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

"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."

Article and photo by Kate Ferranti, www.huffpost.com

"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.

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.

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.

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

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From One Caregiver to Another: No One Knows What We Do

We're family caregivers, you and I. And we're invisible.

By Connie Baher, excerpts www.nextavenue.org

My mom is 105, and I've cared for her for 13 years. So if you've been caring for your older parent, spouse, partner, or friend for the long haul, you know what I'm talking about.

It's a lonely job, caregiving. And no one knows what we do — day after day looking after someone, coping with daunting and sometimes incomprehensible medical issues, hoping that we're doing the right thing as we take on the vast, evolving and endless responsibilities of being someone else's caregiver.

Remember how it started? You offer to help with the groceries and drive them to their doctor's appointments. You bring them to your house on the weekends to watch a movie together and have a nice home-cooked meal. And then the job expands.

Now you're paying the bills and ordering the meds. And at your place, the guest room they used to stay in is currently empty. They can't climb your stairs anymore. So you find help at their home, and it may be time for them to move to a facility.

You spend hours looking for a good place, getting them a medical checkup and TB test, signing endless documents, doing your best to help your person make new friends, acclimate to the loss of their home and the smells and routines and privations of this new place to live.

So, we visit and listen to the problem list. We clean under the bed, find the scattered pills, and throw them away, and we quietly put a new package of Depends in their closet.

Next, we bring their clothes home to wash. It's indelicate. We have breached the line between parent and child, between spouses, partners, and friends — one should not be handling their undergarments.

We wake in the middle of the night, wondering if they are also awake, and hoping that they're not having another one of those frustratingly enduring sleepless nights.

We visit again, and as we leave their room (wondering if this may be our last glimpse of them alive), we take a parting look at them and the room itself. What simple thing should I do before I go — is there a box of Kleenex too far away to reach, a flip-top can of soda that should be opened?

What can I do so they are not left imprisoned by their inabilities? How terrible it must be for them, we think. What must it be like to feel life ebbing away, to suffer the indignities as their once strong handwriting has dwindled to uneven scratch marks, as their hands and legs become mottled with bruises because they're taking blood thinners, and everything causes a bruise?

We can never honestly know what the world looks like through their failing eyes, the panic that grips them in the middle of the night, the bewilderment, the fear, the helplessness.

We're just the family, struggling along. We stumble, pick ourselves up, go at it again, and try to do better. It's hard — no question about it — to look beyond the daily challenges, but if we zoom out for a moment, there is something else to see.

Amy Abrams, a San Diego social worker who has counseled scores of long-haul family caregivers, speaks of caregiving as a transformative experience. "Caregivers find inner strength and competence they would never have thought they had," she says.

There is the son who nursed his mother for four years, sleeping on the floor beside her bed. But then, he told me, "I discovered that weak as I thought I was, I have such a gift of adaptability, endurance, tolerance, patience."

There is the daughter who moved cross country to care for her mother: "I realized how lucky I was to spend time with her. To revisit the home that I was desperate to leave in my teens. I got to appreciate her and all she had been through. It gave me a purpose. So even though it was a mixed blessing, this has been a gift."

And then there is the simple gift of slowing down and spending time together. Occasionally, I have a slow, quiet visit with my mom. The chores have been taken care of, there's enough medicine on hand, we've got the TV working again, and we talk — mostly, though, I listen.

If no one knows what we give — and give up — as caregivers, perhaps also no one knows what we get. We get the chance to live out a unique kind of love.

Therefore, at this season of giving thanks, and as the country marks National Family Caregivers Month, here is a celebration of what we do as family caregivers.

Connie Baher is a writer and speaker on caregiving and re-imagining retirement. Her latest book is [Family Caregivers: An Emotional Survival Guide](#).

What is Respite Care?

By Marlo Sollitto, excerpts from www.agingcare.com

You care deeply for your loved one, which is why you dedicate time and energy to caring for them. Knowing you can be there when they need you comes with rewards, but it can also come with some challenges and drawbacks. Respite care, whether it's provided in the home or in a community, can help you find balance while caregiving.

The daily wear of providing hands-on care adds up. Caregiver stress can have detrimental physical and emotional effects that last long after one's role ends. According to a joint report published by AARP and the National Alliance for Caregiving, those who provide more than 20 hours of care per week are more likely to report higher physical strain associated with caregiving. Physical symptoms can include, loss of sleep loss of appetite, increased pain, and worsened headaches.

Caregiving also has a significant emotional impact, which can jeopardize not only your own mental health but also the quality of care your loved one receives. Emotional symptoms can include physical and emotional isolation, depression, exhaustion, anxiety, feeling perpetually overwhelmed, resentment, guilt, self-punishment, or self-denial. Left unchecked, these difficult feelings can lead to caregiver burnout and serious health issues. To prevent this from occurring, respite

should be part of your care plan. When you don't take care of yourself, you can't provide quality care for others.

Respite care services provide family caregivers a temporary reprieve from elder care responsibilities. Respite care can take place in the home or in a senior living community, and it can occur in the form of mental and emotional support. Building regular respite into a care plan is a healthy choice for caregivers and their care recipients. It can also make it easier to quickly arrange back-up care in emergency situations.

Your well-being may not seem related to that of your loved one, but it's actually very closely intertwined. If you don't take time to step away and recharge, poor performance and burnout can occur.

For some family caregivers, the hard part may not be admitting the need for rest. Instead, they may not know how to get respite care that will enable them to take a break.

There are many professionals, volunteers, and organizations that can help you locate the best respite resources for your unique situation.

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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. 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. 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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NOVEMBER is National Family Caregiver Month. In-home family caregivers have been on a journey of amazing love, loyalty, resilience, and perseverance and in the fight against isolation, loss, depression, and grief. It is scary to think about what we would have done without your ongoing financial support, volunteer dedicated hours of giving, and absolute recognition of caregiver needs. Our Nevada County community has stepped up in a big way, and we are so grateful for the outpouring of support.

BUT we are up against ever growing numbers of in-home caregivers needing help. And there is still much more work to do. The situation is truly critical. As you know, we are a small team. Would you join in and help us battle against the heartbreaking toll that caregivers suffer? If you give today, we will take the lead to accelerate the reduction of risks and maximize quality of care and support to in-home caregivers and their loved ones.

PLEASE SEND YOUR BEST GIFT POSSIBLE for those caregivers that we serve today and for all caregivers who will need our help tomorrow. Based upon your interest that you have taken in our work, put your compassion, interest, and understanding into action by making a generous gift now. Now more than ever, your gift will support and address respite needs of in-home caregivers, promote caregiver and volunteer education, and increase peer support with resources and referrals.

PLEASE HELP US TO REACH OUR \$25,000 GOAL. We are counting on you to help us meet this goal. If you would like to offer a MATCHING GIFT OPPORTUNITY, we would deeply appreciate your support. A donation by check may be mailed to PO Box 311, Cedar Ridge, CA 95924 or at the DONATE site through our website: empoweringcaregivers.org.

With deepest appreciation,
Carolyn Seyler
 Executive Director