



Dementia Care: Supporting Comfort and Resident Preferences Call

Moderated by: Aryeh Langer
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Table of Contents

Announcements & Introduction.....	2
Presentation	2
Supporting Comfort and Preferences for Residents Living with Dementia.....	2
National Partnership Updates	14
Question & Answer Session	15
Additional Information.....	18

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Operator: At this time, I would like to welcome everyone to today's Medicare Learning Network® event. All lines will remain in a listen-only mode until the question and answer session. This call is being recorded and transcribed. If anyone has any objections, you may disconnect at this time.

I will now turn the call over to Aryeh Langer. Thank you. You may begin.

Announcements & Introduction

Aryeh Langer: Thank you very much, Dorothy. And as you just heard, my name is Aryeh Langer from the Provider Communications Group here at CMS and I'm your moderator for today's call. I would like to welcome you to this Medicare Learning Network Call on Dementia Care, Supporting Comfort and Resident Preferences.

During this call, gain insight on approaches to care for residents living with dementia that focus on resident preferences, maintaining comfort, and assisting with utmost needs. Additionally, CMS provides updates on the progress of the National Partnership to Improve Dementia Care in Nursing Homes.

A question answer and session follows today's presentation. Before we get started, you received the link to the presentation in your confirmation email. The presentation is available at the following URL, [go.CMS.gov/npc](https://go.cms.gov/npc), again the URL is [go.CMS.gov/npc](https://go.cms.gov/npc).

Today's event is not intended for the press and the remarks are not considered on the record. If you are a member of the press, you may listen in, but please refrain from asking questions during the question and answer session. If you have any inquiries, please contact press@cms.hhs.gov.

For today's event, I have Michele Laughman here at CMS Central Office with me, and we also have Ann Wyatt from CaringKind joining us by phone.

At this time, I would like to turn the call over to Michele Laughman, a Health Insurance Specialist within Division of Nursing Homes at CMS. Michele?

Presentation

Michele Laughman: Thank you. As Aryeh mentioned, today's presentation will focus on approaches to care for residents living with dementia that incorporates resident preferences, maintaining comfort, and assisting with unmet needs. Our speaker for this presentation will be Ann Wyatt, a consultant for Palliative and Residential Care for CaringKind. I'm now turning it over to Ann. Ann?

Supporting Comfort and Preferences for Residents Living with Dementia

Ann Wyatt: Good afternoon and good morning, everyone. It's really an honor to be on this call and share with you some of the things that we've been working on and learning here at CaringKind.

So, when we started, we have, of course, learning objectives here in terms of understanding why comfort matters. People often ask, how is it possible to honor the preferences of people with dementia when they can't tell us about those preferences? And what we've come to understand is that comfort is the key to this.



Comfort and discomfort are things we can see and things we can do something about. Comfort is a benefit to people with dementia, as it is to the rest of us. People with dementia, as are the rest of us, are experts on their personal comfort, and, but, however, for people with dementia they communicate their comfort and their discomfort through their actions rather than, as a rule, through their words.

Everyone with dementia can be comfortable. Sometimes that's a fairly straightforward and easy thing to figure out, and sometimes it can take days, weeks, and months to figure out, but it can be figured out. And finally, and quite critically, comfort is not just for end-of-life circumstances.

The slide on page 6 shows a chart from the Center to Advance Palliative Care, which shows how the shift in palliative care has occurred over the last many years, that certainly palliative care can and does co-exist with disease-directed therapies. However, there is more increasing room for palliative care as conditions progressed.

And the critical factor here in terms of people with dementia is that the average time between diagnosis and death is 8 to 10 years, and about 40% of that time is in the advanced stage. So that in residential care, people are often with advanced dementia living in residential care for many years, and palliative care can make a difference throughout that period. I would actually make the observation that I think anybody in long-term care could benefit from palliation, but we're really going to be focusing on what palliation can do for people with dementia.

So, on page 7, slide 7, why do we need to look at palliation from a dementia-specific perspective? Well, of course, behavior is communication. It is not the dementia that causes the behavior, or only in the rarest of circumstances. It is, however, the dementia, which prevents the person from expressing or describing or explaining the cause of their distress.

Antipsychotics may remove the person's only means of communication, and not be responsive to the underlying problem. Ironically, when we started our work, one of the things we did was show homes we're working with, on the one hand a picture of on a given unit how many people were rejecting care or aggressive verbally or physically on one page.

And on the other page, we showed the antipsychotic use, which in this particular home I'm thinking of was quite high, and they sort of connected the dots that not only was of not treating pain which we believe was at the source of a lot of the distress, but also said it really wasn't having much of an impact on the behavior, except of course that it may just quiet people more.

And of course, care settings and providers may tend to want the person to conform to the needs of the setting, which means not only that the person's needs may not be met adequately or in a timely manner, but that the setting itself may be causing the person's distress, and I'm going to give you several examples of that.

And finally, comfort will often not reach people with dementia unless dementia-specific adaptations are made and how care is delivered. This is not just about our work and what I want to talk about today is not just about more training for frontline staff. A supervisor or a manager or administrator can undo months of effort if they don't really have their thinking and approach and policies and procedures and alignment with the expectations for frontline staff.



And we found in our experience that as we got more deeply into comfort, every single person who worked in the homes that we've been working with, including administrator, had to step outside their own comfort zone and really rethink how things were coming together in their homes.

So, behavior is communication, slide 8, everyone is taught this. I don't think there's probably a single dementia education program out there that doesn't start with this thinking.

However, what we've discovered is that even though people can say this and say it back and are taught it, that very often it's not followed very deeply, and a slightly humorous example of this is, in a large home we were working with, is they were discussing bathing without a battle and the special bathing kits that can sometimes be used for giving bed bath, and of course they'd all seen in the video and they knew all about it, they'd heard all about it.

But when we went hunting in that facility for the kit, they used to have them. But the only kit we found after weeks of hunting was in the staff orientation department where they used it in the orientation, but nobody used it in the facility. Now this wasn't that people didn't care about this, but somehow it just kind of got lost along the way.

So, and what we discovered was that very often the idea that behavior is communication and what you do with that information had not been really deeply pursued.

We came to understand is that we prefer the word distress rather than behavior, because behavior kind of suggests that the person has control over their actions and can change them if we tell them to, work we can only come up with the right sort of schedule in the facility.

Distress suggest that we should seek the reason for the person's discomfort. Assume it is discomfort and address it on their behalf. Do for them what they cannot do for themselves.

On slide 9, you'll see that there are several building blocks to this approach. One is certainly and absolutely critically the organizational adaptations, which I'll talk about. Then, of course, there are specific dementia-capable care practices, certainly for the person with dementia as for anyone else, because about knowing who they are as much as we can.

It is about how we approach care planning, and about how much we look for and include with the person's active comforts, as well as address their other care needs. And then, of course, it's consistently and persistently getting to the root causes of someone's distress.

Organizational adaptations, they really have to be embedded in facility expectations and reflected in actions, attitudes, assumptions of administrators and managers, and how staff relate to each other, and in the mission policies, procedures, and protocols and set guidelines for daily practice.

One of the things that we learn as we did this work, and I've been working in long term care for an amazing 45 years. And I have never seen the sort of the depth of the teamwork that I saw as people got more deeply into comfort, because comfort is something you can see. Person-centered care, of which comfort is certainly a huge piece. We all believe deeply in that, but it can sometimes be a little abstract.



With dementia, the concreteness of comfort really helps put everybody in the sense, whether it's the housekeeper or the dietary aide or the nurse or the doctor or the visitor or the administrator. Comfort is something we can see; discomfort is something we can see.

So, I'm going to give you an example, and this happened very early in our work. And it was very instructive, and of course one of the great things is when you start exploring comfort invariably fairly soon, some resident will be your first teacher, who will help everybody understand what this really means to bring comfort to people.

Anthony arrived, and I can use his name because his wife wants us to, because of the differences this approach made in his life and certainly in hers. He arrived with a history of combativeness, and was on many antipsychotics, and spent time in a psychiatric hospital, and had been asked to leave other homes.

Early on in his stay, the staff met with his wife and learned that his custom at home had been to stay up until 4 AM, have a snack, sleep until about noon, and have some breakfast.

So, when was Anthony combative? We'll resist not to make a leap to say that or to guess that he was resistant when people tried to make him go to bed before he wanted to and absolutely when they tried to get him up before he was ready to do that.

The home changed the care plan to reflect Anthony's customary sleeping and eating routine, which meant that he could stay up until he was ready to go to bed, and then they would let him sleep as late as he wanted to which was usually around 12 or 1, and then they would have something available for him that satisfied a sort of breakfast need if you will. They also certainly had snacks for him whenever he decided he wanted to go to bed and wanted something to eat.

His resistance almost completely disappeared. He was tapered off antipsychotics and remained off them for many years until his recent death.

Now, I want to describe to you that after all of these changes have been made, and Anthony was far more comfortable, one of the things his wife said to us was that I got my husband back, I got my life back because there was there was a semblance of the person he had been and he was clearly so much more comfortable.

I happened to be in this home about 1 o'clock in the morning at one point, because we were doing part of our work with a research study in which we included staff on all 3 shifts in our assessment. And as I was sitting there waiting for the person on duty to fill out the questionnaire, Anthony was up and cheerful and talking, and then he went off on his own.

In then meanwhile, another resident came in and needed something to eat. The aide immediately went over and said, who was filling out the questionnaire, immediately went over to her, sat her down, brought her some tuna fish sandwiches and a glass of juice.

And at that point I looked up and there was an aide walking across the area, Anthony right behind her. They were both carrying large bags, which they clearly took over to the linen chute and put them down the chute and then the aide turned to Anthony and said, "would you like a cookie now, Anthony?"



So, this was the person that had been in a psychiatric hospital, that had been put out of homes and that had been on a lot of antipsychotics. He was clearly in advanced dementia, but he was also comfortable and responded to comfortably by staff.

So, when before he died, his wife, when we were having a series of meetings with some consultants, his wife found me in the facility and said please tell the consultants I know that if something happens to me Anthony will be well cared for. This has been palliative for me too. And I don't think there's any higher accolade our family can give him. If I'm not there, I know he'll be okay.

So, what were the organizational elements required to bring comfort to Anthony and to his wife? Well, first of all, is that early interaction with the family, in this case his wife. As soon as someone is admitted, to learn about routines and specific comforts and discomforts is extremely important. When his wife sat down with the staff, she was extremely anxious, she was just terrified that in this new place something would happen, and once again he'd be put out and she wouldn't know what to do.

The fact that the staff really sat with her, talked it through, and then her responses made a huge difference obviously for Anthony, for the staff, and for his wife.

Care plans that specifically addressed Anthony's needs were flexibility and ensuring that all staff, including holiday replacements, know and understands Anthony's needs. This is the kind of situation where if you don't have a built-in policies and procedures, if you don't have good communication systems, then a supervisor who's only there on Saturday nights, or a replacement staff person who is a nurse on a unit can undo all the effort. She can say no, no, he has to go to bed now, and a lot of discomfort for everybody will ensue.

Of course, there had to be food that he liked available in the middle of the night. Usually that's not too complicated, and it wasn't in his case. And again, the kind of food he liked when he awakened in the early afternoon.

All 3 shifts supported each other in the schedule adjustments. No one should be questioning and did question in this case why the night shift didn't get him up before they left.

Facility policies and procedures should support flexibility and waking and sleeping. Ongoing conversation with family about what is working and what isn't based upon the resident's level of comfort, especially as a resident's needs change over time.

And of course, you know, we know this, but somehow it tends to get lost. Although each department and discipline has specific responsibilities. Nothing happens in residential care without the participation and hopefully the collaboration of many different departments, could be talking about breakfast, lunch, dinner, nothing happens without several departments or disciplines being involved.

So, I've mentioned as you'll see, a list on slide 14, care practices that promote comfort. Certainly care practices around pain, around the environment, around sleep and rest and sundowning, food and nourishment, balance of stimulation, meaningful engagement, whether somebody is too hot or too cold, anticipatory toileting, and ambulation are all factors that can be specifically influenced in terms of how we approach people with dementia.



Aryeh Langer: One second, is it possible if you could just speak a little bit louder?

Ann Wyatt: Sure, sure.

Aryeh Langer: Thank you.

Ann Wyatt: Pain is what the person says it is, and of course, you know, that's true for people with dementia as well. And we've all known situations where somebody perhaps had a fall and a hip fracture and didn't complain at all, where somebody might have gotten a nick on a finger and yelled and screamed.

So, the point is, their level of distress is their level of distress. People experience pain differently and it does affect cognition. Research has clearly indicated that people with dementia are more likely not to have their pain identified, and therefore less likely to have it treated.

There's a famous hip fracture study where they looked at a large number of people who have had hip fracture surgery, and it was very clear that people with dementia who had the surgery were definitely less likely to have their pain identified or treated.

People with dementia who are experiencing pain may deny it, or they may express their distress through their behavior. We found consistently that very often the source of somebody's distress was pain that might be the shoes didn't fit, it might be that it's an old shoulder injury.

One of the early experiences we had in another home was, the education director said, you know, she'd been called by a nursing assistant to come. The assistant was having trouble dressing someone, and so the nurse educator came and worked it through with the aid and they did fine. They went slowly. They did all the things that we know to do.

And it went fine until they started to put a sweater on this resident and the resident pushed it all away and resisted totally. And then they discovered in their exploration that she had an old shoulder injury, which meant obviously that you have to be really careful about how you -- because those of us who've had shoulder injuries know how excruciatingly painful that can be.

So, it's really important to pay attention, usually when somebody rejects care it's either pain or it's fear and we need to take that very seriously. Also, it's very common with people with dementia if you say are you in pain for somebody to say no.

However, if you have a sense that maybe you know they're rubbing their knee, you talk about is that sore, or you put your hand over or near an area where you suspect they may be uncomfortable and use different words, you're more likely to find out what's really going on. It's just very common for people to say no, even people without dementia will often say "I'm not in pain," but yes, that is sore, for example.

Facility, though this is a perfect example of where facility policies and procedures need to be in place so that this all comes together. Facilities need to have behavior-based pain skills. There are many of them and of course they should provide education for all staff including physicians on how to use them.



And the organizations I have worked with, we used the PAINAD because the language is so accessible for all disciplines, for all different staff roles and for families.

And on slide number 16 you'll see the first half of PAINAD assessment, and you'll see the language which is pretty easy to understand. And it's very useful to be able to have to use this language from all levels with all levels of staff as well as the family members, so that you're really all talking about the same thing.

The sort of critical piece of the education when we use the PAINAD was to help staff understand you didn't just use this pain assessment if you thought you saw pain, you used it if you saw behavior, because that helped you begin to pinpoint whether it was or was not pain.

So that any one of these things could be things that resulted from somebody's discomfort or pain, and the scoring helps you know both to follow whether your interventions are working, but also what level of intervention would be most helpful in a score of above 4 begins to look at medication, certainly.

And we found over and over again that Tylenol was often the thing that was most helpful, however. And this was an interesting reality that we encountered, and that is, when we started, all the homes we worked with on the dementia units gave out pain medication p.r.n., which we came to call "patient receives none".

Because the person with dementia is not the person that's going to come to the nurse and say, "excuse me," but, you know "my back is hurting, and could you please give me some Tylenol." And very often the best way forward was to regularly schedule someone's use of Tylenol.

And also, we noticed pretty consistently that if somebody was, you know, if there is enough discomfort that's pretty much around the clock, it was important to make sure that the medication was given frequently enough so that the entire period of time was covered, if you just give it, for example, twice a day. And somebody is really uncomfortable pretty much all the time, then that's not going to cover it, but you need to really pay attention to that.

One of the interesting experiences in one home we had, and this was one of those teaching moments, was the nurse and the physician sat down on this unit. And again, we were measuring everything month-by-month, so that's why we were able to capture this information so clearly.

They sat down over a couple of days, and went through all the residents, and moved a number of people over to regularly scheduled Tylenol. And that month alone, rejection of care dropped significantly. Because, in fact, a lot of that rejection was people being in pain or uncomfortable.

Okay. Nutritional needs, slide 17. One of the things that, you know, this is, this is one of those truisms that is easy to forget, and that is that people are more likely to eat food they like. And so, you know, we are more likely to have people eating if they are given food they enjoy and like to eat. And one of the drives that we were consistently on, was really trying to move more people off supplements and on to real food.

And we noticed in one home they have consistently reported that residents are less likely to choke when they're eating something they like to eat. In fact, I had a conversation at another home where we were discussing a resident who was being given a speech test to see what about choking.



And as the nurse was describing it to me she was describing the 3 foods that were on the plate that he was given in order to test his swallowing and she described the first two and I forgot what they were, but the third one she said it was this green stuff. And then she gave me a look and she said, "I wouldn't be able to eat it."

So again, it's not that there's a simple answer to any of this, but on the other hand we have to take a step back and think about if we give people food that they really can't abide, is that a fair test, is that really -- either their interest in eating or their ability to swallow, it's just something to keep in mind.

And also, we found that offering snacks every 45 minutes or hour or every hour, small snacks, it can be orange slices, cookies, or whatever, are really important because that's often the way that people prefer to eat, and doesn't mean that they may want to do it in addition to meal times, or sometimes they do it instead of meal times, it depends.

But the objective here is about making sure that they have food that they like to eat and that they eat if possible, they're still interested in that. And one experience we had again, early on, was of a home we began to talk about the snack part and what was actually on it. And one of the nursing assistants piped up right away and she said, you know, she said we've got to stop giving them those hard cookies, they never eat them. They come up every day and we send them back every day because they're too hard. So, could we change to soft cookies? And so, they started trying it on this unit.

Within a week people were coming from other units to get the soft cookies and within 2 weeks the whole facility had moved over to soft cookies. Again, you know, we sometimes just get sort of stuck in routine and stop don't take that moment to stop and look at what we're doing and what the impact is.

And I will say it's very important as it remains on this unit to keep track of that. On their weekly meetings, they always just double check is what's coming up being eaten by the residents, or is it just going back down, do we need to shift, maybe they don't like spice cake, maybe they don't like this cookie or this orange slice or whatever it is, but to make sure that the food that's coming up is something that will actually be of interest to residents.

Slide 18, the care environment. One home that we know of, when they started to take a look at the level of sundowning, they asked the staff just to take a look from about 2 o'clock in the afternoon till about 8 o'clock that night at what they observed in the environment. And what they observed was a TV on that nobody was watching, number of people asleep, and a very noisy shift change, in which there was a lot of discomfort and distress expressed by residents that was definitely in the sundowning category.

So, very slowly they began to work on this. First of all, they took the TV out of the day room, they put it somewhere also could be used, because there certainly are times when somebody with dementia can enjoy TV, but it should be specific and deliberate in response to their interest.

Secondly, they took a look at the shift change and realized that they were causing a lot of the distress just by everybody running to get ready to leave, as well as the people coming on racing around, and they actually achieved a silent shift change. And I've seen that now in some other homes that we've worked with.



There was initial resistance from this particular home I'm thinking of, and which one of the aides said. But Mr. Smith will be upset if I don't say good night to him. And what we had to talk through and really worked through was you can still say good night to Mr. Smith but yelling it down the hall has the impact of really raising everybody's anxiety.

And of course, the home that really was able to thoroughly completely eliminate sundowning noticed that as distress went down, visitors were more likely to come.

On slide 19, rest and sleep wake routines, the importance of resting when tired. Dementia is tiring and I guess it's one of those things that again was, we worked on this, we realized we just sort of hadn't kind of put together how exhausting it is when you can't think as clearly as you used to be able to. You do need more rest period. So, you need time in between stimulating moments to recover yourself a little bit, or needs to be a good balance of stimulation.

And I would say also that it's really important to -- I mean everybody has sort of different needs in this area. So, each person needs, in this as in all things, the situation needs to be looked at individually. We had an experience in one home where at the weekly meeting, at the end of the meeting, the facilitator said is there anything else and one of the aides who was a very experienced aide, generally rather quiet and not somebody who spoke up, but she's been to the education training and among other things that heard the discussion on sleep. And she said yes, she said I have something to say.

She said, I've been trying this week to put Mr. Smith and Mrs. Lewis back to bed for a while after lunch because I think maybe it's because they are calling out after lunch and may have to do with them being tired, at which point the nurse just swiveled her head around and she said, "oh, my God," she said, "I never -- I didn't realize," she said, "you're right, I haven't heard all that screaming after lunch," just haven't thought about it because she was so caught up in her routine.

But, in fact, for those two residents the calling out and yelling was because they were tired, and they just needed to rest for a little while, and then they were much better. Of course, we also, you know, have worked hard to really rethink activities and what is meaningful engagement for people with advanced dementia. And certainly, people with even advanced dementia can still feel lonely or bored or frustrated.

Every interaction, and this is true, of course, whether somebody has dementia or not, but all of the more, all the greater magnitude when they do and have no ability to express themselves clearly, every interaction holds the potential for meaningfulness or for its absence, every interaction, and that means that everybody who interacts with the resident has the opportunity to have that meaningful moment with them.

We had an experience in one of the homes where a resident was constantly, she was constantly in altercations with other residents on the unit, and the staff were constantly having to write up the incident when she would go to a resident and something would occur and they'd have an altercation.

Finally, the staff decided what they really needed to look into this more deeply, and what they discovered was that what this resident wanted was hugs, and she was going to other residents for the hugs and the other residents were not interested and that's where the altercation occurred.



So, the intervention in this case was that the staff started hugging her and those incidents virtually completely disappeared. Because everybody on that unit, whether it was a nurse or an aide or a housekeeper, could go to her and hug her on a regular basis.

One-on-one in small groups for people with advanced dementia clearly works a lot better than large group activities. And that was something which we really had to pay a lot more attention to, because when sitting down with staff you'd say if you're sitting with somebody with one person with dementia, can you engage them, and the staff would say yes, and I said how about 2 at the same time and they said yes. How about 3 at the same time and they said yes. And then when we got to 4 and above, that's a lot harder, it's a lot harder with anybody whether they have dementia or not.

But certainly, if people have dementia it can be very difficult to authentically engage a large group of people. So, we really had to think about that.

And of course, part of this as I've described is that all staff on the unit, regardless of their role, needs to take seriously that they have a role in that meaningful engagement. Personalized music of course is one of those few activities that can be very individualized, not only for people in general, but also for people with dementia, and there's been a lot of success and now some really excellent research that really underscores that.

Slide number 21 shows you a couple of examples. Clearly one person on the one hand is being comforted by an aide and on the other one, this is a housekeeper who for years even before the project would carry around in his pockets extra lollipops to share with residents.

I want to say to that whether we're talking about meaningful engagement, or about any other interaction or activity with people with dementia, that one of the things that we heard, especially initially, was we really don't have time to do this, we don't have time to learn the stuff about the resident, we don't have time to take-- to try these things out.

But the reality is that if you don't, then you can spend a lot more time dealing with the kind of distress in the end resulting behaviors, because that extra time was not taken upfront, and we saw this over and over again.

The processes, I've described some of the care practices, but the processes that we focused on was first of all when we first started our work in 2012 with 3 homes, we asked them just for a year on those units to have weekly interdisciplinary meetings, just for half an hour, to talk through the issues that they were encountering.

And in all three homes, this is now 2019, they never stopped, because of course when you're asking people to be a team in the deeper sense of that word, then the opportunity to talk to each other has actually produced really, just as I say, the strongest teams I've ever encountered.

And those huddles of course are always important you know. But again, to bring people together to talk it through and get a different perspective.

A housekeeper, for example, may actually spend more uninterrupted time with the residents, simply because they're in the room with them cleaning for a period of 20 or 30 minutes and they may actually have observations that are extremely valuable.



We also found that starting the discussion right away with families, not just about what the care worries were, but also what were their active comforts. It really begins to change right off the bat. Starts to align expectations in a different way, like how can we together make your mother, your father, your brother, your husband more comfortable.

And that really changes the character of the relationship and of the set of possibilities going forward. So, that's a really important piece of it. The assessment of care needs and habits and comforts.

Certainly, to begin to provide education for families so that they are as clear as they can be about the advanced directives that need to be in place or that can be in place. Care plans and roadmaps for distress, which I'll talk about, and how we really found some very useful tools for MDS as for care plan meetings, and then, of course, the PAINAD as a tool.

On slide number 23, the roadmap to comfort. This basically on the left-hand side is what is the dementia related behavior or sign of distress that you are observing. What do we think the person is trying to say and what are the intervention that we're going to try?

Now, you may have -- any given home may have its own version of this. What we observed was, the important thing is to use it and use it until the distress has been well addressed. Sometimes there is a tendency to sort of write it down and then not stick with it, or not revisit and say, well, we tried intervention X, but either it didn't work, or it worked partly, but we need to do more.

And that the important thing is to keep at it, and also because if you believe that it's possible that it is distress, and it is possible to address it, then you'll keep going. Also, it's extremely important to get input from all disciplines and all shifts to understand the 24-hour experience of the resident.

And so, even though not everybody can be at the weekly meeting or at the huddle or the care plan meeting, it is important to incorporate ways of getting the perspective of all shifts as well as all disciplines.

I would say slide number 24, you know, certainly we've talked about pain, about overstimulation, boredom, lack of sleep, also about weighing risk. We had a situation where a woman had been in a Japanese internment camp. She was nearly a 100. She really did not like to sit still, she tended to fall.

And after a lengthy discussion with her 2 daughters, it was agreed by all that she - there was really no way to completely stop her from walking around nor did the daughters want her to be stopped because having been interred this woman really needed to be able to move around.

And so, they understood that there would be some falls, but they were willing to do that in exchange for giving their mother the freedom that throughout the day she desperately needed. Of course, they were as careful as they could be and they kept a careful eye on her, but in that circumstance, they were not able to always prevent a fall and there were some.

But they were weighing the risk. There was a risk to her not moving. In this case, the family felt it was really hugely important. Also, years ago, several years ago I heard about a researcher in Minnesota who had gone to



an international sleep conference and went to a session in which the discussion centered on what was the most effective way to torture someone through sleep deprivation.

This was a military presentation and it turned out that they believe that the most effective way to torture somebody through sleep deprivation was by waking them up every 2 hours. So, once again it's one of those things where we haven't been doing that on purpose to torture people all these years; on the other hand, check-ins every 2 hours have been common practice and we need to look at that and find other ways to make sure that we do everything we can to prevent decubiti, but also to make sure that people have enough rest and sleep.

The relevance of past trauma, of course, is really important, slide 25. In this case if we understand out as much as we can about somebody's past life this will help us. You can be a specific trigger, for example, showers for people who survived or had a family who did not survive the Holocaust. Showers can be a trigger to deep upset.

One home told us that when the staff had the TV on during 9/11, they had a couple of residents who hid under the bed because they were so frightened by it.

On the other hand, the other way that trauma can intrude is that something in the present is making the person feel badly, whether they're become afraid or ashamed or embarrassed which then triggers older experiences, older times when they were fearful or ashamed or embarrassed.

So, in either case, the more that you understand about the person's experience and understand how to read this, the more you can attempt to make him the more comfortable in the present.

One of our, sort of favorite discoveries of our process, was that these 4 items on slide number 26, that are MDS items resistance to care and verbal behavioral symptoms directed to others, physical behavioral symptoms directed to others, and other behavioral symptoms not directed to others.

These are things, which anytime we see them, anytime in those care plan meetings, if we haven't noticed it before, that's a signal that this person has some distress and that we need to get to the root of it. It is not something that should be just checked off routinely every 6 months or every quarter, and it's the kind of thing which, if you believe that distress is at the bottom, then these are the clues that you really need to do something about it.

Also, we avoid using agitation and combative because they don't really communicate what's actually going on with the person, we need to know the specifics about the potential contributing factors to the distress that's happening for the person.

Slide 27, it needs to go in the care plan. I think I probably, throughout our period of time of working with a number of homes on the comfort approach, if I've said it once I've probably said it 500 times, when we learn X about the person, needs to go in the care plan if they like lollipops, if they like Frank Sinatra, if they like the color red, or if they don't like the color blue, whatever it is, that belongs in the care plan, because it is a clue to bringing comfort and to preventing or minimizing discomfort.



There are different ways, I mean every home will have a different perhaps way of incorporating comfort into their care plans. Some homes have put lists related particularly to care planning and to comfort on the inside of a closet door for example, or it can be added on to whatever current care plan system they have, or in one case, as in slide 28, they develop what they called 'what comforts me' care plan, and this was the example here. It is specific to adjust somebody's comfort that they learned about the person.

In this case, I have difficulty hearing, so I like it when people looked directly at me when speaking to me, that's one example of a particular comfort thing.

I like to be well groomed each day. I'm very social and like to be with people and like to listen to music. Those are comforts, and if the person is more comfortable that will make a difference not only for the person, but obviously for the staff who are caring for them.

Finally, on slide number 29, we found that, not surprisingly, performance improvement and data were a huge help as we progressed through making the changes that we did. We're not testing the care practices because those have all been tested, but what we were trying to look at is, were the implementation strategies that we were using effective.

When we started the homes, we worked with collected data for the facility as a whole, but they did not break it down for unit level staff. So the staff on any given unit didn't truly see the results of their efforts, and I think this is really a missed opportunity, because in fact when staff began to see that rejection of care was going way down or that the use of supplements was going down and weight gain was maintaining or whatever was being assessed, that really boiled them and reinforced what the goals of care were.

The slide number 30, rejection of care and PAINAD. This is an example of what I'm talking about. The staff reported overtime on the use of the PAINAD and then showed it in relationship to the amount of rejection of care they saw in the unit, and you can see the results there.

And that's really where we come to an end of this presentation. I can only tell you that having been doing this work for all these years, that comfort, as I said, certainly has made an incredible difference in the lives of the people that we've all been caring for, but it's also made a huge difference in the lives of their families and in the lives of their caregivers in residential care.

Thank you.

National Partnership Updates

Michele Laughman: Thank you Ann, we appreciate your presentation. Before I turn it over to the moderator for the question and answer session, I just wanted to talk briefly about the National Partnership to Improve Dementia Care. This is again Michele Laughman. I'm on slide 33 in the presentation.

In July, we released quarterly data reports for the Partnership, and this slide depicts the national quarterly prevalence of antipsychotic medication use for long-stay nursing home residents.



In 2011 Quarter 4, 23.9% of long stay nursing home residents were receiving an antipsychotic medication. And since then there's been a decrease of 39% to a national prevalence of 14.6% in 2018 Quarter 4.

The next slide depicts the quarterly prevalence of antipsychotic medication use for a long-stay nursing home resident by CMS region. Progress had slowed a bit overall, but you'll see on the next 2 slides that we are making great strides with nursing homes identified as late adopters.

Slide 35 and 36 are similar to the previous 2, but they focus solely on the late adopters. In 2011 quarter 4, 21.4% of long stay nursing home residents living in a nursing home identified as late adopters were receiving an antipsychotic medication.

And since then there's been a decrease of 7.1% to a national prevalence among late adopters, of 19.9% in 2018 quarter 4. So, this means that we're nearly halfway to achieving our current goal of a 15% reduction in homes identified as late adopters by the end of 2019.

I'd like to thank you for your participation in today's call and give a big thank you to our speaker, Ann Wyatt. I will now turn it over to Aryeh for some additional announcements.

Thank you.

Question & Answer Session

Aryeh Langer: Thank you, Michele. We will now take your questions. As a reminder, this event is being recorded and transcribed. In an effort to get to as many questions as possible, each caller is limited to one question, please. To allow more participants the opportunity to ask questions, please send additional questions specific to your organization to the resource mailbox on slide 38, so our staff can do more research.

Preference will be given to general questions applicable to a larger audience, and we'll be mindful of time spent on each question. All right, Dorothy, we are ready for our first caller, please.

Operator: To ask a question, press star followed by the number one on your touch tone phone. To remove yourself from the queue, press the pound key. Remember to pick up your handset before asking your question to assure clarity. Once your line is open state your name and organization. Please note, your line will remain open during the time you are asking your question. So, anything you say, or any background noise, will be heard in the conference.

If you have more than one question, press star one to get back into the queue, and we will address additional questions as time permits. Please hold while we compile the Q&A roster. Please hold while we compile the Q&A roster.

Again, if you would like to ask a question, press star then the number one on your touch tone phone.

One moment for your first question. Your first question comes from the line of Carol Bailey.

Aryeh Langer: Hello. Your line is open, Carol.



Operator: Carol, your line is open. There's no response from that line. One moment. One moment. Carol, your line is open.

Carol Bailey: Thank you. Sorry about that. I forgot to unmute it. Thank you for the presentation, it was all beneficial, especially my pet peeve which is the overuse of the antipsychotic. My name is Carol Bailey. I am, I started and own an LLC, Dementia Education and Training. I'm in New Orleans.

I'm wondering, my main premise is getting in training medical professionals, and then separately family workshop, on approaches to care that work. Because obviously, if we don't have the correct way to approach, a safe way and successful way to approach, we don't have real positive results. How much of that is being changed and implemented country-wide. Do you know?

Ann Wyatt: This is Ann and I'll just speak to a piece of that, and then Michele, you may want to add to that. But your absolutely approaches is completely critical and as I said very often rejection or sort of pushing away or discomfort comes from someone being either in pain or fearful.

And so, when you are assessing when somebody is comfortable or uncomfortable that each person, it's going to be a little different. Many people you need to approach them only from the front for example so that they can see who you are, and you can explain to them why you're there or whatever.

But approach is extremely important and is one of the touchstones of whether somebody is comfortable or not. And it's a clue, that's really right there, if someone is pushing you away or rejecting care, then the sign is very clear that they are in some distress and they're uncomfortable, so you have to take a step back and think leave them alone for a while and then come back and/or reconsider how the approach is being made.

Michele Laughman: Hi! This is Michele Laughman from CMS. I think what you were originally asking for, you know, as I've reported on data related to the use of antipsychotics, I think you're also asking for possibly similar data, but on the use of non-pharmacological approaches, and we really don't have data at this time that demonstrates the implementation of the non-pharm approaches to care.

I will say in depth, I have other co-workers here from CMS with me today. Deb mentioned to me—Deb Lyons—that, you know, it is an individualized, of course, that's really where it lies, as it's an individualized approach to care based on each resident's individual needs.

But at this time, we really don't have data to represent and what types or that percentage of non-pharma approaches that are being implemented on a national scale.

Carol Bailey: Okay. Thank you. And this is a response, sorry, a second question. Is there a way to submit our own data on the training approaches to care that we see then help the people come off the Seroquel, etcetera?

Michele Laughman: We don't really have a mechanism at this time to accept that type of data or run that type of data. So, I wouldn't say that there is an option for that.

Carol Bailey: Okay. Thank you.



Operator: As a reminder, if you would like to ask a question, press star then the number one on your touch-tone phone, that is star one to ask a question.

Your next question comes from the line of Carol Mace.

Carol Mace: Michele, this is directed to CMS participant survey agency. We just want to know when the next quarter psychotic use deck will be published.

Michele Laughman: Hi, Carol. This is Michele Laughman again. Unfortunately, I can't give a definitive date of when the next quarter will be released, it is working its way through clearance at this time.

Carol Mace: Okay, thanks.

Michele Laughman: Thanks for your question.

Operator: If you would like to ask a question, please press star then the number one on your touch-tone phone, that is star one to ask a question. Your next question comes from the line of Pamela Longmire.

Pamela Longmire: Hi, ladies. Thank you for the presentation. It was excellent. When I'm doing trainings, I frequently talk to nurses about rounding every 2 hours and waking residents. And I get a lot of push backs from this, and I'm really curious you mentioned the military study and the torture. Is there a link to that or a summary of that, that I could review?

Ann Wyatt: Well, I haven't -- I don't know if I've seen a specific written report, but I can tell you that the researcher who shared this information with us is Sue Ann Gilderman who is a nurse in I think Minnesota.

Pamela Longmire: Yeah, I'm familiar with Sue Ann.

Ann Wyatt: Yeah. And one of the things that we've noticed is that when people really are able to sleep, they do a lot better then. We had the problem early on in our program where we noticed that there was a tendency of staff to sort of bring everybody into the day room, and then to ask them to sit and not move and not go back to their rooms, because they were afraid if the person rested for a while and then got up by themselves and fell, got up by themselves and then they might fall.

And of course, one of the things we began to think through, and again it's not each person, you have to look always at the best solution for each person. But we realized that by telling people not to move and by not, you know, if they didn't get enough sleep, we were actually creating the conditions for them to...

Pamela Longmire: Correct.

Ann Wyatt: ...fall. So, that was the genesis of understanding that sticking to 2 hours without not thinking through some of the other consequences was very problematic.

Pamela Longmire: Yeah, right. And I guess the other part of this is I, like you; I encourage them to say what's their normal response. Because I think a lot of times what we call behaviors is a normal response. If you



started taking off my clothes to bathe with me, I would probably push you away. So, avoiding, you know, the word behaviors, but just encouraging CMS when they do their MDS, when they do their rules and regs, that they too would eliminate behaviors, just in reinforcing the culture change that we're all encouraging to make away from the word behavior to expression or distress, or even normal response to a given situation.

Ann Wyatt: We're going with distress.

Pamela Longmire: Okay, excellent. Thank you.

Operator: There are no further questions at this time. I will turn the call back over to Aryeh.

Additional Information

Aryeh Langer: Thank you, Dorothy. We hope you take a few moments to evaluate your experience with today's call. See slide 38 for more information. An audio recording and a transcript will be available in about 2 weeks at [go.CMS.gov/npc](https://www.cms.gov/npc).

Again, my name is Aryeh Langer. I'd like to thank our presenters and also thank you for participating in today's Medicare Learning Network event on Dementia Care. Have a great day everyone.

Operator: Thank you for participating in today's conference call. You may now disconnect. Presenters, please hold.