

COMMON CHALLENGES FOR BENEFICIARY CARE TRANSITIONS

Wanting to better understand the challenges that people face when undergoing care transitions, the Centers for Medicare & Medicaid Services listened to the stories of 46 people with Medicare and their caregivers. In recounting their experiences, people spoke of a broad range of obstacles they confront. Some of these obstacles were noted as not being unique to care transitions. This graphic depicts 11 insights, informed by this research, on the most commonly shared challenges.

When her mom needed a walker, she just went out and spent the \$500 because, "She didn't know how to navigate Medicare, and she didn't feel like dealing with the hassle."
- Caregiver of Person with Medicare



Off-Road Options

Not understanding their benefits, high cost, and a lack of convenience push people with Medicare to seek medication and durable medical equipment (DME) through informal and often unregulated channels.

"I had a hospital send me a bill for outpatient surgery [for my late husband] and I said, 'he's never been to this hospital and if he has I want to see a picture because he's been dead for 2 years.'"
- Caregiver of Person with Medicare



Lost in Transfer

Even when people with Medicare go to great lengths to track and document their health data, problems with Electronic Health Records (EHR) systems, privacy policies, provider collaboration, and human error make it difficult to maintain complete, accurate health records.

"Intimately, care-giving has impacted us. Literally every nook and cranny of our lives. Our decisions about where to live, our professional lives, decision not to have children."
- Caregiver of Person with Medicare



A Full-Time Job

Caregivers find themselves sacrificing career and personal aspirations to be readily available to provide care to the person they are supporting and to respond to the demands of insurance.

"I'm both the patient and the caregiver which is very hard."
- Person with Medicare



Surely You Have Someone

Many believe that Medicare is built on the assumption that people with Medicare have large support networks to lean on at all times. In actuality, more and more people today are acting as their own caregiver.

"The snow scared me to death...The State doesn't have a plan for dealing with dialysis patients during the snow...So it's on, it's up to you and your family."
- Person with Medicare



Coordination of Care

People with Medicare feel like providers often under-value the realities of how they live their lives and how these realities affect their ability to follow their care plan.

"But even with Medicare, you never know what things are going to cost... You're never told and you never really find out... Like my husband says, 'You go to buy a car and you know what you're going to be charged, and on medical you don't have a clue.'"
- Person with Medicare



No Clarity in Chaos

Coverage options create multiple decision points for people with Medicare. Even with a growing number of resources meant to help people with Medicare navigate the system, confusion is common, particularly when dealing with complex costs and coverage rules.

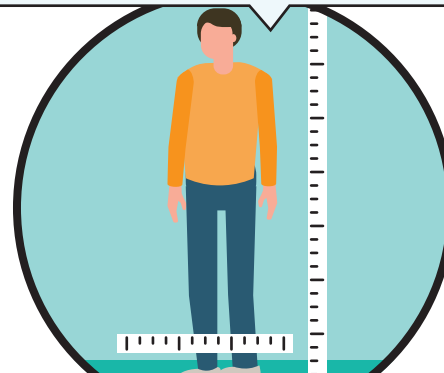
"I went home and got on the internet and figured out what I was pretty sure I had...I made the mistake of telling a doctor...He totally dismissed me. He had no interest in what I knew about my body that could have helped accelerate the diagnosis process."
- Person with Medicare



Dr. Google™

Doctors are no longer the single source of information that people with Medicare rely on to understand their medical conditions. Similarly, what the doctor suggests is just one of many opinions that people consider when making health decisions.

"I was a Medicare beneficiary due to disability. I found it rather unusual the way Medicare is administered and why if you are put on disability then you wait two years to qualify for Medicare. Generally, with an ovarian cancer patient, a two year wait is a long, long time."
- Person with Medicare



One Size Fits All?

Medicare often uses a one size fits all approach, and leaves people with specific needs such as people with disabilities and chronic diseases, people who speak English as a second language, or dual-eligible individuals, jumping through additional hoops to get the care they need.

"You know I've seen situations where doctors stand outside a patient's room and they have their meeting...Patients [are thinking], 'What are they talking about?' If a patient is truly part of the team, the meeting should be at the bedside. Then we get engaged patients."
- Person with Medicare



Count Me In

In contrast to the widely held belief that a shared understanding between providers and patients is about priorities, values, and goals as the basis of good care, people with Medicare largely feel like they are not being heard and are excluded from decision-making.

"Treat the whole patient! Treat the whole body and all its side effects. Keep the quality of life going. Don't just pay for the patient to be treated for the [lymphedema]. Buy the pump that will allow the patient to be proactive at home to keep the arm or leg usable."
- Person with Medicare



Snapshot Treatment

People with Medicare receive treatment based upon the symptoms they present in the moment, unless the patient or caregiver can advocate for inclusion of important information from the past or desired outcomes for the future.

"I'm on a large amount of opioids and when I was on morphine it numbed my brain, it was too hard to figure out Medicare and Medicaid."
- Person with Medicare



Diminished Ability, Increased Responsibility

During a care transition, the moments that require the most decisions often coincide with the times that people with Medicare have the lowest capacity due to stress, fear, or the side effects of medication.