that drink without sugar. He could not think of the word Diet Coke. From this time on he began to go downhill with his conversation skills. He quit praying in church because he could not remember the right words. He never called me by my name. I was the girl. My little brother who lived with him was the boy and my older brother was the boy down the road because he lives down the road from me. Proper nouns because a hard thing for him to use. Right before his 90th birthday he went into a nursing home and died there a year later. He had forgotten how to swallow. Alzheimer is a terrible disease that takes away so much from you. I wonder how much longer he would have lived without this terrible disease. Please help.

[PHI Redacted]

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I have been writing an illustration regarding my mothers' and our family experience with Alzheimer’s. We lost my mother on May 3, 2008 but the journey was heartbreaking and painful. A cruel, slow death. We tried everything to help our mom escape the inevitable. I need to complete my story that is a work in progress. If I can help just one family suffering from this horrible disease, then I have honored my mom.

Thank you!

[PHI Redacted]

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Please approve the brain amyloid imaging test for early diagnosis of Alzheimer's. My sister was misdiagnosed and lost precious time. She declined quickly because she was on the wrong medication and passed away at age 55. Anyone whose life has been touched by Alzheimer's disease would do anything to promote more research, diagnostic tests, and treatments for this disease that currently leaves the victim with no hope. My mom and Sister passed away from this disease within nine weeks of each other.

[PHI Redacted]

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My brother, sister and I knew something was wrong when mom left for a doctor's appointment and was gone for 4 hours before returning home. When asked what took her so long, she admitted that she forgot where her doctor's office was and got lost. Not long thereafter, she forgot where her local bank was, and so we made an appointment with her doctor to look into her memory issues. After some basic memory tests, mom's doctor referred her to a local Neurologist specializing in dementia and Alzheimer’s disease. After conducting some simple in-office cognitive tests, the Neurologist scheduled mom for a cranial MRI and a follow-up appointment when the results came in. Two weeks after the MRI, mom and I returned to the Neurologist who showed both of us on his laptop computer the MRI images of mom's brain, carefully explaining both what we were looking at and how the images indicated the physiological traits of Alzheimer's. He prescribed Donepezil and booked us for a six-month follow-up.

Nearly two years later, mom continues her slow unrelenting slide into Alzheimer's-caused dementia. But - thanks to the advance diagnosis of both her GP and the Neurologist, I believe (as her primary caregiver) that mom's condition has been much less traumatizing to address.

[PHI Redacted].

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I don't know how long it was that my husband had Alzheimer's but I do know that if we had been able to find out that he had it sooner it would have saved us from losing our home, two rental properties and business. My husband was an excavator and he did such a good job of hiding what was happening to him. I think back now and wonder what could have happened with him running that business with the beginning of Alzheimer's. He drove heavy equipment and large trucks. How many people could have been hurt or killed with him driving with the beginning of Alzheimer's. Slowly we started realizing that something was going on but I am sure that he had this so many years before he was diagnosed. He lost his ability to do the paper work for the business then we knew but if we would have been able to find out sooner we could have saved all of our stuff. We just didn't know why he was losing abilities.

[PHI Redacted]

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How do I even begin to explain to you the lack of proper care and knowledge on the part of the medical community in respect to caring for those with the early stages of dementia?

My background, I am an Occupational Therapist who has worked in the field of Alzheimer's care for the last 7 years. Both of my grandmothers died from this disease. Five years ago I started to worry about my father. My trained eye saw the changes in his affect, his temperament, and his slips in memory and word finding problems. I was able to finally talk my parent's into seeking medical care after dad suffered his 13th fall in 1 year. 13!!!

I let them take control and go to their primary care MD, but insisted that I also attend the meeting. The MD did an adequate job with the initial appointment, ruled out other medical conditions and referred us to a prominent neurological group here in NH. That neurology group had a "new associate" that had availability in his schedule so they set up the appointment with him. This is where our first major problem occurred.

We were under the impression that we were seeing a neurologist. When this "MD" turned to me and stated "I don't usually involve family members when diagnosing memory problems", the first red flag went up. Really??? How would he know if the person didn't remember if someone wasn't there to confirm the information?? He proceeded to perform the Mini-Mental Examination, or should I say attempted too. As an OT who works in Alzheimer's care, I was able to see that he did not administer this standardized test as the protocol calls for. Strike two! The neurological exam was also less than thorough! The final straw was when he turned to me, as a medical professional, and said "He's not demented! There's no problem. Go home!" Strike 3!

I went home and did some research on this MD, to find out that he was not a neurologist but a Doctor of Osteopathic Medicine who specialized in headaches. The most difficult part was now getting my parents to hear that this "MD", who just told them what they wanted to hear, was not qualified to evaluate my father.

After another round of MD's and another fall, 2 years later my father is now concerned about his speech problems. I take the bull by the horn and get him an appointment in Boston, more than 1 hour away from their home, at the Boston Memory Clinic. The staff there are true experts and I finally felt like we would get to the bottom of what was happening to my dad!

Hours and hours testing showed a mild cognitive impairment and a CT scan showed atrophy of the left temporal and parietal regions, the first to go in Alzheimer's disease. Only because of my background, I asked when it would be appropriate to do a cerebral spinal fluid analysis or even the new F-18 scan that was approved by the FDA. My father qualified for a clinical trial so he did receive the scan. It came back positive for the amyloid plaque. He has been diagnosed with Mild Cognitive Impairment due to the Alzheimer's physiological process. He has a very early stage of Alzheimer's.

It is only because we now have this diagnosis that my parents are making some much needed decisions. They are beginning the process of downsizing from their home of 40 years, because dad can't keep up. My family is beginning to understand why dad does or says what he does. At 74 years of age, he still works! But, he has just decided that he can't do as much, and is having trouble, and he now knows why.

Please, please, please make the process of diagnosing this disease easier. The wave of individuals over the age of 65 is building! The earlier the diagnosis the sooner people can prepare, make healthy lifestyle changes, and be involved in the decisions that will affect their lives!!! Knowledge is power. Please empower our families and make the F-18 scan a part of the diagnostic process for those with memory concerns.

[PHI Redacted]

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My mother was finally diagnosed in 2012 with Dementia after long months of confusion, memory loss and continual loss of her being. I took her to countless doctors who would simply say she's having 'memory issues' as if they were afraid to say the word. Perhaps it was lack of further education regarding the disease on the part of the physician.

She's now in the early stage of Alzheimer's and I've had to sacrifice including a job, to ensure she receives the best care. But without further research, knowledge and awareness, it scares me every day to see her become a helpless child everyday who one day, may not even remember me.

True, there are other crucial illnesses, but what makes Alzheimer's so horrible is that brain, the central control of our body, is where the illness lives and slowly kills that person twice: neurologically and physically. We need more research and more education for doctors as well as the public. Above all, we need a cure!

[PHI Redacted]

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I am caregiver to my mother, Donna, with Alzheimer's. When I moved her to Reno, NV from Florence, OR I sought out the best doctor in geriatric care in our area, Dr. Denver Miller. He met with my mom initially and tests were ordered in 2009. After tests showed that she had not suffered any strokes or other issues the diagnosis of Alzheimer's was given. I can't help but wonder that if she had earlier tests, while still in Oregon that her progression may have been slowed some. No amount of planning can prepare a family for this devastating disease.

Early testing will help families in this process and provide better care to those afflicted.

I also have a 34 year old son with bipolar/schizoaffective disorder so my sword is double sided. Luckily, today, he gets a shot every two weeks and is now a big help to me when I need him to come over to spend time with his grandma while I do housework.

Mom's doctor does home visits as well, so I do not have to take her out into the public where she is sometimes afraid of all the noise and confusion. Early detection can help families make decisions and plan out what future needs may be. Thank you.

[PHI Redacted]

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On Tuesday, May 21, 2013, my mother died from Alzheimer's disease. She was 80 years and received her dementia diagnosis in 2008. Years prior to being diagnosed with dementia, my mother was experiencing severe symptoms of paranoia. She lived alone; however, she lived in constant fear. In early 2008, I started to monitor her closely and noticed that she was becoming extremely forgetful and lose track of time and dates. Her bills weren't being paid on time and she would forget important dates that she once remembered so well. I did some research and found a neurologist who after some brain tests diagnosed her with dementia. My mother was prescribed Aricept. Although my mother continued to live alone for several months following her diagnosis, it was evident that she could no longer live alone. In late 2009 I moved my mother into my home and I officially became her caregiver. My mother's diagnosis and the medical care she received from her neurologist helped me to effectively care for her and do the necessary research that was necessary so that I could familiarize myself with the illness. In early 2010, my mother was no longer able to be left alone in the house. Simple tasks such as warming up food in the microwave were no longer an option. She was seeing her neurologist every three months and in September 2010, my mother was diagnosed with Alzheimer's. It wasn't until 2013 that I realized that there were different types of Alzheimer's. Since 2008 until her passing in 2013 she remained on Aricept.

My mother was walking daily, was not a wanderer, visited an Alzheimer's Day Center several days a week. On March 2nd, she contracted pneumonia and pretty much went downhill from that day until her death on May 21. On March 30, my mother became contracted and within a week she was so contracted she couldn't even fit in an MRI machine. It was only then that she was diagnosed with Dementia with Lewy Bodies. This late diagnoses was a bit confusing to me and I wondered why she was never diagnosed properly prior to her death. As her caregiver, I did my best to get as much information regarding Alzheimer's and Dementia, as well as seek assistance from the Alzheimer's Foundation. My mother was also being treated by a geriatric, who only saw patients part-time and also did not properly diagnose her stage. I took her to a second geriatric who in October 2012, diagnosed her at stage 5 Alzheimer's. In the last 3 months of my mother's life, she deteriorated very quickly and unexpectedly. Her body just started shutting down and cat scans of the brain showed severe Alzheimer’s; which I was not fully aware. It is a challenge to articulate every detail in this message but the bottom line is that the resources for Alzheimer's patients are extremely limited. Although my mother had Medicare, because my mother was not "ill" or didn't require a nurse, physical therapy, etc., none of her home health aid care was covered. I almost lost my home as a result of covering her home care expenses. I am grateful for the knowledge that I did receive and the preparation I was able to make even with some of the limited information and diagnosis. Alzheimer's/Dementia is a terrible disease that not only affects the person living with the disease, but also impacts the family. More research needs to be done to properly diagnose patients and offer support for the families. I was fortunate to have the flexibility on my job and I was able to sit by my mother's side during her last three months of life. The first month she was in rehab, the second month she was hospitalized and the third and final four weeks of her life she was in a long term care facility. In these last three months, my mother couldn't walk, couldn't feed herself, could communicate her needs and was contracted. Nurses had to turn her every two hours so that she wouldn't get bed sores. For those three months, I sat by her side, fed her, helped change and clean her, talked with her, laughed with her and comforted her. On my mother's last day of life, I held her hand, prayed with her, comforted her and watched her take her last breath of life. I don't know what happened that made her deteriorate so quickly. What I do know is that she was given an anti-psychotic medication (haldol - without my knowledge or consent) on March 6. This medication is known to increase mortality in Alzheimer’s patients this medicine was prescribed by her tending doctor at the rehab center. A doctor who did not know anything about her and refused to let her be seen by a certified geriatric. However, he prescribed her a medicine that increases rigid and catatonic state and within three months my mother was gone. Dementia with Lewy Bodies patients should NOT receive anti-psychotic drugs, but the doctor gave her an anti-psychotic drug without knowing her diagnosis. I hope that adequate funds are invested to properly address the needs of this growing disease that affects millions worldwide.

[PHI Redacted]

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We recently had to make some major decisions related to my grandmother and her dementia. She wanted to live in the home she had built with my grandfather and wanted to be able to die in that home. Due to most insurance companies not wanting to cover in home nurses we were forced to move her to a nursing home to receive 24 hours care. Our biggest problem we had with all of this is that even though she was told two years ago that she was beginning to show signs of dementia, she didn't tell us till 8 months ago, and in January of this year we received a call that she was found driving 35 mph east bound on the west bound side of a highway. Not only was it important for us to know this earlier but to be involved with her being told at the time. Because of many laws and regulations family is left out of knowing this medical information that could be a major safety issue for the relative that received this diagnosis as well as people around them...not just family but the safety of the public as well. Imagine how she would of felt if she were clear minded to find out that she might have killed someone. she didnt thank God but it could of happened. Many of these people are left stranded because power of attorney and legal papers that aren't in place because no one is informed of the issue of dementia and ALZ. This is dangerous. This is careless and this is why so many people we love are not cared for as well as they could be. No legal responsibility to be able to care for them as needed. No knowledge of the issues of dementia and tying of hands to get them the care they need so badly. Early notification of dementia and medical knowledge for the patient's future caregivers (i.e., children, family, nurses etc.) helps to improve the quality of care. It allows people the ability to plan and arrange the care that is needed for the family member. early awareness and scans (which incidentally DID show issues with my grandmother early) help in aiding for the care we know is needed. Maybe allowing that family member to stay in the home they have lived in for 30 plus years and built with their own hands (literally my grandfather built the house she lived in.) Given that most people now exceed the 80s mark in age, this care is even more important. Family is important to that care. I don't want another family to go through what my father (her only child) and I just went though. I don't want another family to hurt, cry, and feel helpless to care for a loved one. Many things need to change and change starts with voices rising. Don't silence their voices... raise them and let them be heard because the person they once were is still there just unable to speak for its self through the confusion!!!!!!!!!!!

[PHI Redacted]

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My mom years suffered with this for years dad kept it quiet and I just thought she was getting older. I knew nothing about the disease. If only there were a test her quality of life. It was heart breaking. I would have a slumber party with here and she was so happy to have me there even if she was in a state of confusion

[PHI Redacted]

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Please help, for those of us who have firsthand experience with this illness we know that early recognition is of the upmost importance!!! I took care of my mother for 8 years. She was only 73 when she passed away. I was living in another state for the first two years if her illness. I line everyone else did not see that she did in fact have this dreaded disease. Perhaps if we had caught it sooner her life may have been prolonged, she may have had the opportunity for cooing measures to avoid the illness all together. I am convinced that early diagnosis is essential to ones well-being. I now feel as though I myself am in the very early stages of this disease; however my insurance will not pay for the necessary tests that need to be run. So I am left to wonder... I have lived through this with my mother. I know the signs; for those who don't know the signs, time is if the essence!!! I do know the signs but I can't get confirmation. My life is spent in limbo waiting till the day the doctor finally decides to believe me when I tell her Taft I can't remember anything. My fear us that by then it will simply be too late!! Help.

Please!

[PHI Redacted]

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After several family and friends noticed some changes in Bob, our PC put Bob on aricept and namenda. From there we went through 4 recommended neurologists where the bedside manner was missing. I got the feeling that these type of doctors sent you home because they didn't know what to do. I feel that the patient and caregiver should have some guidance before leaving or to provide classes for patients and caregivers

[PHI Redacted]

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My father was diagnosis with dementia after a stroke. I believe if he had been diagnosed with early onset to Alzheimer's he could have been put on medications that claim to slow it down the Alzheimer but he wasn't diagnosis for 4 more years then he was diagnosed with late stages Alzheimer, I like to have known the beginning stages and middle instead of jumping to the end last stages diagnosis. There is a big difference between Alzheimer and dementia trust me and there is a big difference in caregiving. A early diagnosis would have prepared me as a caregiver and my father as the patient. Wish I could have put him on the Alzheimer med.'s a lot sooner it would have been a world of difference.

This is a worldwide problem it's growing every day we need help. Alzheimer's isn't going away. We need aggressive help now not later. Any help is better aggressive help would be lots better.

[PHI Redacted]

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My mother went missing five years ago. She didn't leave all at once. It was like she just quietly slipped out of the room for longer and longer periods of time. Her doctors call it Alzheimer’s and they offer no hope that she will one day find her way back to me.

Our relationship begins anew each time I visit with her. I search for threads of continuity from one visit to the next. I have no battle with this woman. Our unresolved issues belong to another time and place, another woman. We have traveled this journey together she and I. I have gone from being her daughter to being the nice woman who will help find her daughter. And now, unaware that she has me at all, she has returned to the company of her parents and others that I cannot see.

It began over a cup of coffee seated at the counter of our local coffee shop. I stepped away for a second and my mother asked the woman seated next to her, "Who is that nice young woman seated next to me?" It culminated in my mother leaving her home and joining the ranks of so many other elderly unable to care for themselves. Forever etched in my mind, I hold the image of her walking out the door of my childhood home for the last time. An image I cannot let go of and perhaps one I need to keep.

My mother was a teacher of third graders for her entire adult life. Even today, she is a teacher. It is not unusual to arrive on her unit, only to find her trying to maintain some order in her classroom. Her voice rises over the din of her class as she calls for quiet. She stubbornly refuses to give up on her students, even those that are clearly disruptive, and hardly aware that class is in session.

My mother spends her days with a diverse cast of characters. In the mornings when I enter her unit, I am greeted by Vern who sits patiently by the door, day after day, waiting for his wife to walk through. I do not know if she ever does. John is a handsome man with beautiful brown eyes that are always focused in another time and place. His fingers move rapidly as he deals from an imaginary deck of cards.

I like to imagine that he was a dealer in Atlantic City and that other dealers envied his skill and artistry with cards. Zelda, a Holocaust survivor can be found hugging herself in silent anguish in the corner of the day room. James cries all day, while Nan, counts endlessly from one to forty-eight over and over again.

My mother is my only surviving link to my childhood and my history. I am already grieving the loss of that connection. She requires me to live in the moment as that is all we really have. We sit in silence most days and I hold her hand, something we never did before. It is a small connection but so powerful. For her it is about texture and warmth and presence. For me it is the holding of our history. This moment, this contact with her, all I have, all that matters.

[PHI Redacted]

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My grandfather on my mother's side passed away from Alzheimer's two years ago. Because of an early diagnosis, he lived 10 years taking medicines to treat his symptoms. It worked at the beginning, but we all know that research is vital to find a way to prevent this ugly disease! It is so hard to lose a loved one before they are even gone. My grandfather leaves behind three brother and two sisters who are all battling Alzheimer's disease at this very moment! It breaks my heart to watch this all over again. Diagnosis wasn't as early for my grandfather's siblings and they are in fast decline.

Now, my grandmother on my father's side has been diagnosed with Alzheimer's disease. All around me I am surrounded by loved ones struggling with this. Those that have Alzheimer's disease and the rest of us that struggle being caregivers struggle financially and emotionally.

I believe that Alzheimer's may be hereditary, and for my family early diagnosis is imperative! I would go to the ends of the earth to prevent my parents, siblings, cousins, myself, and anyone from getting this disease.

I am doing my part by fundraising year long, every year to fund research for Alzheimer's disease, will you?

[PHI Redacted]

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My name is Buffy. My grandmother [PHI Redacted] died from this horrible disease! People with Alzheimer's have no voice.... in fact most of them in the late parts of this disease have no mind. I watched my grandmother for years loose her mind, body control, loose everyday functions. I saw the life that was in her eyes turn into blank nothingness. I wish that a doctor would have been able to give her a test....any test to have told us what was coming. She could have possibly taken trial medicine, or even medicine that was on the market at the time. It was a long time before her doctor could tell that things were not right. But because he could not just go off of what the family was telling him, he had to wait until there was a true need for concern. At least she could have taken medicine earlier. It would not have cured her, and this I know. But she would have a few more years to be here with us. She may not have progressed as quick.

The way I look at it there are test for just about everything now days. It is recommended to have a yearly Pap smear done for women. Men have prostate test done after a certain age. My babies had test done before they were even born. All of the prenatal testing that I went through, 3 times to be exact! People who go in every year for physicals, sometimes come back do to early detection of heart problem, possible cancer, thyroid, diabetes the list can go on! Every year I show the schools that my children have had their vaccinations. Why do we do all of this? Because early detection is the key. So why would we not do a test that could show early signs of Alzheimer's or related diseases? This is a simple question. I watched my Grandmother die. It was not fast....it was slow. I do not mean months or even a year or two. I mean several years. Then I sat the last weekend praying that God would take her. Because like a infant laying there in that nursing home bed, she was hurting. With a blank mind not knowing why. Not understanding, Just blank nothingness looming around, full of pain. I pray that your mom, dad, grandmother, grandfather, or any other love one does not go through this. For this I believe is the most horrible disease to have to watch.

Thank you for your time.

[PHI Redacted]

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In April 2010, my mother was given a diagnosis of Alzheimer's by her GP. He had run some 'tests' and then assured me that she had it as he was 'working closely' with a woman out of Seattle who knew all about Alzheimer's. If my mother had the 'brain amyloid imaging' then we could have all slept better. It wasn't until 6 weeks before her passing (June 2012) that we were able to learn of what she really had but that was only going through hell for 2 years, knowing how she acted and seeing a neurologist that we were able to get what we felt was a better diagnosis of FTD-Frontal Temporal Dementia. Knowing that information right off of the bat would have helped my family and I give her even better care, not to mention the care home and the care they gave to her. We were fortunate to have found such a good home who worked so closely with her but not everyone is as lucky as we were. Please don't let this test slip away as it would have made the last bit of my mother's life, care givers life and my family's life so much easier had we truly known what was happening before our eyes.

[PHI Redacted]

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My father, age 78 is in the later stages of Alzheimer's disease. My mother is his (at home) caregiver. My parents have been married for 56 years.

In the town where my parent's live, there is only one neurologist who sees Alzheimer's patients. This doctor (from our family's viewpoint) has many challenges. He does not have a command of the English language and is difficult to communicate with. He is not a specialist in Alzheimer's, although he lists himself as one through the Alzheimer's organization.

My mother is struggling to deal with the ever-mounting range of symptoms and behaviors brought to bear with each advanced stage of this disease. The neurologist has not provided the kind of care needed to my father, due to his lack of education and awareness of issues like: late stage Alzheimer's seizures, etc.

Through this painful time in my parent's life, there are few resources available to assist in the decision-making needed to properly and adequately care for my father. We need more groups, spread out in a larger geographic arena, better trained doctors/physician's assistants and counselors to provide the help that is needed. Marketing and public awareness campaigns are needed to reach out to families in need. Please help with any funds and support we can to promote this extremely urgent health issue.

[PHI Redacted]

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My husband, [PHI Redacted], died January 28,2013, at the age of 88.

We lived most of our married life (61 years) in South Florida. When my husband started having cognitive problems a few years ago, our primary physician diagnosed him as having dementia, and prescribed Aricept. He had problems with the medicine, and I asked him to change it. He changed him to Namenda. He steadily got worse and difficult for me to manage alone.

My daughter and her extended family in Tallahassee, Fl. and suggested that I move closer to them. So I would have support from my family. I sold my house in Davie, Fl. and bought a home close to my daughter. This was November 15, 2012.

The first big problem we encountered was finding a doctor. Any that we contacted were not taking new patients. We heard that there is a memory evaluation clinic in Tallahassee, but I was told we must be referred by a doctor. He finally was accepted by a doctor in December. The doctor said he would refer him to the clinic to be evaluated. I did not get an appointment at this time.

In January 2013, James came down with diarrhea and was in a lot of pain. I took him to the ER. on 1/4/13, and he was admitted to the hospital. He was also unable to urinate at this time, and a urologist was brought in, and they put a catheter in him.

I was still trying to get him into the clinic, but was told they would not accept him while he had the catheter. The hospital discharged him 1/8/13, but I was able to transfer him to rehab. By this time, he had become very combative, and the hospital, and rehab gave him shots to control him. These completely knocked him out, and we had difficulty getting food and liquids into him. The clinic told me they would not accept him while he was combative. I felt that I was holding his hand and watching him die in front of me. We then transferred him to Claire Bridge Memory Disorder Center Assisted Living. They also gave him sedatives to control him. He lasted three days there. We called Hospice, and that night, he passed away.

He lasted three weeks from the time I took him to emergency. I still can't believe that it all happened so fast. His death certificate listed cause of death as dementia, but he was never really evaluated. I don't know what else I could have done.

[PHI Redacted]

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A little over a year ago, I was diagnosed with early Alzheimer’s. This diagnosis came after I had an automobile accident in which I fainted while driving. My MD ordered a range of tests to determine the cause. The results of the tests revealed that I have Early Alzheimer’s.

This immediate and thorough round of tests has made it possible for me to begin treatment quickly and I believe it has given me a chance to combat the symptoms of Alzheimer’s, and to live a more normal life. Please support legislation which can offer early detection and treatment of this dread disease.

[PHI Redacted]

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My mother passed away last year after suffering valiantly with Alzheimer's disease for over twenty years. Her illness developed very slowly. At first, my very joyful, enthusiastic mother would repeat the same questions when we arrived at my parents' bed and breakfast at the shore. The moment that my family took notice was when we were on vacation and had made a special trip out to get ibuprofen for her headache and she did not remember us getting it for her or even taking it! When my father told my sisters and me stories of my mom leaving the stovetop burner on after making tea, we were more concerned and my father took her to see a specialist. At that time, they were unable to make a diagnosis.

Years passed until one day, my mom took a bike ride on the boardwalk. She normally would have returned in an hour or two, but my father noticed that she had not returned and it had been about four hours! After much worry by our family and searching by the police, my mother was found about 12 miles away and without her bike! It upsets me to this day thinking of what she may have experienced! After this experience, my parents sold their bed and breakfast and a year later, moved away from the shore they had grown to love, and closer to family, for my mom's safety.

Throughout most of her illness, my mom kept her smile and laugh and could communicate through expressions and occasionally could speak a few words, which were very insightful and sometimes very funny! This made us feel glad that we were still connected to her, but sad that she was trapped inside, unable to do what she wished. My sisters and I spoke candidly to her about her illness and the frustration it must have caused and got nods of understanding and even some tears to confirm our thoughts. My mother taught us that, in life we must accept what we cannot change and make the best of it. She was able to remain appreciative and participate as much as possible with our family, because of her acceptance of her illness. She taught us a lot about accepting challenges and being a brave person during this time of her life! More and more of my father's time was taken up in caring for my mother at home, entering her in drug trials and researching and trying whatever treatments were available for my mother. This greatly increased her quality of life. She had some enjoyment in life even when the disease robbed her of her ability to walk, to eat without a PEG tube and to talk. I will forever miss her expressive eyes, but I hope that I carry some of her insight and courage with me!

My aunt (my mom's sister) is now in a nursing home at age 68, after suffering from Alzheimer’s for about 10 years. Her husband died last fall after suffering from the same illness for a couple years. I am now 52 years old and worry about the possibility of getting this illness and how this would affect my twelve year old twins. Please allow brain amyloid imaging to be used for diagnosis, as it will assist the growing number of families struggling to cope with this horrible disease to plan for their futures. Through studies related to this imaging, it could also lead to a discovery, which could lead to a cure! Thank you for letting me tell my family's story!

[PHI Redacted]

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I work with 65 elderly and disabled low income Residents in HUD independent living housing. I connect them to services so they may remain independent and age in place with a good quality of life.

The importance of an early and accurate Alzheimer's diagnosis is especially crucial for these citizens as their resources are very limited and early and accurate diagnosis has repeatedly been demonstrated to help both contain costs and significantly improve quality of life. Medicare coverage of the diagnostic test called brain amyloid imaging would be a huge benefit to not only the Residents here but to their entire families, and especially for those without families.

Any disaster can be mitigated by planning. An early and accurate Alzheimer's diagnosis as provided by Medicare coverage of the diagnostic test called brain amyloid imaging would have a profoundly positive impact on the capacity to plan for how to deal with the disaster of Alzheimer's for an ever growing segment of the population. Had this test been available when my parents and in-laws were in the early stages of their decline it would have been so very helpful and would have saved all of us, my children included, years of uncertainty and suffering. As with most families, one member, myself in this case, needed to spend basically a full time job in caring for them. The impact on our family: lost wages and opportunities, pain and suffering, was profound. I urge you to offer Medicare coverage for this test and other early and accurate Alzheimer's diagnosis options as a means of reducing suffering and cost containment for this disastrous and devastating disease.

Thank you for your consideration

. [PHI Redacted]

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My husband was diagnosed with younger onset Alzheimer’s when he was 52 years old.

Unfortunately, he had exhibited significant symptoms several years (more than 10) prior to his diagnosis. The emotional toll was significant on our family and two young children. The financial toll has been devastating to our family - my husband was extremely well educated and took care of our finances. Prior to his diagnosis, he took out loans, ran up credit card debt, cancelled his life insurance (just stop paying premiums), got into an automobile accident and forgot to show up for a court date which eventually led to his going to jail and significant court costs. My husband is now in the final stages of Alzheimer’s. It has been devastating watching him slowly slip away. I will have to live with the financial and emotional hardships for the rest of my life. I have worked my entire life and put money into retirement only to see it all slip away. Had he been diagnosed earlier, better care and planning would have been possible.

An earlier diagnosis would have made a huge difference in my family's lives. An early diagnosis would also be helpful for research studies.

[PHI Redacted]

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I can't stress enough the importance of an early and accurate diagnosis for Alzheimer's. My mom suffered with this horrible illness for close to ten years. The earlier the diagnosis is made, the sooner the proper steps can be put into place. The doctor having the patient on the correct medication as soon as possible is so very vital to the quality of life. My mother passed away in 2005. With the help of my doctor, I was able to get "Namenda" from Germany (before it was approved here in the United States). What a wonderful change occurred with her taking this drug - it bought us some quality time. This is truly priceless. With the disease of Alzheimer's, there is no real "better" - you can only pray that they stay constant for a longer period of time. As soon as the patient is diagnosed, besides the medicine available, you can also work on stimulating them both physically and mentally. My mom went to Adult Day Care and the socialization was such a blessing. This is why early diagnosis really matters!

[PHI Redacted]

I cared for both of my parents with Alzheimer's while working a full-time job.

My father was diagnosed with Alzheimer's first but my mother, as his caregiver, was not diagnosed properly by her own doctor! It appeared that she was overstressed and overwhelmed with caring for my father.

The horror started when I became more involved with trying to help them. My mother's hysterics, yelling and illogical thinking made her a stranger to me when we had been very close. For six months I tried to make sure that my father was getting the care he needed while I endured verbal abuse from my mother. Luckily, I was able to obtain valuable advice from Caregiver Support Services offered in my community through Family and Children's Service of Ithaca. Their expert was familiar with my mother's symptoms, and told me I should obtain a referral from my mother's doctor to see a particular neurologist here in Ithaca. If I had not obtained that directive, there would have been dire consequences.

I would never have known to seek help from a neurologist, and I don't understand why my mother's doctor seemed clueless about her condition. There were many signs, including extreme weight loss. Some of my own health issues were ignored then and I am currently trying to make up for lost time...a little too late. Alzheimer's diagnosis definitely needs to be brought to the forefront. If brain amyloid imaging will enable proper diagnoses, there is no question that it needs to be done.

[PHI Redacted]

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My father and mother live with my husband and I because my dad has Alzheimer’s; it's terribly hard on my mom so we are there to help. I urge you to do what eerily you can to keep the test for early diagnosis, it's a long drawn out disease that needs the help of the medical establishment to take care of patients and early diagnosis help with medication and preparations to treat and take care of our loved ones.

[PHI Redacted]

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It took over a year and four neurologists later to diagnosis my husband with early onset Alzheimer’s disease. It was 2007 when we started noticing some of the signs.

Please approve the brain imaging for Medicare patients. Early detection can make a great difference.

Thanks.

[PHI Redacted]

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Researchers like Reisa Sperling say that amyloids start building in the brain 10-20 years before Alzheimer's symptoms appear. Given this, it is CRITICAL that brain amyloid imaging be approved as a diagnostic tool. The earlier one knows about the diagnosis, the better you are able to treat it and assist the person.

I wished this were available for my husband who is 65 and in the late stages of the disease. It's been a devastating journey on so many levels. We need better tools for the diagnosis and treatment of Alzheimer's disease. Please do all you can to help and support this effort on my behalf.

Thank you

[PHI Redacted]

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In 2004 my mother was diagnosed with a genetic form of ataxia that can affect speech and gait. The diagnosing neurologist told her that nothing could be done for her and that we should get her affairs in order.

After mom began to exhibit some odd behaviors (not tied to the ataxia) we took her to another Neurologist. This Neurologist asked her several questions and told us that she was in the early stages of Alzheimer's and gave us a Namenda patch. This did not help. We requested that her Primary Care physician do blood tests and test her urine. She had a bad UTI. Once her UTI was treated her normal behavior returned.

We have been told that she has Alzheimer's several times since based on her behaviors and not taking into account the issues related to her genetic ataxia. It took us several years and many doctors to discover that she has vascular dementia.

This is a heart breaking adventure, made more difficult by a lack of real understanding of dementia illnesses by the medical community. This needs to change. Help us help our parents!

[PHI Redacted]

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Many times we move so fast and haven't paid attention to what's important until it's too late. Congress needs to pay attention NOW! We must support the persons living with this disease and their families. Congress act now and support accurate diagnosis test "brain amyloid". By doing so, you will improve the health outcomes of many and their family.

Sincerely,

Ms. Tonya Buford

[PHI Redacted]

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My great aunt died with Alzheimer's in 1991. Her children cared for her in their homes for years until the burden became too great and they had to put her in home. The diagnosis took years, costing the family thousands of dollars, not to mention the heartbreak they endured. An accurate diagnosis early on would have saved the family so much financially and emotionally. Their story is proof that an early, accurate diagnosis would have allowed their family to better plan and manage Alzheimer's.

[PHI Redacted]

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My mother is recently diagnosed with Alzheimer's. When it is my turn I have the right to know. Please reverse your decision and cover this important diagnosis.

[PHI Redacted]

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I am a caregiver and a hospice volunteer, I work with Alzheimer's victims every day, they still vote. I will be informing them of how you voted on this matter. Don't let us down.

Sincerely,

Mr. John Caro

[PHI Redacted]

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My name is [PHI Redacted], in 2008 my father was in the hospital. During that hospital stay his doctor had a CT scan completed of my fathers brain. Now in 2013 my father was admitted back into the hospital on July 14. The day we took him in he was having trouble breathing and he looked as though he may have suffered a TIA. (he has had a couple of them in the past.) However, his doctor did not request a CT scan until my sister asked him to have one done. When the results returned the doctor asked my sister what she knew of my father's brain tumor; my sister was shocked because we were never told of this brain tumor. So she stated to the doctor that we knew nothing about it. I mean not being in the medical profession I couldn't say for sure but I would think that over the course of the last 5 years if anyone had knowledge of this but the previous doctor my dad would have been receiving neurological treatments of some type but he never had. By Monday July 15, 2013 my dad was way worse; he had no recollection of who anyone of his family members were, nor did he know what year it was or for that matter where he was. My dad was taken from me way too soon. He is displaying all of the signs of Alzheimer's but the doctors for some reason don't want to give him a diagnosis. Now my dad is going to be living in a skilled nursing facility because he requires 24/7 care. I feel in my heart had the doctor told us about the brain tumor my dad would have been able to receive proper treatments and possibly prolong his enjoyment of life. It would be a wonderful blessing for everyone to have earlier detections of this horrible disease. I can truly say that this cause is of great importance to me. Even though it's too late for my dad I still think it would be amazing for others to receive the assistance they need so that they can have their loved one for just one more day, or week or month. I know I wish I had my dad back.

So I ask you to please place this amongst your top priorities and help families get the answers and treatments they need to just have one more smile, I love you, hug, and memory.

[PHI Redacted]

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My wife was diagnosed in 2004 and didn't pass away until 2012. However she died of a stroke. Because of the early diagnosis we learned how to take care of her and extend her time with us.

[PHI Redacted]

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Well it was a shock to all my family members when my own mother developed Alzheimer’s. God knows what she went through. I hope and pray that I don’t get that sickness or anyone else. I hope and pray that they will find a cure. Thank God and thanks for doing a wonderful job. God bless you all.

[PHI Redacted]

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My mother in law was diagnosed with Alzheimer’s in April of this year. The challenges were tremendous. We almost had to force a referral for an MRI out of her primary care provider. She is already in he moderate to severe stage. In my opinion it would help for a standard check to be given to everyone at age 65 or even 50. My mother in law is only 65 and is already facing severe symptoms. Right now the only thing is catching it as early as possible. This disease is horrific and very stressful. Hope a cure is found soon.

[PHI Redacted]

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I work in hospice and literally every 3rd patient I tend to is dealing with some form of Alzheimer's or dementia. Every year the numbers seem to go up and up as I meet other residents in each facility. This isn't going away. On the contrary, it is indeed on the rise. Early detection must be given full attention if we are to ensure loved ones and all patients can maintain as close to a normal semblance of life uninterrupted for as long as possible. This takes just as much toll on the loved ones and caregivers when they see the current rate of change take place in those who are not afforded early screening. Please. This problem is growing exponentially. Don't wait for it to happen to one of your loved ones when it's too late to undo the damage.

Sincerely,

Mr. Michael Partain

[PHI Redacted]

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My sister-in-law is in an assisted-living facility; but may soon have to be moved to the extended care part of the institution; because she is losing ground. It would have been better for her, if she could have had treatment earlier. She no longer knows me.

[PHI Redacted]

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It was very hard to watch my father's personality disintegrate. At first he became irritated, argumentative and mad at anything and everyone. Later he became a quiet little lamb so unlike his former self. If he had been diagnosed earlier with Alzheimer's disease then he could have started taking medication earlier and maybe we would have had my real dad around a bit longer. I still feel cheated and sad about how my dad left this world as someone who didn't know me, my mom or my brothers.

[PHI Redacted]

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My mother was formally diagnosed with dementia caused by Alzheimer's over 7 years ago. We recognized changes in her 2 - 3 years prior to that. If she had precise test as the brain amyloid imaging or even a MRI, we would have know what she was suffering with and made sure she was prescribed with the right medication, life-skills and care she needed without the 4 -5 years of doctors telling us to stop worrying. I strongly support and agree with the Alzheimer's Association support of early and accurate diagnosis of Alzheimer's disease. An early diagnosis has been found to lead to better outcomes and higher quality of life for people living with the disease and their families by: enabling earlier access to appropriate treatments, allowing the family to build a care team and seek out education and support services, enabling enrollment in Alzheimer's/dementia clinical trials, and providing an opportunity for the development of advance directives and financial planning.

Please help us help my mother and others to come. As baby-boomers get older and more and more are facing Alzheimer's and dementia, please decide to offer an earlier and more accurate testing and diagnosis. I'm afraid it might be hereditary. I want to know if I am not sure if I have this horrific disease that I can be tested and assured of what I am dealing with by being tested earlier and precisely. Thank you!

[PHI Redacted]

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I am an occupational therapist working in home care who sees the daily struggles of those with dementia and the caregivers who support them. It is a tough journey for the whole family. The earlier that family members can get a diagnosis, while devastating, gives families time to gather financial and supportive services so that their loved one can age in place as long as possible with the correct home services. As an occupational therapist with specialized training in dementia care, I know first hand how early interventions can delay and/or increase patient participation in meaningful activities and ease caregiver burden and stress. Please reconsider this decision.

Sincerely,

[PHI Redacted]

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This disease is the worst of all I think because when you lose your capability to even understand what is going on within you. It separates you from reality.

Sincerely,

Ms. Yolanda Figueroa

[PHI Redacted]

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Daily I watch my wife of 50 years live in fear, fear of the unknown, fear of being abandoned, fear of being lost, fear of all the crazy things happening to her, such as dizziness, anxiety, abdominal pain, and depression that she doesn't understand.

She's unable in a few short months to do simple things, forgets where she's found something so she can't put it back, which leads to more turmoil and anxiety.

She's beginning to forget me, she doesn't remember things in our past, she doesn't remember that I have some medical issues - Rheumatoid Arthritis and Fibromyalgia (15yrs) so she becomes alarmed when I encounter a pain or difficulty, which is more than often these days - probably due to the stress related to her situation. We've had difficulty finding help or even practitioners to help her they don't seem to know what to do. I'd trade places with her in a second if I could.

This is our golden years!!!!!

[PHI Redacted]

-

I am taking care of my mom with Alzheimer’s, she is 87 years old, and I do not have enough help, I am all alone, no more family. I am trying hard to hold on to my job at the same time.

[PHI Redacted]

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I am a 56 year old woman who was recently diagnosed with Arteriosclerosis of the White Brain Matter. My cardiovascular health is excellent otherwise. This is not yet a diagnosis of Alzheimer's nor does it mean that it will turn into Alzheimer's. However, it can be a early sign of dementia. I also have a family history of Alzheimer's losing two grandparents to the disease.

I was diagnosed with Generalized Anxiety Disorder two years ago, with no prior history. I am on medication for depression. These too can be symptoms of Alzheimer's. In recent months I have noticed that I lose my words when I am trying to converse with people. Words come out of my mouth that make no sense and I don't know where they come from. I can not complete tasks that I use to complete easily, like cleaning my house. I end up all over the place never seeming to complete anything. Sleep has become a real issue. I am currently taking medicine to aid in sleep, but still find myself waking several times during the night and feeling exhausted when I wake up in the morning.

Maybe what is affecting me is nothing other than normal aging. I don't know for sure. I will be meeting with a Neurologist next month to discuss these issues. (I don't have health insurance so this is quite a large expense for me.) My primary care doctor recommended that I see a Neurologist when I was first diagnosed, but I waited until now due to financial reasons.

I am frightened and I want to know what is going on. I am one small voice in a sea of many. As a nation, we need to start researching and looking for a cure for this terrible disease. We need help and I believe that you, our government is the answer.

[PHI Redacted]

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My mother has Alzheimer's. She was alone for years and we didn't know she was deteriorating until it was quite severe. Maybe we could have planned better for her care. I want to be able to know if I have it at earlier stage. We need better diagnostic tools for this disease.

[PHI Redacted]

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My mother was diagnosed with Alzheimer's after having official testing done. This was very helpful for my father and the rest of our family to proceed with making decisions pertaining to her care and treatment along with financial planning. It was very expensive to pay for all the medication she required up until her death in 2012. I felt like I had lost her years before she actually died due to her memory loss. I couldn't ask her about parenting questions, menopause, etc. Please pass laws to help with this horrible disease. I am worried since it might be hereditary.

[PHI Redacted]

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I had a great aunt who passed away but had Alzheimer's prior to that and I also work as a social worker in health care. It is VERY important to have a specific diagnosis as soon as possible because more services and specialized care is available to the patient/person suffering from Alzheimer's symptoms. We need more home care and services like transportation, nursing home placement, etc. available to Alzheimer's patients. It would also help to have more support and education for family members. It would help for patients to be diagnosed as early as possible because the patient can have more control over planning their future care, etc. Advance directives and such. I am not speaking on behalf of my company/agency. I am speaking from my own personal experience. I do not represent my agency or company either.

[PHI Redacted]

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My mother has Alzheimer's. She most likely had it at least 5 years prior to being diagnosed. We need to make it easier to get a diagnosis. This will also help reduce the stigmatism of being diagnosed with this awful disease. If she had been diagnosed earlier, she may be doing much better.

[PHI Redacted]

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Alzheimer’s has affected my grandmother. It was too late when she was diagnosed because we didn't understand the signs. It turns out Alzheimer’s probably ran in our family after talking to family from Mexico who described very similar symptoms in family members years ago who now have passed. They thought they were loosing their minds they didn't know Alzheimer’s was a disease. I pray that myself and my family members don't get Alzheimer’s when were older but we are so aware and watching for signs now so we don't go as long undiagnosed with this horrible disease should that happen. There's a test that is going to help with early detection and it needs to be utilized. It's what's fair to people who are trying to be proactive and treat the disease early.

[PHI Redacted]

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My father died with Alzheimer’s. He suffered for 12 years. As far as I am concerned the father I loved was gone after 3 years. He did not know me or my other brother and sisters. He comes from a family of 8. His mother died of ALZ along with two sisters and three brothers. I was leery of wanting to have a test but now after thinking about what I went thru with him and all his affairs I would want the test. This would help me get my affairs in order so my children would not have the burden I did. Of course knowing would cause stress but like any decease a doctor tells u that u have it comes with the territory. I am all for testing of any kind for any decease. Our government would rather worry about the energy a ceiling fan causes something I read in the news yesterday than the well being of its seniors.

[PHI Redacted]

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I have been in the medical field for about 14 years, I am now in the mental health field. I have worked with many patients including dementia. My aunt was diagnosed with dementia some years ago. The problem I see in society today is not about the people anymore who need assistance, it is about making a profit. what has happened to the quality of life? Its not just about wealth its really about health. If one diagnostic test can help thousands suffering from dementia, then provide the necessary diagnostic testing to determine a proper diagnosis. Many people have been misdiagnosed because of what? Insurance does not want to pay? Because of technology today people are living longer and are need of more medical care services. I believe for proper medical care and correct diagnosis there has to be further testing. If this diagnostic test will help thousands of people with dementia, then provide the diagnostic test to actually determine the diagnoses, and provide proper treatment. This is not about money this is about a family members love one who's life is slowly decreasing. If a simple test will help proper care for a loved one then so means do it. This diagnostic test may help in the future of maybe a better understanding of dementia and maybe down the road better treatment options, and maybe a medical breakthrough for people who are suffering with dementia. I believe in quality not quantity.

[PHI Redacted]

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Please help us find a cure for this dreaded disease. Early detection may be the key to this cure.

Sincerely,

Mr. Lawrence Skara

[PHI Redacted]

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I am 55 years old and I am beginning to show signs of preliminary Alzheimer's (forgetting people's names, uncertain where I am) and knowing whether amyloid plaques are forming would allow my physicians to address the problem immediately rather than waiting for the disease to progress to the point where it's damage is irreversible. My father died of two strokes and had Alzheimer's as well, so there is a family history of it.

Please, allow brain amyloid imaging to become a standard test. There are many tests for other diseases that physicians can use to give credence to potential diagnoses; adding this would increase the chances that Alzheimer's could be found and addressed early rather than after it is too late.

[PHI Redacted]

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I was the caregiver for 4 years 3 months and 5 days of my beloved husband before he died in 2010. There is no one that will ever fully understand the pain and confusion it causes a care giver when one moment you have a husband that seems to be on the same page with you and seconds later he asks "where is my wife". It begins slowly and at first you point to yourself and say "here I am" and his response is "oh yes". Some day he will tell you there is something wrong with him and you assure him it is only because we are just growing old, but he is fine.

I can go on and on with how this disease robs you of the wonderful person who in the end "will die" and does. That is the only diagnosis you get when you are told your loved one has Alzheimer's. With the growing number of baby boomers I would think there would be a cry out from this group to get funding for more research and try out's of any possible findings. Better to test on those that already know that unless some medication will work they will die.

[PHI Redacted]

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After decades of research, early diagnosis remains the strongest single avenue for help with dementia sufferers. It's the only time when they can come to grips with the disease themselves to any degree, and still take a role in planning their future.

I would say ask my father but he's gone. Ask my dear friend, one of the most brilliant and creative people I've ever known, but she can't remember what her affliction is called for more than seconds.

[PHI Redacted]

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I have worked with Alzheimer's and dementia patients for 5 years now. And I care for my failing, 88 year old grandfather who is a WWII vet!

[PHI Redacted]

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My grandmother suffered very early with Alzheimer's disease. Numbers are climbing.

[PHI Redacted]

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Alzheimer's disease and dementia have afflicted my family across the board, as they have millions of Americans. In the long run, "knowing" is better than "not knowing," and it's more cost effective too. Early and accurate treatment can help all folks to be more self-sufficient and require less care for longer.

This makes sense. Please act responsibly and compassionately.

Sincerely,

Ms. Mary Day

[PHI Redacted]

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I was diagnosed with Alzheimer’s and vascular dementia this past March. This was done through neuropsychological testing, an MRI, and interviews with my psychiatrist. I am comfortable that these diagnoses are accurate.

[PHI Redacted]

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I work in a senior retirement village so I am in constant contact with many residents who have been diagnosed with dementia or Alzheimer’s. I also have contact with the families who must watch their loved ones suffer with this terrible disease.

Many times I have been asked by the families how you can tell the difference between Alzheimer’s and dementia. I will often refer them to a specialist in the field so they can have their questions answered by someone with first hand knowledge of this disease.

I also see the devastation when these families watch the deterioration of their loved one but often do not have a definitive diagnosis to go along with the symptoms.

In my experience as a long time nurse it seems that the families that deal the best are the ones who have a definitive diagnosis and know what to expect.

I feel that everyone should have the right to know exactly what they are dealing with so that they may prepare themselves with the very best care and treatment available. It could make a very big difference in everyone's life to know at the earliest possible time what they are facing in their future.

Sincerely,

Mrs. Debbie Polonoli

[PHI Redacted]

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My mother is currently 85 year old. She was diagnosed with Alzheimer's when she was 83. Her mother and three of her sisters all have had the disease. There had been several years of increasing memory loss before she was diagnosed. Although her doctor knew of a family history and knew I joined all my mother's appointments for several years because she couldn't remember what he told her, there was no move on his part to test for Alzheimer's. Only after there was a sudden significant drop in memory were any tests ordered at my request. Even then, her doctor looked for signs of a stroke, not Alzheimer's. At my request, we were referred to a neurologist to find out what was going on with her. He did some testing - having my mother draw a clock, walking, remember a list of words. I'm sure he reviewed the MRI, but I don't think he mentioned anything about plaque and in fact did a test to rule out one other cause of her memory loss. When he made his diagnosis, he asked if we wanted to know the root cause or just go on with knowing she had a bad memory. I'm not sure why he thought we wouldn't want to know so we could plan for what was to come.

In retrospect, I should have insisted earlier in the "slipping memory" stage for testing and perhaps we could have delayed the onset of the worst of the symptoms. We were able to keep my mother home for about a year after the diagnosis by having increasing amounts of support throughout the day. She's currently in a nursing home on a floor specifically for Alzheimer's patients. Earlier diagnosis and some treatment may have allowed us to keep her out of the nursing home for a longer period of time and saved an enormous amount of money on care.

Please continue to fight for early detection and treatment of this disease.

[PHI Redacted]

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My husband is the youngest of seven children, whose mother had vascular dementia .Our former physician clearly did not know very much about Alzheimer's disease. He asked if I were afraid to ride while my husband was driving. An MRI was done. Not getting a diagnosis, I assumed that my husband's behavior was due to depression. His only living sibling was in a nursing home due to dementia and his oldest daughter was battling a recurrence of cancer. Whenever, we made the 5-6 hour trip to visit the two of them, he would start an argument just 5 minutes from home. The return trips often were marked with discord. This occurred over a span of about 3 years. After having sleep tests for apnea and attempting to use a device to correct apnea, we were referred to a neurologist, who took information and then suggested that we have a return visit for a memory test. We did not keep this appointment. Perturbed, we went to another doctor,4hours, away and received the diagnosis of Alzheimer's. The former physician was no longer with the practice we had been with for several years. Our new physician and his nurse have been very helpful. Finally, we are able to treat and live productively with the disease.

[PHI Redacted]

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My dad finally got diagnosed with Alzheimer's. 2 years earlier my mom took him to the doctor to get tested. Insurance would not cover the test because he did not have the "alz shuffle". So, he went 2 years without starting medication, which would have helped him stay at the moderate stage for a longer period of time. We need to get different guidelines approved from insurance company's, so more people can get diagnosed and benefit from earlier treatment.

[PHI Redacted]

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My wife has finally been diagnosed with Early Onset Alzheimer's disease (age 52) after a long hard road and several years of physicians and specialist telling us that she is too young and that it does not run in her family.

She was put through ever test under the sun except the one test that would have been beneficial in her diagnosis. (all because of big company money - Insurance and government). It is truly SAD what America has come to.

It is terrible to think that all that was needed was a PET scan with amyloid to make a true diagnosis and save us and her from all of the personal pain and medical costs that lead us no where but frustrated. Now that we have a diagnosis in the late stages my wife is suffering when she could have had a lot of good years left with accurate early diagnosis. I know we are no one in the eyes of the people who control these things but i do hope those people would stop and think for just a minute, 'What if it was some one you loved' make it personal and then see if the decisions would be the same. Please consider making this test available for everyone. Please fund the research to find a Cure for Alzheimer's. Offer it the same support as other terminal illnesses.

[PHI Redacted]

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My dad passed approximately 18 months ago from what was eventually determined to be dementia / Alzheimer's. If we he had received an earlier diagnosis, we would have known what we were dealing with and could have prepared much better for it which would have made the experience much less taxing on dad and the whole family. Unfortunately, we stumbled through most of the stages, unprepared, ignorant and somewhat in denial of what was happening to him. Mom was very courageous and we all pitched in as we were able but we ended up keeping him at home for much longer than we probably should have causing her, my dad and the whole family significant hardship and pain.

My brothers and I are all in our mid to late fifties now and the likelihood of one of us being affected by this horrible disease is pretty high. I will be speaking to my doctor this month on the topic but I truly believe that early diagnosis as a rule will not only save millions of people from suffering much of the same hardship that my family has, it will also save billions of dollars in emergency room visits, police and safety personnel calls, etc. if patients and families of patients knew what to expect and properly prepared for the inevitable issues that arise.

[PHI Redacted]

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Please don't underestimate the importance of early diagnosis for the people who are at risk of Alzheimer's. Not only does it affect the millions with the disease, but millions of others who are caretakers. Early detection will incent people to do things differently (the things we should do anyway) but don't do because they don't believe it will happen to them. It could lead to better treatment to delay the progress and lighten the load on society as well.

If there is a scan/test that will give early information, please allow it and support it's implementation.

Thank you.

Sincerely,

Ms. Hazel Beard

[PHI Redacted]

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Never think that you or your loved one want be the victim of Alzheimer’s. I have lived through the effects of Alzheimer’s on a loved one, it is a terrible thing. Just remember it could be your life that it affects next.

Sincerely,

Mrs. Carole Hollis

[PHI Redacted]

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Our family is now in the second generation of dementia/Alzheimer's disease. My grandmother lived with dementia (never officially diagnosed) for the last 14 years of her life, and now her son, my father is one year past diagnosis.

Because I was familiar with the symptoms (and really pushy), I was able to get my dad in and diagnosed as borderline between first and second stages of Alzheimer's almost 2 years ago. He started on medication immediately, and it seems to have halted his decline for now, which is really great! (Although we don't really know for sure whether it's the meds or not...)

Because of his diagnosis, we were able to explain and understand some of the problems and odd things that had been happening the few years before, and put in place some safeguards in my parent's household to make sure finances, medications and other things my dad has always handled are taken care of. We also have educated ourselves and know what to look for as time goes on.

Just knowing his diagnosis has really helped with family dynamics and emotions - we know what to expect, and we children can talk about and plan for the future.

[PHI Redacted]

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Hello, I am the primary care giver for my mother. She had been showing signs of memory lapses, repeating herself and changes in behavior for 2 to 3 years before I interceded with her Primary Physician. She was seeing an internal medical specialist on a regular base but was being treated for high blood pressure only. I began accompanying my mother and saw that her physician never addressed the memory concern and had her diagnosed with dementia. I asked that my mother see a specialist for specific diagnosis. The neurologist did a "brain scan" and performed memory test in the office. Based on this he gave a diagnosis of Alzheimer’s disease. She was then started on Namendia and Aricept. I feel that these years without a diagnosis and the delay in receiving proper medication has been detrimental to my mother's well being.

Please consider moving forward with this diagnostics tool and encouraging its use by the medical profession.

[PHI Redacted]

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I am begging you to recognize the importance of early detection for Alzheimer’s. From my own families experience I know how horrible the disease is and what is like to have someone you love's body there with but their mind somewhere else.

Early detection may not be care but it can help keep people more independent for longer.

Everyday I think about my father and how he suffers. I watch my mother take care of him and see her exhaustion. Just about 2 years ago I realized my father is already gone and that my fate may be the same.

[PHI Redacted]

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My husband John was diagnosed at the age of 56. If the health care system was more informed on younger onset. He may not have wasted and agonized with the diagnosis of depression and adult ADHD. We must fight this disease with all we have! We put more money in a disease that is caused my self-abuse/ as in smoking and over eating with heart disease. Until you watch someone on a daily basis stop being able to do the simplest of tasks, like tying their shoes or cutting up their own food you have no idea how heart breaking this disease is! Please do what ever is in your power to fight for the people affected with Alzheimer's.

[PHI Redacted]

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My husband has Alzheimer's just as his two older sisters. The difference is that I am a medical Social Worker who worked with families caring for their lived ones. I was able to see and know the early signs and was able to get him into see a neurologist quickly and start treatment with Aricept. This was in 2005 and he is still functioning well at home and I credit that to him receiving an early and accurate diagnosis.

[PHI Redacted]

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I am the caretaker of my 86 year old father, who has been diagnosed with Alzheimer’s. I work a full time job, my shift starts at 0400 daily. I have a family member come to my home to care for him while I go to work. He has gotten to the phase that he can never be left alone. He wondered off from home one day, when left alone for fifteen minutes. He crossed a four lane busy street... This was a turning point. The heartbreak of him being lost for those fifteen minutes changed all our lives. The role that family members take is very important to his peacefulness and happiness. He is very comfortable at home. And he seems to remember more in a familiar surrounding. We have tried to get assistance, for care. But that say his retirement pay is too much. I can barely support us both. The medications are costly. I pray that Alzheimer's will one day be recognized as a priority, we must remember this may someday be my disease and yours. I do not want to put my own children through what I am going through now at this time with my father. A cure must be found! Please hear our Plea!

[PHI Redacted]

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In 1978 at the age of 72, my mother died with Alzheimer’s. She had been in a nursing home for seven years. At the time of her death, she had wasted away to nothing and could not see, talk or walk. I like to believe she could hear but that was even questioned. Now 35 years later, my older sister, age 75, has dementia. I have watched it coming on for the past six years. It is so sad and she often says, “I don't want to be like Mama." Unfortunately there is nothing she can do about it. At the age of 74, I continue to teach and help with children at my church. I read and sew, and do other activities hoping to keep my mind active. It is scary and I would like to see things done and done soon.

[PHI Redacted]

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My grandma had Alzheimer's disease, my mother had Alzheimer's disease. If I get it, I would like to have an early diagnosis so that I can join a clinical trial. This is my only hope. As of now, there is no cure. There is no medication to even slow it down. By joining a clinical trial, I will either get help for myself, or possibly help someone else and my children from getting it in the future. Please do not make people wait until there is no hope. The only hope is to get help early, before too much damage is done to the brain. The cost of this test may be high initially, but if a cure is found or even a way to slow it down, the savings will be astronomical! I think Alzheimer's research is where Cancer research was many years ago. Both are diseases, both are fatal. Would we deny people early diagnosis for cancer? Didn't early diagnosis for cancer help move the research along?

Please help us get closer to a cure by allowing this test for early diagnosis.

[PHI Redacted]

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Please make it easier for individuals to be accurately diagnosed in a timely manner!

Sincerely,

Mrs. Lenore Jackson-Pope

[PHI Redacted]

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When my husband was in his early to mid-fifties, at the height of his career, he began to have behavioral changes and memory loss. At first I thought he was depressed, but I sought medical attention. Through a research study, he was given a PET scan and diagnosed as a frontal-temporal dementia.

Even though the drugs were few and were thought to only slow the progress, having a diagnosis helped me understand his often problematic behavior, and use the available resources. It is believed that considerable damage has been done to the brain before symptoms occur, so it is important not to delay in getting a diagnosis and starting available medications.

Alzheimer's and related dementias are so devastating, not just to the affected individuals, but to the whole family, that it is critical to get an early diagnosis and utilize available treatment and resources. Much more research is needed, but good diagnosis is critical to the progress.

[PHI Redacted]

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I support the policy initiatives of the Alzheimer's Association and vote to elect representatives of like mind.

Sincerely,

Mr. Nichol Nunn

[PHI Redacted]

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After a nine year battle with Alzheimer's, my brave and beautiful mother finally passed away on May 7th of this year. She was not diagnosed until 6 years ago, and was immediately put on Aricept, however, her memory and function had already deteriorated to the point where she needed a part time aide to continue to live at home. Within a year of that, it was apparent that she needed full time care, so I brought her from Oregon to Connecticut, where I live, to take full responsibility for her care for the remaining five years of her life. I believe that if she had been diagnosed sooner, it would have led to earlier access to appropriate treatments, which would have given her a better quality of life for a longer period of time. In addition, two of my mother's brothers passed from this same horrible disease, making it something everyone in our family fears.

For these reasons, I am deeply disappointed by the Centers for Medicare & Medicaid Services (CMS) draft coverage decision on brain amyloid imaging, particularly given the clear, scientific consensus recommendations provided to CMS by the Association and the Society for Nuclear Medicine and Molecular Imaging. I understand this is a draft decision from CMS, and is not yet final. I strongly urge CMS to reconsider their position on this most important diagnostic tool for the early detection of Alzheimer's disease.

[PHI Redacted]

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My dear, sweet mom was diagnosed with early-onset AD at the age of 54. Sadly, she died at 64, six years ago. With the diagnosis at the time, we obtained valuable information and support services form the local Alzheimer's Association, she was told that she was not allowed to drive (i.e., safety issues addressed), and retired with disability (her boss of many years initially thought that she had become apathetic and didn't want to do her work, but she had forgotten how - even tough she had done secretarial work for decades. He even sent her a scathing letter about this, and she was so upset). I am now 46 and would really like to get the amyloid PET scan and genetic testing (there is currently only one lab in the country who tests for one of the three genes associated with early-onset AD, and I cannot get my doctor to return calls about how we could go about getting me tested) so that I can see if I need to start planning for a huge life change, if I were to have the disease, which is genetic and has a high incidence rate if a parent has/had it.

[PHI Redacted]

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My 91 year old mother was diagnosed with Alzheimer's several years ago. My brother and sister decided to withhold the diagnosis since they didn't agree with it. By the time I learned of it, it was too late for her to make her own decisions that affect her quality of life now, as she was no longer competent. It has caused family problems because of differences of opinions between me and my siblings. And I believe that my mother would have made different choices if she had known. Watching a loved one slowly disappear as a result of the disease is hard enough. Having to make these choices makes it even worse. As we know that there is a genetic component, I am aware of the possibility/probability that I may develop the disease. I would like to know as soon as possible so that I can make decisions about and provisions for my care and make it as easy as possible for my children to deal with this. This is a quality of life issue and so an early, accurate diagnosis is critically important to all of us who face this terrible possibility.

I urge you to reconsider the decision to cover the testing. It would be an act of utter cruelty to deny this coverage.

[PHI Redacted]

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Please reverse this decision and improve the ability to know early diagnosis of Alzheimer's. My family is caring for my mother who has this disease living hell. Would have been helpful to know earlier.

[PHI Redacted]

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Please include Alzheimer’s testing in covered Medicare services.

Sincerely,

Ms. Kay Johnson

[PHI Redacted]

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Mom was 90 when she passed away on December 18, 2012. The death certificate indicates old age caused her death, that cause seems reasonable. So when the statistics are gathered, mom will not be included in the population with Alzheimer's. This is unfortunate. We are unsure how many medical providers suspected that mom had dementia. None of them ordered a test, nor did they discuss their suspicions with our family.

Mom had an engaging personality, full of laughter, intelligent, kind, generous, and compassionate. So, when she would joke that she "...did not have a problem remembering, it was just that her forget-ter-er was working overtime..." we laughed with her. Mom was able to mask the dementia with clever questions, humor, and a self depreciating demeanor.

Eventually, depression became the diagnosis....medication for the symptoms however mom's failure to thrive persisted.

After a few years of decline, someone suggested that mom might have dementia, one month before she died, the psychiatrist diagnosed mom's condition as Alzheimer's in the last stages.

Financial planning is not the issue for our family, instead, we responded to mom's sense of personal failure in ways that minimized her self-understanding, treating mom's depression devalued mom. We failed Mom!

Routine testing for Alzheimer's would have valued mom, giving her validation that her decline was medically, and could possibly have been mitigated.

[PHI Redacted]

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I am a nurse who works with Alzheimer's patients every day. The patients who receive an early diagnosis, are provided with the level of care and support they require, and are educated along with their families have more positive outcomes. These patients decline more slowly, exhibit lesser degrees of anxiety-related symptoms in the later stages (wandering, repetitive statements, looks of worry) and are more willing to participate in brain exercises, physical activity, and comply with medications to slow the progression of their illness.

Sincerely,

Ms. Kristen Eubanks

[PHI Redacted]

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Hi! Since last year the neurologist performed many tests on my mother based on the familiar history of the disease (grandma and uncle). All the tests were negative, except the mini mental (questionnaire), it had values that “indicate” that my mother is on the first stage. For us is challenging, because we’re not certain about the diagnosis. Although she is taking a medication(Aricept), we continue monitoring the condition with a neurologist and other doctors. The early detection for us(family), gave the opportunity to observe and monitor closer, without taking away her indepence.

[PHI Redacted]

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I want to know of other alternatives to treat Alzheimer’s disease. I don't think that drugs are the only thing to treat MCI. My husband was diagnosed with Mild Cognitive impairment on April 2012. He is stable at this moment. If there is anything we can have to stop this process I am the first as many human beings in do what I have to do to stop this disease.

Let me know of any program in which my husband can be registered. Thank you.

[PHI Redacted]

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My husband had signs of memory loss for many years before he was finally diagnosed with Alzheimer’s. I will always have questions about how much better he would have been if he had been started on medications earlier. His first symptoms started when he was in his mid 40's and we did not get a diagnosis until he was in his early 50's. At the time of diagnosis we had one child in college and one in high school. These children lost quality time with a loving father because medications were not started earlier.

Early recognition of symptoms and early diagnosis would have allowed my husband to keep his independence much longer.

[PHI Redacted]

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Tragically I have witnessed Alzheimer's destructive forces as my once kind and talented mother's entire persona was crushed. She experienced an incredibly rapid decline living barely two years from "diagnosis" to death.

My mother's well intended, but pitifully superficial, internist's assessment of her orientation, memory, potential confusion etc was so inadequate, it seriously undermined her safety. It was only one month after his dismissal of Alzheimer's that mom experienced a long string of catastrophic events, Hallmark signs of the disease.

Her "stall the disease" medications of Aricept and Namenda were probably helpful but far too late as the irreversible damage of Alzheimer's brain cell devouring progression was too late. Like far too many other daughters, I watched helplessly as my mom withered further into oblivion.

The Alzheimer's tsunami is here now! Research in early diagnosis, better medications, better differential diagnoses of potential variants of Alzheimer's and more, is desperately needed NOW. Memory loss is NOT a normal part of aging! Before we lose another mother, friend, brother, please ACT!

[PHI Redacted]

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My mother was diagnosed with Alzheimer's in her 70's. The disease can now be diagnosed years earlier through a blood test and then treated even before symptoms arise. One of the worst experiences in my life was watching my mother’s memory erode. All childhood stories, recipes, recognition, cognition wiped away as if it was never there. Lately, I have been thinking of taking this blood test. I am 56 yrs old, work full time as an RN responsible for the care of many people all day in my job. Please protect and preserve legislation that would continue insurers to keep paying for tests such as these.

[PHI Redacted]

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My mother died 4 years ago from dementia. When she was first diagnosed she was given Aricept, but really don't think it helped. It was so, sad to watch her decline from an independent, happy person to someone who ended up, depending on others a basically into vegetation.

I fear for myself (and others) that I will develop this. I'm not even sure when or what to do for an early diagnosis.

[PHI Redacted]

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My family and I (brothers, Sisters, Nephews, Nieces) have an 87 year old mother that has dementia. She is unable to care for herself any longer we take turns staying with her and preparing her meals, changing her, bathing her (if she will let us) and keeping up her house. She will not leave her home she does know her home and her bedroom. She does not remember who everyone is or when was the last time she saw one of us, but she does know her room and her bed, so we cannot keep her at one of our homes. It is very hard and sometimes she becomes very aggressive and angry and runs us off, or refuses to take her medicine or will not eat. We have to treat her like a child and baby her and cajole her until she cooperates.

She does not have central A/C and she does not like the cold, so we sweat it out on hot days unless we can sneak the AC on. On Cold days she wants the heat up full blast and we sweat it out again.

She is not the mother we once had, but she is still MOM but we feel very exasperated and sometimes we feel WE can't cope.

Maybe if we had tested her sooner we could have gotten a better grip on her situation. None of her doctors have suggested the amyloid test to this day. I don't know that it would do any good but it would give us a better prospective on her condition.

[PHI Redacted]

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Early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. The evidence that a diagnostic test called brain amyloid imaging improves health outcomes. Please allow this tool to be utilized!

Sincerely,

Mrs. Darlene Saucedo

[PHI Redacted]

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I recently lost my father due to Alzheimer's. I saw my father struggle with the consequences of this disease. He went from an independent person to a confused person who often had no idea of where or when he was. Although he died with his family around him, I am not convinced he knew who we were. He may have felt he died alone among strangers.

Given the magnitude of this problem, any steps the government can take to help detect this disease early on (especially to distinguish its effect from treatable problems) must be taken.

Please act!

[PHI Redacted]

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I cannot believe that the government is considering this!!! I have a Masters degree in Nursing, and wrote my thesis long ago. Even then I was warning what this terrible disease would do to this country if steps were not taken to increase funding for research and help for families.

I worked at a UCSF in the diagnostic center and later retired as a consultant for the Alzheimer's Association. My professional passion for this disease became a personal tragedy when my husband was diagnosed in 2011; he died in January 2013.

I wish I could tour this country and talk more about this illness that destroys everything and everyone in its grasp!!!!

Recently I was asked to speak at our Rotary Club; I told the audience that I would guarantee each one of them would be touched by this disease in their lifetime!!!! A family member, a friend, a neighbor, and perhaps themselves.....they were dumbfounded by that statement. Sadly, what I said was very true!!

I will pray that our government views this disease as a priority for expanding current measures rather than taking a big step backward.

[PHI Redacted]

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Early and accurate diagnosis of Alzheimer’s disease is crucial to victims economically, emotionally and clinically. Lost jobs instead of early retirement or disability can be avoided if a diagnosis has been received. Families can make legal and financial plans and patients can become partners on their treatment and enter clinical trials going for a cure or improvement of symptoms.

Sincerely,

Mrs. Joyce Botti

[PHI Redacted]

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My father in law has Alzheimer's. It caused him to not only be forgetful, but also to be paranoid and violent. Without an Alzheimer's diagnosis, my mother in law would have kept him at home and it probably would have cost her her life. After his diagnosis she was able to get him into an assisted living facility where he could get the help he needs. Now that he is getting the proper treatment, she has been able to move into the assisted living facility with him, without living in fear of his violent tendencies. The diagnosis kept my mother in law safe, and allowed her to be reunited with her husband. Please don't keep others from reaping the benefits of early and thorough Alzheimer's testing. Thank you.

[PHI Redacted]

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The only living grandparent that I have had since I was a 6th grader doesn't even know who I am. I am 25 years old now and I still remember the first time she didn't recognize me. I was 19 and home from college for Christmas break. Me and Nanny were sitting right beside each others on the couch. My mom asked her to hand a present to Kelly (me) and she turned to me and asked who Kelly was. She had dementia and early onset Alzheimer's at the time so I was used to her being confused and asking me questions that she already knew the answer to, but to not know who her granddaughter was? Heartbreaking isn't a big enough word. I left the room and cried. I still cry. I am crying as I am writing this. Nanny is living in a home and has been since I was a senior in high school. She cannot walk or form sentences anymore. Just lays there and looks around and mumbles random words. I go in as often as I can. I feed her and talk to her. I know in my heart she can still hear me. She hears all about my life, grad school and running and boys, and I know she is proud of me even though she cannot express it in words anymore. When I hold her hand I can feel her love for me and I know she can feel mine. Dementia and Alzheimer's stole my grandmother from me. It's time to stop them from doing the same to others. I am here to share my voice and my story. I will stand and be strong, not only for myself and my family, but also for my sweet Nanny.

[PHI Redacted]

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My husband was diagnosed with AD in July 2008 (at age 58) at Mayo Clinic in Jacksonville FL. He was able to have a PET scan to give a correct diagnosis and let us know which lobes were (at that point) affected but only after Mayo Clinic checked to make sure our insurance would cover the PET scan. If he would have been on only Medicare at that time we could not have had the scan. It was a very scary time for us. I currently lead an Alzheimer's support group and many (most on Medicare) cannot afford to get a correct diagnosis because they cannot afford a PET scan. There's a much different approach to treating Vascular dementia, Lewy Body dementia, Parkinson's disease or Alzheimer's disease (just to mention a few) and a correct diagnosis cannot be made without the scan. I pray Medicare can be changed to cover the scan.

Thank you.

[PHI Redacted]

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Only those of us that have suffered the path of this horrible disease truly understand the urgency for this. Once you've watched someone close to you that you love dearly suffer from this horrible disease, you too will then understand. It is imperative to detect early on to help slow the progression of this disease.

Sincerely,

Ms. Anne Richardson

[PHI Redacted]

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My father [PHI Redacted], was diagnosed with Lewy Body dementia in 1995. This involved vivid hallucinations and Parkinson's symptoms. He was prescribed medications that controlled the Parkinson's symptoms and slowed the progress of his dementia. That helped in his care and my mom and I were able to care for him at home of six years and then he was cared for at a Veterans nursing home for another seven years. We were thankful that his medications helped control his frightening hallucinations and behavioral acts that come with dementia. My dad lived thirteen years with his dementia and I feel early diagnosis helped him have several years of high function despite his illness. Doctors told me and my siblings that we each have a 50/50 chance of also getting this disease. It is important for our government to understand how many families are suffering with this fact. My husband also cared for his mom with dementia. We need help to manage this disease and early detection is part of this.

[PHI Redacted]

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I watched my poor mother suffer with this terrible disease. I would hope Medicare would cover the cost for early testing and hopefully lead to the prevention of Alzheimer's. I honestly do not understand how lawmakers could consciously not approve the necessary funding. If there is any doubt how dreadful this disease is, go to an assisted living center or nursing home and see for yourself how intelligent vibrant people are reduced to not even being able how to eat with utensils or when they need to use the restroom. Once again I beg that Congress provide funding for research and the funding for testing patients who might be able to benefit from early testing.

[PHI Redacted]

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I have had the experience for caring for my mother with Alzheimer's which started in 2008 with dementia, slowing growing into that world of change. It was not the first time I was caring for some one that had Alzheimer's it was my Grandma. Now then it was old age and probably so but years prior I think back it was the stages of dementia into Alzheimer's.

With My mother I had to make the decision to place her in a Nursing home which was the hardest choice a daughter could do. I was able to care for her on my own prior to placing in the Nursing Home. I did just about everything, washing her, dressing her, cook for her, get the medicine for her take and shots she was diabetic too. Make appointments for both of us to see the doctor which I always would tell them we come as a "Pair". From time to time she was admitted to the hospital and I was there on those awful pull out beds but I did. Even in the Nursing Home I was like a doctor on call which I was 24/7 but do not regret. I was there as well in the Nursing Home to help feed her, wash her clothes and sit with her. I did all of this on my own, no home health, no nurses even those were there but my job, not a job just the love and able to care for her I did. You do it because she did it for you growing up. I was not working do to my own health which took the back seat to her. It is a tough job yes a job to be that 2nd person you take on that responsibility, it seem to come natural at times and you find a spot to cry away from everyone not just for me but what Alzheimer's takes way from her.

The day she finally was gone not in body the mind was the day I say to her "I am going now mom will be back soon", I kissed her as always, and she grabbed my face with both hands pulled me down kissed me on the cheek and said " I love you Debbie good bye". That was the last time I was with my mom after that she was just there in body and I was just a visitor that she did not recognize me anymore. Within a month before she passed away Hospice Care was provided and that was helpful but did not keep me from being there day after day. The day before she passed on I and many family members were there. I was the only one there with her the hour she died.

It is a tough job but loving someone a Parent, Spouse and any Relative or someone you love it is hard, it is hard to let go. Think about that when it is your time to have to make a choice and deal with this hands on. Your life forever changes. It is hard when you don't have a job or even if you do. I think of the time, the money and things you have to adjust to add things to their need that are not covered by insurance and out of pocket you spend even if at home or Nursing Home care. Yes out of pocket. It is one thing you have to struggle but you find a way which I think it that time you shouldn't have to. One thing to ease the mind of a Caregiver. I know it would have helped me at times.

[PHI Redacted]

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When circumstances are pulling you and your family member apart and you don't know why, it's so important to know what's going. An early diagnosis is imperative to alleviate the stress Alzheimer's causes. Stress causes physical ailments. Physical ailments cost heart aches and money to fix, if you're able to catch the physical ailment in time to turn it around. Knowing what you're dealing with alleviates stress and gives time to regroup, to figure out how to handle the circumstances. It took several years of watching our mother's weird behavior and worrying about her safety living alone before we got a handle on her Alzheimer's. Heart ache and confusion on both sides could have been prevented if early diagnosis had told us what we were dealing with. Better options sooner could have alleviated the stress endured.

[PHI Redacted]

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My grandma is 85. We have been battling Alzheimer's for about 8 years. It took them 4 years to tell us she was sick. As a human being you deserve the best and upmost care from your doctor. It’s a very emotional and traumatic to watch someone die slowly. We all know the end result in a patient with this disease. All I want is for some doctor to find a cure. My grandma has slow progressive Alzheimer's. In my own words she is dying a slow and sad death. Don’t get me wrong she is very happy and healthy. Who would want to watch their mom, dad, or your kids to slowly slip away from you? All you feel is helplessness and sadness. Please we need all the funding to find a cure and diagnosis this disease. The government pays for rehab and abortions. So why not help someone diagnosis that they have Alzheimer's. This world is hard enough to live in. Why make it even harder. Thanks always fighting for a cure....

[PHI Redacted]

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My grandmother had Alzheimer's in her 80's and now my mother age 84 has early stages of this disease. I would like to know if I or my kids will have it when we get older.

[PHI Redacted]

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My mom was diagnosed with dementia 3 years ago at 86 years of age - thank God! The medication Namenda was a God send for her - it put a sparkle back in her eye & really helped manage her dementia. Over the years that had to increase the dose but it has really helped her.

Diagnosis & care is imperative!! This cannot be a question – this saves lives.

[PHI Redacted]

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My mother was diagnosed with early onset of Alzheimer's at the age of 52. She is now 62 and still battling this horrible disease. She lost the ability to speak approximately a year after she was diagnosed. All of her words became gibberish. I made appointments with specialists of all kinds to find a reason and no one could explain it. I am not a doctor but it is my gut feeling that the plaque that has built up in her brain accumulated in the area that controls her speech. It has been a long 10 years and more than anything I miss being able to talk to my mother. It is hard to sit with her and talk to her and get nothing in return. I have grieved a very long time for my mother who is still physically with me. My heart aches for people and family members that have to experience the ravages of this disease. I believe that the brain amyloid imaging could be a possible break through for people suffering from Alzheimer's disease and I urge you to make the right decision in regards to covering this test for Medicare beneficiaries. It is possibly too late for my mother. But I beg you to please do this for the future. You could be afflicted by this disease one day. Wouldn't you want to be able to have access to this testing?

[PHI Redacted]

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This subject is so important!! If my husband had not been able to get a PET scan to obtain a definitive diagnosis of Alzheimer's he would not have been able to retire from his job, receive long term disability or even apply for social security disability!! He was only 54 years old when we were told he had mild cognitive impairment and he would need a PET scan to verify it was Alzheimer's. Of course our healthcare provider, Blue Cross, did not pay for this! I knew my husband needed to retire because he was commuting over 50 miles daily to work and also needed to do other traveling for his job, and he was having difficulty with these travels!! He was having major memory and cognitive difficulty! I was trying to figure out how I could sneak the $8000 out of our savings account to be able to pay for a PET scan. My husband would not hear of spending that money for the PET scan! We got very lucky and blessed that our local hospital just happened to get new software for their PET scan and needed to do two brains for accreditation!! We were lucky enough to get one of those spots!! Needless to say, he was able to retire and get his benefits based on this PET scan!! This should be available for ALL!!!

[PHI Redacted]

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My mom has lived with this awful disease for 6 years now and it is only getting worst. I know there is no help for curing her, but I want as much testing as I can get. I am only 35 with a husband and 2 small daughters, and if i have this awful disease I want to fight it harder than anything I have ever fought. This is a terrible and heartbreaking disease day after day. Please help get funding for all testing.

[PHI Redacted]

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When my family started seeing some signs of personality change in my mother, I wrote a letter to the family physician explaining our concerns. I also mentioned that her sister had been diagnosed with Alzheimer’s disease, so there was concern that there might be a genetic factor. The doctor did some "testing" which involved a verbal memory response over a short period of time. The results were inconclusive, and so nothing was done at the time. It took another full year before my mother's disease had progressed much further downhill before she was finally put on some medication. The first prescription did not seem to help so that was changed. At this time, my mother is in a nursing home, and her disease has progressed to the extent that she even needs anti-psychotic drugs (hopefully for short term). I certainly wish there were a more definitive way to make an earlier diagnosis. In addition to regrets about the quality of my mother's care, I now also have concerns that I may become a victim one day. How will I know, before it is too late?

[PHI Redacted]

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My mother passed from dementia a few years ago and I am 52 and it seems like I am forgetting more and more each day. People on Medicare should be able to get an earlier diagnosis and have a fighting chance.

[PHI Redacted]

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Early and accurate diagnosis is critical to being able to try to get a head start on managing this disease. The earlier the diagnosis, the earlier treatment and management of the disease can begin. Early diagnosis and treatment can greatly slow down the progression of this insidious disease. It also allows the patient and family members to better plan for managing the disease and the care of the patient and managing the finances of the family.

It took my husband over 4 years to get a diagnosis from the first time we took him to the doctor because we were seeing problems (he was only in his 40's). If he had been able to have the MRI diagnosis early on, his medication and disease management could have begun 4 years earlier. The stress and pain during those 4 years, before the diagnosis was finally made, was difficult for the entire family, as we knew something was wrong, but did not know 'what' was wrong or how to deal with the things that were happening.

We have a simple, painless way to help diagnosis this horrible disease - MRI! Early diagnosis equals earlier medical intervention, treatment and management.

30 years ago AIDS was an automatic death sentence, but now there are treatments to manage the disease, AIDS is no longer a death sentence. Right now in 2013, Alzheimer's is still a death sentence - however research is seeking for ways to make it a treatable/manageable disease, I look forward to the day that, like AIDS, Alzheimer’s is no longer a death sentence. However we will reach that day sooner by earlier and earlier diagnosis and treatment. That early diagnosis, at this time, is the MRI. Early diagnosis is critical in combating this disease.

[PHI Redacted]

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From reading educational material I recognized something was not right with my wife. The symptoms were so mild that our doctor didn't think it was significant. I insisted on tests which included MRI and PET scans. Sure enough, they detected noticeable brain atrophy. Thanks to these early diagnostic tests we were able to start her on drugs to hopefully slow the progression of the disease.

Please do not cut funding for early diagnostic testing.

[PHI Redacted]

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I lost my dad to Alzheimer's. My mother in-law passed & they called it dementia.

Please keep up funding & whatever programs help.

I'm 60 years old & very forgetful. It scares me I may be next to come down with these.

Please don't forget us!

[PHI Redacted]

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My wife did not a dementia diagnosis until her condition was advanced. Even then I had to pry it out of her neurologist partly because no definitive diagnostic tool was available.

The delayed diagnosis and her lack of acceptance meant she was not able to take any role in planning her care. An earlier diagnosis might not have helped, but it sure couldn't hurt.

I realize a diagnosis will not change the outcome because currently no cure or even an effective treatment is available but an early and accurate diagnosis could improve the patient's acceptance and help families make plans.

Please reconsider.

[PHI Redacted]

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My aunt suffered from Alzheimer's & I was her only caregiver. The disease robs a person not only of his memory, but also his/her life, health, personality and dignity.

The disease not only affects the victim but also family, friends, and caregivers. Alzheimer's affects the family's finances because, as the disease progresses, the afflicted person needs a person 24/7 or must live in an Alzheimer's assisted living place because of the constant supervision needed.

A person w/ Alzheimer's will die of complications of the disease. It affects balance, ability to fight off pneumonia, etc.

These victims act in ways that are contrary to their normal behavior. If she was in her right mind, she would never have been embarrassed by her behavior. My aunt like to take off her clothes & walk outside naked. In the early stage of the disease, she was susceptible to criminals. She gave her bank account # to a person on the phone in the Bahamas and he stole over $100,000 from her account. She also left her door open overnight.

We need a cure for Alzheimer's soon. Many baby boomers will become victims to this horrible disease.

[PHI Redacted]

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I work on clinical drug trials to find a cure for AD. The sooner a person is diagnosed, the sooner they can consider the option of a drug trial. The current thinking is that treatment needs to happen as early as possible, before too much damage happens to the brain. The ravages of Alzheimer's begin 10-15 years before a person becomes forgetful!!!! Pay for the test, let us find a treatment!!!

Sincerely,

Mrs. Michelle Herman

[PHI Redacted]

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My mom was diagnosed with early stage Alzheimer's 5 years ago. She was able to continue to live in her house for another 4 years because of the early diagnosis and treatment. She moved in with me last year because she needed more stimuli and she is doing just fine. The doctor took a brain scan which showed that my mom's brain had shrunk in size which helped in the diagnosis. I think it is important for early diagnosis and testing and it would be a shame for government to try to cut corners in this area.

[PHI Redacted]

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Early detection gives the family time to enjoy the few precious times they have left with a person. To withhold payment for this very important test is mind numbing. Colonoscopy, mammography, and Alzheimer's detection should be included together as one test.

Sincerely,

Ms. Lynette Fink

[PHI Redacted]

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Alzheimer’s runs in my family, mother, father, brother, grandparents, and now me. I have written a book about this horrible disease and hope it helps a lot of people. It is a very light hearted personal story about my experiences as a caregiver of my mother and our time together. "Mother, I Am Your Daughter....Do You Want To See My Driver's License, AGAIN!" I don't think there is anything out like it and I feel like it will be uplifting for a lot of caregivers as well as family and friends that know someone with Alzheimer’s disease. You can the book on Amazon.com Enjoy and let me know your thoughts and my prayers are with you all.

[PHI Redacted]

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My mother has lived with Alzheimer's for more than 12 years. Her quality of life is terribly diminished by this disease. I fear having my husband and children having to cope with a similar case with me if I inherit this terrible disease. Please approve this tool for early diagnosis so that I and others like me can do everything possible to slow this disease from robbing us of our future and our families of us as their spouse and parent.

[PHI Redacted]

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I would really benefit from a more objective diagnosis of Alzheimer's disease. My grandmother, father, and three aunts all have/had it, and I am the oldest grandchild. I noticed changes in my brain power years ago, and received a tentative diagnosis six years ago

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It has been difficult living with the progressive changes, while others try to reassure me that "there's nothing wrong with you." At the same time, they find fault with me regarding a few behavior changes and lapses that are obvious to them. This is not an easy way to live and has caused me great distress and loneliness.

Luckily, I chose to take Aricept at the beginning, a choice left up to me. Otherwise, I fear I would be more advanced at this point.

An objective, accurate diagnosis would definitely ease my mind and heart, no matter what the outcome.

[PHI Redacted]

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My mother has Alzheimer's and I am her caregiver. I was fortunate enough to catch it early and was able to get medicines to help right away. It's such a sad and painful journey watching this disease take her away from me. It brings tears to my eyes when my mom forgets who I am. I'm so grateful to have her around but she's not the same mom I grew up with. Seeing your parent lose their independence is a very hard thing to watch happen. She has a very good Neurologist and primary Doctor that stay on top of her care and we have been doing all we can to make sure she has a good quality of life. I pray this can continue throughout the time I have her here with me. Please help to make sure Medicare can continue helping me give her that good quality of life she so deserves by covering needed tests and medicines and doctor appointments. Thank you.

[PHI Redacted]

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We had no diagnosis for my dad because he refused to see any kind of doctor other than his family doctor. About two years before his death he was hospitalized with a stroke. It was a doctor in the stroke unit who said he exhibited many signs of Lewy Body dementia. Had we known that 5-10 years earlier, we could have avoided giving him the cough and sleep meds prescribed by the family doc. Both increased his paranoia and hallucinations, leading him to leave the house in the middle of the night scantily clothed because he thought he was being chased. He was subsequently placed in the hospital psych ward, released only when his family could guarantee he would be placed in a locked unit. How sad when he was not at all like the other patients in the home except when he had occasional flares. During these years my mother and brother, the two closest to him, both died, likely brought on by the stress of caring for him. I then brought him to live in an AL near me in another state. He lived three more years. How much better would his quality of life had been as well as my family's wellness had we known from the start what we were dealing with.

[PHI Redacted]

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My 81-year-old father was diagnosed with this horrible disease four years ago, although I suspected he had it long before that. My mother, 79 years old and not without her own medical problems is his primary care taken who cares for my father with very little assistance. My father is a Holocaust Escapee who tried to immigrant to the US during the war, but could not obtain a visa as the US closed their doors and shut him out, therefore, his family with to China and latter after the war was able to come to America where supposedly dreams are realized.

He now has this horrible disease and doesn't remember his life previously. My mother manages his care in addition to her own, it isn't an easy life, but then again, I really do not think my father ever had an easy life. It is of paramount importance that the US Government not take away tools that aide in diagnosing Alzheimer’s disease, or any other form of dementia as these tools are a necessity in dealing with the diseases; particularly Alzheimer’s disease.

By 2050 Alzheimer's disease will affect up to 16 million people, loves ones, perhaps yours. Caring for our love ones who have this disease is estimated to cost in the upwards of 20 trillion dollars; Medicare will absorbed 60% of those costs. If people had available diagnostic tools; such as, brain amyloid imaging then those costs could be reduced by 45% allowing families to deal effectively with the knowledge of this disease. Fortunately, my parents have private insurance and a diagnosing of this my father's disease wasn't difficult to detect. But, the costs to care for my father is prohibitory costly and that's something we could not have predicted ahead of time.

Please, for the honor of our senior population and vets and even younger who are plagued with this diagnosis of Alzheimer’s disease do not allow the federal funding to stop providing these necessary diagnostic testing tools.

My own family for a year had lost insurance once COBRA ended after my spouse was furloughed from his job so this is huge for my family. As a family who supported our active duty Naval Officer, and my father who served in the Air Force we aren't as fortunate to have the medical coverage that you and your families enjoy so this is very important to us. How else do I drive home the importance of this funding?

[PHI Redacted]

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It is vitally important for individuals to be treated with dignity and respect. We have the right to know what medical conditions we have. It is unconscionable for CMS to not cover this important test to diagnose Alzheimer's disease.

Sincerely,

Mrs. Susan Beilman

[PHI Redacted]

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My mother was diagnosed in 2002 with Alzheimer’s. I have a copy of her medical records in which it documents the many times my sister and I requested she be evaluated for Alzheimer’s. Her doctor stated tjat she showed up on time with her lipstick straight and her clothes coordinated. I had to move my mom from her home to mine. It was extremely difficult for her and for my family. Had she had the benefit of early diagnosis and treatment, she may have been able to live independently with some supervision for years. Instead, she spend 3 years in assisted living, 2 in dementia care and 3 more in a nursing home on Medicaid. At 5,000 dollars a month, the government paid out quite a bit for her care.

She faded away slowly to nothing. I am my mother’s daughter. I have her hair color, her eye color and her same sense of humor. As I enter my 50's, I know that I may be next. It happened to my mother, my grandmother and my great-grandmother. There is no more undignified way to die. My mother went like most. The brain forgets everything....including how to swallow properly. She had been clear about a feeding tube and 5 days later, she was released from the bonds of her shrinking tortured brain.

Early diagnosis is critical to treatment and to keep the patients at home. I can think of nothing worse than not knowing my children when they come to visit me at the nursing home.

[PHI Redacted]

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Knowledge is key in establishing both a treatment plan and just as or more important, providing caregivers as well as the individual diagnosed with the most accurate diagnosis possible.

A reliable diagnosis establishes a starting point for the individual diagnosed. Treatment as well as predictions of the likely course of the disease are dependent on the accurate diagnosis of the type of dementia responsible for memory loss.

Acceptance of the disease by both the individual diagnosed and the family begins with this authoritative diagnosis; the person diagnosed is enabled to begin the process of acceptance. In addition, accurate diagnosis often motivates the family to address. Long-term planning for potential care needs as well as estate and legal planning.

An accurate diagnosis is also critical for the primary care provider who faces an uncertain future and caregiving burden that poses a strong negative threat to the caregiver's health. Armed with a diagnosis, the caregiver is enabled to identify the disease, relay this diagnosis to family and community with certainty and move forward in seeking sources of support, acquiring knowledge of the disease; studies have established that a care provider's feelings of competence do lead to greater confidence in their care giving role.

Sincerely,

Ms. Susan L Kivisto LMSW

[PHI Redacted]

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Wished we had an earlier diagnosis for dad, with AD being more widely diagnosed we need more accurate medical procedures to improve ways do diagnosing.

[PHI Redacted]

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My husband was diagnosed with Early Onset Alzheimer's in February 2013, at the age of 56. His very earliest symptoms began as early as 2007, and was diagnosed as anxiety by our family physician. He was prescribed anti-anxiety medication. I noticed in 2008 he wanted to sleep a lot during the day and was easily agitated. Again, medications were changed and in mid-2010, he was admitted to the hospital, with what they thought was heart related. After many tests, he was advised to retire from 33 years in law enforcement, due to stress/anxiety. In 2011, he had to quit his part time job at a gun shop, due to what seemed to be anxiety attacks and he also had problems with money and numbers, etc. He got another job in late 2011 as security for a local American Indian reservation casino. He worked nights and it quickly caught up with him. We went to our family doctor three times in 2011, while I described to him the problems he was having, such as constantly misplacing items, agitation, couldn't keep up with dates and our physician advised him to find another job. He did a mini-mental exam in his office in March 2012 and he scored a 23, then in August scored a 21. He referred us to a neuropyschologist, but the wait was several months. In January 2013, he had problems tying his shoes, extreme agitation, problems driving and confusion. I called and asked for a referral to a neurologist and was seen a week later. After a mini mental evaluation and EEG, which showed slowed brain activity and exam by the doctor, he said because of his age and family history of Early Onset Alzheimer's and Parkinson's disease, he wanted to send us to UAB Hospital in Birmingham, Al, for a second opinion. He started him on 5mg of Aricept daily. We were seen by a neurologist at UAB and he ran a SPECT scan, because our insurance would not pay for the PET scan, but he said it would show him what he needed to see. Also, his mini mental evaluation was in the low teens. He called me at home a few hours after he had the SPECT scan and said he had Alzheimer's. He was also too advanced to qualify for any of the clinical trials. He increased his Aricept to 10mg daily. We had a follow up visit at the end of May and he re-evaluated him again and he has remained fairly the same as he was at the end of February. He wanted to put him on coconut oil daily and said it was a wait and see situation. He was too far advanced for the clinical trials, so we are doing all we can at this point. I have noticed he is becoming less active again, making me think he might be progressively getting worse. I just wanted to share our story and encourage people to stay on top of your loved ones medical care. Insist on a second opinion. Alzheimer's is not just for the elderly. We have three sons, our still living at home, our youngest is 13, our oldest is 21. It's a very devastating disease, physically, emotionally and financially. Hopefully a cure will be found soon.

[PHI Redacted]

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My husband and I are caregivers to his mother, who has dementia. I am with her majority of the time and it so hard to see a women who was a strong independent become so needy and childlike. She is always asking to see her mom and grandmother who died when she was a lot younger. A women who now can't bath herself or even go to the bathroom by herself. Sometimes she realizes something is wrong with her and other times doesn't realize. She is to the point that she can't even make complete sentences. When this happens she becomes upset. Before this I personally thought dementia was an illness that only happens once in a while. I have found that this is more common today. My hopes are to be able to get more assistance to help all of us to understand and to be able to deal with these changes.

[PHI Redacted]

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My father was diagnosed with mixed dementia (vascular and Alzheimer's disease) by his physician after a thorough medical screening and CT-scans. This allowed the physician to prescribe Namenda to treat his disease. I absolutely saw a positive improvement initially with medication. Working closely with his doctor throughout the progression of the disease allowed us to work together as a family to keep our father at home, and help give him the best quality of life possible until he passed in 2011 (9 years after initial diagnosis). Having an accurate diagnosis was crucial to our understanding of the disease process and to adjust to changing behaviors as cognitive processes declined. Without proper education and understanding of the disease process, and the proper medication, we would have had a much more difficult time being able to help our father through this very sad disease.

I think the best advice the doctor gave to my mother was to stay calm and be patient. He said "If you are happy, he will be happy, if you are angry, he will be angry". We found this to be very true. We also found that a steady routine is very important to keeping things calm. We tried to stick to the same routine as much as possible; eating, bathing, some exercise (mostly walking, doing simple math, functional task like watering the flowers and sweeping the garage) and especially keeping bedtime early, were all helpful things. Also, I used to say thank you to my dad whenever we did something together, as I believe it made him feel useful and appreciated. Kindness is the best medicine to bring to those with dementia and Alzheimer’s. Try to always treat these people with dignity and kindness. Remember that they may not always be able to express their feelings, but they certainly can sense your feelings toward them.

Again, I know that my father's quality of life was made better due to an accurate diagnosis. Proper medication and caregiver education are crucial to the proper care for persons with dementia. Thank You.

[PHI Redacted]

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Early diagnose is the key to treating the disease and preventing the progression. No-one wants a family member to forget who they are while they are feeding them and bathing them because they no longer remember how!!!

Sincerely,

Ms. Sheila Burnett

[PHI Redacted]

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This study is very important. If you ever had a loved one with this terrible disease you would do everything in your power to make it better.

Sincerely

Mrs. Janet Hultbrerg

[PHI Redacted]

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The ability to get an early, accurate diagnosis for both my mother and my mother-in-law would have enabled our family to plan for their care and plan for the future. We bounced from doctor to doctor trying to get information, playing with medication, basically grasping at straws, thus allowing both of these wonderful women to lose valuable time. We need to be able to get an early, accurate diagnosis!! My husband and I are both at greater risk due to our family connection and we need to plan.

[PHI Redacted]

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My family has experienced Alzheimer's disease in both of our parents. Our dad died in 2000 as a result of this heartbreaking disease. He lived with this disease for over 20 years. He had to go to an Alzheimer’s facility in his last days. Currently our mom is suffering with frontal lobe dementia. She attended an adult day care, then an Assisted Living facility where she broke her hip. Currently she is in a skilled nursing facility. She pays over $6,000 monthly for needed care. She has recently run out of money and as of today Medicaid has denied her application for money. What do we do at this time? This is a very difficult time in my families' life.

[PHI Redacted]

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My name is [PHI Redacted] and my mother, Helen recently passed away from the ravages of late stage Alzheimer's disease. And a true disease it is. A lot of people think that "old age" is synonymous with "Alzheimer's" - and or dementia - and so it is just a "natural " occurrence or part of life as we age. It is not . It robs all of those involved of emotional connections and physical limitations ~ not to mention the difficult and challenging day - today changes that happen; which is SO distressing and sad ... I cared for my mother, personally, for the last six weeks of her life and witnessed, firsthand the devastation and confusion of - living with - and dying because of this tragic disease. My mother and all of her family struggled with and coped with it for about 6 years - until the disorientation caused her to fall (for the 3rd time in 6 months) and sent her into a downward spiral until she died ~ after 24 days without food or water and around the clock vigils by myself and family and a nursing staff. Plenty of morphine, fetanyl, ativan, percocet, and for awhile ~ I.V. drip to replenish her fluid levels until her body and her fight to LIVE finally gave in to DEATH BY " ALZHEIMER 's " ... Please allow all current and future testing to be available and financially available for those living with and dying from " Alzheimer's " disease !!! our government needs to step up all efforts regarding this horrible disease and help those who are suffering with it !!! To live with it ~ is to suffer with it ~ no real "living " is involved ~ BUT ~ enormous AND daily suffering IS ..

. [PHI Redacted]

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My grandfather passed away when I was a very young boy. My Grandmother eventually remarried a neighbor and they moved from Chicago to Pennsylvania.

I then moved out of Chicago for educational purposes. I never saw my Gram except when she and I would end up visiting Chicago at the same time which was very rare.

If she had been diagnosed early and the family was aware then I would have been able to make better preparations to visit her.

The last time I saw her was the first time in over five years. When I reached over to kiss her forehead she looked at me like she was terrified that this stranger is kissing her.

That was hard because Gram doted over me. She spoiled me rotten.

Early diagnosis is a must for families who want to prepare to say good-bye to their beloved ones while they can still remember who they are.

[PHI Redacted]

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Please cover testing needed to help detect Alzheimer's! This disease stole my grandparents and dad from me. The thought of millions if not billions of families facing this, not to mention my family, scares me so much. We need to put every available resource we can towards detection, treatment and a cure!

[PHI Redacted]

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I just spent the last two months at several appointments with a dear elderly friend who was diagnosed with Alzheimer’s disease yesterday following brain imaging. The physician thought for sure it was frontal temporal degeneration based on MRI findings. Then he decided to confirm it with a PET brain scan and it turned out he was mistaken. This completely changes the course of treatment and care and we are so grateful for an accurate diagnosis. It is allowing her family to have a better picture of what the future holds for them, to make plans, and to optimize life as much as possible for not only my friend, but her entire family. Alzheimer's disease is not a singular diagnosis, it affects everyone around you.

I feel that Medicare should cover ONE brain scan per lifetime when symptoms are manifesting themselves. Criteria can be defined for the scan. Too often we place the ambulance at the bottom of the cliff instead of a fence at the top. It’s time to turn that around and invest in the fence with brain scans and health education instead of just skilled nursing facilities (bottom of the cliff) where dementia training is woefully inadequate. I know, I am a certified long term care ombudsman and I see it every day.

Sincerely,

Ms. Nancy Madsen

[PHI Redacted]

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Please fund early diagnosis.

Sincerely,

Ms. Patricia Carlucci

[PHI Redacted]

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My mom suffers from Alzheimer’s. It took us 3 years to get any of her doctors to listen to us and test anything. We kept getting told that they were not allowed to give us any information due to HIPA laws. They couldn't or wouldn't understand that we didn't want them to give to us information that we were trying to give them information. I took over her health care in 2005 because she kept missing doctor’s appointments and forgetting to pick up her prescriptions (she has diabetes, kidney issues, high blood pressure, and a heart murmur as well). She would forget things like where she was going or how to get to her job. She would ask a simple question like "what time is it?" and as soon as she was answered she would say things like, "2? OK. What time is it?" Sometimes she would finish dinner and as soon as her dishes were cleared she would swear that she hadn't eaten yet. She would stay up all night for 2 or 3 days at a time and when asked if she was ready for bed she would say it's not night time (pitch black outside). Even though I was the one making her appointments etc and going to ALL appointments with her no-one would listen to me. It wasn't until 2008 when she had a heart attack and the doctors in the hospital noticed her strange behavior and symptoms (because she was in the hospital for 8 days rather than just the 20-30 minutes she spent with all her other doctors at a time) that someone would finally listen to us. She was diagnosed 3-4 months later. By that time there was 3 years of Alzheimer’s progression that went undiagnosed and untreated. So much was lost. Nothing can bring back what is lost, all we can do is slow it down and try to hold on to what's left for as long as possible. The sooner this dreadful disease is diagnosed the more that can be saved.

[PHI Redacted]

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My father passed away from dementia in 2002. Alzheimer's and dementia ran through my father's side including my grandmother, 3 aunts and an uncle. Imagine then having to see your mother start to show signs. We were fortunate to get her tested last year but unfortunately my sister and I were correct. Early onset Alzheimer's. She has been placed on medication and we learned ways to keep her active. After one year she hasn't gotten any worse, which is a miracle! We already know the final outcome, but having these next few years with her are priceless. Early diagnosis helped us find the correct plan of action. Please help others get tested. It truly is the difference between life and death.

[PHI Redacted]

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Early diagnosis helps the individual and the familyget the needed help for him/her.

My mom aged so quickly before me it was heartbreaking to see her that way and know she felt the changes. She would get mad at herself and when we saw a doctor, they said it was just normal aging. She had an MRI done several years before so they used that and saw nothing. If an updated MRI was done or tested differently she could have started meds early than she did.

Within two years she is unable to provide for herself. She needs assistance in showering, feeding, diapering and walking. With no diagnosis, we were unable to get her social services for two years because Medicaid stated she was fine. She couldn't be left alone during the day in house. My husband had to stop working to care for her. Thank god we were able to do that.

I had the scare of my life two years ago. When a medical assistant left my mother alone in an examination room. She walked out of the room, the office, onto an elevator, out the building and onto a shuttle. She was missing for three hours. She somehow recognized the neighborhood and went to my father's business that had been closed for 15 years and waited for him there. He is deceased also. Driving around with the police I found her in front of my father's business. My heart came back, my life came back. I thought my world had come to an end because she was lost. God gave her back to me.

If she was diagnosed early on we could have had things in place or started things early on and not go through what we went through and have things bother her and irritate her when we didn't know what was going on.

I thank the Alzheimer's Association New York City Chapter, for when I had questions and concerns, they were there and still are. They helped me deal with all the emotions I went through in understand this disease and caring for my mom who changed before my eyes. I can't volunteer the way I want with the Alzheimer's Association because of time constraints. But there will be a day when I can give them my all and dedicate all I do in my mom's name.

[PHI Redacted]

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My husband passed away February 2011 after a diagnosis in February 2007. He hid rather successfully many of his symptoms prior to his diagnosis. Only when he could no longer hold a job, got lost visiting friends which was never an issue, did we question him. At diagnosis, he was almost 61. We were his second family. My children were in middle and high school. The test for the diagnosis nearly bankrupted us. Medicare did not kick in until two years after the diagnosis. Two years struggling to pay for meds.

There cannot be enough help for Americans and their families struggling with this disease. You do not just get over it. It impacts everything you do. It robbed my children of a father, made them caregivers and they dealt with issues that many adult children turn over to professionals.

Please do not deny the coverage of this test. It may not stop the disease but it starts patients on a path of treatment to slow symptoms. And that helps the patient and the family.

[PHI Redacted]

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My mother had Alzheimer’s, & I fear I do too. My homocysteine is very high & if I take certain over-the counter vitamins, I understand this helps. Please comment.

[PHI Redacted]

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Because my mother is 83 years old and sometimes forget thinks, so she is lucid but I'm worried and i would like to take actions to prevent the Alzheimer’s disease. Thank you.

[PHI Redacted]

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I had a patient today with severe dementia vs. Alzheimer's. He will get to go home because he can't be diagnosed with Alzheimer's. He was screened by psychologist with the survey that's done. Because this pt was caught on a good moment & didn't meet criteria for Alzheimer's, he will go home without any good support systems due to his history of alcohol abuse & could possibly forget to turn his stove off or something & die (worst case scenario).

Sincerely,

Mrs. Jessica Campbell

[PHI Redacted]

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I realize that when she is with me or any adult, she feels insecure, lost, and forgets even the name of simple things.

However when she is with my daughters (who are teenagers, but for her they are just girls), it looks that she feels a certain power that helps her to remember things. Even that power lead her to teach them.

I understand this should be investigated. It could be that people with Alzheimer's are losing the self security and is why the brain stops remembering. If that is true, as a treatment instead of sitting with the patient to teach them, we can sit to ask them that teach us.

Sincerely,

Ms. Iris Machado

Kissimmee, FL

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My mother and her mother and her brother all have dementia. I was told I was likely to have it now. I am 52 years old! Please reconsider the law that you want to pass. This as important as cancer if not more so. The pain it brings to the families the heart ache and pain it brings to the person that has it. They don't just get up one morning and they have no memory. It is a gradual process. A true knowing of the word "loss". Loss of what could be, what has been and what the future will at this point always come to an end without your loved ones because you don't know them anymore!

[PHI Redacted]

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The diagnosis of Alzheimer's early is crucial especially since medicines are geared to slow the progression. Also, Alzheimer's patients like my own mom suffer from anxiety and depression and the sooner those issues can be addressed, the more comfortable and relaxed the patients can be make life a better quality for them and their caregivers and families.

[PHI Redacted]

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My father a strong Marine who was in the Korean war and could remember back when he was a young child everything!!! Is now in a home with Alzheimer's he becomes very violent and has had to leave a faculty due to his behavior. It just horrible he was a man full of life and lived on his own now he has strangers changing his diapers..how can this happen to so many people now. It seems these memory care homes are everywhere and are so expensive, how can an average person afford 5-6 thousand a month for the 24 hour care. There needs to be action very fast to diagnose and find a cure ASAP!!!!!

The care is ok but such a high turnover of help which causes stress for the patients. Let's gets this terrible disease to the front of the line for research so we can cure it .

My mom passed away from brain cancer and suffered for years but I must say this is worst.

[PHI Redacted]

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I've been through this with 3 out of 4 grandparents and my mother. All have passed on. The grandparents were not diagnosed. My mother was, but way after early symptoms. Please allow others to have early onset diagnosis to better prepare for this debilitating disease. Trust me, the caregivers live on a roller coaster every day. Any chance of setting up costs and housing, if necessary, would be a huge step in the right direction. Thank You.

[PHI Redacted]

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Please provide coverage of pay for this test.

Sincerely,

Mrs. Kimberly Standridge

[PHI Redacted]

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I am 51. I watched my paternal grandmother, born in 1903, and her two sisters die of this disease. Presumed to be Alzheimer's because she was not evaluated after death and she was a devout Christian Scientist who allowed little to no medical intervention.

Now my dad has dementia...we are the generation who, through the miracles of medical advancement, know there is a genetic component to the disease. So if we know that, do successive generations really have to sit and wait for it to strike us or other loved ones, or can we get an early diagnosis, and all the benefits of current research and treatment? The alternative to sit in the dark and wait and eventually be the next to succumb is a special nightmare I do not want to dream.

Please help us! Allow Medicare to cover this disease which may well cost the system so much more if we don't meet it head on. Your endorsement of coverage for diagnosis and care may well spur research as much to save lives as to save dollars.

Thank you.

[PHI Redacted]

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I have personally witnessed the devastation that Alzheimer's wages not only on the person effected but on the family unit as well. My grandmother was a bright, beautiful, and vivacious woman who loved to travel. Alzheimer's robbed my grandmother of her mind, then her beauty and ultimately her life. Near the end, I didn't even recognize her anymore. I lost my grandmother in November 2012 and my dad started showing symptoms of developing the disease himself round the same time. I fear that one day I will fall victim to the same fate.

Denying seniors who depend on Medicare access to tools their doctors needs for early diagnosis is making a devastating disease even more destructive. More work needs to be done towards finding treatments that slow the progression of this terrible disease because the hard truth is that no one knows if they or one of their loved ones will be stricken by this destructive disease. Please reconsider Medicare coverage of brain amyloid imaging.

[PHI Redacted]

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I noticed that my husband, Kyle was having some memory problems, and asked that he mention it to his doctor. His doctor gave him a simple memory test and said its normal aging. Since we see the same doctor, I expressed my concern at my next appointment, so he referred him to a neurologist. In October 2010, after some brief, in-office testing, he was told he has mild cognitive impairment and additional testing was done. Those results apparently gave some additional information, but the neurologist just said to not worry, be happy. Literally. We received a diagnosis of early onset Alzheimer's from Mayo clinic in Rochester in February 2011. Our out of pocket costs were $5000.00. He applied for and received social security disability after a slew of tests, including 3-4 hours with a psychologist. I can't imagine the total cost of all of those tests.

As a result of the diagnosis, my husband was put on two medications, quit smoking cigars, quit drinking beer, started exercising and has worked very hard to delay this horrible disease. He is declining, but he is enjoying life. Every day I still have my husband, and my children still have their father, means everything. Knowing you have this disease is horrible, but knowing is better than having it and not knowing. If you know you can at least do something about it, and enjoy the quality time you have left. And, although the hopes are dim, you can hope for a reversal and cure.

[PHI Redacted]

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Please allow this important diagnostic tool be part of Medicare coverage. I know firsthand how debilitating this disease is, as I lost my wonderful mom to it last October. Planning is so necessary with the right diagnosis. We should be able and be covered for this very important tool we are lucky to have in this great country. Please listen to our pleas. Thank you for your consideration.

[PHI Redacted]

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My mother and grandmother both had this terrible disease. I want to be diagnosed as early as possible to help delay this deadly disease.

[PHI Redacted]

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My mother and both my grandparents had Alzheimer's. An accurate diagnosis is so very important for the future of MY children!

[PHI Redacted]

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As a horticultural therapist who works with the elderly full time, I see the horrific effects of Alzheimer's on both patient and caregiver. A correct diagnosis would lead to better treatment and less stress on all concerned. This would cut down on medical treatment costs.

The wrong diagnosis of this disease often leads to physical violence, lost patients wandering streets and I have seen it happen more than once. Death.

Improper placement of seniors in ALFs and ACLFs due to not knowing exactly what is wrong with them, combined with families in denial leads to other residents and staff getting physically and verbally abused by the sick resident.

Tests to determine if the patient has Alzheimer's disease will save the government millions of dollars in medical expenses in the long term due to proper placement and treatment.

Sincerely,

Mr. Robert Bornstein

[PHI Redacted]

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I have a mother who passed 3 yrs ago and had Alzheimer's. I was her caregiver for the last 5.5 years of her life and let me tell you there was nothing nice about this disease. I was happy to know that there was a test to prove that she had it, instead of wondering what was wrong with her all the years prior. I have an uncle who has it (mom's brother) and possibly an aunt who is in denial.

If it weren't for these tests, family members and doctors will not know how to treat the symptoms without the tests. It is very imperative to have this accurate and early diagnosis.

[PHI Redacted]

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This year I lost my mom at the early age of 66 to what her family doctor, unbeknown to us, diagnosed as dementia. My brothers and I had been trying desperately for several years to get a diagnosis for my mom. We tried psychiatrists, family doctors, a neurologist and even had a trip to the ER where they did a CT scan and tested her for drugs such as cocaine! Not until it was too late, her health was declining fast, did her family doctor start to consider sending her for more tests to diagnose her with dementia. We feel like had we known sooner that she had dementia, we could have understood what she was going thru, provided better care for her, and made our time with her more valuable.

I can't stress enough how early detection would have helped my family cope with this disease that leaves family members feeling helpless.

[PHI Redacted]

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Please help citizens get help diagnosing Alzheimer's. My mother suffered from this dreaded disease. My brother in law has it and so does a friend of mine. Please.

[PHI Redacted]

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Our best friend was diagnosed with this terrible disease. A bright, intelligent man was going to get lost in this limbo word...he could not get the necessary medications because he didn't have the means to do it...You all know, that each year more and more younger people are being diagnose. If we don't assigned funds for research, how is the system going to deal with these???????? They are younger, they are going to need more years of care...act wisely!!!!! The people need for the proper authorities to work on their behalf...assigned the most needed money for research and make sure, Medicare and Medicaid and Insurance companies have them in the OK list that approve paying for them.....we need help!!!!!!! My own husbands CT is here, we need to take it to the MD, but we need the Spiritual and Emotional Strength to do it....

[PHI Redacted]

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I have had three members in my family die of this dreaded disease. My father is now battling it. I sure hope that this treatment will be approved by Medicare. This disease is worse than any cancer on everyone including the afflicted and loved ones. Please open your hearts and let this be a covered treatment!

[PHI Redacted]

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Alzheimer's can destroy a family! The earlier the diagnosis, the better the chance of intervention and family management!

Sincerely,

Ms. Tami Holloway

[PHI Redacted].

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My husband was diagnosed with Alzheimer’s in 2003 when he was 64 years of age. We had noticed problems with his memory at least 3 years prior to that but thought it was normal. We all forget things or don't listen. He was started on Aricept and we had many good years of traveling, enjoying our family. He was changed to Namenda and Exelon when the Aricept seemed not to work as well. All these medicines gave him diarrhea. Then in 2011, he started to become combative when he had been asleep. He didn't remember anything that he had done during the night but he was his same gentle man during the day although he was very confused and had to be watched all the time. He punched me in the face one night and cracked a bone in my face. I knew it was time. We put him in Sugar Creek Special Care Alzheimer’s Unit in Normal, IL. He was only there about 5 months when he began hitting other residents and he had to be taken to the hospital. He was put on anti-psychotic medicine and taken to a Galesburg Hospital where they had a unit to regulate medication. After about 2 weeks, he was transferred to a Galesburg nursing home because no other nursing homes would take him. This was a 2 hour drive for me to see him. He was there about 3 months and was doing fairly well when LeRoy Manor agreed to take him in their locked Alzheimer’s unit. He loved to walk but didn't participate in much of anything else. He had to be forced to sit down to eat and he would be irate. He was combative and uncooperative so they transferred him to a Decatur hospital for medication adjustments. All they did there was confine him to a wheel chair and add Excelon to his medication. He could not walk when he came back to LeRoy so he was given therapy to get him walking again. He aspirated food and got pneumonia. He was taken to the hospital where we didn't expect him to make it through the night. He did make it through the night but couldn't swallow after that ordeal so we brought him back to LeRoy Manor to die. The one good thing about this experience was that he couldn't take the horrible anti-psychotic medicine. I had asked all along if these medicines could be working against him and was told yes they could be but no one wanted to reduce them. He went nine days without food or water and he came back to his old self. He was not dying and they finally decided to give him a swallow test again. He passed that test with flying colors and was able to resume eating. They had to give him therapy again to get him walking. Gradually he did seem to be getting more agitated and they put him on 1 mg of Risperdol and 1 mg of Xanax. Before he had a chance to see if this medicine was working, LeRoy Manor decided they needed to send him to a place in Champaign that would try to get him on something that would help. So one day we were loaded into a van with a CNA and a person from Social Services. We had to go to Carle Hospital first for tests and then see if this facility would accept him. I thought it was all arranged before we left LeRoy. After hours and hours at the hospital, the place decided they would not accept him. So we had to go back to LeRoy cramped into a small car. Larry had many episodes of agitation while we were at the hospital until they finally gave him some Xanax. This was a traumatic experience for all of us and was totally unnecessary. Larry is finally doing fairly well on the Risperdol and Xanax. He still has period of agitation and dementia but he is much better. LeRoy Manor has been good to us and maybe all nursing homes are alike but some of the CNA's are not very caring or loving. He is allowed to sit in urine in his wheelchair for hours and some CNA's are not very good about cleaning him. I am thinking about moving him to another nursing home but I'm worried about whether it will be any better. It is more expensive and we are paying for Larry's care from his IRA. I don't know how much longer the money will last and what I will do. The amount the State of Illinois will allow me to keep for myself will not be enough for me to live on.

[PHI Redacted]

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This is an awful disease for the patient and the entire family. Please do the right thing!

Sincerely,

Mrs. Camille Hines

[PHI Redacted].

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My mother recently passed from Alzheimer's. We spent 5 years watching her slowly disappear from us. Thankfully she maintained her wonderful sense of humor which made it much easier for us. Although there are 8 children in the family, it really came down to 2 of us that took care of her with others locations & job schedules not allowing for the daily care she required. This is a disease that will rob more & more people of their once proud dignity and is a disease that needs all of our attention TODAY if we want to stop it. The time & cost associated with the care of Alzheimer's patients can be debilitating to our families & our nation’s financial well being. Please do what you can NOW for the future wellbeing of our citizens.

[PHI Redacted]

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My mother has been diagnosed with dementia! My mother is only 72 and is in perfect health other than dementia! She had a onset when she was about 62 after her mother passed! My mother is still holding strong to her independence but she has become so mean! I want my mother, best friend back! This disease has stolen her personality and her grandchildren have suffered not knowing what a great person she is! Please find a cure!

[PHI Redacted]

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It could be me...

Sincerely,

Dr. Katharine Cartwright

[PHI Redacted].

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For God's sake.... we need all the help we can get! This is an epidemic and needs funding and research! What are you waiting for, the whole country to lose their minds? Then what??? What if I as a caregiver get Alzheimer's... who's going to care for my mom and I, then??? I need to know if I'm going to get it without being penalized by my insurance company! Get with it people, and see this for the catastrophe it has become! My God!!! Will someone step up and help us??? Hiding your heads in the sand isn't going to make this go away! Wake up... you and your family could be next!!!!! Thank You

[PHI Redacted]

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Well my dad just passed away on 7/15/13. He was my shadow. Always with me, with the exception, when his memory began to slip away into that space. My dad had Alzheimer's for 10 years. Every day something new we would see. His character just fading away. It hurt when he no longer knew me and could not speak to me. For he could not form a sentence, let alone a conversation. He also had cancer of the bladder, But it is not about the CA, but about his memory. How this disease just steals every memory. Like a thief, except he is right before your eyes. He was not diagnosed right away. It took time. Until we were given the sad news. He has Alzheimer’s disease. Until you have a love one with this illness, you cannot begin to know or understand. Walk in our shoes and see how difficult it is and how hopeless you feel. To see someone you love just slip away n look at you w/ a blank stare. When I needed him as a dad, to hold me, when I did not feel well, he could not. For he did not know how to any more. He would sit and stare. But to have him, meant the world to me. Until the lord said, it is time to come home. Just knowing that in heaven, he finally has a clear mind. Cancer free too. But it does not change the fact that I miss my dad very much. The ache in my heart. Please find a cure. For we. as his daughter, don't know if we r next in line. Don't want my son to go thru it with me. He suffer enough watching his grandfather. So sad. Thank you.

[PHI Redacted]

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Back in 2003, my father had just completed a series of surgeries and chemotherapy, in the battle against two types of cancer. We were elated to learn the surgeries had been a success and that his prognosis was great! Then we were devastated when it was confirmed he was suffering from Alzheimer’s. We were at a loss, so perplexed at the irony. Our only consolation was knowing that the diagnosis would provide doctors with an approach to his healthcare, that they were able to map out a plan that might help us share more time with our dad, who had just fought so hard to survive. He lost his battle to Alzheimer's in April of 2012, but I am certain that, left undiagnosed or untreated, we would have lost him sooner. Every minute a loved one's life that is extended is immeasurable. By extended, I mean the ability to see recognition, life, in their eyes. Anyone touched by this disease knows the empty stare I refer to. This brings me to the fact that I too have children. One of my greatest fears is that they too will face that empty stare in my eyes some day. We, who represent the future generation of elders, need the benefits of testing and early detection. I want to be mentally and emotionally present in the lives of my family for as long as possible. If I am struck by this horrible disease, testing and treatment are the ONLY hope for me and millions more.

[PHI Redacted]

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Mother was diagnosed early on at a Memory Disorder Clinic in FL. She was the first person in her town in PA to be prescribed Aricept and this helped her local medical community keep current with the latest developments in the field. Early diagnosis is key, for it gives a name to a set of symptoms, thus eliminating much scolding, harshness and unkindness towards the loved one. Early treatment prolongs quality of life and there is no price tag for one's quality of life. I strongly urge legislators to continue to cover brain amyloid imaging for Medicare beneficiaries. Thank you.

[PHI Redacted]

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Unless you are experiencing this debilitating disease you have no idea how awful it is, My mother has this and taking care of her is by all means a challenge. I am worried that I might end up like she is and it is really scary. I am 67 and my mother is 89. If there is a way that this can be detected early and get help with it I do not see why we are not doing all we can.

Unfortunately most families in the US will experience this with a family member, relative, or friend and to see the decline if their life quality and the quality of life that a family member has that is the caregiver is heartbreaking. My life has been reduced to nothing, I cannot go anywhere, I find that friends stop coming by, and my health has gone down the toilet.

Please help us to be able to find out if we have Alzheimer's early while we are able to handle our affairs, make rational decisions, enjoy what we have now and be better prepared. I never want my children to go through this without being prepared and decisions that I could have made while I was still able to make decisions. This is not just for the patient it is for the family also. You need to look at the whole picture of devastation the disease can do to a family. I know I would like to know and I think you would want to also.

[PHI Redacted]

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My mother died of Alzheimer's. The death certificate said, "cardiac arrest;" but it was Alzheimer's. Progress has been made since then. If that is a path I also must follow, I want to be better equipped to fight it. We have better tools and relief now; hopefully, some day a cure. We all deserve to be able to take our best shot and/or help our loved ones take theirs. Due to the nature of the disease, those on Medicare are apt to need this testing the most. Alzheimer's needs to be recognized for the horror it is, and testing early testing and research be given the priority it warrants.

[PHI Redacted]

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My husband was in his fifties when he first went to a neurologist with memory issues. It took about 3.5 years to get a dementia diagnosis. He had 3 MRIs, 4 EEGs and 2 lengthy exams by a neuropsychologist. The fact that he was young and still able to work made the doctors believe if he could control his stress and anxiety that his memory issues would improve. Since there was no clear cut test to do that would show the problems in his brain, the doctors just kept trying different medication.

If you go to the doctor and suspected you had cancer, there are tests to see it. Same thing with HIV/AIDS. Same thing with heart disease. Same thing with diabetes. There needs to be a test to determine Alzheimer’s disease and other dementias so that the patient and the families are not left in limbo for so long.

[PHI Redacted]

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I am the caretaker and wife of my husband Dennis. I wished that we knew about this test 6-10 years ago, because I really believe that my husband would have taken this test. He is only going to be 65 in Oct. of this year and has had Early onset Alzheimer since he was 60 years old. It might have impacted his life in a different way and would have made some crucial decision on how he was going to protect his family and love ones. He would have had a chance to tell the ones he loves how much he cared for them. His Alzheimer came on quickly and with the fire of a dragon. Consuming his thoughts in a short four years, to as of date is in a nursing home. Not being able to care for himself or others, not knowing who he is or to be able to know the people that love him. This is such a dreadful disease and to deny anyone access to knowing or have knowledge that could predict an early knowledge that they might have this disease. Is horrible for the government to strip away this away from anyone. As a elder this might give them a chance to get their household in order. It might give them a chance to move closer to family members so they can get on hand help as this dreadful disease called Alzheimer takes a hold of their mind and body. Don't deny this or any test that gives them this satisfaction to maybe take control of their own life. Thanks for taking the time to read this and maybe having the heart for someone else that loves their own life. Have a good day and God Bless.

[PHI Redacted]

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We had diagnosis by default. My stepdad went through a battery of tests and many specialists to prove what it wasn't. All along it was suspected to be Alzheimer's. We were told the only conclusive test was an autopsy. Meanwhile we were living through extremes moods and behavior changes and praying for help and relief. Unfortunately, he injured someone physically in the process.

[PHI Redacted]

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My husband has Alzheimer’s disease & I want so desperately to help him....but there is no help, his brain is dying.

[PHI Redacted]

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In 2010, my mother was hospitalized for treatment of a non-neurological illness. As a result of this illness, I moved my mother and her husband in with me. As the weeks progressed, I noticed changes in both my mother's and her husband's behaviors. Because my mother and Charlie had not previously lived with me, I had been unaware of their behaviors and of the challenges that they had apparently been experiencing in their ADLs (activities of daily living). Once I noticed the odd behaviors, I took both my mother and Charlie to a neurologist, who advised me that they were both exhibiting symptoms of dementia (in particular, Alzheimer’s disease). The doctor advised me that the only definitive testing that could be done for Alzheimer's was an autopsy. I therefore elected to allow the doctor to begin treatment of my mother and Charlie utilizing the common dementia medications of Exelon, Aricept, and Namenda. As the next 2 1/2 years progressed, it became more and more evident that the two of them were suffering from dementia. I believe wholeheartedly that the medications that they were given were extremely helpful in controlling their symptoms, in giving them a better quality of life, and perhaps even in prolonging their lives.

I urge you to consider the early testing for dementia as a standard of care provided by Medicare. I would be willing to provide more information and documentation of our experiences.

[PHI Redacted]

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My nana was my like my mother and meant the world to me. AZ had started early and when the doctor put her on enchanting for smoking it exacerbated it to the point where she never regained her ability to communicate clearly to tell us what she wanted or properly tell us goodbye. I cared for her for the last 14 months where she was a healthy woman and then was bed ridden and died within months. I fed her, washed her, changed her diaper and brushed her teeth. All the whole she fought me, slapped me and cried. If it wasn't for me helping my grandfather would have met a an early grave due to the stress of caring for her solely. As divorcing her or selling his house he had worked his whole life for and spend his retirement savings to put her in a home would have left him destitute. It enrages me how our health care system only came to help the last two weeks. It would have been nice to know what was going on before it was too late.

[PHI Redacted]

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My mother was diagnosed with Alzheimer’s disease a little over a year ago. The diagnosis was heartbreaking but gives my sisters and I the ability to work closely to keep our mom at home and safe at this time. Without the diagnosis we might not have the opportunity to understand the changes taking place in our mother. Please do not allow a denial of diagnosis as early as possible - life can only be better with information.

[PHI Redacted]

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My mother was recently diagnosed with dementia. She is 79 years old and is in good health physically. However, this mental illness is beginning to take a toll on her as well as our family. She has been back and forth to doctors the past 5 months trying to get a proper diagnosis, so they can prescribe the necessary meds. She's seeing a neurologist now and he diagnosed get as being severely depressed, which could have triggered the dementia....medically that sounds good, but not 100% sure that us it. She was taking anti-depressants and the Exelon patch. She took it for about 2 weeks and then said it wasn't helping her, she didn't need it and stopped taking it. She has been acting out verbally and paranoid about a lot of things, namely electrical, cell phones, lights and Internet. She thinks someone is after her and she is blaming her family for her illness. She doesn't want to live in her home anymore because she thinks someone gas wired it to harm her. She gets SS monthly and is on Medicaid, therefore, she is limited on facilities for assisted living. She's very competent and her memory is still good however, by her not taking her meds, her condition is worsening. There definitely needs to be more thorough tests to diagnose this horrible disease. Please do not take away the small ray of hope there is to better diagnose and treat Alzheimer’s disease. Thank you.

[PHI Redacted]

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My grandpa had Alzheimer’s and no one knew till grandma died. If there were early testing, he could have gotten meds and interacted with his family instead of getting mad and always trying to escape the family watching him.

[PHI Redacted]

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My husband (Cesar) passed away 3 days ago after a long struggle with Alzheimer's disease.

He had worked as an operating room nurse at Mass General Hospital for over 40 years. He worked long hours and commuted 3-4 hours a day. We looked forward to his retirement as a time for him to enjoy the fruits of his labor. Tragically, he was diagnosed with Alzheimer's a few months after his retirement. As a result, much of his retirement was spent in diapers eating baby food.

Cesar was a very proud and dignified man who developed a horrible illness that robs a person of their pride, dignity, and quality of life. For this reason, I chose to keep his illness a private matter. I cared for him at home for the last 5 years while maintaining a full time job. I watched him progress from a very intelligent, energetic man to an immobile, incontinent person who was unable to speak, communicate and eventually swallow.

His death was merciful. I will be attending his funeral in a few days and I will be speaking to many of his old friends and explaining why he just "dropped out of sight" for years. I will also speak about the horrors of Alzheimer's and how we MUST work to eradicate this life destroying disease. Please do not let this be his children's legacy.

[PHI Redacted]

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[PHI Redacted] was my mother. She was a fun, loving and teaching mother. She raised 5 children on her own without any child support from our father. She never drank, smoked, used drugs, but she had to live the last 13 - 14 years of her life not knowing how much I regretted not washing thoses dishes when I was in high school, not knowing how much her grandchildren really appreciated her, not knowing they graduated college with honors and not knowing one of her granddaughters got married. Why, because my mother passed away last September weighing 97 pounds. She wasn't much more than a skeleton and although I know it was God's kindness she was taken to her ultimate Home, this Wednesday July 31 would have been her 87th birthday and it will be my first without her. This Wednesday we will all get together to celebrate my mom while I sneak off to the rest room to cry a little. I wonder, will this be me one day not knowing anything and will my children be the ones in the rest room on my birthday crying. This is a cancer of sorts, just of the brain and we need more research. MORE... Please think of how you can pick up the phone and tell your mom you love her, while I can only do it in my dreams and let's get rid of this horrible disease called Alzheimer’s.

[PHI Redacted]

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My father at the age of 48 and after began to act differently, his mood changes, started forgetting simple things and overall was not the man we knew. After years of wondering and not having insurance to get him checked out due to the fact he could not hold down any jobs, we found a doctor that would help. The doctor diagnosed him with early onset Alzheimer's. a few short years later at the age of 62 he passed away. My mother had to quit her job to take care of him foregoing her insurance and mean of living. No help from anyone .until his last 2 years of life when Hospice came in. They were amazing. I am now 42 and are one of the youngest enrolled at the Alzheimer's research program at Emory University. I plan on making it my life's work to help find a cure!!!! Help me because I have no insurance and can't afford it to keep my health in check. I am doing what I can but I need more help.

[PHI Redacted]

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My husband David (age 78) recognized memory issues in 2008 & engaged in consultation, vitamin/mineral supplements, and physician recommendations & treatment. An article in the local newspaper announced memory testing at the Shiley_Marcus AD longitudinal annual review connected to UCSD Medical Center in La Jolla, CA. We have just completed the third year testing & review with SM, with outstanding dedicated staff. Literature and organizations have provided a wealth of helpful information. His progression is considerably slow - Donepezil & Namenda are two prescribed drugs he takes daily - he's healthy and good natured. Vital factors are family support and spiritual (faith community) involvement.

[PHI Redacted]

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My Nana suffered with this dreadful disease. We had to watch her so slowly vanish before our eyes. I watch my 46 year old sister struggle every day with the fear of our mother and us getting this disease. I just know how very sad it was to watch a perfectly healthy woman lose her mental faculties. Nana in the last three years just kept talking about how tired she was and how she "wanted to go home". We lost her December 28, 2012 and although I miss seeing her physically, we had lost her almost 10 years earlier. RIP Eula Mae Lecco. We love you.

[PHI Redacted]

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There is nothing more devastating than losing a person who is still with you.

Sincerely,

Ms. Jola Schraub

[PHI Redacted]

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My mother has Alzheimer's. She was and is a lovely, kind woman who raised 7 children, as well as numerous other children in her day care center. She was vibrant and full of energy- rarely sleeping more than 4-5 hours a night so she could prepare for everyone else's schedules the next day.

Her disease started slowly- so much so that we made excuses for her. She was 'just busy' with her life so, of course, she forgot things. My father's illness masked my mother's progression too. She was trying so hard to care for him that her own health was slipping and we couldn't see it. The day my father died was the day I realized how far advanced my mother was. She didn't know how to use the phone to call me to tell me he had died, so she waited for me to call her. She has progressed rapidly, yet her physical health is quite outstanding. Had mom had earlier testing done, we could have given her a longer, more vibrant lifestyle. Instead, she does not know us, nor does she remember my father, and she can only smile and try to make small talk with the 'strangers' that come to see her. She is the child of an Alzheimer's parent, and now, so am I. We need earlier diagnosis.

[PHI Redacted]

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I have learned about a long list of family members counting back from my grandparents that if they could have been diagnosed with what we now call Alzheimer’s disease then we would have known how to help my Aunts, my mother, and my older sisters. What about me and what will I and my children have to go through as I age. I know to look out for memory loss, forgetting certain things, but I never want my children to see me forget their names, watch me have hallucinations and not know what to do with me, or be afraid that I will not be able to care for one of my grandchildren. These are things we live with watching our parents slowly forget our existence and the meaning of a family unit. Watching them go through these changes also changes the meaning of our lives as well forever.

[PHI Redacted]

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My mother died almost two months ago from Alzheimer's disease. When she started losing her memory which was incredible when she was younger, I took her to few Neurologists. They did some tests but they could not identify the disease. It was basically a diagnosis by exclusion.

One doctor told me that all she had was that she was getting older. That was not the case. We lost valuable years when we could have started treatment for her and maybe delay the advancement of the disease. When they finally said it was Alzheimer's and she started her medications it had already taken my mother's sense of direction and orientation, her ability to do her daily chores and her immediate memory. If we had better diagnosis tools at that time, even when we don't have a cure we could have given her the right medications and make important lifestyle decision when there was still time. Alzheimer's reality is worse than what the statistics say because there are no definite diagnostic tools to distinguish Alzheimer's from other diseases. There are lots of people in their 60's that have the disease and are being treated for depression, or stress related illnesses when the reality is that Alzheimer's is doing its work. The thing with this disease is that you start mourning your love one day by day as you see her memories and cognitive abilities decline slowly first and then very quickly. You don't know who you will meet the next morning. This disease not only affects the patient it affects the whole family spouses, daughters, sons, grandchildren that cannot understand what is happening with their grandmas. This is an urgent issue. It's the disease that is going to define the baby boomers. If nothing drastic is done the emotional cost to whole families and the economic burden due to lack of resources will cost much more in the future.

[PHI Redacted]

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Watching what my great-grandmother went through with Alzheimer's, and our family was beyond heart-breaking. How do you tell your loved one that the mother she's trying to call is in Heaven? Or the son that was in the Air Force that she lost decades ago (he was 31), that she keeps looking for is also in Heaven??? Watching the stress and worry eat up my great-aunt, worrying if all the preventative measures we'd do to keep her safe would be enough just so we could use the bathroom or go to the corner store for milk/bread? Anyone who says there is "insufficient evidence that a diagnostic test improves health outcomes" clearly has not had a family member with Alzheimer's - if they did, they would do ANYTHING they could to make sure they had the best quality of life; and to do ANYTHING they could to stop or slow down the progression of a horrible, horrible disease. My great-grandmother's doctors weren't that familiar with Alzheimer's, if they had been, and maybe if they knew of things to do to help her - maybe her quality of life would've been vastly different; and we could've created better memories for our family.

[PHI Redacted]

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It was hard getting a diagnosis for my mom. Once she was confirmed she was able to get medicine to improve the quality of life she had left.

[PHI Redacted]

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Dementia/Alzheimer’s pierced my life thru my mother who now resides in a memory care facility. The heartache I feel is at times is overwhelming to have her look into my eyes and her not know me, the daughter of a loving mother who worked so hard and kept our family together thru distressing times. My love for her will never fade-as I look into her eyes she is still my mom. So this I do for her. She began repeating her stories, over and over. Then she began dressing in layers, mood swings, and forgot she had eaten. My brother lived next door, but worked every day. I live 200 miles away.

Then the day came when my sister found her sitting on her swing in the back yard in the pouring rain. She was not safe to live alone anymore. So we placed her in a facility. But they were not equipped to keep her secure. She went missing and was found in a field near the local creek. Unharmed but scared.

We then found a wonderful memory care facility that she resides in at present. She does not know any of her children or what day it is, but I hope she know she is loved very much.

This is why we need more funding, testing and research to possibly prevent or have an early diagnosis for treatment

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If this was your mom or dad, you would have done it yesterday.

[PHI Redacted]

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Early diagnosis has helped me to better care for my husband, use medication to treat and seek assistance to plan for the future. We need more research and care options for all dementia patients.

[PHI Redacted]

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I lived with my grandmother and I watch my husband slip away every day. It is very hard watching your loved ones disappear. It is very important if we have a chance to find out early

[PHI Redacted]

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I had back surgery; when I went back to the doctor he asked me if I had any problem; I told him that my short memory did not work very well. He told me to go and see a neurologist. I did; after a battery of tests I was told that I had Alzheimer. I am taking my pill (Aricept) every morning and I am feeling very good.

[PHI Redacted]

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I don't know that my mom has ever really had a formal diagnosis for Alzheimer’s, although she does exhibit a lot of the signs of early stages of the disease. She is very forgetful and sometimes gets confused. But she does have her good days, where she is pretty normal. I wish there was something out there that would eliminate this terrible disease.

[PHI Redacted]

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My husband Tom has been diagnosed with this sad disease it is changing his sweetness to a mean and angry person to me and others I get so sad and hurt by this because he was always so good to me and his four children. Sometimes he seems okay then turns around to his new self .I am so confused at this but trying not to take it personally to .He is often accusing me of cheating on him I have never done this in our 46years of marriage .I get so hurt and very sad.

My mom is 90 and she also has dementia going on she is not mean she seems to be better than my 74 year old husband. I pray this disease can get some help soon seems like everyone is getting this it is so sad for them and their families

[PHI Redacted]

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We thought my grandmother was just mixing up her pills and we hoped that her "forgetfulness" would subside once we got them straight. However, it was just the first signs of her Alzheimer’s. Because of that, the last ten years of her life, she had no idea who anyone in her family was. We lost my grandmother last weekend, and I would have given anything to have at least one more year with her.

[PHI Redacted]

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Years ago, my grandmother was told she was forgetful. Then, it was dementia. Then, it was Alzheimer's. Once she started the treatment, it did not progress- which was a blessing for her. Then, she needed heart surgery, which meant she had to be taken off all of her medicine prior to the hospitalization. Since that surgery, things changed drastically.

From 2007, when she and my grandfather were both hospitalized for broken hips, we battled this disease constantly. Her husband of 70 years was a distant memory. My brothers and I were unfamiliar. Our mom was known many times as her cousin. None of those were the most painful. That came when Grams believed her mom and sister to still be alive. Not knowing any better, at first we corrected her, breaking all of our hearts each time.

Last year, we lost her. Her failing health was no match for the progressing Alzheimer's taking over her mind and body. She needed more help. She needed stronger therapy programs, pharmaceutical help, and knowledge of the disease, not uncertainty.

We miss her terribly each and every day. She was an amazing woman, my grandmother, and my friend.

A cure is out there. We need help!

[PHI Redacted]

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You can't know unless you have a loved one with this disease how important early diagnosis is.

Sincerely,

Mrs. Janet Hultberg

[PHI Redacted]

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Over a period of years I asked my husband's doctors several times to test him in some way because he was behaving oddly and in a manner not consonant with his personality and beliefs. They all asked him to do silly little things, like subtracting 7 from 100 backwards. The man had a Ph.D. in Mechanical Engineering and he just laughed at them and did it. A CAT scan showed nothing. So they told me he was fine.

My husband and I fought and fought, I nearly left him, and our life was a misery. Finally we got a diagnosis of Alzheimer's, but he only lived a year after that - died in a nursing home of pneumonia. If we could have had an earlier diagnosis, those last years could have been managed much better.

[PHI Redacted]

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My dad is currently in a facility with Alzheimer's. We didn't even know that he had the disease until the death of my mother sent him in a tailspin. Looking back he probably had it quite awhile before she died. If we had known it would have made quite a difference in his "quality of life" and he might have been able to remain home longer. It's important for an early diagnosis without repercussions through the health industry but also an accurate diagnosis, as some things mimic Alzheimer's. It is a devastating disease and as I watch my dad decline it is like a "descent into hell" not only for the patient but the family as they watch helplessly.

[PHI Redacted]

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My spouse started neuropsychological evaluations in 2005 and was consistently diagnosed after testing with mild cognitive impairment every year until April 2009. After that test, the diagnosis changed to dementia. Because of an auto accident when he was 20 years of age where he was in a coma for five days, the possibility was raised of traumatic brain injury now affecting his brain in the form of a dementia. MRI was inclusive. Thus we were told he simply has unspecified dementia, perhaps vascular, perhaps traumatic brain injury. Doctors do say he does not have Alzheimer’s. So other than "cognitive disorder NOS, Vascular dementia, Memory Loss, (all noted on the discharge diagnosis after the most current testing done in 2010, we still have no idea of what kind of dementia he has.

He is on the usual drugs: Aricept and Namenda and an antidepressant. If there is more testing/drugs available than we currently use, it would be most appreciated. Until one has lived with this disease, you have no idea.

[PHI Redacted]

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This test would save families the unfortunate situation of having a catastrophe because they were not prepared for how involved the dementia was. For instance, it often takes a catastrophe to move a parent from their home and a change in their level of independence. Many adults are also very socially adept and can MASK the symptoms of dementia to family members, thus robbing them of needed support and medication.

Early detection would get the appropriate level of support when it is needed, not when it is too late, as was the case for our family. It took a psychotic episode that involved the sheriff and a psychiatric center to change a placement from home to assisted living.

So unnecessary.....the consequences were FAR more costly than the test.

[PHI Redacted]

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Let's make sure we do everything possible to find a cure for Alzheimer's. This horrible disease took both my father and mother and having 4 siblings approaching mid-life, we need to investigate and pursue any options that are available.

[PHI Redacted]

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My father had dementia for about a year and a half before he died. Since his death, I have determined that he probably had Lewy Body dementia. However, his doctors within the VA system and those he saw through Medicare never provided a diagnosis. If we'd had a diagnosis, we could have learned how to better care for him. We also could have avoided 2 costly emergency department visits for two episodes of an unexplained loss of consciousness (a fairly common symptom of LBD). I encourage you to support the appropriate use of tools to help provide an accurate diagnosis for individuals with symptoms of dementia.

Thank you.

[PHI Redacted]

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Please cover this service as it can increase quality of life which is improving health outcomes.

[PHI Redacted]

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I urge you to reconsider the diagnostic test called brain amyloid imaging. It took two years of testing for my mother to finally be diagnosed with Alzheimer's disease. I'm confident that more could have been done during that two years to help treat her if she was diagnosed earlier. I've watched my active, intelligent and vibrant hero deteriorate into a woman in a wheelchair that mumbles nonsense all day long and has no recognition of me, her only child or her only 2 grandchildren who were her while life only a short time ago.

This disease is horrific and a cure must be found. I don't want my children to have to go through this again with me.

Please do everything in your power to help!

[PHI Redacted]

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Doctors and patients must have all resources available to make an early and accurate diagnosis for this incurable and debilitating disease.

Both of my grandparents were diagnosed with this disease too late in life because no tests were available to them. Six years ago when my father began showing signs of this disease there were more options available to his doctors to help them identify and begin treating the disease. My hope is that the medical community will continue to progress to the point where they will find a cure. Until that day arrives, all medical procedures, tests and treatments must be available to begin and continue treatment.

The Centers for Medicare and Medicaid Services (CMS) issued a disappointing draft decision on coverage for a particular type of diagnostic test called brain amyloid imaging (read more). CMS stated they believe there is insufficient evidence that use of this test improves health outcomes for Medicare beneficiaries with dementia or neurodegenerative disease in specific populations.

In certain situations amyloid imaging should be covered by Medicare immediately to improve the quality of care for Alzheimer’s patients. One of those situations is when a dementia expert is unsure whether a decline in memory is due to Alzheimer's or some other perhaps preventable cause. Removing this testing as an option to diagnose patients will surely hinder doctors from early diagnosis of this disease.

On behalf of my father, my children, my extended family, please continue to allow this testing to be available and accessible to all who may require it.

[PHI Redacted]

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My darling wife Anne was diagnosed with Benson's Syndrome, the visual variant of Alzheimer’s disease in 2005. She has continued the expected downhill course and has been in an ECF since March 2010 when I could no longer care for her. It is heartbreaking to see someone who you love so much deteriorate. She is absolutely helpless, no longer knows who I am, and requires help to do anything. She is no longer able to speak. My wife has gone from a successful, brilliant professional woman to this current state. Others who have witnessed this in a loved one know that Alzheimer's disease and its variants rob the person of who they are. It is an incredibly cruel disease.

I see her every day and will continue to do so since I don't feel that we have much time left. I do see a therapist to help deal with this situation and that has been a godsend to me. I would recommend seeing a skilled therapist to help deal with the loss from Alzheimer's. We both have to agree that the love of my life is now lost. It is easy to say but very difficult to incorporate in my being.

God bless anyone dealing with this awful disease.

[PHI Redacted]

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My dad was diagnosed 8 months ago with Atypical Parkinson’s with dementia, he is 65. Parkinson’s didn't scare me but the "with dementia" terrified me. We had already seen a quick decline in my dad's thoughts and memory. All of the sudden my hardworking, handyman and "I can build or fix anything" father could not help me change out a dryer plug A dryer plug that he had changed out 3 times already. I was thankful he had already taught me but I cried the whole time fixing it because he didn't know what was going on. "What is happening to my dad?!?!" He was fine 3 months ago and now he barely knows where he lives. 8 months later he doesn't know the home that he has lived in for 30 years and as his youngest child, he sometimes doesn't recognize me at first. We have been told that dementia is such a broad disease that we can't be told of a stage that he is in, nor can we stop it. He is on two types of medication that is supposed to help with dementia and Parkinson’s but he is still declining and so are our hearts. It is incredibly hard to watch my dad slowly go away. His physical presence is still here but my precious daddy is slowly disappearing. He will never know who I marry and he will never see his grandchildren. I cannot understand how he is on two medications for dementia and Parkinson’s, vitamins that are supposed to help and valium that is supposed to keep him calm and not see ANY improvement. Could we have prevented this 3 years ago? Could we have done anything at all to help him not get this diagnosis so early on in life?

[PHI Redacted]

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Several years ago we noticed my dad making small mistakes in his business. He was an auto mechanic my entire life. He put the wrong oil filter on a car and ruined the motor. He got to where he was always searching through things at home, yelling at mom for nothing. He would put things "away" and forget where he put them. He would lay something down, and mom would make him put it where it belonged so he could find it when he needed it. But if she wasn't looking he would get into a searching mood and move things, like the dog leash. Then when it was time to walk the dog he would get mad because the leash was gone. As the next few years went on he got worse. We all begged mom to get him checked for Alzheimer's. Well she finally did and she told us that the Doctor told her that he had a slow blood flow to his brain, so when he got upset the blood flow slowed more so he would forget more and get caught in a vicious cycle and the only way to stop the cycle was several days of calm.

Then in May 2012 mom got sick, she went in the hospital in July of 2012 and I had my son go stay with my dad. By this time dad was able to pretty much take care of himself but he has never known how to cook so feeding himself was a real challenge. Mom never came back home she passed on September 3, 2012. At this point dad went into a really bad tail spin. He would forget or refuse to take any of his meds (none of them were for Alzheimer's), he got very combative and said things I know he really didn't mean. At one point he said he was going to take his own life, 30 seconds later he didn't remember saying any such thing.

From September through October I started taking dad to Doctors wanting answers, got dad to sign releases so the doctors could talk to me. Got him to a neurologist and got the diagnosis of Alzheimer’s. So at this point I talked to dad with the help of an uncle and dad gave me Durable Power of Attorney and if for some reason I cannot or will not carry out the P.O.A. then my sister will automatically take over. We know have dad on 2 medications and in assisted living. Up till two weeks ago he was doing really good.

I often wonder how much better off he would be if steps were taken years ago when we 1st started noticing these issues. If one of the doctors he was going to would have started asking the questions we were asking. Or telling my mom something needed to be done. Besides marking days off the calendar, because when she died he refused to do that. Then when he did he would mark 2 or 3 days at a time. Now, he keeps better track of time because the assisted living apartment keeps the date current on the wall in the hall and has him on a time schedule with a list of what time things happen in his room.

There are so many times I feel so alone. Like last week he got it in his head that I spent all his money (he never really had any), told me I was never his daughter, that I was never loved. For the 2nd time in just over a year he told me that his oldest daughter was killed, I wasn't needed as a daughter because he had my little sister. I know it's the disease talking but that doesn't take the hurt away. I thought at least this week he remembered my older sister being killed. Times like this the only one who can calm him is my baby sister or one of his best friends, who is more like an Uncle to me. I'm always the one he lashes out at.

Regardless of what he says to me I show up every Sunday to see if he's ready for church. If he's having a good day we go to church together, I take him out for dinner, then take him back home.

I have people ask me why I set myself up for this pain. I ask them what am I supposed to do, walk away from my dad and never go see him again? I can't do that! I do wish more people were trained in the care and treatment of this terrible disease.

Growing up I knew about Alzheimer's, I knew old people lost their memory and it was called Alzheimer's. I didn't know the confusion it caused; I didn't know the pain it caused, not only for the person who had the disease but for the family of that person. I had no idea that there was more to this disease than just someone losing parts of their memory.

[PHI Redacted]

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My mother was diagnosed with Alzheimer's in 2011. Her mental decline can be traced to the first anniversary of her only son's death. My mother is also diabetic. Her doctor ordered a brain amyloid test last year to determine the extent of her dementia but without insurance my parents were unable to afford the over $2000 procedure. The doctor had hoped to gain valuable information on my mother’s condition. We sit here waiting for the procedure to be accepted by her insurance to determine the extent of my mother's dementia. With diabetes my mother has seen many days of confusion due to her illness. The possibility of depression has also been expressed by doctors but no medication appears to help her. So is her Alzheimer's progressing or is there something more. Unfortunately without the brain amyloid imaging we may not know until it is too late.

[PHI Redacted]

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My wife Kay started showing symptoms of memory loss at 56 in 2004.

She stopped working in 2003.We went from doctor to doctor specialists at banner Alzheimer’s clinic Eisenhower medical center, Rochester New York and Salt Lake City. All had different theories, most said it was due to depression but she was not depressed.

This was extremely stressful and expensive and time consuming, finally after extensive testing in 2009 we went back to Banner Alzheimer’s institute where they diagnosed Kay with Alzheimer’s and prescribed Aricept along with Namenda. We tried to apply for disability with SSI for Kay they said it was over 5 years since she worked and denied her claim. In May 2010 she started collecting ss of 465/ month much less than wait SSI would have paid her had she been diagnosed earlier. Now Kay is in the early late stages of Alzheimer’s at age 64. Had she been diagnosed earlier and had different medication earlier maybe she would have had a higher quality of life now and then. Early diagnosis is critical for all involved as all suffer from the affects of this disease financially, physically and emotionally.

[PHI Redacted]

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My wife Lynn was diagnosed with Alzheimer's disease 3 years ago at age 52 after she had been misdiagnosed 2 years earlier as having a vitamin deficiency. In those two years after being misdiagnosed she lost her job and began to exhibit more and more severe symptoms of short term memory loss and general cognitive loss. Since being correctly diagnosed she has been taking Aricept and Namenda and has been generally stable for the past two years. But the loss of brain function can never be recovered from the years where her disease went untreated.

[PHI Redacted]

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Alzheimer's victims and their families know that early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. Yet, the federal government has said there is insufficient evidence that a diagnostic test called 'brain amyloid imaging' improves health outcomes. This is very upsetting to me and every family who has been touched by Alzheimer's for I know and every family dealing with loved ones with Alzheimer's know for certain that early detection and accurate diagnosis is KEY to helping Alzheimer's patients care and outcome! I ask that you look more closely at the facts or even take into consideration those Americans like myself my family and the hundreds of thousands of other American families dealing with loved ones with Alzheimer's and ask them!

Sincerely,

Ms. Florence Eaise

[PHI Redacted]

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My mother had dementia. She came down with it in 2008. The doctors think she got it because she had hardening of the arteries. She was one of the sweetest and nicest people you would ever want to meet. Everyone loved her. She was always a very active and productive woman. When she came down with the dementia, she was still cooking and cleaning. We would have to watch her, when she cooked. Sometimes she would forget that she had left the stove on. She remained sweet and friendly up until the end. She passed away in February. I loved my mother very much. I miss her terribly. I have admit I missed the old mom, in recent years. It was very frustrating when she would ask me the same questions over and over.

I hope the Dr's find a cure for this horrible disease.

[PHI Redacted]

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My mother-in-law has dementia of some type, one that makes her clear-headed and nice at times and mean or even psychotic at others. My wife and I have repeatedly asked if it could be Lewy-Body or something similar, but around here, few healthcare people have heard of it. So we still don't know what she has or the best ways to treat it, but we know that some meds seem to make her much worse.

[PHI Redacted]

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My mother began showing signs of Alzheimer's when I was in college. I begged her visit her doctor and receive treatment; it was a very contentious subject between the two of us. She did visit her doctor, who was reluctant to diagnose someone so young (she was in her early 50s). She was told her memory loss was a result of menopause and then told it was a result of post-traumatic stress. After years of struggling to receive a proper diagnosis, my father took my mother out-of-network to a specialist who diagnosed her with early onset Alzheimer's. She received the very best care and was part of a clinical trial, but valuable time had been lost while doctors misdiagnosed her. It's been over a year since she passed, and we now know that she had the genetic marker for early onset Alzheimer's. What will this mean for me? I saw the terror that my mother lived with; knowing her own fate. I gave up part of my youth caring for my mother in ways that my peers were caring for their newborns. Will this become my life or my sister's? I fight for my mind and my body every day, but I need the help of emerging technologies that are funded through government grants and funds to ensure my future one that is otherwise so bright as an elementary school teacher, volunteer, friend, and family member.

[PHI Redacted]

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My mom was diagnosed more than two years ago with this horrible disease. I moved back to Michigan from Minnesota two years ago for a career opportunity and to be closer to family during a time of need. My father's health took a turn for the worse while he was caring for my mother and his brother in Florida. My father had a mental breakdown from all the stress. After my father started to get better, my mother's Alzheimer's started to get worse. After two years of being a caregiver, I could not imagine doing anything else. It has been a rewarding experience for me to be here for my family. I want to do everything that I can so that my parents can enjoy life and have great experiences, during the best years of their lives.

[PHI Redacted]

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My mother died of Alzheimer’s and we need improved ways to diagnose and treat this painful illness.

[PHI Redacted]

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Of the many important reasons for an early and accurate diagnosis I can think of, nothing is better than a early and accurate diagnosis before giving a person a death sentence with a diagnosis of AD!

[PHI Redacted]

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Our mother lived near the rural town of Antigo, Wisconsin. When several of us children recognized early signs of dementia, I took my mother to see Doctor Meyer, who was located in the Aspirus Clinic. He asked our mother to do the "clock test" which she failed. An R.N. asked many verbal questions, in rapid succession. A week later he ordered some sort of brain scan, which showed she had vascular dementia. A prescription was written for Aricept. She was 88 years old at the time.

My siblings believe this early and accurate diagnosis, along with a perfect match of medication, bought our mother five more years of quality life. She was able to remain in her own home, later with the assistance of Hospice. She died peacefully at the age of 92 in the fall of 2012.

[PHI Redacted]

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Alzheimer's is a major issue for this country.

Sincerely,

Ms. Vivian Bert

[PHI Redacted]

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My dad presently has the disease! It is very emotional and physically exhausting for family watching the person fall to the Alzheimer's diseases.

I have witnessed the disease as a nurse and research has not kept up with helping these patients. It is sad and degrading to watch a family member lose all control and turn into someone you don't know with character all totally away from their normal. I have a hard time watching my dad's health diminish each day knowing as a nurse how everyone one of them will end. Lost my mom at 8 years old to cirrhosis of the liver and never drank! To lose my dad now to weaken as she did over time is just is unbearable. My paternal uncle died of the disease too! My dad worried he may get the disease too and he does have it! God Bless all who deal with this family degrading disease! May a cure be found yesterday.

[PHI Redacted]

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My husband was diagnosed with Lyme meningitis 7 years ago. At that time, an MRI of the brain showed no atrophy. Because Lyme disease can affect the memory, we were aware of that; however 2 years ago, my husband asked me if I thought he might have Alzheimer's because he felt his memory was getting worse. I knew his doctor would want another MRI, which she did, and this MRI showed mild atrophy of the brain. Because I had worked in the medical field, I knew that dementia is only a symptom, not a diagnosis. A visit to the Neurologist confirmed that he has early stage Alzheimer's. He has been on Aricept and Namenda and we are hopeful that it will keep him where he is at this point. Because we have been married for 48 years, I am usually able to give him the word he is stuck on. When I'm not sure what word he's looking for, he sometimes gets very frustrated because he is so very much aware of what's going on his comment today was "I wish I never got sick".it's very sad, but so far we are fortunate in that we have not have to deal with some of the things that occur with Alzheimer's patients time will tell. I'm just thankful that I have him!

[PHI Redacted]

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My mother was diagnosed with Alzheimer's at the age of 82. She lived for 9 years with the disease. She was diagnosed by a world renowned doctor (now deceased) at the University of Kentucky, Dr. Markesbury. My husband, daughter, and I attended free classes to understand the expected changes that would occur and how to cope as caregivers. When she passed away, her brain was donated for research and we received a lengthy, detailed report that gave us additional insight to this devastating illness. Without the support of the Dr. and his medical team we would have been lost. Thank goodness my father, who was a federal employee with the postal system, had excellent insurance to cover her medical needs as he passed away nearly twenty years earlier. As this disease seems to be escalating, I would urge the government to continue to fund diagnostic testing in order to give families AND patients the relief, contacts, and ability to care for these poor souls who have no idea about who, where, why they are or how to manage what's left of their life.

[PHI Redacted]

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For several years now my brother and sister in law have been telling me that our father has been showing signs of dementia. I thought that my sister in law didn't like him and found all kinds of excuses to put this off. Recently my mother's illness has caused me to spend more time around him and I see more what they mean!

Within the last two weeks he has had incidents with the microwave that could have caused severe danger! First he tried to cook toaster waffles in the microwave and caught it on fire. The second time he put a 3 oz piece of meat on a Styrofoam plate and set the microwave on 4-burning the styro plate into the glass plate! Both times someone was there and we were able to avoid complete disaster. Next time we might not be so lucky!

Please do what needs to be done to make this test available. We are just beginning our long walk down this rough road. I want my father to have the best outcome possible!

[PHI Redacted]

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I have a very long story of all the ups and downs that we went through in trying to get a diagnosis of dementia, whether it was Alzheimer's or another form, so that we could act on my mother's behalf.

My mother's physician told my mother that it was okay if she continued driving short distances to the grocery store a few miles away. I was furious. We went to the physician for support in removing my mom's ability to drive and she simply gave her a pat on the back and told her to continue on.

As a teenager, I had seen several fatalities as the result of an elderly driver with dementia driving the wrong way on Interstate 35. I related this to my older sister, who had the power of attorney. I tried to encourage her to get together with me to take the keys from our mother, but she was consoled by the physician's reassurance.

Last year, my mother disappeared from her home. She traveled over 80 miles, during a busy college football weekend, and ended up the wrong way on I-35. She was taken to a hospital and was about to be released (to where I don't know) when one of the health practitioners noticed the APB. Thank goodness she didn't kill anyone and thank goodness that was not her end either.

If these diagnostic resources were actually physician guidelines, then perhaps it would have never come to this.

Patients with Alzheimer's disease learn to cover their condition very well in the early stages. The diagnostic procedure would not only help in their care plan, it could potentially save the lives of others.

[PHI Redacted]

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I lost my grandmother in November of 2011 to dementia and in March of 2012 my grandfather (who had been married to my grandmother for 75 years) passed away from complications of dementia. In the last year of living with the disease my grandmother lost her ability to independently eat and use the bathroom and she needed round the clock, 24 hour care. In her last week of life she was not able to eat and she died with my grandfather by her side. At the time of her death, he was also deep into the throws of dementia and suffered many medical setbacks shortly after my grandmother passed away. He eventually "forgot" how to swallow and starved to death in a nursing home. Watching these 2 very strong individuals die the slow deaths that they did was absolutely devastating to me and everyone involved with their caregiving. If more time, resources, money and so on are not devoted to the treatment of dementia then I predict this will be the disease that kills many of us living today.

[PHI Redacted]

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My mom was diagnosed in 2006, I first started noticing something was happening in 2003. My dad died in 2001, I had moved over to help her with my dad. I started noticing little things like repeating and losing track of things. I was working so I wasn't seeing everything. One day I saw her run right into a car with her truck, get out as if nothing happened and walked into the bank. I asked her if she knew she did that and she said she didn't. That's when the tests started and I took away her driver's license.

They said she had moderate Alzheimer's and put her on medication. (2006) She is in her late stages now, never went thru the wondering or meanness. She is still a beautiful woman. I caregive for my mom. She lives at home. At times I have help and at times I don't. Her Alzheimer's doctor never inquires about her. Mom can no longer speak, still eats and drinks, sometimes on good days will get up in her wheel chair with help. I change her, brush her teeth and hair, dress and bathe her. The hardest thing is not knowing if she hurts.

[PHI Redacted]

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I am a Registered Nurse working in a social model of Adult Day Care. It is imperative that something be done to help in the diagnosing and treatment of this devastating disease. Please help NOW! Sincerely,

Mrs. Annamaria Testa

[PHI Redacted]

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By the time my wife was diagnosed as having Alzheimer's, it was too late to do anything about slowing its progress. Strange as it may seem, her first cognitive test did not wake us up to the fact that two close relatives died with dementia, putting her at high risk. I was forced to retire and become her full-time caregiver. Earlier diagnosis might have allowed us to enjoy many activities that are now simply impossible, especially since we live on a fixed modest income. Please, please do everything possible to promote early diagnosis.

[PHI Redacted]

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Imagine yourself at home sleeping and thinking you are safe and secure. You locked all the doors and windows just like you do every night before you go to bed. Suddenly you are awaked by a noise. Do you just roll over and go back to sleep or do you get up and check out what it is. You get up and check it out only to find yourself face to face with one of your biggest fears, a thief has broken into your house and is taking everything that is of value to you. Do you protect yourself and your family, or do you tell the thief help yourself to anything you want and by the way the safe with all my most precious valuables is up stairs. So what does this have to do Alzheimer's? Alzheimer's is a thief. It is a thief with no mercy. It is a thief that does not need to be told where the safe inside you is. It already knows that your safe is your mind. It knows that this is where every thought, every memory, every way you go about life is stored . It is a slow thief that begins by taking your words from you. Then it slowly takes away the way you go about your daily way of life. Then it takes away from you your ability to eat, walk and think until it puts you in bed because you no longer can understand how to sit up or walk. You can't feed yourself, nor care for yourself. Then the thief sits back and becomes a murder. In 2013 this thief and murder we call Alzheimer's will invade and kill 450,000 Americans. 5.4 million Americans have Alzheimer's and this number is just those that know they have the disease. There are many that do not even know that they have this thief in their brain,. Most pass off the warning signs as just old age . Well the facts are that anyone at any age can have Alzheimer's. Every 68 seconds someone in just this country alone will develop Alzheimer's. Just think about that number for a few moments. In 68 seconds this thief could be on your neighbors door step, your workers door step, it could be on your door step, or one of your family members. This thief and murder has a track record of being the 6th leading cause of death in the US. And by 2050 the number of people living with Alzheimer's is expected to triple. Alzheimer's not only steals from its victims it steals from those that care for the individual and those that care for those with Alzheimer's. There are more than 5 million care givers and they provide over 17 billon hours of unpaid care valued at more than 216 billion dollars. If these caregivers were the only residents in a single state it would be 5th largest state in the country. Alzheimer's cost this country 203 billon dollars a year. The number is expected to rise to 1.2 trillion by 2050. Alzheimer's has no cure, it cannot be prevented, nor can it be slowed. It is like a thief. No matter how many doors or windows you have locked IT WILL find a way in. Now when we catch a thief that is this destructive we lock them in prison and throw away the key. So I am asking you to help me catch this thief and murder we call Alzheimer's and lock it away and throw away the key before it steals or kills another person. My mother lost her father and brother from this disease and then in 2010 this disease took her. This tells me that the chances of any member of my family has a high risk of getting this disease. So I am asking you to look closely at the figures and the statistics of this disease and find it in your hearts to look it to early detection of Alzheimer's. I would like to know if I have this thief and murder inside me so I could make the necessary arrangements to get my personal life in order so not to burden my children.

[PHI Redacted]

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I am a woman and I am sixty two years of age. I have always had an excellent 'photographic' memory - it was very useful when studying for exams and my husband, of 33 years, used me as his personal memory bank!! I am a retired Registered General Nurse, midwife and health visitor and ironically did a lot of work with the elderly in the 1970's and 80's. Approximately fifteen months ago we started to argue on a regular basis, something we had never done in our married life. We suddenly started arguing because he would say he had told me something and I would have no memory of it and would tell him he hadn't told me!! Eventually we both realized that something was amiss - I went to see my GP (to prove I was fine!!) and was horrified when the memory test showed that I did indeed have early onset Alzheimer's. I was referred quickly, my diagnosis was early, my treatment was started promptly (although I have to pay for the medication privately) and I am holding down a very busy job as a Medical secretary!! I believe that the early diagnosis and treatment has given me a chance to look forward to my retirement and not fear it. We have discussed, as a family, what will happen if my memory deteriorates as I will not be a burden to our children or grandchildren. Meanwhile we are enjoying life and I believe the early diagnosis has truly made a difference!!

[PHI Redacted]

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My name is [PHI Redacted] and this is the story of my dad, Sam. We were fortunate enough to have an early diagnosis of my dad's Alzheimer's. Without that diagnosis all of our lives would have been dramatically different. Although my dad was diagnosed later than most, the fact that we actually knew what we were dealing with aided us in making the best life choice decisions for my dad. Because of the early diagnosis we were able to access hospice and several wonderfully compassionate doctors. Thanks to the information we received about my dad's diagnosis we were able to make his last two years with us comfortable and loving. my dad has been gone for almost five years and not a day goes by that i am not reminded of the loss our family has suffered at the hands of this disease. Please, any legal or official movement you can make on behalf of the families who have lost so much due to this disease will be appreciated.

[PHI Redacted]

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I took care of my wife with Alzheimer's for 16 years. You can google Pete Roth Alzheimer's and read the article in USA Today "Love Endures in Alzheimer's Care" and I give some good advice. Upon passing her brain was sent to the UAB's Alzheimer's Disease Research Department and later received a letter definitely diagnosing Alzheimer's.

[PHI Redacted]

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My husband B[PHI Redacted] was diagnosed with beginning Alzheimer's disease. He is taking Denopezyl but sometimes he starts making stories; it's a little scary. Please let me know what can be done.

[PHI Redacted]

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My wife was diagnosed with dementia Alzheimer’s about one year ago and has already got to the point where she does not know our grand children and sometimes me her husband. I am disappointed that Kaiser permanently has no therapy for people with this disease but do for knee replacement and other disabling things. They say they are going to do that but I have not seen it yet at our hospital or medical center. I am sure it would help if even a couple hours once or once a week and it would be good for the care taker as well. Is that asking too much? I am my wife's care taker all but four hours a day. My wife was diagnosed just by asking her questions about what the doctor had told her a few minutes earlier.

[PHI Redacted]

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My mother that had dementia died in 2010, when she wandered from the foster care home that she resided in on a very chilly night, because some safety issues were not in place she wandered the neighborhood, fell, had a brain hemorrhage with many other injuries and passed away 4 days later. With that being said, I believe that if we would have had this test available to us and made it aware to the public as a form of a preventative test, I think my mother's dementia would have been caught at a much earlier stage I would have been able to help her live a more productive and independent life but what occurred was she was diagnosed and right away put on medication I truly believe did not help her. One made her sick, the other one she tolerated it rather well but I did not have anything to measure her progression or her stability by. Most of her years with dementia were years of frustration for me as her caregiver not getting the right physicians to care for her disease. I always felt that the neurologist did not know how to treat these patients and probably still don't. I'm not in the mist of this anymore so I can't say how much stride the doctors have made. I strongly believe that this new test brain amyloid imaging should be used as a preventative tool just like mammograms, colonoscopies, immunization, etc.. to allow family members a chance to find the best care and the best quality of life possible for their loved ones. So whoever is stopping this, step back and ask yourself, "If this would happen to be my mother or father, what would I want done?” I bet your answer would be "I want the brain amyloid imaging test as part of their preventative care". So let’s stop the arguing and let’s focus on the patient, ok? We need to provide Alzheimer’s and dementia patient with a patient center care, which would include the best test, imaging, treatments not only taking care of their mental state but also physical and spiritual being. Hope this message gets to someone that will and can make a difference. Hope we are being heard!

[PHI Redacted]

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If one of your personal family members has Alzheimer’s or will in the future you would want ALL the help you could get. My husband has Alzheimer’s and it was diagnosed early on. He is doing the best he can with what he has. If you have met one person with Alzheimer’s you have met one, because each case is so different. Please give the help that so many of us need. It is a disease that either the people die from it or die with it, because there is no hope or help. Thank you, please listen to your heart. Thank you!!!

[PHI Redacted]

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My father was diagnosed with Alzheimer’s disease approximately 4 years ago. He has changed so much since then. He is now 78 years old, he doesn’t talk anymore. He does occasionally laughs and I can see the smile in his eyes. He used to love to tell stories and tell jokes but this disease has silenced him. He has been robbed of memories and this affects my mother, my brother, his grandsons and other family members. I pray every day for a cure. I am hopeful that someday a cure will be found.

[PHI Redacted]

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I had two sister-in-laws who had this terrible disease. It affects each person in different ways. Not only are the symptoms different but also the length of life they have to endure the degrading way it imposes on each patient. I do not know what early diagnosis was given to either one of them. One sister-in-law lived with Alzheimer's for eight years and the other one lived six years.

[PHI Redacted]

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I got a call from my mom's friend, she just had my mom tell her that she was coming from a restaurant and couldn't remember how to get home so she showed a stranger her license to get directions. That's how it started. That was 5 years ago. She then forgot her words. And now cannot speak. She uses an adult diaper, cannot do anything for herself. It is absolutely horrifying! I have my mother with me but I also lost her years ago. It's a very draining disease. I chose to become her caretaker because in the beginning, in a lucid moment she wanted to come live with me, she was scared of having to go to a nursing home and scared of what was happening to her. It is scary, it's very, very sad. I'm now 45 with no life other than her. I have lost everything to keep my mom as long as God allows her here. I have lost my business, I almost lost my home. I have had to file bankruptcy. It sucks! It really, really sucks! And there is no real help! No grants, no money allotted to help us caregivers. We couldn't even file for disability. I couldn't even get food stamps! Nothing. We need help! Every single entity should be focused on Alzheimer's. It's happening. I have a very real chance of getting it within the next 20 years! This is serious, very serious!!!

[PHI Redacted]

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I am a Senior Citizen Advocate and have worked in my community for fifteen years. I have always supported the Alzheimer's Association, and shared the information from Alzheimer's Association with all those I make contact with. Last year I had started my own personal journey with my 93 year old Grandmother, when she was FINALLY diagnosed with Alzheimer's. For the past four years I had been trying to explain to my family that some of my Grandmother's actions were not because she is "getting old", it's because she was in the early stages of Alzheimer's. My family did not realize how bad my Grandmother's dementia was until I called them last October and told them that I had received a phone call from my Grandmother's Senior Citizen Nutrition Center manager contacted me and told me, "Come get your Grandmother, we just brought her back in.” I asked what happened and the manager stated to me that my Grandmother, who has been living independently for the past 90+ years had driven into the middle of crossing traffic, and stopped and parked her car. Only by the Grace of God was she not hurt. Since then I have taken in my Grandmother to live her last months with the best quality of life possible. Now, less than a year later her Alzheimer's has taken over to the point of her not recognizing, or remembering her family. I believe that if there had been more education not only to the community, but also to the doctor's that my Grandmother would have been diagnosed in her early stages. Now more than ever I advocate for the Alzheimer's Association, and for the tremendous work that they do within our community.

[PHI Redacted]

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My husband fell off the treadmill at the gym eight years ago when he was 57. His GP could find nothing wrong with him after running several tests. He was referred to a neurologist who found nothing wrong with him. My husband has been a salesman for his entire career, usually as an independent contractor. We had a disability policy on him while he was employed. He started having trouble remembering things when he was 59 and was "laid off" along with most of the sales force in his company at his 60th birthday. We let the disability policy go because he was no longer employed. At 62 he was diagnosed with early onset Alzheimer’s. We are struggling financially because of his early departure from the work force and we could have really used the money from his disability policy for the past 5 years. It would have made a huge difference in his/our retirement.

[PHI Redacted]

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My mom always had a quirky personality so over the years growing up, I never thought much about it. Then she really started to have a complete personality change and my dad, sister and I became concerned. She at first was diagnosed with bi-polar disease. We let it go though thinking that was all that was wrong. Then a few years went by and I noticed she was becoming very agitated in public. I'd take her shopping and she'd yell at people, which was so unlike her. Then at her apartment I noticed she was writing down names of friends, songs she liked, etc. At this point my dad and mom were divorced unfortunately and she was with her bf who apparently wasn't noticing these changes. Either that or he didn't care enough to do anything about it. My dad and her remained good friends though so he noticed something wasn't right either. He came over with me to her apartment and found her pantry filled with foods, some expired. It was then he knew she needed help. She was only about 53 maybe at the time that happened give or take. I'll never forget one of the last conversations I had with her. We were in the car, we shared the love of the same type of music so a band came on that she should have known. I playfully tapped her on the head and asked her what was wrong because she didn't know who the band was. She said she didn't know and that she felt nervous and depressed. She said she thought she had Alzheimer's. I laughed and said no way. I just didn't think that was it. She was young in my eyes and I was not as educated as I am today. Eventually my dad and I got her to see a doctor,. She at that time was feisty and fought us but we got her there. The doctor asked her a few questions, did a memory test and knew right away it was Alzheimer's. Well at first she thought it was FTD but after getting PET scans and an EEG it was proven by the neurologist that she had Alzheimer's. He said if it had been detected earlier, she might not have been as advanced as she was now. So this proves that early detection is key. It breaks my heart to think that right in front of me she was taken by Alzheimer's. The mother I knew is gone forever and all that's left is a shell of who she used to be. She was full of live, loved having fun and her bf couldn't see what was happening. Thankfully my dad stepped in and now he and I are taking care of her ourselves. She's 58 now and in the final stages of the disease and I only wish it was caught earlier. But now we know what we're dealing with and that diagnosis, regardless of how late in the game it was, we are able to care for her better. We know what to expect and are able to meet her needs. That is why getting an accurate diagnosis is important as well.

[PHI Redacted]

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My mom is suffering from Alzheimer’s; she has had it for 14 months but don't know how many years she has been showing signs of it. Don't know what stage she is in. I know it the hardest thing to watch. Me and my dad is her caregivers. It is like taking care of a child really. She doesn't know us most of the time. My dad doesn't want her put in nursing home because he said what my purpose of life sad, sometimes I think I will have this and be like my mom, sometimes it scares me then other times I would want to know if I will get it. I try to stay strong for my parents but some days I fail. We love her and want her in her own house, I don't know how long my mom will live with this horrible disease, but I do know one thing I miss my mom and my best friend every day.

[PHI Redacted]

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Hi my name is Michelle. I have been taking care of my 88 year old mother for about 10 years now. She was diagnosed with Alzheimer's in 2004. When my dad died in 2003, she was living alone. My sister and i would take turns staying with my mom. It was taking its toll on us both. We noticed little things. She would miss place her money that she had hidden in the house. I finally opened an account to make sure it was safe. She was having allot of falls and started Hallucinating to the point we would take her to the ER which they could not do anything for her. She was not bathing like she used to. She was leaving the stove on while she was on oxygen. We took her to her primary then that's when they diagnosed her with Alzheimer's. My sister and I take turns with our mother. She stays with us each month. She has gotten to the point where she is just like a five year old. She does not remember her own kids and grandkids. Sometimes she doesn’t know who I am which is difficult when I have to bathe her. She does not do much without help. It’s sad to see my mom lost and not herself. She was caregiver to her first husband he passed away with Hawkins Lukemia. Then she cared for her father until he passed away at the age of 93. He also had Alzheimer's. My mother just could not do it anymore when my grandfather passed away in a rest home. Then she had a massive heart attack a month after. Then in 2004 one year after my father died we notice she was not the same. I refuse to put my mom in a rest home. I am doing the best I can. I also care for my son who is in remission from cancer and now my mom. My plate is full and there are times when I wonder if I will too have my mom's fate.

[PHI Redacted]

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Tenia dudas de la forma en que estaba actuando mi madre de un tiempo a la fecha que fue después del fallecimiento de mi padre. Tuve la oportunidad de leer un cartel en el cual decía si alguien que uno conociera tuviera mas de cinco síntomas descritos en el de diez, nos preocupáramos podría ser Alzhaimer de ahí se trato con un geriatría el cual determino era Alzhaimer ahí el laboratorio dicto charlas en la cual un medico Neurólogo explico la enfermedad y todas sus etapas ya sea con familiares con geriatras con psiquiatras lo cual comenzó a dar los primeros pasos como hija. La segunda parte la comencé cuando me informe si existía alguna Corporacion del Alzhaimer y si en ella me enseñaron las etapas, como se produce el deterioro como hay que tratarlos como debemos protegerlos en fin lo mas importante es saber el diagnostico y cual es la diferencia entre enfermedad de Alzhaimer y otras enfermedades mentales ya que la gente tiene el mal habito de decir MALA MEMORIA - TIENE ALZHAIMER _ MENTIRA no todas son iguales. Hay que darles mucho pero mucho amor mi madre falleció el año 2007 un 20 de Mayo.La quise y la quiero mucho.

[PHI Redacted]

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My family has had and has many people with Alzheimer’s. I am so scared I too will get it. My mother is in stage 5 now. I would like to know early if I have this so what drugs are available will be there for me. More research needs to be done too!

[PHI Redacted]

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I have been scared for years now if I may have the beginnings of this. One it runs in the family. two I have had a number of occasions when I was hit in the head; a) balance beam fall two times in high school where I hit the balance beam. I hit the back of my head both ended up with bleeding but no stitches; b) twice in the last seven years I had severe falls where my face met the pavement ' one on a bicycle and a few years ago on a moped. three; three I had a brain tumor (discovered on the right side of my head) it was non-cancerous and finally after four years following it I got gamma knife surgery. I have noticed since the radiation they gave me for my tumor removal that I move slower, think slower, no more multitasking for me; I use to be "speedy. " After four months from gamma knife I got bells palsy on right side of face; I was told at my first consultation in 2007 that it could be a possible side effect to have paralysis on one side of face; The meds they gave me plus the previous ones on my! After 18months from surgery or more I am thinking "clearer" but sure not any faster; I believe all the above and the aging process I am experiencing (menopause) can contribute to the dementia that I feel at times; I have worked on my diet; spoken with past physicians, exercise, recognize when my stress is up etc..... Just like it took two years from the first CT scan about the dizziness and vertigo I I would like to know before it is too late. I don't want to be paranoid but view all the facts and options. Will the MRI they took to follow up on tumor in my head be helpful to see my brain and if there is signs of dementia.

[PHI Redacted]

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Alzheimer's robbed me of my daddy!! He never got to know the man I married...he couldn't walk me down the aisle...he will never get to be a grandfather to his grandchildren because of this horrible disease!! He was diagnosed at 55 and dies this past April at age 65! Way too young way too soon!! Please do what you can so that another "baby girl" doesn't have to endure what I did!

[PHI Redacted]

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My Grandmother (mother's side) was put in a nursing home because of Alzheimer's. Every time, I would go to see her she would say the same thing to me. "I should know those beautiful blue eyes, it kills me that I don't." My mom developed COPD and lung cancer. She was put on 27 different drugs that all had side effects that messed with memory and emotions. My dad stuck her in their family room with her oxygen in a chair to watch TV all day and night without lights on and with the shades drawn. He swore she had Alzheimer's too. I will go to my grave swearing that it was her environment, low oxygen levels and medication that caused her sometime dementia. He swears she had sundowners, I don't know. Yes, she had bad times but they happened during all times of the day. Now, he looks at me like I'm next! I'm terrified.

[PHI Redacted]

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My husband of 33 years was diagnosed with AD in 2006 at the age of 56. We have traveled a long and winding road together through this terrible mind stealing disease. We had tried all of the medication that were out there, and all of the "fad" things that people come up with, such as coconut oil, low fat diet (which we already had), nothing stopped the progression. He is still at home with me, where he belongs in my eyes. I am able to take care of his daily needs, but do have respite 2 days a week. I was taking him to a daycare when I was working full time but the job and coming home to take care of him and my mother were just one job to many. I retired from the school system where I worked with children that were at risk and mentally disadvantaged. I believe my job had prepared me for this. Most people do not have that advantage as I did. There are still times where I lose my patience with him, but for the most part we are journeying this as best we care. I often tell people who seem to admire me for my efforts, that I am better and stronger then this disease. Until the end, I will keep fighting.

[PHI Redacted]

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Sitting next to Mr. [PHI Redacted]. One of our last days together. His compulsion to suck on anything still prevents us from meaningful interaction. None of my old tricks are working. No matter what I say, or how I emote, it's so rare to trigger a flicker of memory in him now. To permeate his fog. To reach him. His wife, his daughter, his son, his hospice team and I tried everything we could conceive of to block, impede, distract, delay, or disable Byron's suck instinct. It just got worse. The geriatrician said there was nothing we could do. When all else seems to have failed, I roll Byron up to the piano, give him something to suck on, and pretend to play piano for him. I have sat next to him at the piano hundreds of times. Listened to him play. Watched him forgetting how to make music. Song by song, note by note. Mr. [PHI Redacted] was an unabashed ragtime and showtune showboater. His family told me about when he would sing and play "Old Man River" at family gatherings. Or how he would avail himself to an abandoned piano at a bar, and play for the patrons. I've watched his piano prowess dwindle now to a one-fingered plinking of the keys. But he is still very attuned to music. So I pretend to play piano next to Mr. Driftwood. For the Byron beside me, in this moment. For the beautiful pieces of Byron that have drifted away. And for the Byron I never met. I know he's listening because when I stop, no matter how consonant or dissonant I've played, no matter what songs I've banged out, or sounds I've made, Byron looks over at me. He usually says, "yes yes yes" but sometimes he says "dear" or "Mary." It breaks my heart seeing a person like this. And I love this whole family for their toughness and caring. Thank you Byron for teaching me (kind of) how to play piano. http://www.youtube.com/watch?v=tDxkdwNWagw

[PHI Redacted]

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My mother was in her mid-fifties when she was diagnosed with Alzheimer's. My step-father was first to notice she was having trouble with working appliances, reading and memory. When I began to notice I asked her about her memory loss and going to the doctor, she told me it was menopause. It was probably a good year after we both had begun noticing symptoms we finally were able to convince my mother to go to a doctor. She was again only 55years of age and Alzheimer's wasn't known to run in our family at the time. After a series of testing at the mayo clinic, my mother was diagnosed with early onset Alzheimer's. About a month later my grandmother was diagnosed with Alzheimer's. My grandmother passed away 7/4/12. My mother died 7/6/13. My mother was in trials, consistently had Alzheimer's medication, started eating healthier and took we took every step to keep her healthy as long as we could but ultimately the disease took over the brain that controlled basic functions. I am hopeful that by the time another family member or myself may start to show symptoms for Alzheimer's there will be advancements in early diagnoses and possible even a cure. Early diagnoses may give me options my mother never had for a longer better quality of life. If nothing else it will allow for me to prepare for long-term care.

[PHI Redacted]

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My message is not about Alzheimer's, although I am strongly sympathetic about the need for better detection, treatment, and CURE for this devastating disease. My message is about the importance of more research about ALL types of dementia, not just Alzheimer's. I recently lost my mother to Parkinson's. Parkinson's causes physical tremors, but also brain dysfunction of "sequencing" abilities of the brain and body, especially in the elderly. This mental dysfunction is "Parkinson's dementia." Most people with Parkinson's die from other things first, but not mom. Her heart and lungs were finally no longer correctly directed by her brain. But she could still think in the afternoons (between medications). Her death certificate lists only one death cause "Alzheimer's". My father died from leukemia, his white count reportedly more than 122,000. His death certificate listed Alzheimer's also. Yes, he had difficulty thinking during the last week of his life, but his circulatory system was clogged with white blood cells, and few oxygenated red cells were getting through to the brain. Let's get this right, for the sake of epidemiology statistics! ALL types of dementia need more research. But let's make sure we don't lump them under one name, because each type has a different cause and different manifestation. I have heard that brain amyloid imaging may be a definitive test for the definitive disorder of Alzheimer's. What are we waiting for? We have learned that not all cancers are the same neither are the dementias. Let's study each type individually, and compare and contrast. Most important let's try to find what to do about them. You can't derive a correct result from incorrect data. An approval for this test would surely aid accuracy of subject.

[PHI Redacted]

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My mother, aged 87, was "officially" diagnosed with Alzheimer's 5 years ago. Up until that time she lived by herself in Pennsylvania. I am her only child and live in Massachusetts. I tried to get her doctor to do something, but he only sent her to a neurologist which she "forgot", also prescribed Aricept which she also "forgot" to take. There was really nothing I could do, short of moving in with her which was not possible. I tried hiring a caretaker, mom would not speak to them on the phone and would not let them into the house. I drove from Massachusetts to Pennsylvania to get my mother after numerous calls from her building manager, telling me my mother kept saying she was going "home" and would leave. Finally she left and was found 3 days later, her car crashed and her staying in a Holiday Inn in New York State. Brought her to my home, had a psych eval done and my life changed forever. Currently, she is in a nursing home. I felt rage, helplessness and despair and still do.

[PHI Redacted]

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I was diagnosed this month with Alzheimer’s. I turned 60 last month. I was able to get a free PET scan which showed that I do have the Disease. I have already begun medication. If I had not been given a free PET scan I would not have been able to pay for it. Hopefully, I can slow the progress of the disease, and because I know that I have it, I can plan accordingly.

[PHI Redacted]

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My father recently passed away this March, after a horrible battle with alz/dem he wasn't officially diagnosed with alz until 2003, although his symptoms were long before that. He was under the care of a Va doctor, who eventually prescribed Aricept, we all feel too late (we later took him off as it was not working and causing uncontrollable bowel issues) his decline continued into full blown dementia 2009 2010.Again still under the care of the va doctor, in retrospect we feel had we pursued additional diagnoses/opinions, it may have helped him. Sadly the proper help came to late after moving him in with me and finally getting some answers, he was unable to swallow and passed quickly as was his wishes. His level of dementia (according to the doctors/hospice/facilities we tried to place him) was off the charts. I have learned soooo much in the last year of caring for him and realizing how there are no real resources to help (at least not nationwide) I want to become a voice and help not just people going through it, but agencies that are trying to help, but still don't understand the real magnitude and frustrations this horrid disease can cause.

[PHI Redacted]

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I was born to parents who were much older. My mother was 8 days shy of her 39th birthday and my father was a few months away from his 59th. (Yes, those numbers are correct). I always lived with the thought in mind that my parents would die while I was still young. Thankfully, they lived right on past my twenties. The unfortunate part is that both of my parents were affected by this horrible disease. My father was diagnosed at the age of 84 and died from a massive stroke. His development was not as bad as my mother's was. My mother was about 73 years old when the disease began to really take effect. I ended up having to move so that I could receive help from family. I know the move affected her more. I finally had a dishwasher that was used as a pantry because it prevented her from eating everything. I had a small fridge in my bathroom for deli meats and miscellaneous items to prevent her from getting to those as well. The list is quite long. My mother died at the age of 78 due to complications from Alzheimer's. I believe that greater focus needs to be directed to this mentally debilitating disease that affects not only the patient, but their loved ones. I am thankful that my parents lived as long as they did, but I would wish that Alzheimer's would never have been involved.

[PHI Redacted]

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My mom died of dementia at 69. Her mom died at 83 from dementia. I want to get diagnosed NOW in case its genetic so I can mentally prepare my family, plan for a future, and see Italy before its too late. I want to live while I am alive and while I have a brain - I want to know so I can write a plan out for my son and husband to follow if I have it, so they know what steps to take and when. I want to get checked NOW at 49 because what if I only have 20 years to live? I could retire early and travel as I dream of doing at 70... mom died with so many dreams left undone because she was living for a future that didn't come. The last 3 years, her brain was ravaged by plaques and tangled nerves. Maybe that is my fate, but I'd LIKE TO KNOW ASAP. I want an early diagnosis so that I can live while I am alive. If we have a way to find dementia before it ravages severely, we should use it as we use markers for breast cancer and for other genetic diseases. Grandmother – yes; mother – yes; Daughters - want to get tested ASAP; [PHI Redacted] - granddaughter, daughter, mom, wife, contributor to the general welfare via taxes

[PHI Redacted]

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Our Dearest mom Bernice was a mother who young in life at the age of 65 received the worst news she could have ever imagined that she had the beginning stages of Alzheimer's. Mom was a young woman who lost my dad at the age of 48 from throat cancer, she raised my older sister & I her whole life as our dad who entered the service at the young age of 18, his whole life was in the service. Our late Grandmother (our mom's mom) was diagnosed with Alzheimer's & mom always feared this would affect her. Mom passed away at the age of 76 she was an independent woman & hated when she was diagnosed with this. Our mom even paid for by herself a "beautiful wedding for my husband & I” to see this vibrant woman deteriorate so fast almost killed my husband & I. I have a back problem & every year my husband & I do the Alzheimer's Walk-a-thon in Buffalo, NY we have done this since my mom passed away. We miss mom more than anyone could know & we send butterfly kisses to heaven & back forever. Mom you will be in our heart "forever"!! Love your daughter Donna & "son"-in-law Michael.

[PHI Redacted]

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My father had Alzheimer's for many years. He was the strongest man that I have ever know and became this child in an adult body. He required 24care that my mother and I provided. It was very hard on my mother when I was working because there are no places for him in our area. We live in a very small rural town. Even the nursing home would not take him because he required so much care. He passed away 2 days after my mother had open heart surgery. This disease almost took both of my parents because of the care that my father needed. My mother was under so much distress and there was no place to get help with my father. There needs to be somewhere that can help the caretakers of People with Alzheimer's. My father was diagnosed early and was able to live a somewhat normal life for many years. He lived a lot longer than of the doctors expected. He got to the point that his body just forgot how to do things like eat and sleep. He never slept. He would stay up for days without any sleep and someone had to be with him at all times. My hope is that that find a cure for this disease so that no one has to go through what my family has been through. Not only did my father have this disease but his 4 brother also had it. So my family ahs been hit hard with this and I pray that no one else has to go through this.

[PHI Redacted].

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This may be well-intentioned, but truthfully, the Alzheimer's Association's outreach to me, such as it is, comes via the mailbox and weekly - if not daily - solicitations for contributions. I would if I could, but I'm carrying a debt load not lightened by having to pay for home care for my young onset spouse so that I can continue to work and be sure we have health care. Can't say a monthly coffee hour and café meet and greet is going to do much to help us manage the next day, and the next, as well-intentioned as it probably is. I lose sleep worrying about what this disease is going to do to my retirement future - IF I can ever retire, which isn't the point. I want to remain able-bodied, and need to in order to take care of a spouse who, probably in another couple of years, will no longer be. I'm too busy trying to hold things together to emotionally or temporally invest in national movements. Dismiss me and my kind if you will, but we're the ones living on the battle front of this disease. And it's a pretty lonely battlefront.

[PHI Redacted]

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My father was a WWII veteran having served in the Army in France, then Germany. He was there on D-Day. About 1995, at the age of 69, dad started showing signs of memory problems. His father (my grandfather) had died 5 years earlier having had several heart attacks before his death that none of us were aware of because his memory and ability to communicate had deteriorated to the point of not being able to tell us that something was wrong. Back to my dad, I started taking him to Hines VA Medical Center and asking the doctor to do an MME on him to check his memory. Since dad was so good at 'faking' his illness, the doctors were reluctant to test him. We went through a few years of me almost begging the doctors to test him because as we later found out, the medications doctors were prescribing for him were not working because they were to treat symptoms of illnesses that dad did not have. He had bad reactions and was hospitalized because the medications that were not working for him were actually interfering with each other and making my dad more ill rather than helping him. The doctor kept telling me that he didn't believe dad had Alzheimer's disease and that he didn't need to be tested. I began making notes on things that happened to and with dad, things like the time he found the car keys and snuck out to go see his brother 8 miles away and we had to have the police look for him because he was gone for so many hours and could not tell us where he went, not showering, not eating, not remembering names of people he was with every day. I made the notes, noting what day, time and if and when he had taken his medications and what the medications were. After I submitted the notes to the doctor, he decided to test my dad with the only (to my knowledge) test that they had at that time. The doctor asked my dad what month it was. My dad said it was May. In reality, it was October. He asked my dad what his address of 25 years was. He couldn't remember. The doctor asked my dad who I was. My dad looked at me and with great thought, he said that's my daughter but he couldn't remember my name. It took several years to even begin medication and treatment for Alzheimer’s disease and a lot of money for medications that dad didn't need because he was being treated for illnesses he didn't have. After my dad's death in January, 2010, my sister was asked if she would like an autopsy done on my dad and she said yes. The autopsy revealed that he was in the advanced stages of Alzheimer’s disease. Please keep in mind, what I am telling you is only the 'softer' part of this disease. I am not telling you the aggression that my dad showed in the earlier stages or of the suffering he and the rest of us went through all the way to the end. The things that my sister and I went through in order to take care of our father were stressful to say the least. It took a toll on her health and mine. My sister and I worry that we may get Alzheimer’s disease. Our dad had it, his brother had it, we believe their father had it, our mother's sister had it and our maternal grandmother had it. Please, early detection can slow the progression of Alzheimer's disease. The worst part of my mental battle with this ravaging disease on my dad was getting someone to LISTEN to and BELIEVE me. The professionals thought I was wrong in my 'assumption' that dad had Alzheimer’s disease. Oh how I wish I were.

[PHI Redacted]

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My husband died just three weeks ago from this horrible disease. He was diagnosed seven years ago when they discovered plaques in his brain. He had been taken to the hospital because we thought he was having a stroke. They ran the important tests to discover the amyloid plaques. While the diagnosis was devastating, we were able to start drug therapy right away. My only regret is that the test wasn't available earlier when he had had similar symptoms. He did live with the disease for most of the seven years still aware and able to be present in his life. Then one day it all changed, he moved into the advance stage and his condition changed rapidly. He was home with me until last February. If the imaging had been done sooner we might have had a few more years together. And who knows, a cure might have been discovered.

[PHI Redacted]

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It would be extremely useful to have early diagnosis techniques for dementia. Early diagnosis could potentially mean early treatment. Treatment strategies become more difficult as the disease progresses and plaques build up. Scientifically, there is more of a chance of changing the outcome with early treatment rather than late treatment. Additionally, how can the community determine if this technique is predictive of dementia if it isn't tested in a large number of people, as long as it does no harm? It is an unreasonable standard to say that a diagnostic technique should improve outcomes when there currently is no treatment for ALZ that will improve outcomes. It should be judged simply on the basis of does the technique predics the onset of dementia. Additionally there is another advantage to early diagnosis, patients and their families can make plans accordingly. There was a very difficult stage in my family member's dementia progress in which she needed medication for behavioral modification, but her general physician didn't feel comfortable prescribing such medication. He directed us to the hospital only. By this time she had no desire to see any additional doctors or hospitals, although she was quite anxious, angry and confused. It put us in a circular situation. She needed medical and psychological help but also had progressed so far that she refused to move in the direction of help. She learned that she only had to say "no" and everyone from the police, ambulance, or medical profession would go away. The only advice I could give to others is to possibly get a diagnosis before the dementia becomes so severe that the patient is no longer safe in their own home or a danger to others. Once you have a diagnosis, at least the behavioral modification meds can be prescribed to calm them down when needed.

[PHI Redacted]

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Last November I left my home to go get a haircut at the same place that I have been going for 13 years. After I had been driving for a few minutes, I realized that I did not know how to get there. I drove around for about 30 minutes and decided to go home. On the way home I passed the barber shop and went in. When I returned home, I told my wife of the incident. We decided to see a neurologist right away. In Dr. Kumar's office, I was subjected to about 45 minutes of different tests, and at the conclusion of my visit, Dr. Kumar decided that something was wrong, and I should have some testing done. Dr. Kumar set me up for a lot of tests including an MRI, Cat Scan, 2 1/2 hours with a Psychologist and finally a PET/CT scan at Arizona Molecular Imaging Center. Dr. Kumar indicated that the PET/CT scan indicated that I did indeed have early stage Alzheimer's. He put me on medication and instructed me to get lots of exercise, get good rest, eat well, stay socialized and exercise my brain with brain challenging exercises and games. I have done everything that Dr. Kumar instructed me to do. I went back to see Dr. Kumar on

July 12, 2013, and he performed a long series of tests. After the testing he re-evaluated me as MCI level 1. He explained that was Minor Cognitive Impairment, level 1.

[PHI Redacted]

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I quit my job last year to become my mother's caregiver. She was diagnosed about 7 years ago and the first six took a health toll on my sister, [PHI Redacted]. Although some days are better than others, I know now why they call it the slow goodbye. I am her baby of 5 siblings one day, the next day I may be my father, the next day she might be ready to go home when she is actually in her home of 20yrs, and the next day she might be my mother. Those days when she IS my mother, those days make it all worth it. Though, It is one hell of a emotional roller coaster for sure, I will always stand by her until the her final days. The past year was very difficult to me, but finding the Alzheimer's Association web site and reading stories and testimonies has helped me better understand this disease, the patient, and caregiving. Thank You ALL for your support, it means the world to me personally.

[PHI Redacted]

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I have to hope when my mother dies and her autopsy is done that she really did have Alzheimer's and not something else that could have been treated. I am an only child who has been taking care of my mother 24/7 for the past 5 years since she was diagnosed with having Alzheimer's. She was diagnosed with vascular dementia based on a CT scan when her unusual behavior started. The Alzheimer's diagnosis was made based on the fact she couldn't draw the face on a clock, remember the sequence of a list, and things like what day it is.She's legally blind...she can't see the calendar and hasn't seen the face of a clock since 1974. Come on. This can't be the gold standard for a medical test? A friend was diagnosed with Alzheimer's and then retired from his job and his volunteer position. He later found out it was a cerebral blood clot not Alzheimer's. Thank goodness he had a car wreck so he could get the proper diagnosis and get treatment. If there is a way to diagnose someone early enough to halt the progress of this awful disease, people should be able to have that technology...rich or poor. If early diagnosis would help researchers understand the disease better to help them find a cure, the American public deserves that. I hope you never know about Alzheimer's personally or from a family member. It is a life changer for all that it touches. Thank you for your consideration.

[PHI Redacted]

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My story is the opposite of what you are expecting, but it is very relevant to the issue. My husband was diagnosed with dementia of the Alzheimer's type 11 years ago. Today, I got a phone call from his doctor telling me that the results of his PET scan were negative he does not have Alzheimer's disease. The PET scan did not exist for diagnosing A.D. 11 years ago. My feelings about this news are all over the place. At first I was in disbelief because many doctors over the last 11 years have confirmed his diagnosis of A.D. He was even in a clinical trial for two years. I am sill numb, and now I am beginning to feel both happy and angry at the same time. Happy that he is not going to die of Alzheimer's Disease and angry because there is something wrong with him that still needs diagnosis, that should have been diagnosed and dealt with 11 years ago so that he and I could have had a life these past years instead of always living under the cloud of A.D. How many tears have I shed, how many support groups have I sat in on, how many happy times have we missed because of a misdiagnosis? Too many.

[PHI Redacted]

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Our mother was diagnosed in 2002 with Alzheimer's through brain testing and immediately started on medication. It is my true belief that without this early testing she would not have the same outcome as she does today. We are fortunate to still have her with us 11 years later.

[PHI Redacted]

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I knew there was something wrong about a week after my mom moved to my house after my dad passed away. I am sure my dad was hiding the truth from us. He died from super high blood pressure which caused his aorta to dissect. My mom was putting butter in her iced tea and other disassociated things. She called me one day at work & said she had fallen and couldn't get up. I came home to find her on the ground in a floor full of water. She had turned the faucet on and never turned it off. In the evenings she would get agitated and wanted to go to her momma & pappa's house. Both of them have been dead for years. After 6 months we finally got the diagnosis of Alzheimer's :(. Within the next year, after many hours of crying, we had to put our mom in an Alzheimer's unit. She has been there for 5 years and is closing in on the end. She has no idea who I am. My heart hurts but I enjoy being with her. I wish we would have known years before so my father wouldn't have been alone in taking care of our mom. Please know the early signs & get the care that is needed. Could have saved my dad's life.

[PHI Redacted]

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I am a registered nurse and currently working with a dementia patient, now going on five years . Because of my previous experience in caring for my father and mother-in-law who were both diagnosed with dementia, and the progress that has been made with this disease, I was able to have him diagnosed and treated with medication earlier. Because of earlier diagnosis, and appropriate medication, this World War 2 veteran is able to experience a quality of life and still reside at home with his wife of 57years.

[PHI Redacted]

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I took care of my mother who suffered from Alzheimer's. This is absolutely the most horrific disease I have ever seen. Something HAS to be done to increase the research on this terrible illness.

[PHI Redacted]

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My mother, [PHI Redacted], died on June 2, 2013. My sister and I have no idea when she was diagnosed with Alzheimer's. My father died last August - a victim of not being able to get proper medical care for himself because he had to take care of mother and could not bring himself to put her into a memory care facility. Today, when I was going through a hand-made oak desk that I brought home from a weekend trip to their home that I am now selling, I found a hand-written note dated March 2003 that she wrote telling the history of that desk made by her mother's brother-in-law. When I posted the picture of the desk and the note on Facebook this afternoon, my sister and I wondered if mother already had a diagnosis back then or if she feared she had it. She made a decision when she was still clear that she wanted to donate her body to West Virginia University Medical Center so that studying her might help others not suffer. I can tell you the first place I signed mother into turned out to be a living hell where she went days without having her clothes changed. My sister found a much better place and we are grateful she spent her last several months in a place where she was safe. I am a biologist and I truly believe that early diagnosis saves lives. Please help save lives from Alzheimer's! Thank you.

[PHI Redacted]

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My mother had the disease for three years before she was diagnosed. If this test have been available her prognosis would be better. I quote my doctor.. This disease is ‘hard to diagnose’ and unless they specialize in this type of disease most doctors and nurses ‘don't have the training to help with this disease.’ I quote my doctor's nurse, “The test doctors use is very unreliable. I know firsthand and my mother's doctor who specializes in memory and Alzheimer’s agrees. I don't know what else I can say that will convince you the necessity and the urgency of using this test for the over five million people with dementia and their families and caregivers but also for the millions of baby boomers that are going to get diagnosed in the next few years.

[PHI Redacted]

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Ten years ago, my beautiful step-mom Linda became forgetful. Sadly, we knew this was not a personality quirk. Only 10 years prior, Linda buried her own mother, an Alzheimer's victim. But, since she was merely forgetful, the doctors minimized her condition. Until it was too late to do much. Throughout this horrific journey, Linda has been acutely aware of the path laid before her. Initially, it was devastating when she would beg not to be put in a home. And later, even more so when she would beg her own grandchildren to get her a gun so she could kill herself. Now she nears the end. To watch someone we love die before our eyes is the most cruel experience a husband & child can endure. My amazingly sweet & funny Linda is gone. I remember she used to sing "You are my sunshine... my only sunshine..." when she was feeling happy & silly. Those same words bring me to my knees in anticipated grief. As I prepare to say forever goodbye, I can only hope another family can obtain an early "official" diagnosis. So that they don't have to make decisions for someone who is already too far gone to make them for themselves. Thank you.

[PHI Redacted]

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When I suspected my husband was having memory problems and behaving out of character, I discussed it with our PCP. The PCP gave my husband the mini mental test and said there was nothing wrong with him. I knew something was not right, so I started looking for a second opinion.

I wanted a practitioner who specialized in memory issues, but nobody advertised that. I started calling all the neurologists in my area, asking what portion of their practice consisted of dementia patients. After calling MANY with no dementia "specialization," I finally talked to a neurologist's nurse who was sympathetic to my search. I asked her if she knew of any neurologists who specialized in dementia, and could be considered on the cutting edge of research and treatment. She suggested I look at the staff of the local university teaching hospital. I did, and I was astonished at their depth of staff and level of research devoted to memory issues.

I selected a neurologist MD PhD who specializes in cognitive disorders, including dementias such as Alzheimer's disease. (He conducted Neurogenetics research at Harvard Medical School, was chief neurological resident at Johns Hopkins, and completed a fellowship in dementia and Cognitive Disorders at the University of California, San Diego.) He is also Director of the Memory Disorders Clinic at the university hospital, Assistant Professor of Neurosciences at the university, Associate Medical Director of the NIH-funded Alzheimer's Disease Cooperative Study, and Attending Neurologist at the local Alzheimer’s disease Research Center. He is the Principal Investigator in several clinical studies on Alzheimer drugs. And, he is one of the most caring, compassionate people I have ever known.

After extensive neurological, neuropsychological, and nursing assessments, including a volumetric MRI, my husband was diagnosed with MCI. Based on this diagnosis, he is enrolled in a clinical study. Because he has been somewhat in denial, the diagnosis has allowed me to plan for the long road ahead and equip our entire family to handle it in the best way possible.

The value of early diagnosis has taken on new emphasis now that research studies are increasingly focused on targeting identification and treatment at the very earliest stage of the disease.

[PHI Redacted]

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My mother has dementia and it's a horrible disease and I wish nobody had to deal with it. Her brother has Alzheimer's and it's very hard on our family. Luckily my mom was diagnosed early enough that the meds are helping some. She has no short term memory really but does still remember the long term stuff at least a lot of long term memories are there. She also still remembers her children but the grandchildren she doesn't see all the time are a little harder for her to remember their names. I used to do all kinds of things with my mom and now we can't do anything together. When she comes to visit me she gets messed up because it's a strange place and then doesn't get back to her own schedule when she goes back home for a while. I hate this disease and wouldn't wish it upon anyone. Aricept has been a great help and I hope you can find it in your heart to approve anything to help with the diagnosis of it so that more can be caught early and prevent their children from going through what we are dealing with. My mom just isn't my mom anymore. I fear it will happen to myself or my siblings or children as well. Thank you!

[PHI Redacted]

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My dear mother has suffered with Alzheimer's for the past 8 years, and went undiagnosed by a top area neurologist. Her mother before her died while suffering from it, also diagnosed too late and unable to be helped. Once I suspected this I took her to another neurologist/psychologist who said had I come 2 years earlier he probably could have helped her. It was already too late and the inevitable was now staring me down. Although mom thought she was as prepared as she could possibly be for possibly being inflicted like her mother with this, nothing could have prepared us for the velocity and young age, along with the fervor with which it struck. She was unaware of her quick and dangerous mental decline, constantly leaving our home to "go home" getting lost and often times causing me great anguish while at work calling repeatedly crying to "go home". It got so bad that I had to hire a friend of a relative to "watch her" so she wouldn't run outside and get hurt or worse, and after a while she stopped allowing that person in. What made an already bad situation worse was fighting tooth and nail for help. I work full time and as a divorced single mother who took my mother in, had nowhere to turn for help and had to subject my 14 year old to abusive language, threats and confusion and fear watching her deteriorating Nanny decline mentally. My mother worked all her life, sometimes two jobs to make ends meet and was very proud that she retired with a generous medical plan. Well, it was all for naught, as nothing was covered by her insurance considered some of the best in the business, and I was then counseled by the hospital staff to abandon this coverage and sign her up for public Medicaid to get her bills paid. After needing a diagnosis by a PRI nurse, out of pocket $150.00 every time I wanted to get her into another facility, all I heard was that she was not a candidate for full care. No one would accept my mother as she was not drooling in the corner or soiling herself. In fact, she was worse as she fought everyone insisting she was fine, making getting her help even more impossible. Then having not one option for a New York City facility which accepted those patients like mom who were a flight risk, I had to spend ALL her nest egg on Assisted Living just to keep her safe, a service residents of this and other states get for free through public assistance - some illegal immigrants, some who've never worked a day in their lives. Now after the spend down, I was, after years of worrying and suffering and constant rejection, able to get her into a facility to fit her needs however it was not without a c however every year Medicaid goes through her files with a fine toothed comb hoping to find some crumbs of a financial trail to suck up. Instead of investigating the millions of welfare and food stamp fraudulent recipients, they persecute people like my mother who was honest and hardworking all her life and barely got by but proudly paid taxes and deserves the care that she's getting. While every American deserves health care it is unfair and gravely critical that people like my mother who contributed her entire life to this country's economy and allowed her tax dollars to take care of others, get the care they deserve and have options that ARE covered by private insurance in addition to more state subsidized facilities to offer assisted living options for transitional patients who can't afford $5,000 per month to live comfortably and not in squalor by some state-run factory style facility. I implore the powers that be to meet the challenges that face families and loved ones caring or worrying about someone with this dangerous and horrendous disease as they are the forgotten silent sufferers and have no voice to fight for the care and options they deserve, just as they would want for their own mothers and loved ones.

[PHI Redacted]

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Hi I am writing this note to say I have many friends that have Alzheimer's or the onset of it. When I visit them each week in the nursing home the way they are treated is awful because they can't speak out. I will continue to fight for them and in hopes that one day we do have a cure.

Sincerely,

Miss Sarah Whittington

[PHI Redacted]

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My mom was the most loving human being ever. I wasn't the only one who believed it. Everyone who ever came in contact with her believed she was somehow better than everyone else. She didn't think so, she just loved people. Full of compassion and love for life and every little creature. She loved her children and her grandchildren and everyone else's children, even the ones their own parents did love. My mother never hurt anyone. She truly had no enemies. And yet, through no fault of her own, little by little a silent murderer began to take her life away from her. Stealing her memories and her cognitive function and eventually robbing her of her dignity and her ability to manage life on her terms. My oldest sister did the very best she could, keeping her at home as long as humanly possible. I was so grateful for her being able to keep mom with her. My last visit broke my heart. My mother was a shell. Somewhere, inside her, were the memories and love she had all those years I was growing up. I could see glimmers of it while we sat watching the same old television shows we'd watched when I was a little girl and she told me how I could be anything I wanted to be. I never got the chance to tell her I was finally going to college, thirty five years after high school. I'll be her first child to go to college. She'd be so proud.

The M.E.s office listed my mother's cause of death as "Natural". My dear sister insisted it be changed. Nothing natural killed our mother, an insidious, evil monster stole her life. The world deserves to know, Alzheimer's killed my mother.

[PHI Redacted]

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[PHI Redacted]

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My dad was diagnosed with dementia after, I must say, a strange search.. He went to a Hearing Loss Center, to a Neurosurgeon and many other doctors until he was diagnosed with dementia. It was a difficult thing to grasp because he was such a vital, funny and fun loving man. Everyone loved him. His personality changes were so unlike him. He became very paranoid, accusing people of stealing from him. He became verbally abusive to my mother and this was such a departure from the "real" Him. He loved and adored my mom and we couldn’t understand this behavior. Thankfully this didn’t last long. Finally he was diagnosed with dementia.

Shortly after this my Sister died very suddenly from undiagnosed Ovarian Cancer. My dad cried that it should have been him dying and not her. He was so right. At the time I was living in Denver, CO. My parents lived in Los Angeles, CA. I couldn’t leave my mom alone and decided to move to Arizona and move my parents too. L.A. was just too expensive and we couldn’t afford to buy a home there. My mom was so grateful for this. My mom and I had a very close relationship and I was definitely a daddy's Girl. I was very fortunate, I loved both of my parents. For the first 3 years my mom took care of my dad but when he could no longer walk and was constantly falling his doctor advised us that the best place for my dad was a Nursing Home. We found a really nice place close to home, he never asked to come home. He completely accepted this.

A year and a half later my mom died of a sudden massive heart attack. I think she died of a broken heart. Now it was dad and me. I couldn’t tell him right away, I had my own grief to deal with. I told him she had the flu. About 3 weeks later I got a call from the Nursing home. Telling me he was sitting in front of the window crying and calling my mom's name and this had been going on for a few days. I immediately rushed over with my husband and told him that my mom had passed away. He cried and looked so forlorn, it was just heart breaking. Now it was just me to care about him and love him.

The next day he asked me where my mom was. He continued to do this for a few months and I kept telling him she was gone. Finally I told him she was sick and kept telling him that until he stopped asking. He was deteriorating rapidly then. One day I walked into my dad's room and he has a really odd look on his face. I asked him if he knew who I was, I could see that he was confused. He started to guess and asked me if I was his cousin. He never knew me again. I knew this might happen but the reality broke my heart into a million pieces. I wanted my dad back! My mom used to say she wanted her husband back too.

When I would visit I would have to introduce myself and tell him I was his daughter. His physical condition was getting worse. He forgot how to chew. I was visiting one day and there was food stuffed in his cheeks. They put him on a puree diet. He was getting thinner and thinner. A year and half later he was gone. In 3 yrs + years I lost my Sister, my mom and my dad.

[PHI Redacted]

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Although current medications cannot cure Alzheimer's or stop it from progressing, they may help lessen symptoms, such as memory loss and confusion, for a limited time. This statement hits home for me. I lost my mom to Alzheimer's, two months ago. Her doctor prescribed Aricept which caused all of the listed side effects. Nausea, vomiting, loss of appetite and increased frequency of bowel movements. And did little to improve her life only prolonged the inevitable, death.

Something inside of her decided enough was enough and she refused food for 10 days and then passed away. It was an awful thing for her family to have to watch, but after seeing her struggle for 5 years it was accepted. Medications that lessen the disease for a limited time is not acceptable. More research needs to be done NOW as more Americans are rapidly being diagnosed with Alzheimer's so their families do not have to suffer.

[PHI Redacted]

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My mother has Alzheimer's. Do I have it in my future? Do my siblings? We need to make early diagnosis a top priority.

[PHI Redacted]

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My father was of the old school, born in rural CT in 1929. He was the last man to reach for an aspirin and into his 80s had no PCP other than a good relationship with his cardiology team.

He realized something was wrong with him and confided in my mom, who did not share with us in order for us to help him.

His trigger event was when he got lost on a route he traveled daily for over 20 years. First responders intervened and he landed in the ER. Staff in the ER of the unfamiliar hospital called his children to "come get him". I demanded that they admit him, perform tests and provide us with their assessment/diagnosis. If MY dad ended up in the hospital, something must be WRONG.

After over a week and a waiting period to cure a UTI, we got the diagnosis: Alzheimer's disease. He was so progressed that he would need to go directly to memory care.

Wishing we had a more comprehensive health care system in the USA, in which health care was not rationed by ability to pay. Also that the oldest & weakest in our society could be cared for in a way that other countries have managed to do at a higher standard than we have in America.

The expense of care was doubtless what put him into withdrawal/hiding mode; he did not want to have to spend down his assets. As soon as we got his diagnosis and placed him into care, he knowingly chose to cease eating, drinking and taking medications, hastening his death such that he was dead within two months of diagnosis. Thanks to hospice, he went as peacefully as he could have under the circumstances.

Our system is not working and the increase in the senior demographic as the Boomers age up will indeed be the Silver Tsunami, wreaking havoc on our healthcare system and the cost of care. We need a revolution in our healthcare system and need to look elsewhere at models that are caring for seniors in better ways.

[PHI Redacted]

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This is a great news about Blood Test may be available to diagnose Early Alzheimer's "Alzheimer's blood test edges closer" http://www.bbc.co.uk/news/health-23465965 Researchers believe they are closer to developing a blood test that could diagnose Alzheimer's. Reported from Reading England. UK and Germany. Please do share this with others.

Sincerely,

Dr. Diamond Lakhani

[PHI Redacted]

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Because my girlfriend was so young when she first started displaying symptoms (50), we didn't immediately believe this was something like Alzheimer's which is only for older people (we believed).

Also, her general doctor didn't think that way either so it took a while to get to a neurologist that prescribed an MRI which showed the evidence of plaque on her brain.

So early detection and education for both the population as a whole and general practitioners is critical, especially as people are developing this terrible disease at younger ages.

[PHI Redacted]

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As a long term care facility's nurse I want it made plain and easy for people to gain accurate early testing for Alzheimer's. it would make things easier for not only patients but their families as well to obtain counseling and support and better manage their options with this debilitating disease such as getting good in home care to reduce the strain on the healthcare system and keep them independent in their own home for as long as possible

Sincerely,

Ms. Robin Goodfellow

[PHI Redacted]

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My father was diagnosed with Alzheimer's approximately 5 years ago at the age of 67. To have the most benefit from the medications that are available, they need to be started as soon as possible. It is imperative that an early and accurate diagnosis be made as to assure the best medical care/decisions possible. Imaging needs to be done to advance our understanding of this disease and hopefully bring an end to it one day. This imaging is a learning tool that has to be done.

Thank you.

[PHI Redacted]

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I can't understand why everyone is not behind this cause - no one is immune from old age and its related health issues. We don't balk at using the best research tools available for cancer or heart disease.

Sincerely,

Ms. Gail Angeluski

[PHI Redacted]

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It is vital that there continue to be early detection for Alzheimer's and treatment to assist w the disease not progressing so quickly. We have experienced this disease first hand w a family member. I believe w early detection patients can live a fairly productive life like my family member has. I pray that Obamacare does not decrease covering claims for this illness.

Sincerely,

Mrs. Lisa Martin

[PHI Redacted]

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My 84 year old mother has Alzheimer’s, which was just diagnosed a few months ago. I had seen signs for years and expressed her memory issues to her physician. Early diagnosis would have made a difference in the care and treatment she would have had and in the way I cared for her. Now I know and I can better take care of her. I see her memory slipping away almost daily. She does not know that she has Alzheimer’s because her diagnosis came too late for her to remember or know what that means. She is now in a memory facility but we almost moved her in with us, which would have been a disaster.

I am 60 now and I am certainly concerned about the genetics of Alzheimer’s and I want to know if my memory changes are caused by Alzheimer’s so that I can plan my life. Early and accurate diagnosis is so very important with this disease.

This is a long difficult road to travel with anyone. Please help.

[PHI Redacted]

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[PHI Redacted], my unmarried partner of 30 years, began to act strangely about 4 years ago. Then about 3 1/2 years ago we began testing. the testing resulted in a diagnosis of dementia probably Alzheimer's.

Knowing if it is Alzheimer's or not; would give me some comfort by possibly removing the wondering and anxiety I feel, and possibly help me be a better care giver I realize that this will have no impact on Dot. However, it would give me some peace of mind.

I am Dot's primary care giver.

[PHI Redacted]

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My mom and maternal grandmother both succumbed to dementia in their last years - It was awful watching my mom go through it, as I was one of her caretakers - I myself have memory lapses that concern me greatly - As a single parent about to make some big decisions in the next few years as my daughter graduates high school, I feel that having some idea of what my future may hold will assist me in making responsible decisions about where and how I choose to live on my own, what kind of work I should plan to take, whether I should look into long-term care (and how to finance it), and how I should handle my health insurance and health care considerations. Having some information about my likelihood of developing dementia would improve my quality of life as well as my daughter's, and lead to responsible choices regarding my future and end of life considerations.

[PHI Redacted]

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My father is 87 years old and has Alzheimer's as did his sister. Early detection and treatment are essential. Without a definitive diagnosis taking very expensive medications "just in case" is the only option. Please approve any option available to Medicare beneficiaries for a diagnosis so that the proper treatment can be initiated if appropriate.

[PHI Redacted]

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As a concerned citizen and family member of multiple Alzheimer's patients, I always wished a diagnosis before these loved ones were half gone. My grandmother, currently in this fight, wasn't diagnosed until she was in vicious repeat cycles and were told there wasn't a lot that could be done. Please support early and accurate Alzheimer's diagnosis. I hope no one else's loved one or family needs to suffer what my Nanne suffers, when there is something we can do about it!

[PHI Redacted]

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I spent a year with my mother, at about 85 years old, starting to act differently. She accused me of trying to take her money, telling me I put my aunt to sleep when she died as she saw me feeding her water in a teaspoon, hallucinations of all kinds, I took her to her doctor of many years 3 times in one yea to talk about this and he would tell me she's fine after asking her what is the problem. Mother would say everything is fine. He'd say, "how can we make you feel safe, Effie?" She said she was just fine and agreed that I was trying to take her money. The 3rd visit her said he would give a referral for her to see a psychiatrist to make ME feel better. I was angered at that as I knew it wasn't me, I knew there was a problem but had no idea what. It was just a few days later that mother met with a psychiatrist who put her thru the tests and she was diagnosed with dementia. I then moved my mom from a senior apartment complex to a condo two doors from my condo. Within three weeks she called the police 2X one night complaining someone was trying to break into her back door. At 2AM the police came to my door to tell me about this. Fresh snow, no tracks. In the morning I called the psychiatrist who said to take her to the ER at the hospital and she would arrange for her to be admitted to the psych ward. Two weeks there she was put on horrible meds that made her totally comatose... it was explained to me this was to find out what meds would level her out. I quickly went into the search for a safe facility for my mom, which I found. It was a wonderful place for Alzheimer's and dementia patients. She was there almost two years and then had a stroke and passed away in December of 2000. Prior to meeting with the psychiatrist, she had an MRI of her head. The neurologist told us that her brain had some shrinkage but that is expected for someone her age. So, when in the ER she was furious with me, asking to see the neurologist who diagnosed her as being just fine.

In the facility she lived the last 23 months of her life, she seemed happy and content. I visited her almost daily and spent quality time as well as I was able to take her on frequent visits to family and friends for many months until she became too confused when she'd return. She never completely lost her mind. She always knew me and my three children but she did get confused with who her great grandchildren were. She told many stories of her childhood while in this facility. They loved her there. She was comical in many of her remarks and she had never been comical. I have a cousin who has an interest in past-lives and feels she can converse with those that have passed on. She told me she asked Effie why the dementia? Effie told her it was her way to become close enough to Suzann (me) and make up for the negative happenings in our lives together over 60-some years. I prayed for her to die as it killed me to see her not be able to function to the fullest. I've always been so happy that I was able to spend so much quality time with her. Of course, now my concern is myself and my children. Something I have no control over.

[PHI Redacted]

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Had I had this available to me when I cared for my mother would have made her last year of life so much better. I also would have taken her driver license so much so much sooner. I suspected something was not right 3 years t prior but she hid it so well for so long until a major stroke. This is a nasty disease and folks need to know as soon as possible!!!

[PHI Redacted]

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My name is Mary, I was diagnosed with Alzheimer’s 2 years ago and I have good days and some not so good. I was put through a nerve wracking batch of tests and when I was so frustrated and exhausted after hours of this I finally got up enough nerve to tell the lady that was administering the tests "I quit, I got to get out of here now." Later I received a batch of papers about the outcome of the tests. To make a long story short it basically said I had alz and expectation life span 4-5 years. That was a shock to me but being a Christian I simply said God is the giver and taker of life and to Him I will go when He is ready for me. My husband and I go about our daily routines and if I feel up to taking a trip we go if not we spend our time enjoying our home, family, and friends who understand that sometimes I am dull and other days I am bright and happy. Meds make me dizzy or cause other side effects so not consistent in taking all of them but try to take as often as I can tolerate. I enjoy taking care of my flowers and have a private fully stocked reading room with windows all around so I can watch the birds and wild life that venture into our yard. I also have an old 8 track player/radio combo that I enjoy oldie music while I read or just watch the birds at my feeder or taking their bath. God is good and I will be ready when He calls my name. Until then I will do all I can to be all that God wants me to be and know Heaven is my home in His time.

[PHI Redacted]

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My husband, who is just 65, has gone through a dramatic change in the past 8 months, experiencing memory loss, confusion and loss of ability to do most things he has enjoyed in the past. This accelerated expression of symptoms is likely manifested from the disease quietly progressing over the last 10 years or more.

If only a test were available earlier, he might have been able to start treatment and participate in planning for the inevitable. Fortunately he was able to retire at the beginning if this year. He could no longer handle the responsibilities, but if he had known earlier he would have retired earlier and been able to enjoy the good years he had left.

His mother had Alzheimer's, but it came on in her late 70's and my husband we just found out he has the gene.

This is a horrible disease and affects every family member, even the very young. We must do whatever we can to expedite treatment..And we all need to be made aware of symptoms to look for early on. These are much more complex than forgetting where you left the car keys.

[PHI Redacted]

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I am a caregiver for my 80 year old mother who was diagnosed with Alzheimer’s disease approximately three (3) years ago. This is the most difficult thing I have ever tied to do in my life. I have helped care for a father dying with cancer and a mother in law in hospice as well. This was a difficult time as well but no way does it compare to the pain of Alzheimer’s disease.

Early diagnosis and better treatment is certainly one of the most important things to help a person with Alzheimer's.

With my mom I am watching her daily as she leaves me but she is still right in front of me. There are days that she doesn't know me and that really hurts. Please make all funding available that you can.

Thank you for taking the time to read my letter.

[PHI Redacted]

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My mother was diagnosed with Alzheimer's about 81/2 years ago. This allowed my siblings and I to learn early on in her illness what the future would hold and to begin immediately to make plans for the future, allowing her to be much safer and more supported than they would otherwise have been. It gave us the opportunity to communicate with her while she could make important decisions, and allow her to make the choices regarding her future. With assistance of one child or another, my mother took care of her financial concerns, her end-of-life medical desires, and her housing choices. This gave her the life she deserved to have, and gave us as her children much more confidence and peace in the decisions we later carried out and made when she no longer could do so on her own.

My mother passed away in June this year. It is a tremendously difficult and ugly disease for individuals and their families. I'm quite confident that it has touched someone in your family or among your friends, or soon will. The number of people who are living with Alzheimer's is growing at an alarming rate. We must give it the attention it needs. Please do all you can to assist all who have to face this in their lives, and all you can to help find a cure for this disease.

[PHI Redacted]

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My mother was diagnosed with AD at age 64. I am now 59. I worked with Alzheimer's patients from 1987 until 2010, I know the devastation it causes. I also know the peace of mind patients and families have when they get an early diagnosis and can plan their future! Don't rob them and me of this opportunity!!

[PHI Redacted]

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I took care of my mom for years. She was diagnosed with the insidious disease. I noticed something was wrong years prior but every family member told me I was crazy. If we had had a test to definitively diagnose her, maybe she would not have had to suffer so. No one should be able to have heart transplants, strokes fixed, bypass surgery, etc. and yet have no recourse for their memories. To have a mom not recognize her own children, cry over the loss of their own parents which have happened years prior but they forget that, the same for the loss of a spouse and ask why no one told them....is not right! We need research in this area and any tests we can have to help with both early diagnosis and care should not be left to politics plain and simple.

[PHI Redacted]

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My dad's first diagnosis was depression and anxiety, but his doctor realized that it was not the case. He was quite sure that he had Alzheimer's and started medication right away.

My dad was doing well, although he had to go to a nursing home at some point, and my mom didn't think the pills were working and she insisted that the doctor shouldn't give him his prescription any more. His doctor said that it shouldn't be stopped and if, and when, he got worse and my mom put him back on the medication, he would have plateaued and he never got any help with the meds after that. He went downhill very fast - from the time of his symptoms started, he had died in two years. He had been doing quite well and I couldn't talk my mom to keep up with the medication.

I'm not sure that this is what you are looking for, but to me, I think the medication would have helped for a longer time - had he stopped taking the medication. My doctor couldn't go against his will. I realize that doesn't mean that he would have gotten better, but something could have turned up and could have made a difference. I just wish he would have had that chance.

[PHI Redacted]

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My grandmother was diagnosed with dementia in September of 2005. It was a huge blow to our family. It started with her forgetting the little things. Where to put dishes in her own kitchen to asking the same question over and over. In the beginning she wasn't prescribed anything for her dementia. But as the disease progressed and she forgot to eat even after we told her over and per that she needed to, it was then that she was prescribed Aricept. We were told that it couldn't reverse any damage but it could hopefully slow it down. But it was so far progressed that the med really didn't do anything. We were also told she had sundowner’s syndrome. She would get very agitated at night and had no clue who anyone in the house was. We had to call 911 because she became so violent and accused me Of kidnapping her and my daughter. Nothing slowed this awful disease down. I watched her become a prisoner in her own mind and body. I watched her go from healthy and active and loving to her not knowing how to use a fork anymore, and not knowing who any of us were. It’s watching someone die a slow death. Not being able to communicate pain or hunger. It's the worst thing in the world. I know mine is only one story but I think more research should be done on how to at least slow this awful disease down. It's taking a person’s mind first, then slowly it takes their body. Watching someone you love go through this is terrible. No one will ever know what it's like to deal with this day in and day out. It's terrible. I feel like I was cheated out of a grandmother for the last 5 years of her life.

[PHI Redacted]

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I am sure my mother could have been helped must better if she had got help many years before. since i was teenager my mother had some problems in her life. Now I am studying psychology and I see that it started as a sadness, then nervous, then she could not remember the date. then she could not know the faces and remember the names of our neighbors. Then she could not administrate her own medicine. More and more problems in remember and think.

I think she got a depression because she cried every day because she could not cook and she forgot to switch of the Things in the kitchen and it was sometimes dangerous. She also forgot the water and there was water all over the bathroom and sleeping room.

Then some problems dress herself in the right way. Also incontinence and then my father send her to a house for elderly people.

But she ask us for help to go back home. She cried a lot. She live there now 1 year. she miss walking as she adjusted to. She got the wrong medicine. I cried as well. My sister is also sad. And my father is very sad.

I think if someone had given her better treatment, she would not have been crying so much.

She should have help very soon in the long process.

[PHI Redacted]

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I lost my dad one year ago, Aug 3rd, 2012. His disease progressed so fast, he went from functioning pretty well with mild/moderate dementia symptoms

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to his death within months. In his last month, while heavily medicated, due to severe delusions..in semi-coma state, I noticed a good sized lump on top of his head. It was never there before, I am a hairdresser and cut his hair for years. They said they did an MRI a few weeks beforehand. His symptoms just became so severe, so fast. I have other family suffering with AD, and they seem to linger for years.

I will always wonder if AD was really his demise. The death certificate did say severe brain damage/ AD. Would be a big help to have a more definitive test. Thank you,

[PHI Redacted]

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I'm living with an Alzheimer's victim though it's in the early stages, I can already see the decline.

Let's have more research on better diagnostic tests, a broad-based strategy to improve patient's lives, and ultimately a chance for a cure.

[PHI Redacted]

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Her name is Kitty. In years past she was a neighborhood stalwart: a feisty, talkative, petite white haired Italian dynamo. Friend to all-little kids, dogs, ladies with baby carriages, local drunks and panhandlers. And one confused woman, coming out of a bad relationship. We were such good friends that people assumed, incorrectly that she was my mother. Her husband died and left her a widow, and though they were not happy, she never complained. Her years without him were the best. She learned Tai Chi (the LONG form, mind you!), accompanied me up to Columbia University on academic dinner nights, walked to Chinatown and back for fresh bok choy, played the ocarina, comforted me in those early, dark days while I was getting sober, babysat my cats when I was in class...and made a mean apple pie! Full, rich, strong and accomplished was this individual life: though she never got past high school, she worked in a downtown bank. During 9/11 Kitty won special mention for keeping her fellow employees calm after the planes hit the WTC towers and no one was allowed out of the building until security gave permission to leave. Her decline? Gradual. So much so that no one really 'got it'. Losing a word here, a phrase there. Crossword puzzles became a challenge; dates, names; her animated face would grow puzzled, clouds of doubt passing across...she would 'fish' for a word. Then, call repeatedly, having forgotten that she had hung up the phone with me only moments before. Fast forward eight years: A clean, well run nursing home on the Lower East Side of New York. She sits, wheelchair bound, facing the television. Her legs are elevated, her expression a blank. It is doubtful she is aware of much at this point, her Alzheimer’s is late stage now. She can no longer feed herself, and in a very short time will probably be en-tubed for nutrition. That funny smell? Diapers. But her hair and nails are clean, her clothing spotless. The staff, to a man, cannot do enough for me when I come to see her. An insensitive neighbor said, "Well, I personally don't know why you bother to go visit her anyway! I mean..she won't recognize you!" I smiled quietly, "Maybe. But you see.. I'll recognize HER." There needs to be a space, between the life she lived, so aware, so engaged, and the wheelchair phantom she has now become. An interval between - during which, medical science can go beyond shaking its head sadly. It must offer families and loved ones more than nursing home referrals and, consolation. Kitty is well looked after. But in time, she will die. That is a given. Can we in Heaven's name advocate for earlier, stronger interventions, support research which will work to find new medical solutions: be that the development of targeted screenings which might in time predict an Alzheimer's gene, or brain scans of people over a certain age and suggest therapies based on results suggestive of Alzheimer's factors being present? Facilitate more sensitive insurance compensations which will allow for the specific needs of late stage Alzheimer's patients - solutions which do not leave families financially devastated, as they must also deal with the expected death of a dear one? And work to produce new, aggressive medications, which when administered - act on the chemicals produced by a brain which has begun to develop early signs of Alzheimer's? If it is so often a 'retroactive diagnosis' and autopsies are performed to verify that in fact it was Alzheimer's that killed a loved one. Certainly that may comfort the family, give them closure and critical information. Well and good. But there must be more. And, earlier on in the process of each individual person's Alzheimer's journey. My story, by the way, is not unique. There are Kittys...everywhere. The more I speak about her, the more people respond - with an Alzheimer story of their own. This illness is a national calamity. Never, ever doubt it!

Sincerely,

Mrs. Cynthia Hawkins-Legorreta

[PHI Redacted]

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My mother is a fiercely independent woman. Having raised 4 children and working as a real estate agent, she then was a gift shop owner for 25 years. Her father died from dementia, a fact which she kept very private from us. When she started showing signs of struggling with bills, driving, and remembering birthdays about 5 years ago, we became alarmed. We contacted her doctor who agreed she should be checked. She changed doctors and gave them instructions not to talk to us. Her primary care doctor's notes show that she (the doctor) only thought mom was a "sweet lady" who was unfairly targeted by her children. The screening test she gave mom was cursory and not at all able to pick up the signs. So we waited and we watched as mom delved further into dementia, being taken advantage of by scammers for $5,000 and then withdrawing tens of thousands of dollars of cash from the bank (nobody knows where it went). Finally, the doctor called me and said "It's bad". Well, we knew that a long time ago. We went to court to get guardianship, and finally got her to a neurologist. He said, "I have never given a first-time diagnosis of Alzheimer’s to someone so advanced in the disease." By this point, there was only so much that medications could do. If mom could have been diagnosed sooner, she would have had access to treatments that would have delayed the disease's progression and improved her quality of life. Perhaps we could have gotten her to sign Powers of Attorney, avoiding court with lawyer's fees and court orders now required to liquidate her belongings to pay for her care. I moved mom to assisted living memory care last week. She is plenty mad at me. But she doesn't even know who I am. The mom I know slowly disappeared starting 5 years ago, and there was nothing I could do but watch as she slipped away. I miss her.

[PHI Redacted]

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My mother in law was diagnosed with Alzheimer's about 3 years ago. This was only after we realized she was not paying her bills, which included her Medicare part D, and long term care insurance. Had she been diagnosed earlier we might have been able to save this insurance. She is currently living with my husband and me. Having paid over $100 per month for several years it just seems sad that she lost this coverage which would be a life saver for us now.

I hope that future sufferers of this disease can be diagnosed quicker and more accurately when you approve the 'brain amyloid imaging'.

Until you live in the hell involved with caring for someone with this disease you cannot understand the urgency of a more accurate and earlier diagnosis.

[PHI Redacted]

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Having a diagnosis of dementia for my dad helped us decide what kind of care he needs now and will need in the future. This allowed me to place him in a facility that also specializes in memory care so that we won't have to move him multiple times. The staff is excellent with knowing how to treat him and the care is so perfect for him

[PHI Redacted]

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I am writing to urge funds be spent to deal with Alzheimer's. I am a gay American together with my spouse for 15 years. We have just bought a home in the last year, paying our taxes, and trying to live a normal life. I lost my my job a few years ago, went back to school obtained a job, however I have decided to leave that job to spend time at home enjoying our time together. Law makers nowadays look for ways to cut spending any way they can. And yet in the news you hear that this disease will affect more and more Americans in the coming years. With that in mind, how could reseach spending be cut, and on the other hand more people are affected with this illness, Just like our new home, you have to spend money to keep it running, help the value, and at the same time the economy. With this in mind, I would think there would be no issue to help cure this disease, saving millions of dollars in the future, with the care that those affected will need. Stop building other countries, spending dollars overseas and keep funds here to stop this disease from continuing

[PHI Redacted]

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I wish to tell you about my mom, who's 96 this June. She was diagnosed with this horrible disease several years ago. However, looking back, it started to manifest itself several years before that. I really didn't know about the disease, but at a certain point, well into the disease, I asked the family doctor to administer a cognizance test to determine what was happening. I was losing my mother

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She has been bed ridden for over a year now, She is home with me and a 24/7 home health aide. She eats perhaps twice a day, with each meal consisting of 2-3 teaspoons of farina and a sip or two of chocolate milk. She is so frail, she is unaware of her surroundings. She once in a while knows me. She used to talk many hours during the day, but now barely able to make a sound. And yet with all this, her heart is strong and lungs are strong. The muscles in her legs are atrophied so much, they hurt when she has to be changed. But her caretaker is so wonderful, not one pressure or bed sore.

She is no longer on hospice, because although the "failure to thrive" is evident, she is not eligible due to the condition of her heart, lungs, and blood albumin. I imagine the idea that all us baby-boomers are aging scares the government with the amount of money that might become necessary.

Anyway, I wish I knew years before what was happening with my mom, perhaps more might have been done to retard the symptoms. And may I add, that perhaps Medicare might have helped a little more, as a lifetime of savings is gone.

[PHI Redacted]

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I am the wife and primary caregiver of my husband who was diagnosed approximately 10 years ago with Alzheimer’s. I also worked full time till February of this year. Since he got diagnosed and got treated right away, he is still with us today! It took a lot of my energy to organize, study our finances and take thing to our layer .I also hired a geriatric care manager. From both these professionals I got long lists of homework of what to do. Most interesting that I used at least 30 copies of my husband power of attorney. Even the gas company and doctors needed that. Even I felt always need to rush with things, early diagnosis gave me years to do this things. The early start of medication also helped that he is still not a bedridden person and able to leave at home with the family.

[PHI Redacted]

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When my mother first developed Alzheimer's disease, the diagnoses was missed because having never navigated this issue before and being new to taking my mother to doctors on my own and of my own decision, I took her to the now defunct United Hospital in Port Chester, NY, for a geriatric assessment.

My mother passed the test very well, but it is because he flaws in functioning were made up for by the fact that she lived with me and my dad.

The result of her passing the geriatric assessment was only to have my father angry at me for being a drama queen and it put off getting help. What should have happened was that the administrators of the test should have pointed out that although she passed the geriatric assessment, she got every question wrong that was related to short-term memory.

Since I was the only person saying that there was something wrong with my mother, the only result of having taken her for the wrong testing was to have my sisters irritated at me and my father angry for me having taken my mother to the hospital. Treatment and understanding was delayed.

[PHI Redacted]

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I will make my story short and to the point. I am a nurse of 30+ years and I took care of my mother for approximately 15 years. When I look back at the early years of this devastating disease, I recall so many difficult decisions and alterations in our lives that could have been eased by a simple diagnosis. But instead, we went from a multitude of medications to CT scan to MRI, etc. All of which were unhelpful or negative and costly!

It is vitally important for the patient and the family to know what they are dealing with in order to establish a plan of care. This diagnosis literally involves the entire family. Many of us are still in the workforce and are trying to make arrangements to fit this into our lives.

As heartbreaking as this diagnosis is to hear, the sooner you hear it the quicker you are to prepare for what you have in store. The cost of this disease is astronomical. If there is a test that can be more definitive, then no one should chase a rainbow.

[PHI Redacted]

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Hello - my wife, Marie, has CBS w/ AD as the underlying pathology. She is only 59 years old.

It took 2.5 years from the early symptoms to arrive at a firm diagnosis. Along the way, it felt that my wife and I were in a fog of uncertainty and high distress bouncing from one doctor to another (many said "come back in 6 months for another check up"). The diagnosis was established using a variety of testing procedures (some covered by our insurance and some we had to pay thousands out of pocket).

Even though there is no known treatment for her condition, it was critical to us to arrive at a firm diagnosis. This allowed us to aggressively seek out clinical trials targeted specifically at her condition. Without this knowledge, this would have been simply impossible. Trying something, even a 50-50 crap shoot, is better than passively watching her decline and doing nothing. Also, knowing her condition, helped us to make key life decisions to better support the situation - for example, I retired early in order to assist her and find a clinical trial. We have also accelerated our vacations/family events in order to fully enjoy the quality time we have left.

We were fortunate to have the time and financial resources to drive the diagnosis. We urge the government to financially support early diagnosis testing such as PET scans to assist in the definite diagnosis of AD and its variants. Knowledge is better than ignorance - even when the answer is unpleasant - it provides the foundation to make decisions and act.

[PHI Redacted]

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Maybe as early as twenty years ago, my husband began to show what I now know as Alzheimer's disease symptoms. They were mainly during times where he was telling of camping trips, fishing, etc. I knew the facts were not right, but they happened so seldom that I forgot about them. As time went on these occurred more frequently.

About fifteen years ago, my husband's sister, who was a nurse, told me she thought something was wrong. It was nice to talk to someone who saw what I saw. I mentioned this to our doctor and he had my husband take the standard test to remember certain things, spell backwards, etc. My husband did very well on these tests for two years. If he got something wrong, the doctor would just say oh that's nothing. It was very frustrating and meanwhile my husband was getting worse to the point where he was beginning to get angry at me when I would say, "Remember......" because he didn't remember. Finally I pushed the doctor and he sent us to a neurologist, who diagnosed Alzheimer's right away.

With proper medicine, my husband had a number of good years where he could still do the things he loved. He was diagnosed at 63 and had to go to a nursing home almost five years ago. At 76 he doesn't know anyone, cannot walk, doesn't talk and has to be fed. I go to visit him almost every day to check on him and feed him. Alzheimer's is a terrible disease. Early detection might have given him a few more years to enjoy life and less time in a nursing home. The last 13 years have been very hard on me, our children, and all the family and friends who love him.

[PHI Redacted]

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Years before the more profound symptoms of dementia appear, victims begin to withdraw, lose interest in that which had been important, and start to show signs of memory loss. This early stage is not always recognized as dementia/Alzheimer's and so receive neither the treatment nor attention that such a serious disease should have. If it's impossible to diagnose Alzheimer's at this stage, we could at least identify the early markers and perhaps develop a program that would help the victim maximize and extend a normal life.

[PHI Redacted]

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I got married to my college sweetheart July 3 2009. I was 28 years old. It was a long awaited day but the morning of my wedding I saw the first sign that something was wrong with my 63 year old mother. She woke up at 4am and walked around the hotel aimlessly in her mother of bride dress. When I found out about this hours later, I tried to shrug it off as to her just being anxious and excited but there was a terrible feeling in my gut that would go away. Mom had been acting different lately. Fast forward a few weeks later and I found myself sitting in my mom’s primary care office with her head down and a look of defeat on her face. Her doctor informed me that for 3 years they had been referring her for a CT scan. She never followed through with the scan so they discharged her as a patient. The doctor informed me that they felt she might have had mini strokes or might be showing signs of something else. Fast forward one month from that day and my husband and I are packing up my mother to come lives hundreds of miles away from us. Her neurologist informed me that she was diagnosing my mother with cortical basil ganglion degeneration and to prepare for a quick decline in my mother’s functioning. Fast forward over the next few months and my newlywed husband and I are living with my mother and her "strange" behaviors. We decided to buy a two family house and have her live downstairs with all of her belongings and us living upstairs to help care for her. This doesn't go as we plan as my mother’s symptoms get worse and worse. She is not able to be left alone and my husband and I struggle to pay her daycare. I contact my local Alzheimer's Association and they provide me with a medical alert bracelet for myself and my mother. This helps a great deal as my mother wonders nonstop. She no longer speaks and is still only 64 years old. She is a target for danger. My husband and I place alarms on all of the doors and enroll her into a dementia day care program all day while we are at work. My husband spends hours with her a night trying to get to speak. With all of our efforts my mother keeps leaving the house in the middle of the night. Although we have children locks on the windows she is able to get out of them and there is nothing we can do. At this point our new marriage is very wounded. Multiple attempts at having a family end in miscarriage. I no longer sleep through the night as I'm worried about my mother wondering. My feelings towards my mother turn from love to resentment. I know it is time to place her in a nursing home. My mother is 65 years old when she is placed. She is 10 minutes up the road from me and she is safe. I have tremendous guilt but I know her disease needs a level of care I just can't provide. I find myself with extra time and a void to fill. I contact my local Alzheimer's Association northeast NY chapter. I start a walk team and raise over $2,000. I take any opportunity I can to share my mother’s story. I never thought at such a young age that this was going to happen to my mother. Thank god I knew to ask my mother about her wishes when it came to the end stage of her disease. I was able to have this conversation and obtain health proxy. She is now on hospice level of care and I know I'm following her end of life wishes. I visit my mother almost daily. Everyone knows my name there is she still is aware of me. She might not know I'm her daughter but she knows I'm this girl who visits all the time and shows her love and kindness. It is important for me to share my mother’s story. I'm her voice and always will be.

[PHI Redacted]

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Had there been a test for ALZ earlier, we could have started meds earlier, rather than depend on a single diagnosis of trial and error.

Five years ago I mentioned to my mom’s MD that her memory was starting to fade, and that she was repeating the same questions, and doing things that were out of the ordinary. He told me it was just age. He gave her some memory enhancing meds, and meds to lessen her hallucinations.

Well, fast forward to now, after discussing many more symptoms and suggesting another MD diagnosis, and an MRI, she was referred to a neurologist who diagnosed her with moderate dementia and added another med to her list. I realize this is too late in her life to make any kind of dramatic change, but 5 years ago was much different from now, and had we been able to slow it down I still might have had the best friend in my life.

Thank goodness for the ALZ Support Groups where I have learned very much, the what's, how's and why's of what they do and why they do what they do, and how they really aren't the person we think they are anymore.

She knows who I am, doesn't know her other children and grandchildren, and doesn't remember her husband. She can't cook, clean, or make decisions, can't write out a check and sends out mail without stamps.

[PHI Redacted]

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Intuitively I felt that I was "getting old" and should have my memory checked when that service became available under my health plan. This the first important thing, the availability of services - evaluation, MRIs, etc. Further evaluation was recommended. I sensed the concern and went into denial. A few years passed. I was celebrating Passover at a friend’s home. Her husband is a doctor. T told him about the above testing hoping he would agree with my primary care doctor who had assured me that I did not need to follow up with more testing. (I was, and sometimes still am quite intellectual having been well educated and well read.) My friend insisted that I reconnect with the specialist, and so on which eventually led to MRIs, more testing and bringing in my family to speak to the doctor who had done the initial evaluation (Oh, I was mad at her! How could I, a well educated intellectual, with little family history of dementia, have a diagnosis of Alzheimer's?) My daughter-in-law came with me at first to the various appointments. Today I am taking Aricept, and next month I am moving into a "mom living space" my son is having built for me in the lowest level of his house. I will have its own kitchen, bath and entrance!) I feel grateful, happy, anxious, sad, and hopeful. I look ahead to the things I am still able to do and to the care that friends are expressing towards me. But it has been the influence of my Alzheimer's support group that has informed, and cushioned me during this time. I still ask, "How could this have happened to me?" I am gathering a supportive community around me which I think is a good thing, a good thing to do now.

[PHI Redacted]

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My mother was always a sharp card player. When I started winning and realized she wasn't able to remember the cards as she did before, we had her tested. She was diagnosed with frontal lobe dementia and given medication to slow the progress of the disease. It is very hard to determine what is normal memory loss and what is not. A test is necessary. Also, as a side note. Mom’s dementia affects her judgment and she was giving money away to everyone and was scammed twice. Early detection is very, very important.

[PHI Redacted]

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In 2005, it was apparent my then 63 year old father was experience early onset dementia. It took several years for the rest of his Family to jump on board. Yes, Alzheimer's is an irreversible disease but to dismiss the importance of a brain amyloid imaging test is unwise.

Preparation for the inevitable hinges on the family's ability to recognize the reality of the health situation surrounding their loved ones.

We do this with Cancer, AIDS, Parkinson's, etc. Why are we not aggressively trying to do everything in our power to recognize the early stages of Alzheimer's so the necessary steps can be taken to protect American citizens?

You don't disappear once the diagnosis is official. Life still continues but the health care burden is tremendous and if the family has a one day, one week, one month or one year advantage in preparing for the battle that awaits, it's a win.

[PHI Redacted]

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My mother's diagnoses of dementia was immediate from her waking of a 60 day coma, after a brain aneurism and bleeding in her brain for 90 days with multiple heart attacks and strokes, 3 brain surgeries and filters and drains she was suppose to die, but miraculously awoke full memory, had the brain surgery and a 54 year old woman, mother, grandmother Now became a 3 year old and remembered or knew nothing, and no one. Had to be taught how to sit, stand, talk, everything even put clothes on because she preferred nude and claimed she was kicked out of heaven because God told her, she must come to earth and bring me, her daughter, to heaven before she could live there.

Every day, I have to re-teach her who me and my children are, that she was fed, to stay awake, to sleep, a name, daddy's dead, TV, noises scare her, people scare her, she locks herself in her room, leaves the house, sneaks out, if she walks outside doesn't remember what house she came from and looks for her car and cell phone over and over and she doesn't have one anymore. her Anger gets worse as days pass and she is evil to those who love her. Life is all about her and what danger she is in. She hates everyone but will tell you she loves you for caring for her but hates you because she can do it for herself. She is terribly evil and hateful and it gets worse every day.

She yells If you tell her she is sick, she claims she was never sick, nothing wrong with her heart, but she does acknowledge the headache every few hours every day. She asks the same questions over and over and writes every nasty negative thing down. And if she doesn't write it down she forgets it. Then she forgets where she hides the paper she wrote on because I think she's embarrassed she has to remind herself of everything.

The doctors tell me she will get worse, it gets worse, she needs a nursing home and activities to make her thrive, but social services won't help me. Says I am best for her. I can't do this so I keep taking her to different doctors.... And every new doctor claims they need to re-diagnose her!!!!!! What? Not right! And my life has been HELL since her 2008 aneurism and the past few years of dementia that I can guarantee has progressively becomes WORSE. And with me being poor, it's impossible to keep her fed, since she don't remember eating, all she does is eat over and over and over, she was 120lbs now she is an unhealthy 224 lbs because she never feels full, and she is 64 yrs old and poops and pees herself and then hides it, she poops on toilet and I mean ON the toilet and leaves it smeared, because she forgets what she was doing.

My family lives a horrible life because of this life, and I can't understand new doctors needing to re-diagnose her every time, or the hospital asking HER what's wrong with her when she is scared and doesn't remember why she's even there. I took my mom to local emergency room for a sore throat pain and fever and the treating doctor told me she needed to hear from my mom and my mom said she was having a heart attack with pain and her head was exploding and she was scared she was dying (because it was a memory of 5 years ago when it really happened) but because she told doctor that, they had to treat and test her for her complaints and $130,000.00 later sent her home with antibiotics for a virus (like I said was why I brought her). Mentally I am lost and this is killing me!!! No one listens to the Caretaker.

[PHI Redacted]

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I have been responsible for two elderly family members who have been diagnose with dementia; my uncle with Lewy Body like dementia and my father with Mix dementia and vascular dementia. Since so many elderly are suffering from this disease it is crucial that cognitive testing becomes part of a routine test for people 60 years old and older. If any cognitive decline is detected a neurological exam should be performed immediately. If it is detected early certain medications can be prescribed and families will be spared additional trauma from the effects of the disease.

My uncle was very wealthy and suffered with the disease for years before it was diagnosed. Often the demented person refuses to see their physician and legally they cannot be forced to seek medical care. My uncle's attorney, who had a strong desire to become a trustee in his estate, allowed my uncle to make changes to his estate planning when he lacked mental capacity in order for him to become the trustee he longed for since becoming his attorney. The State Bar of California allows attorneys for their clients’ estates to act as an executor and/or trustee even though it is a conflict of interest since they also act as the attorney for the estate. I tried to undo what this attorney did, but the newly named charity hired a powerful law firm, who had more knowledge of the law then my attorneys. Everything my uncle worked so hard to protect such as all our family heirlooms for generations (that were suppose to stay in the family) were auctioned off so the proceeds could be given to the charity. His doctors were ready to testify he lacked mental capacity and the judge in our mediation stated if my attorneys followed the law I would have undone the horrible acts done against my uncle and our family. The effects of this disease has a negative impact in other areas of our lives, therefore, the sooner a diagnoses can be obtained the slimmer the chances are that it will cause damage to other areas of our lives.

My dad also refused to see a doctor as his disease progressed. He got aggressive and confrontational. He would not give up driving and caused an accident hurting three young people. The police were aware he had cognitive decline, but would not arrest him or force him to seek medical attention when he declined. He hit a neighbor, walked in the middle of the street when cars were trying to pass, put garbage on neighbor’s property, etc. I had to force a meeting with the Public Guardian of the court, Adult Protective Services, the Chief of Police and family services to seek assistance in order to get the help my father desperately needed. Again, the laws do not allow a loved one to force a sick family member to the doctor. Finally, my father hurt another neighbor and the police did a 5150 and took him to the ER. When the hospital became aware it was dementia they wanted to remove the 5150 since his problem was not psychiatric. They determined he didn't have the mental capacity to care for himself, therefore, he needed placement in a facility. Many hospitals automatically give difficult dementia patients anti-psychotics most not being aware there are horrible side effects on the elderly often causing death. The ER rarely has a neurologist exam these patients, try to determine what kind of dementia they are suffering from and then prescribe the appropriate medication. Since these patients can be so difficult the hospitals main goal is to sedate them and then try to get them out as soon as possible.

This is a serious problem that effects so many families in different ways. Because of their cognitive decline and lack of understanding they can easily be taken advantage of even by our professionals. Reports indicate that 1 out of 3 elderly are dying from this disease. If there are not some major changes this is going to be an epidemic. The State Bar of California needs a major over haul in the way they set rules and regulations for our attorneys. There are good attorneys, but because the State Bar of California does not get a handle on their bad attorneys they have allowed them to tarnish the reputation of the good ones. Hospitals, especially the ER's, need better training in dementia and how to treat it. UCSF has been doing research and studies on the disease, the testing that needs to be done to get a clearer picture of what kind of dementia a person suffers from and some of the best medications to treat particular dementia's with the least side effects. Hospitals can go to their website or call them when they are not sure what to do or how to treat the disease. All of us need to start being proactive and stopped burying our heads in the sand hoping this will go away. We need to make sure the appropriate changes are made at hospitals, government agencies, care giving facilities, etc. The longer this goes unaddressed the larger the problem will become I know all of us want to work together to make this an easier situation until a cure is found.

[PHI Redacted]

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Family member diagnosed in December of 2011 after noticing word-finding problem since January 2011. Treatment with Exelon patch began and seems to have enabled him to continue in early stage Alzheimer’s, which is for him a word-finding difficulty.

Sincerely,

Ms. M Curcio

[PHI Redacted]

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American's have a right to this test. Alzheimer's is a devastating disease.

Sincerely,

Mr. Robert Manduca

[PHI Redacted]

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My mother had just recovered from a massive cerebral hemorrhage, which was not an easy task, she was only 63 years old. The recovery took over 8 months and she was left with little use of her right side. But, she was still with us and struggling along the way. She was able to walk with help and communicate. We had our mom back, and were blessed to have her.

Within a few years of her stroke she began to have memory problems and in a 4 year period my mother no longer recognized me, or my children. My mother was only 70 years old. We brought her into our home to live with us. We could not imagine what she was going through, but we knew it was horrific for her.

When my mother passed away she was in a complete fetal position she was only 79 years old. The disease ravaged her body.

I am 65 and last year I had a stroke. Fortunately, I am OK, but do wonder if the disease is just around the corner for me.

[PHI Redacted]

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We had a terrible time! Living with my fabulous husband for so many years ... I knew something was wrong. His brother came out and he, too, could see that something was amiss. I took husband to the doctor who sent him to neurologist, who told him to come back in a few months. Oh ya... did an MRI, too ... still just told him to come back in a few more months. This went on several times! It was pretty obvious something was wrong! I finally switched - went to someone else in an attempt to get help and not just patty cake stuff. The new doctor ordered a pet scan and then on October 23, 2011 ... told us the news that it was, indeed, Alzheimer’s. It wasn't my favorite day but at least we knew what was going on.

Then they put him on Aricept, Namenda, and an anti-depressant. I have since weaned him off all of them....the side effects were so bad, it just was not worth it.

In dealing with this and even in my own issues - I cannot find a "doctor" who gives a flying fig about anything except lining their pockets.

I know medical stuff is downright amazing what they CAN do… but 99% of them ......WON’T!!!!

[PHI Redacted]

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My mother was diagnosed with dementia through a series of brain tests. It was critical that we understand what was happening in order to make plans for her. We are grateful we were able to get the diagnosis and get here the help and care she needed.

Please understand this is critical for families.

[PHI Redacted]

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My mother, Irene passed away June 3, 2013 at the age of 94. Her cause of death was "vascular dementia". She had been institutionalized for five years preceding death. At the age of 82 she remarried with the promise that her new spouse would "take care of her". During the next few years he did so but a divide seemed to widen between her and her two sons as more signs of dementia were becoming evident. Her family history included dementia in her mother and a sister but signs were ignored or denied by her and her husband. Recommendations to plan for the future were considered meddling. Her husband became ill in 2008 and died in 2009. She was unable to care for herself by this time and was forced to join him in a care facility for his rehab. He was unable to care for her after this and she moved directly into the facility where she remained for the next five years until her death.

I believe an early diagnosis would have led to better planning and possibly avoided the considerable expense required to appoint a guardian and associated legal expenses incurred over the last five years of her life.

[PHI Redacted]

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My wife was diagnosed with Alzheimer's in 2003, right about the time I had a heart attack. I recovered, but my wife condition keeps going the opposite to mine. It has gotten to the point that I have to get up early in the morning, tell her what to wear, make sure she takes a shower, brush her teeth, heir and yes, make sure she eats.

When a baby is born, that baby will tell you when it's hungry or has soiled underwear, by crying the baby can tell you all this, but how a person suffering from dementia communicate with you? And tell you she is hungry or has soiled underwear. How can she cry when she does now how?

It is with a sense of urgency that I ask you look into more research. My wife won't benefit from it, but the next person may and it will avoid all pain and suffering from the patient as well as the provider.

[PHI Redacted]

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7 years ago, I was diagnosed with mild cognitive impairment and was given a cat scan and an MRI to check the state of my brain. We were told that, in light of family history and the results of the scans, I would most likely end up with Alzheimer's disease. I was immediately put on the Exelon patch and I thank god every day for early diagnosis and medication. I have continued to lose abilities to do things I used to do as a matter of routine and I have a great deal of trouble thinking and participating in group activities. I did receive the diagnosis of Alzheimer's disease over 3 years ago. I now use Exelon as well as Namenda and know that these will be ineffective in the near future. Each day is a gift that we do not take for granted!!! I cannot truly look forward to what may be in my future and worry about those who cannot afford the very expensive drugs that I take. It is very difficult for us to pay for these but we have made decisions to make them a priority.

I would ask for your support for anything that would diagnose or spot potential for AD early!!! Without early diagnosis, the medication, and support of my husband I would most likely be in a very different situation!! AD is a cruel disease and often the symptoms are dismissed if the doctor is not properly educated in what to look for. I am one of the lucky ones!!

Please, please, for the sake of our younger ones, do all that can be done to fund research to deal with this disease. Thank you!!

[PHI Redacted]

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The test is a horrendous waste of time and money. It is done to appease people who want to something done. Because medical tests are so necessary for diagnosing in order to treat, it is assumed that tests are necessary for everything.

My mother had this test and it only confirmed nothing. It was inconclusive. Yes, she was losing her memory. Yes, we all could observe this, and known for years. She also has lifelong PTSD and depression. Even if it is Alzheimer's, there is nothing to be done. The fallacy of the entire thing is the term early treatment....by the time memory loss is recognized, it is already too late for anything to make a difference.

There is no effective treatment for Alzheimer's. The test provides no useful information that can be acted on in any effective manner. It is a total waste if time and money.

[PHI Redacted]

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My husband was diagnosed with vascular dementia about 18 months ago since when he has been using Exelon patches which are changed daily, and this has helped alleviate restlessness, sleeplessness, anxiety. Also, for the last 4months I have been including one dessert spoon of coconut oil in his three meals (these are spaced out for maximum effect).I purchased Dr. Mary Newport's 2nd edition-Alzheimer’s disease, what if there was a cure? He never misses a dose and the effect has been fairly dramatic. Improvements were obvious in his condition almost immediately and most days and weeks see gradual further improvements. Some days I really feel as if I have my old husband back. I am so grateful to Dr. Newport. She never gives up trying to make things better for all dementia sufferers

[PHI Redacted]

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The first time I knew there was a problem with Mom, she was frantic that she couldn't remember if she put egg in her homemade turkey stuffing. Frantic and inconsolable with my assurance that yes she did, for all my 35 years, she did...she called the turkey hotline, her sister and still wasn't sure. As time passed, she would forget that I was ever married, and to whom, and that she was indeed present at the wedding that occurred 4 years ago. Shopping was a nightmare of refusing to redress in the clothes that she wore into the store, insisting they were not hers, and having people stare as your frustration and embarrassment was evident when you couldn't convince your mother that they were indeed her clothes (even if she DIDIN'T like them) and the other clothes either needed to be purchased or put back on the rack. Watching her apply her lipstick on her eyebrows broke my heart, as she was always very conscious about her appearance, and finding her beloved jewelry in odd places, scattered randomly. My mom, always a wonderful letter writer, would write random notes, which made no sense, beautiful penmanship that spilled out random words like the rolling cage of a bingo game throws out the out of order letters with numbers. Those hand written notes of random words gave me a clue as to how her mind spit out thoughts that made no sense, only adding to her own confusion and frustration as well as ours. It's no wonder that the world no longer made sense to her and how "her world" made no sense to us!

My already fractured heart fell into millions of pieces when she no longer recognized me or my sister (though you could tell she almost always showed signs that the recognized my step father). He'd walk in the room and her eyes would get big as she'd walk to him, babble random words, sit on his lap and pat his shoulder. Alzheimer's also stole her husband, the love of her life away. His attention and affections were now divided....Though he still came to see her and to assist in feeding her, those times diminished greatly as he found a different woman to fill my mother's place (I could not find, nor did I want to find a different mother). To him, He'd already lost his wife, as I had lost a huge part of my mother. Bitterness filled my already grieving heart, and anger toward him for deserting my mom (and me) at this most awful time weighed like a freight train on my heart! I felt I had then lost both my mother and the man who raised me...and the anger and hate I felt for "the other woman" consumed me! In deserting mom, he also deserted me, leaving important medical decisions for me to make without him while he would travel for periods of time (many times unreachable by phone), moving on with his life leaving a heavy, heavy responsibility on my already fragile state. I truly felt like an orphan that had now lost both her parents by this disease!

Little did I know the pain I would feel, that I would have to endure feeling "If my mother loved me as much as I loved my own children, she could have never forgotten me..." as if love would have, could have prevented her memory loss...Silly, but that's how this disease made this "child" feel. For the first time in my life, I felt like an orphan! My mother had been moved to a nursing home when she was found walking alone in the field of her out of town home following her little dog around, and later wandered again with her little dog across the busy road without looking for cars. For her own safety, the difficult decision was made. My mother forgot many things, but she never forgot how to show love. Every so often, as her disease progressed, she'd give me kisses on the cheek. I'd ask her "Am I your baby"? She'd respond with a nod. She'll never know how that watered my parched heart! That maybe, somewhere in some far distant corner of her diseased memory bank, she knew she loved or had loved this person whose face had no name to her.

As the years passed, I wondered if I'd really miss my mom when she would take her final breaths in this world, for I have been missing my mom for quite a few years already. I was an orphan in MY mind and heart already. This woman I'd go to see in a nursing home rarely, if ever knew that I was her own, her baby. When my mom passed away, I once again "lost" my mother. Grief overtook my entire being. And I was surprised at how much I missed her ...once again....(our hearts are much bigger than we realize.) I missed her soft hands, her random kisses, and her babbled syllables and words. I will however see her once again and when I do, she WILL recognize "Her baby" and my name will flow smoothly and without effort across her lips...and what a reunion that will be! Please, continue the research on Alzheimer's disease. I hope there is a victory to prevent this kind of pain in families. I hope to never, ever have my children think that (I must not have loved them enough) . Even though there is nothing further from the truth! I never want that thought to ever cross their minds. I never want to "forget" them! Thank you!

[PHI Redacted]

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My dad has Alzheimer's. He was in his late 50's when we started noticing his thinking wasn't the same. My mother was in denial and so were we in a lot of ways. Several tragic things had happened and I thought he just had a lot on his mind. His 1st cousin that he had grown up with committed suicide, and my dad was diagnosed with prostate cancer in 2011. My mother had also been having some heart problems and I and I know that weighed heavily on his mind too. My dad and mom were high school sweethearts and got married at before they were 20. They have been married for 51 years now. My dad is 69 years old now and can't take care of his self at all. My mom does everything for him. He can't find his way to the bathroom in their own house now. Dad had to retire from his job when he was 64.He was an inspector for the government. He tried to work as long as he could. My mother in law saw him at work one day and said he couldn't make a phone call to the main office because he could not operate the phone he had called on a million time before. My dad is still a real pleasant man and has been all his life. The one thing that we noticed 1st is his lack of being able to communicate. He would start to tell something and he would forget what he was going to say. He was always such a talker and such a happy person. It is such a terrible thing when your whole memory is robbed from you. I am going to the doctor on Aug. 15th to talk to him to see if there is anything that I need to do or should be concerned about myself. I sure hope one of these days there is a cure for this horrible disease.

[PHI Redacted]

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My mother lived with Alzheimer’s dementia for the last 10 years or so of her life. I was her primary caretaker for most of that time. She lived alone in a senior building until it was no longer safe for her to be alone. By alone I mean she and I had the blessing of having a caring and loving church across the street from her residence. The members there embraced my mother and me and were her safety net when I couldn't be there. Had it not been for these people my life would have been so much more difficult, and so would have my mother's. The worse part of dealing with the disease was not so much the diagnosis, but the difficulty in getting mom the help she needed. I remember how a social worker from the Welfare Department told me that they were "not there to babysit adults who could take care of themselves." I had just applied to Medicaid in order to receive what I thought would be 24-hour care for my mother. Needless to say I was floored. It was obvious the mom could not care for herself. Had this been the only instance in which I encountered a roadblock I wouldn't have been so upset, but over and over again several agencies, like the NYC Dept. of Aging, could only give me phone numbers and very little help. Getting mom into a good nursing home proved almost impossible. Had my mother not called me one day saying she wanted to throw herself out the window she might have had to stay home much longer. I immediately called the Police department, her best friend from church, and although I knew mom would not really do what she had threatened to do, I went along with it. After the longest day of my life in an emergency room, I convinced the psychiatrist that mom needed to be hospitalized. She was in the mental health unit for three months. It was there that the most wonderful social worker took interest in my mother and was able to place her in a great nursing home not too far from me, in their Alzheimer's unit. There she stayed for over two years, until she passed. I have skipped many details in this story, but my point is that both my mother and I went through needless red tape, anxiety, and frustration because of the lack of a central information and care center. Taking care of one's loved-ones should not be this hard.

[PHI Redacted]

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We understand that the U.S.A. leads the way with the highest percentage of dementia & Alzheimer's diseases just as the different types of Cancers. This says to us and countless others, that we've been spending too much $$$ and time on studies & research when in fact PREVENTION is really key. Environmental and lifestyle issues. Our aging population along with their families for the most part has been put into direr situations of either placing our loved ones in a facility at exorbitant costs or the same at home. These costs are and have been causing countless families into financial ruin! Our mother has been in an Alzheimer's for seven months at $5,250.00 a month! OMG! We are and have been in a quandary. Our analogy is... ..."collected commodities", meaning- Coral the elderly impaired and then pay away one's savings. Medicare & Medicaid, expressly for use for Nursing Homes! What?!! This all needs to change!

[PHI Redacted]

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Life for our family was in complete turmoil until there was a diagnosis for my mother. There were car accidents in parking lots (4) with my mother behind the wheel, money flying out the door to every solicitor by mail it phone who asked for it and anger outbursts that were impossible to live or deal with... That's just to mention a few major problems as there were multiple others. The CT scan ordered by the doctor was inconclusive. Getting mom off the road and to stop participating in scams was almost impossible. It wasn't until we sent mom to Bryn Mawr auto testing in PA that they were able to test her cognitive skills (at the recommendation of the geriatric internist at U of PA Hospital that we saw where she was and sent her to The Institute of Aging at NJISA in Stratford NJ that we were able to get a clear cut diagnosis. The testing there and the Social Worker that has helped the family deal with the problem and final diagnosis and planning has been invaluable!!!! The Psychiatrist there as well I cannot say enough about. The neuropsychologist who tested mom explained very distinctly how the various areas of the brain can be tested and, how they know for sure that it is Alzheimer’s. It is Imperative that ALL is done to obtain a diagnosis for the quality of life for the patient and their family!!!!! A doctor in an office asking them to draw a clock on paper or remember just 3 words is ludicrous!!!! We need proper testing and diagnosis!!! Please!!!

[PHI Redacted]

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In the beginning, my mother would say, "I feel like I'm losing my mind". In the end... she did lose her mind, her memories, and her ability to care for herself to Alzheimer's.

We know the warning signs of Alzheimer's. My mother's Aunt had Alzheimer's as did five of her friends in the neighborhood. Seems strange to think we should ask everyone to ignore it all when those afflicted with this horrible disease are crying out for our help at an alarming rate.

Early intervention, diagnosis, treatment, and the preservation of human dignity are within our grasp. If we do nothing...then maybe we are the ones who are in fact losing our minds.

Now is the time to do the right thing. Think about it. While you still can...

[PHI Redacted]

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I have facilitated groups for individuals with Alzheimer's disease for 25 years. They continue to express a gratitude for finally getting an answer to why they have become so forgetful and confused. Many have lost their jobs due to this disease and blame themselves. An early diagnosis gives them the chance to plan for their future, to meet others with this disease and know that it is not their fault.

Sincerely,

Mrs. Sarah Ollerton

[PHI Redacted]

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My experience in both diagnosis and treatment of my mother was a nightmare. Her Death Certificate states she died of dementia but because she belonged to Secure Horizons, an HMO, she received no care. The HMO's do not recognize dementia/Alzheimer’s and therefore, there are no diagnosis or treatment. By taking her into Medicare I was finally able to obtain an MRI of her brain which showed that the Cortex and Cerebellum had atrophied (this towards the end of her life). The doctor who did the diagnosis refused to tell me anything because he only got paid for one visit by Secure Horizons. An EEG showed simple strokes and shortly before she died another EEG showed complex strokes. So, there are many needed forms of diagnosis. I took her while in Medicare to Sage Clinic in Van Nuys which specialized in dementia. She was nasty and angry and the doctor refused to continue to see her. How crazy is that!!! dementia often causes fury and anger.

Whatever information I finally found was on the Internet and from Canada where they have socialized medicine. Obamacare, I am afraid will continue to honor the insurance companies and the HMO's and we will all pay the price.

[PHI Redacted]

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My mother was diagnosed with Alzheimer’s disease in 1996. It was not only difficult to obtain, it was even more difficult to hear and accept. Although, it was imperative that we heard the diagnosis, so we could prepare for the impact the disease would have on my mom. We got her enrolled in a clinical trial of Aricept and were fortunate that she received the drug and not the placebo. Rush University in Chicago told us to stay a step ahead of the disease and we did. We wouldn't have been able to do that without a diagnosis. My mother lived for 14 years and remained her cheerful and friendly self up to her passing. Her cause of death was heart failure and not listed as Alzheimer’s related of which my father was very pleased. He was her primary caregiver throughout those years. As difficult as that role is, he managed it with strength, dignity and resolve. Had he not known of the diagnosis, he wouldn't have been able to educate himself to the caregiver role and what he could expect as the disease progressed.

[PHI Redacted]

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I've never known an instance where ignorance helped improve treatment. People are suffering. We have an opportunity to gather data about this horrific disease. If there is a snowball's chance in hell that it could help future victims, it's unconscionable not to test the willing.

Sincerely,

Ms. Peggy Rathmann

[PHI Redacted]

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In 2001 I took my mother to a neurologist to have her tested for Alzheimer's. Her symptoms where severe confusion, blocks of recent memory loss and agitation. Sometimes she would wonder off looking for her home. Her older two sisters had recently died from Alzheimer's. The neurologist told us that the only diagnosis for Alzheimer's was autopsy. Nothing was done for her except a medicine for her agitation. My father retired and cared for her until his death in 2010, at that time my sister took her to live with her at her house in another city. My sister established her with a family doctor who says she has dementia but has not tested or treated her for Alzheimer's. Mother wanders off from my sister's house often. Sometimes the police need to look for her. Sometimes it is obvious she has fallen. She is often left with young members of the home and one of these occasions she fell in the home, broke her right leg and left arm. She needed to recover in a nursing home where she thrived and did very well. She saw a doctor while there who verified she probably had Alzheimer's. Before mother was released by the doctor to go back to my sister's home, my sister took her, saying she did not think mother was getting the physical therapy she needed, she disagreed with the doctor's conclusions and employed a home PT that I believe never visited the home.

There are four of us siblings. Three of us are in agreement that our mother should be in a memory care. We have tried several times in the last few years to have a voice in our mother's care. Our sister has shut us out of what is going on and in any decision making. At our attempts to be involved in our mother's life has resulted in our sister obtaining guardianship.

There has been great emotional pain dealing with our mother's care that is unnecessary. Health wise mother is doing well and the Alzheimer's will most likely be the cause of her death.

[PHI Redacted]

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I lost my grandmother to Alzheimer's over 15 years ago. She was diagnosed before she was 65 and suffered from it for almost 15 years. Still today, there aren't enough answers, not enough hope. My parents are now 64.....what are we to do for this generation? They are still working, still active and still have much to live for. How can we help them and ultimately help future generations? We need more accurate and early diagnosis. We are curing diseases left and right but not this one? Why? Brain Imaging and Mapping could be the way to a future...why would you stand in the way of someone’s future? It could even be your own.

[PHI Redacted]

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Hi, my personal story may be worth asking a doctor or two if your loved one is taking Adivan/Lorezapam. My mom has been taking this medication for years and has recently been diagnosed with Lewy Bodies dementia. She is 88 years old and has just moved from her home to a seniors residence in January. I know the move was hard on her but she really went downhill mentally the last few months. Hallucinations, depression, confusion, anger and irritability. I have suspected this medication wasn't right for my mom over the last 15 years and have tried desperately to get her off it and a new prescription (she uses it for sleeping) but no doctor would help. I noticed in her that it was very mood altering.

Three weeks ago she had a fall and was hospitalized, nothing serious. The doctor there took her off the Adivan/Lorezpam and noticed a complete change in her personality within the five days. She has been off it since and is like a new person. She even notices a difference with her brain and is much calmer and happier. I wish I could send you an attachment of recent before/after pictures of my mom. You wouldn't believe it.

Again this is just our experience. Hope it helps someone else. Good Luck

[PHI Redacted]

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My mother was diagnosed with Alzheimer's at the age of 73. My father was the primary care-giver for her until he was unable to manage her care... sadly, our family decided to relinquish her care to a nursing home facility. It was one of the most heart-wrenching decisions our family had to make. None of us could fathom letting someone else care for our mother other than family, but her needs had become so demanding that extra support was needed.

Much more is known now about Alzheimer's today compared to when our family was dealing with our family member. Her diagnoses occurred in 1990. As a family, we were not aware of any support services in our community to help with this debilitating disease.....it took us time to research what was actually occurring with our loved one....trying to learn why her behaviors were changing and that the person that we knew and loved was becoming someone totally different. Becoming informed about Alzheimer's is key.....the more aware and educated you are about the disease is paramount in understanding, supporting, & coping, with the affected person in your life. My mother lived in a nursing home for 10 years with this disease.....it creates such an emotional hardship on everyone involved in the caregiving decisions. Early detection is important in the planning process. It is key!

[PHI Redacted]

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I am concerned about my mother’s cognitive issues. She has not accurately been diagnosed with Alzheimer’s or dementia officially at this point. However she is 81 turning 82 in September of 2013 and is displaying very obvious cognitive changes. Her PCP has performed a mini-mental test on her two years in a row now and he has stated to me that mom is definitely showing significant memory deterioration. Mom’s sister had an Alzheimer’s diagnoses when she passed away in a nursing home at age 79. My mother lives with my husband and I and we keep her socially active and engaged in conversation continually so she does not fade rapidly. I talk to her about current events although at time that is followed by a lot of questions and she has a blank confused appearance on her face most of the time.

She accuses my husband and I of not telling her things and sometimes of being mean which is far from the truth. She constantly accuses me of yelling at her when admittedly I have raised my voice, however, she also has some hearing deficit. If do I raise my voice it is because I have told her the same thing 100 times and when I ask her to write it down she gets mad and states she doesn't need to or is quiet because she’s insulted.

I often call her now to remind her to eat lunch and take her medications when I am able. She will often eat lunch at 3 or 4 pm and then she is not hungry for supper at 6p when we usually all eat together, That is usually when I find out she has eaten her lunch so late. She will say I just ate and I then remind her of the best time for her lunch.

My husband and I are finding this all an extremely difficult challenge and even a strain on our own relationship of 37 1/2 years. Raising our three children was not this much of a challenge. I love my mother dearly and will not put her in a nursing home or even a day-hab at this point. There may come a time down the road when we have no choice but for now we are still exploring options and welcome any guidance. Mom's PCP retired in July and she will see a new doctor soon so hopefully we can at least obtain an actual diagnosis and move forward from there.

[PHI Redacted]

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My wife bounced around among 3 or 4 gynecologists for 2 to 3 years who told her that she was going through the change of life as a woman before finally being diagnosed at 52 that she had early onset Alzheimer's. She died at the age of 60 as a result of the disease. I don't know if an early and accurate diagnosis would have changed this outcome but it certainly is one of the steps along the way to treat and ultimately cure the disease.

[PHI Redacted]

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Jul 29, 2013

The importance of an early and accurate Alzheimer's diagnosis

now

Dear,

Please cover early Alzheimer's detection!

Sincerely,

Mr. Ryan Flanders

[PHI Redacted]

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An accurate Alzheimer's diagnosis is important not just for the patient and his/her family, but also for businesses and the rest of the community. My husband visited neurologists for about 4 years, feeling "something" was wrong, before someone finally diagnosed him. During that time, his job was to manage a portfolio of almost a billion dollars of municipal debt. His disease initially presented as an increasing difficulty with numerical and spatial reasoning, so his job became increasingly difficult and he had no idea why. His expertise was sufficiently esoteric that he had no one to back him up, point out errors, or ask for help. He knew that if he made a mistake, the municipality he worked for was subject to legal action, potentially damaging fines, and/or defaults to bond holders. He retired within days after his diagnosis, his boss agreeing that their government had a HUGE potential liability if he remained working. What about doctors with dementia? Business leaders? What about a President like Ronald Reagan? What about drivers who don't realize they are impaired and families without enough justification to take away the keys? ALL of us need to be worried about people with beginning stages of dementia in positions of power, influence and responsibility who cannot get an accurate diagnosis of why their brain isn't doing what they know it should.

[PHI Redacted]

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My name is [PHI Redacted], until July 7, 2013 I and my two sisters where the primary caregivers of my mother [PHI Redacted]. Yes, she died on July 7, 2013. In 2007 I attempted to have my mother diagnosed for dementia however, her Doctor at the time refused and in fact strongly suggested that we find another doctor. Why because I was insistent that he refer her for testing. He wanted to contribute her forgetting as an age-related issue, however, having known my mother better than he told me this was more that a age related issue. We did locate another doctor who was very understanding. After conducting the in office baseline test he referred us for further clinical testing. Her first doctor refused to even contact the baseline test. The test results indicated that she in fact have Alzheimer's disease. As difficult as it was to hear the results of the tests it at least gave us an indication how we needed to prepare for her future care and to educate ourselves on this devastating disease. Without a diagnosis or proper education, families are left to only wonder how they can cope. So please I beg of you to please help families to obtain a diagnosis so they can at least be headed in the right direction of helping their love one with the disease and obtaining assistance as a caregiver. Everyone in the family of an Alzheimer's patient is affected! Everyone.

[PHI Redacted]

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We are true believers in early diagnosis. My wife, Barbara, started to repeat herself and we immediately saw her GP who administered the MMM test on which she scored a 24. After an MRI we saw a Neurologist who made the diagnosis of Alzheimer's. Barbara was started on 8 mg of Razadyne (now Galantamine) twice a day and has had that increased to 12 mg twice a day 18 months ago. Barbara's only significant dementia symptoms are short term memory loss and cognitive skills loss. Barbara otherwise is in good health for a 78 year old woman. Barbara was first diagnosed 10 years ago. Barbara is and has been a participant at the Shiley-Marcos Alzheimer's Disease Research Center for 9 years. We are true believers in early diagnosis!!

[PHI Redacted]

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I am a 61 year old Registered nurse working for over 30 years at the same hospital. I was well respected the go to person for questions, due to my extensive experience in ICU, Trauma, Oncology, Med- Surg, Pediatrics & Home care. One year before I was unable to work because of a grand maul seizure at work. I started making mistakes at work that I had never done in 30 years at work. This was very disturbing to me, feeling that I was moving too quickly and not thinking before making decisions, an thought brought to me by my husband, but did not seem a reason for this change. Then I had a grand maul seizure at work a first seizure in my whole life at 59. I went through 1 1/2 years of extensive tests and several doctors, was sent to UCSF at San Francisco because my seizures were uncontrolled by numerous medications. UCSF did epilepsy treating. They had all my previous testing over the past two years, They felt I had symptoms of Mild Cognitive impairment and was sent the memory and aging center for further testing. I was diagnosed with mild cognitive impairment, MCI. All the prior tests I had over the past two years, CT scan, 3 MRI's, PET scan, another MRI at UCSF, showed abnormalities, brain atrophy, abnormal PET scan, and finally a MRI at UCSF showing atrophy of my hypothalamus of my brain all sign of Alzheimer’s, with the diagnosis of MCI. The Alzheimer’s did a lumbar puncture that identifies the beta amyloid and the tau in the spinal fluid which were very abnormal. The diagnosis of early Alzheimer’s was made. I am now on Aricept, which does nothing to stop the progression of Alzheimer’s but does in some people enhance the what memory you do have. After over 2 years of changes in behavior, memory loss, decrease in math, spelling, wordfinding, decision making, CT, several MRI's PET scan EEG's, cognitive testing, and finally lumbar puncture a diagnosis was made of early onset Alzheimer’s. When the earlier testing pointing to very abnormal findings it would have been much easier on me to have this special MRI to rule out the possibility of Alzheimer’s, the money, time , and frustration of no diagnosis was so unbearable the toll it takes on me and my family over 2 years. The money spent myself and the insurance company to try to find out what was going on, now seems to be a waste of time and money by everyone. Getting the diagnosis was really a relief amazingly easier than the fear of the un known. We are all trying to find a way to diagnose the disease early, to try to find a way to slow down the progression of this disease, then a cure is so important to help researchers in finding a cure. Most Alzheimer’s patients are not made to patients until they are no longer able to contribute to the symptoms and beginnings of the disease process that when there is a new promising possibility of new medications the patients are too far into the disease. I am in a study at the memory and aging center at UCSF but we need a test to possibility diagnose Alzheimer’s earlier to be determine if researchers have patients who have this horrible disease can help determine if the new medications are working. It can also allow patients like myself make the most of the time they have with their family before the disease progresses. This disease progresses slowly so I feel I may have many years left of quality time before it takes my memory and function away. To be able to help myself and my family and children in the future I have made very clear that I very willing to do whatever I can to help researchers find new medicines for Alzheimer’s. This needs to be done if they have patients with early disease to enable them to try their promising drugs. The government wants to stop Alzheimer’s because with the baby boomers aging it is going to devastating to the economy, families and the insurance companies in the future why not use this new test now to expedite the diagnosis. The government must approve, insurance companies and Medicare needs to pay for this test. It will save everyone time and money for all involved in trying to stop this disease. I am just one example of it, can you imagine my story being multiplied hundreds of times over. Please do this for everyone!

[PHI Redacted]

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My husband, Chris, has dementia even though most of our doctors seem to like to go around the subject. They do not live with him and watch as he gets worse, sometimes it seems by a lot, but always some more as time goes by.

When it is mentioned to your primary care doctor that a spouse is having memory problems, they should be made to acknowledge it as much as the signs of heart problems and cancer, not just say, "Oh, we all are having memory problems as we age." We are a part of the Cigna health network and not nearly enough is being done for dementia patients. Just because the patient may be having a great day on the day of his appointment, does not mean that patient is not much worse than the year before!!!!

I answer questions like what day is it, what time, what month, what is a certain TV channel, how do I work the remote and because my husband is a diabetic on an insulin pump - how to use it - he can't remember most of the time. More than anything, it has stolen his personality, he is not the person I have lived with all these years. He is withdrawn, can't do math or spell, can't figure out simple day to day living and what most people probably do not mention, the arguing. I never tell someone that my husband has dementia, but what they say that someone in their family has dementia. This is so serious - something has to be done to help.

[PHI Redacted]

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Growing up my grandparents lived with us. My grandpa would garden and do home maintenance while my father was at work. My grandma would cook and tell us bedtime stories while my mom did the laundry or took a night off. Ours was a multi functional home and we were all together- always. Then we started to notice my Grandmother getting angry for things she wouldn't normally be angry about. It started slow but then the amount of times a week there would be a fight increased. Soon after she got sick and needed some surgery done as a preventative. In the hospital after the initial drugs wore off, she was out of sorts, delusional, confused -she didn't know where she was or who she was. The hospital staff restrained her instead of using techniques to calm her, help her, soothe her. They restrained her. That act, it turns out was the beginning of a 5 year battle with rapid Alzheimer's. After the hospital stay grandma was not the same. She hit every phase of Alzheimer's like the pamphlets were written about her, very atypical. Looking back we all should have thought more about her bouts of anger that seemed displaced, we now know to be a warning sign. Looking back we should have told the hospital to take extra care with her, the hospital where she would later take her last breath those early morning hours in 2010. But nothing ever truly lets you forget the bad days, when it's a battle to eat, when you look into once vibrant eyes and see nothing, when your role model doesn't know you. We still cherish the good days shared and hope that a cure comes so no other family ever knows that pain.

[PHI Redacted]

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Five years ago my mother had an office visit with a geriatric physician due to some noted memory issues that were mild at the time. The doctor conducted some paper cognitive tests and she met with psychologists. At the end of the appointment, the doctor told her directly that she had Alzheimer's and had about seven years to live. This was of course devastating to her and put her into a deep depression. Months later, after overcoming her fear of seeing another doctor, she saw another geriatric physician. They diagnosed her with mild cognitive impairment and began a medication regimen. The MCI diagnosis was much easier for my mother to deal with. If we could have had a definitive test, besides the subjective paper tests, medication could have been started earlier

Since that first appointment her dementia has advanced considerably. An early and accurate diagnosis is important to both the patient and their family. It is important to get medications started early in the disease, and also helpful in planning for a challenging future. Financial and care considerations need to be made with the Alzheimer's diagnosis. We want our family members to get the most out of their remaining years and an early and accurate diagnosis can help to do just that.

[PHI Redacted]

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My husband passed away three years ago from Alzheimer’s.

I noticed the signs of the changes and expressed my concern with my doctor.

He was put on medication right away that helped for five years.

He was a very active person. Being a veteran, police officer and a minister so this illness can affect any one.

Even when his mind was gone he talked about God the whole time which was a blessing to me.

[PHI Redacted]

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I have been so involved in my father's care for the last six years that I wrote a book about it. I felt that our family’s experiences deserved to be shared with other families, who may be on the same journey. The book is titled, "Dance with dementia" and it includes many actual events and episodes that we experienced while watching over our "dear old dad."

I'm currently giving presentations about the book to Alzheimer and dementia outreach groups. It continues to amaze me how similar our various experiences with our loved ones have been, although each case is unique there appears to be a common thread connecting them.

I would be happy to work with your Organization in any capacity that would help to share information with other families dealing with dementia or Alzheimer’s disease

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My mother started exhibiting symptoms of dementia right after she had cataract surgery in December 1978. She lost the ability to read she blamed this on the surgery being unsuccessful, but then started having difficulties with her speech; she also had strange hallucinations. She hallucinated that her neighbor’s dog was eating the fruit from our fruit trees, but this was in midwinter when there weren't even any leaves on the trees. She insisted that I play one Broadway musical on the phonograph (Don’t Call Me Madam) over and over again, and finally only one song on the record. The she started losing her memory by then she knew something was seriously wrong. She was very arthritic, and was taking steroids and narcotic pain killers in massive doses, and her doctor thought that was the cause of her mental problems. She developed a craving for sweets. She began repeating the same phrase over and over again "Pay attention, your mind is wandering (she had once been a schoolteacher). About six weeks before she died, all of her symptoms disappeared, but two weeks after that, they returned much worse. She lost control over her bodily functions and lay in bed in her own excrement. We had to put her in a nursing home and sell our house to pay for her medical expenses. On December 21, one day after my birthday in 1979 she was found dead in her wheelchair. From the time she started showing symptoms to the time of her death was exactly one year. I have never heard of Alzheimer's progressing that fast, and no autopsy was performed; she may have had some other form of dementia a friend who is a doctor suggested Pick's disease, but that also progresses fairly slowly. Creutzfeldt Jacob disease seems a more likely diagnosis, In fact one of her sisters died the same way, although her illness lasted several years, and was diagnosed with CJD. Her mother also exhibited symptoms of dementia before she died. My mother was 73 when she died; her mother 87.

[PHI Redacted]

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My husband was diagnosed with early Alzheimer's about 5 years ago. Due to the early diagnosis we were able to make plans according. We were living in the Atlanta area, with no family close. I was still working. We started planning, and within the year, we had built a house at the current address and moved within a mile of our daughter. As much as I would have loved to stay where we were, I knew that I would need help with his care. In late March, my children convinced that I could no longer keep him at home, and reluctantly placed him in a nursing home. I have said, it can't be any harder to bury him. He still knows me which is a blessing. Early diagnosis, gives you much needed time to adjust and get things in order, as in our case many of the things had to be done by my husband.

[PHI Redacted]

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Early and accurate diagnosis leads to better outcomes and higher quality of life for people with Alzheimer's and their families. We were desperate for a diagnosis and treatment options for my mother after her stroke.

Yet, the federal government has said there is insufficient evidence that a diagnostic test called brain amyloid imaging improves health outcomes. I've had firsthand experience with dementia diagnosis and care for my mother.

I urge you to fund the diagnostic test called brain amyloid imaging to improve health outcomes.

[PHI Redacted]

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My father was diagnosed with Alzheimer's disease about 5 years after noticing his brain was not working as it had or should. Early planning was critical to us as my mother's health was not good either, and she would not be able to care for him as the disease progressed. My father had brain imaging, which I believe was what allowed his neurologist to properly diagnose it in a timely fashion so that legal and living arrangement could be dealt with before a crisis situations occurred.

It was imaging that helped our family accept and deal with the diagnosis of the Alzheimer's disease in a practical, effective, and loving way.

[PHI Redacted]

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I was very surprised to learn that PET scans would not be approved under Medicare for diagnosis of an apparent problem. Thankfully they were allowed for a diagnosis for my wife in 2008. The result of a PET scan were indications attributable to Alzheimer's and have allowed us to better plan future needs.

Why a PET scan for my wife?

1) The question began with depth perception. Was it a brain tumor causing the problem?

2) An MRI confirmed no tumor. However "black" spots.

3) Were the spots TIA's or something else? A PET scan could confirm.

4) The scan confirmed a lack of nutrition to those cells indicative of dementia associated with Alzheimer's.

For us the PET scan was most important.

My wife really didn't want to know this was the problem that would change our life and lifestyle. TIA's would have been more desirable. However it meant the proper medication, the right therapy and the best future planning. We decided to keep our home. The living room was changed to a bedroom, closet and an ADA bath. Our caregiving remains in our home and will probably be so until in the future we don't know we're being out.

Why not allow the best technology to be available for all and not limit the need only to those who can afford the procedure? Will not costs significantly decrease as usage increases?

I was very surprised on the PET scan decision. Hopefully there is a solution to not take a step backward on medical advances that would also help the poor and middle class.

[PHI Redacted]

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I wish I could be more help, I do the best I can.... My mom had Alzheimer's disease and this sadly is what did her in. She had it for approx. 15 years, hid it as best she could... lived in Sr. housing, then with me and then sadly in a nursing home (she was a wanderer and always tried to light the stove. Perhaps this may help, she had many trauma's in her life, was a single Mom, worked in a Nickel Factory and was a hair-dresser for many year, (chemicals etc... this was in the 50's, factory work in the late 30's.. She also was a heavy smoker and drinker. I feel that it was ALL those factors that caused her problems... She was diagnosed here in the Boston area... I am now 76 and doing OK, if you need or want further info let me know, I am an only child... I took care of Mom and when she was in the Nursing Home I visited her every day. It was a terrible time... Research is needed!!!!!

[PHI Redacted]