

VOICES

How I took care of my partner with dementia and saved myself

People told me to put Alex in an assisted living facility. Here's why I didn't.

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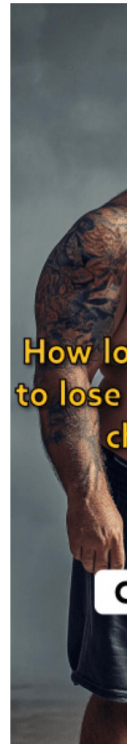


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Guest column by Sue Dickman
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In the months after my partner, Alex, was diagnosed with dementia in 2019, more than one person advised me to “save” myself. What they meant was that I should move Alex into an assisted-living facility and get on with my life. It wasn’t an unreasonable suggestion. Alex was 23 years older than me — 75 to my 52. Although we had been in a relationship for 18 years, we had lived together for less than a year. We were not married. He had two adult daughters. It didn’t have to be me.

And yet, I never seriously considered it. Alex’s diagnosis followed months of realizing more and more urgently that something was seriously wrong. It was as if we had entered a tunnel in which the only exits were into doctor’s offices



for tests and scans and increasingly concerned conversations. Along with the diagnosis, Alex was told he had to immediately stop driving and retire from his job as a therapist. We were thrust into a world of new doctors, unfamiliar terminology and multiple layers of bureaucracy. It required skill and smarts to navigate, qualities Alex no longer possessed. I didn't have time to plan an escape route.

But also, my longtime partner had just received a devastating diagnosis. I couldn't imagine racing to find a way out. What I imagined instead was going to visit him at a facility, and Alex asking when he could come home to me and our cats. I imagined facing this day after day after day. It hadn't even happened yet, and already I couldn't bear it. That was what it came down to: what I thought I could bear versus what I couldn't.

Besides, even if I had wanted to find somewhere else for him to live, Alex had no money. His younger self had always opted for the adventurous or interesting over the stable or lucrative. By the time we met, he had settled into a later-in-life career as a therapist and social worker. Eventually, he would qualify for Medicaid, but that turned out to be elusive. To be eligible for the programs that offered assistance at home, Alex had to qualify clinically as well as financially. This meant he had to need help with the most basic elements of everyday life — things like bathing and dressing. For a long time, he was able to manage these himself.

This left me completely torn. Of course, I didn't want him to get worse. But until he did, help was limited. I learned the hard way that there isn't an exact correlation between a person being able to perform daily activities and being able to live independently, or even be left alone for an extended period of time. A person could shower and dress himself and still, say, end up a half-mile down the road with one shoe on, chatting with unknown neighbors.

The pandemic complicated things even further. The bit of volunteer help we had evaporated and nothing replaced it. But as challenging as that was, I was grateful every day that Alex was not facing covid lockdowns in a facility, unable to see me or anyone from outside. I didn't want to be living alone with a person with dementia during a global pandemic. But the alternative still seemed worse.

Early in the pandemic, I made my own list, not of things Alex could or couldn't do, but things from our former life that we could still enjoy. The list was modest — only four items: drinking tea in the morning, going on hikes,

watching something on TV in the evening and taking the occasional day trip. This is the list that guided me through the long, lonely days of lockdown.

Even as Alex, the former athlete, no longer had the stamina he once had, we were able to walk in the woods near our house. Even as we used to bicker fiercely about which show to watch, we worked our way harmoniously through every season of every British, historical TV show I could find, from “Foyle’s War” to “Call the Midwife” to “The Crown.” In the midst of our “Call the Midwife” marathon, Alex once asked how many babies we’d seen being born. The only answer I had for him was “a lot.”

Inevitably, over time, things started to fall away. He began to put his shorts on backward and could no longer zip his jacket. Our hikes turned to meandering walks until even those were too much. He could no longer focus on a TV show, even his beloved “Foyle’s War.” He tried to eat salad with a spoon. His pleasure in his morning tea was the last thing on my list to go, and by then it was clear that I could no longer manage his care alone. Four days after he was finally admitted into a Medicaid program, he went into the hospital with pneumonia and what turned out to be a nasty tick infection. Six weeks, two hospitals, two rehab facilities and one covid outbreak later, he was dead.

What I think about now, more than two years after Alex’s death, is that there is more than one way to save yourself. Those well-meaning acquaintances had wanted me to be spared the hard work and heartache of taking care of someone with dementia. They’d wanted my 50-something life to continue uninterrupted. That isn’t what happened.

The silver lining, though, is that now I’m not consumed by things I wish I had done. I know, without a doubt, that I did everything I possibly could have. Even as Alex’s world shrank, we could still have tea together every morning and watch TV at night. He could still take comfort from our beloved cats. He could stand in the woods behind the house and look at the light on the trees. He could live with someone who loved him, even in his diminished state. In opting not to save myself from the burden of Alex’s care, I ended up saving myself from the burden of regret. And that is going to last me a lifetime.

<https://www.washingtonpost.com/wellness/2024/09/07/dementia-partner-assisted-living-caretaker/>

Tending to the escalating needs of my parents, especially my demented mother, was the hardest thing I have ever done. It was also the best thing I will ever do. It cost me a career and financial comfort, but my only regret is that I didn’t do it more willingly and better from the beginning.

TJB