



If you think Medicare will pay for long-term care, either at home, an assisted living facility, or a nursing home, think again.

Read the article below to learn of one family's unfortunate yet not uncommon story. Mozaic at Home can keep this from happening to you.

My Dad Was Diagnosed With Dementia. Medicare's 7-Word Response Baffled Me.

HUFFPOST PERSONAL by Kate Ferranti

"If your parents were poor, I would say don't worry about this. And if your parents had 2 to 3 million in their IRA accounts, I would say don't worry about this. But your parents are middle-class, and in this case, that's a problem."

An elder care lawyer said this to me when my father was diagnosed with Lewy body dementia. While navigating his care needs over the past six years and contending with the emotions of watching him slowly deteriorate, worrying about paying for care is a constant.

My parents are middle-class thanks to my father's union job, which provided a decent wage and a modest pension. When my mother went back to work, the company matched her 401(k) contributions. She put in as much as possible, scrimping in the short-term to plan for the long. It would be by no means a lavish retirement, but enough for peace of mind.

Three years ago, at 72, they started taking their 401(k) Required Minimum Distributions. The money provided an added cushion to their social security and pension income, and they seemed secure. What they didn't plan for was a catastrophic illness not covered by Medicare.

Like the majority of Americans, they don't have long-term care insurance because they could not afford the premiums. The cost of my father's memory care is rapidly depleting their nest egg. It is not clear what will happen to them when the money runs out — none of the options are good, which is a terrifying feeling.

If my father had cancer or heart disease, he would probably live at home with some home care covered by Medicare. But with dementia, an umbrella term used to describe everything from Lewy body dementia to Alzheimer's and much more, Medicare deems the needed care as "custodial" or "companionship" and says this care can be provided for by family members.

"We don't consider dementia a medical issue," a Medicare rep told me, to my great disbelief. But my dad's brain — which can no longer translate commands to his muscles — is not working properly, which certainly seems like a medical issue. He cannot take a shower, use the bathroom, take his pills, get dressed or walk unaided. He cannot be left alone. He cannot put together logical sentences.

My mother cared for him at home for as long as she could, but by mid-January, when we moved him to a memory care facility, her physical and mental health were giving out. I balanced helping them with my demanding career, which was exceptionally challenging.

"Families are in crisis, and no one is talking about it," said a friend who lives in New York and flies frequently to Michigan to manage her mother's dementia care.

I'm not a policy wonk or elected official. I'm not a medical doctor or a social worker. I'm simply a daughter who cares about her parents. And I'm a citizen looking around at our irrational health care system and feeling helpless, enraged and scared.

Here are some suggestions for how we might begin to talk about this crisis.

First, neurologists should mention financial planning at the onset of disease — especially when dementia can hit people in their 50s, 60s and 70s. My father saw two doctors, and neither mentioned long-term care or offered the help of a social worker. When I asked the second doctor about the prognosis, he brushed me off, saying, "My advice is to go home and live each day. Your father seems like a happy guy." When I later asked about home care, he told me to "Google Visiting Angels."



Because brain diseases are mysterious, doctors will not predict how long my father will live (and therefore, how much money is necessary). But doctors should warn families of the financial challenges particular to dementia care, especially when there is a spouse. There is living to plan for, even if that feels perverse while dying is taking place.

Second, policymakers should reconsider how Medicare can better support dementia patients. Classifying the care needs as non-medical companionship, especially in the later stages of the disease, is terribly misguided. Recently, my father lost his ability to walk and feed himself; we are told the next phase could be forgetting how to swallow.

The brain is our most vital organ — if it doesn't work, that is a medical issue affecting the whole body. My father is in a memory care facility where nurses and other staff trained in dementia provide treatment 24 hours a day. Families can provide assistance, but only to a certain degree.

Finally, middle-class families should plan for aging, sickness and death, even though it's hard to discuss. Having some basics in place — wills, powers of attorney, health care proxies, a trust for a home before a disease is too far along — is a good first step and way of starting a conversation.

Further, families should understand what long-term care covers and costs. The average cost of memory care in New Jersey, where my parents live, is an astounding \$8,150 a month. Those of us in middle age should start to plan for ourselves, especially since long-term care insurance is no longer viable for most people due to outrageously high premiums and caps on coverage.

My father is a gem of a human being, beloved by all who meet him. He and I are extremely close. He taught me how to swim, to hike, to ride a bike, to drive a car. He taught me to be curious, to delight in the ocean, to appreciate nature and fresh air, to love to

eat, to devour chocolate in all forms, to laugh at the silliest things, to give others the benefit of the doubt, to believe that most people in the world are good and kind, to be confident in myself and trust my decisions, and to be loving and grateful.

He is the most mentally healthy person I know, and to lose him this way — with his compassionate, calm, beautiful brain failing — feels particularly unjust.

Still, I cannot simply sit in this grief and just be present with him in whatever time we have left because there is always more research to do, more Medicaid planning to try to understand, more numbers to crunch, more lawyers to call, more anxiety to manage, more hoops to jump through while navigating a disjointed health care system. To couple this slow loss, this long goodbye, with extreme worry and uncertainty about my parents' finances — How many months or years will he live? Can we afford that? Will my mother be able to stay in her house? Where will she go if we have to sell it? — is brutal and draining and tiring.

Every time I visit my dad, our beginning is the same. He takes one look at me, registers who I am, and says, "I love you so much." This sentence is usually the only clear one I get. During those precious moments, I get to be simply a daughter. But the moments are fleeting, for the financial problems and stress are never far away. It should not be this way for me or my family, or for anyone. If illness can lead to bankruptcy, I'd say our system is broken.

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*Our Portability feature covers members anywhere in the United States.



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