NARRATIVE MEDICINE

WHAT DEMENTIA COULD NOT STEAL

Kirsten Johnsen Martin, DO, FAAFP
Director of Osteopathic Education, Family Medicine Residency Program
Penn Medicine Lancaster General Health

The morning after Thanksgiving in 2022, I helped move my mother into a secured memory care facility.

The contrast felt cruel. Just hours earlier, I had been surrounded by my husband's large family, stuffed full of turkey and all the fixings. Cousins had played together, while adults chatted or dozed off from the tryptophan surge and the sounds of football murmured in the background on the TV. The next morning, I was unpacking my mother's belongings in a new and unfamiliar space, one that I never imagined she would need.

Someone once told me that dementia is a terrible thief. At the time, I understood what that meant for them — someone grieving the loss of their own parent to dementia. But now I, too, live inside that truth.

Dementia has stolen my mother in pieces. Some days the process unfolds in slow motion, and other days bring sudden unmistakable change. But every year as Thanksgiving approaches, I feel that loss all over again. The holiday that once meant comfort and celebration now is associated with a different kind of remembering.

We had been told just two weeks earlier that my mother needed to transition to memory care. We should have seen it coming. Her confusion had worsened. She could no longer perform the simplest tasks of daily living, and she had started wandering in the early morning hours. The reality was that my mom's care needs had surpassed what my dad was able to provide on his own.

Even knowing that, the phone call felt like an ultimatum. And it left me numb and raw. Moving her was the right decision. Nonetheless, the messy emotional bundle of frustration and grief from the process still lingers even years later.

Fast forward to Thanksgiving 2025, another anniversary arrived. This time, I enrolled my mom in hospice care.

After years of relative stability, further evidence of her decline was apparent. She can no longer feed herself, although she will still eat if someone gently offers food to her lips. She especially loves ice cream, and watching her enjoy it reminds me of life's small pleasures. She sleeps much of the day and only rarely speaks. Her brain no longer reliably tells her feet how to move, so she depends on the assistance of two people to transfer from the bed to her wheelchair.

I am a family physician. I have spent years caring for aging patients and walking with families through the long journey of memory loss and the grief that accompanies it. I have tried to offer compassion, dignity, and honesty to patients whose lives are being rewritten by cognitive decline.

But nothing in medicine prepared me for watching my own mother disappear. While I understand dementia clinically, I did not until now know what it would feel like to become its daughter. The moment that shattered me came shortly before hospice care began. I gently removed her socks and saw pressure wounds on her heels. I had seen and treated wounds like that in numerous patients. I knew what they meant. But seeing them on my mother's frail body felt unbearable.

How had the woman who once cared for everyone else become so fragile that her own skin could no longer protect her?

As if losing my mother is not enough, dementia has begun to steal my father too. When my mother moved into memory care, my father faithfully visited her daily at 11:00 a.m. for lunch. For a long time, that ritual remained unchanged, but gradually his visits have become less predictable. Sometimes he arrives an hour or two early, sometimes not at all. If I call him after noticing he hadn't been there, he sometimes insists he has already seen her.

My phone alerts me whenever he leaves his apartment. AirTags tucked into his wallet and keys help me track where he is. Those small pieces of technology do not lie. They have become quiet witnesses to a truth I would prefer not to face — dementia is no longer taking only one parent. I find myself grieving the slow but steady loss of two parents.

After visiting my parents, I often sit alone in my car for the long drive home. No music. No one else sitting beside me. The silence feels more honest. I find myself more reflective than usual, and the weight of it all catches up to me — anger, sadness, grief, and most certainly fear.

I recall the joyful times of yesteryear around the holidays — Christmas trees the day after Thanksgiving, family outings, concerts, meals, traditions that once felt permanent. I think about what my parents imagined for themselves in retirement, and all the years I imagined with them: lunch out with my mom on afternoons off, Sunday hikes, family trips, my children growing older with their grandparents beside them. Dementia has stolen those futures too.

As a physician, I was trained to try to fix what is broken — to intervene, to treat, to help. Over time, I have accepted that I cannot always restore what disease takes away. I have told families that there is both power and comfort in attending to grief, that suffering feels lighter when it is shared. Yet in my own family, I feel utterly powerless and often very alone.

> *"Grief and gratitude can coexist. That may be the most important thing my mother is still teaching me."*

For a long time, I searched my mother's face for signs that she recognized me. I wondered whether she knew my brother, her grandchildren, or even my father. Now I no longer ask myself that question as often. She has not spoken my name in well over a year. Most days she speaks little at all, and when she does, her words dissolve into sounds I cannot understand.

And still, parts of her remain. Even after dementia changed her so much, my mother continued to extend care and compassion toward others. Before her illness, she served as a chaplain. The way she had provided pastoral care to many remained beautifully woven into her personality, changed by disease but still shining through. In memory care, she still reached for other residents, offering quiet companionship even when language was gone. The staff often told us she remained a joy.

I cling to that. I cling to the sparkle that occasionally appears in her eyes. The way she still responds to a familiar hymn. The unexpected word that sometimes emerges from silence. And the flicker of recognition that feels like a gift, even if only for a moment. Those moments are brief. But they are still hers. They are still ours to share.

Thanksgiving now holds more than gratitude for me. It also holds grief, anger, fear, and longing for what has been lost. I resent the years we will not have, and I mourn the ordinary moments that once seemed guaranteed.

But grief and gratitude can coexist. That may be the most important thing my mother is still teaching me.

Dementia is indeed a terrible thief. It has stolen memories, language, independence, the future my family thought we would have. It has taken far more than I ever imagined it would. But it has not taken everything. I will continue turning my focus toward gratitude for who my mom was, all that she taught me, how she cared for me and my family, and how she touched the lives of so many others.

Each Thanksgiving, I feel the ache of what dementia has taken from my family. I suspect I always will. But I am learning that gratitude does not require the absence of grief. Sometimes gratitude is simply choosing to hold tightly to what remains. And I am doing my best not to let dementia steal that too.

Kirsten H. Johnsen Martin, DO, FAAFP
Family Medicine Residency Program
Penn Medicine Lancaster General Health
540 N. Duke St., Lancaster, PA 17602
Kirsten.JohnsenMartin@pennmedicine.upenn.edu