

Alone Together

When a spouse develops Alzheimer's disease, the painful goodbye can last decades

By MERYL COMER

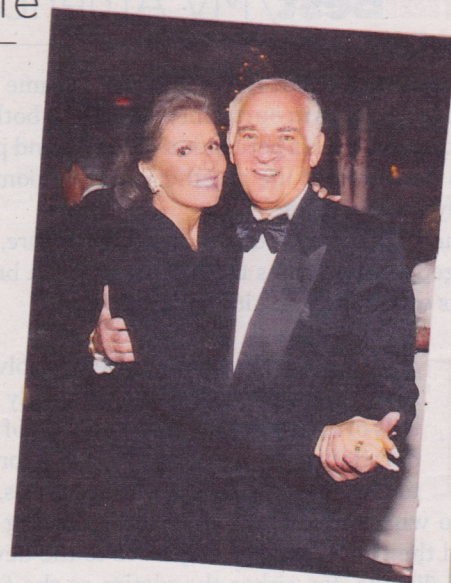
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he man I live with is not the man I fell in love with and married. My physician husband, with his athletic torso and steely blue eyes, has slowly been robbed of something we all take for granted: the ability to navigate the mundane activities of daily living—bathing, shaving, dressing and using the bathroom. His inner clock is confused and can't be reset. His eyes are vacant and unaware, as if an internal window shade has been drawn.

I am not sure when people at work realized that something was wrong with my husband, but I remember vividly how his behavior changed at home. This strong-willed man became upset when things didn't go his way. The slightest thing set him off. If he couldn't find his wallet, keys or papers, he'd accuse me of taking them. A once-eloquent speaker, he hijacked my son's wedding rehearsal dinner with a disjointed and inappropriate toast about a distant, dead cousin. When I mentioned any of this, he erupted in anger. In the face of his wrath, I went silent, infuriating him even more. These episodes usually ended with Harvey storming out, slamming the front door and driving off. It was painful, and it made me fear for my marriage. But my feelings dissolved into unconditional empathy in 1995, when I understood the cruelty of his diagnosis: early-onset Alzheimer's disease. He was 58.

Now I know that inexplicable anger is common in the early stages of the disease. The American Academy of Neurology reports that the pressures on family life due to Alzheimer's begin long before active dementia is apparent. People with early dementia start to fight the symptoms privately but are unable to articulate what is wrong. The stress on them and their loved ones is overwhelming.

At first, I ran interference for Harvey because it was the right thing to do. He was slipping out of control—



A delicate dance

The author and her husband, Harvey, at a 1982 gala

confused, childlike and helpless, his social filters stripped away. He shadowed me because I was familiar and safe, even when he could no longer remember my name.

I have always loved Harvey, but earlier in our marriage, he was often aloof and unreachable. He was a respected research hematologist and oncologist at the National Institutes of Health, and the truth is that his research and his patients took precedence over our family life. I grew used to his missing holidays, canceling vacations and rescheduling dinners with friends. In illness, unlike in health, he makes me feel needed and important to him.

Harvey's work as a doctor—the scaffolding of his identity—unraveled over several years. When confronted about a lapse, he told colleagues that he was not feeling well and had already been to the doctor. This wasn't true. Harvey continued to refuse my entreaties that he see a doctor. And when he finally agreed to go, I learned that doctors tend to avoid giving an Alzheimer's diagnosis, preferring to rule out other conditions first. It took two and a half years of inconclusive doctors' visits before we had a name for his disease.

Neither a scientist nor a neurologist myself, I have now spent close to two decades trying to get inside my husband's head. How hard and unfair it is for such a smart man to lose pieces of his intellect and independence as the circuitry of his brain misfires and corrodes. No new short-term memories stick: His internal navigational compass has shut down. His disease is my crossword puzzle. But there's no solution. There is not a single FDA-approved drug that even slows the progression of Alzheimer's disease, let alone reverses it.

Harvey has long forgotten me, but I am constant as his copilot and guardian. Every conversation we have is inclusive and respectful, even though he is often unintelligible or mute. It is a charade that never ends. The demons

and terror of his world define mine. When he became unable to navigate the stairs in our home, I moved us both to the first floor. I play into his perception of reality and pretend that his fate and our life together are not doomed. Unfortunately, I know better.

My bookshelf is lined with tomes on dementia care, yet the page I need always seems to be missing. Each brain unravels in its own quirky and idiosyncratic way.

Many times, personal stories involving Alzheimer's gloss over the unseemly details of care. They are told as stories of unquestioned devotion or living memorials to the patient. Why not? As caregivers, we deserve to do whatever works for us. But softening the edges around the truth does not do justice to the devastation of the disease, for either the victim or the family. I used to avoid sharing the details of the dark side of Alzheimer's because most people don't want to hear them. Unprovoked and paranoid, Harvey has tried more than once to choke me from behind. During an early stay in a psychiatric hospital, while I was bathing him, he hauled off and punched me so hard that my mouth gushed blood. He seemed confused by the sound of my crying, but he never unclenched his fist. Those experiences are part of the reality of Alzheimer's for me.

Early on, I attempted to place Harvey in a residential facility, but because of his violent outbursts and inappropriate behavior, we were asked to vacate almost immediately. Private-duty, round-the-clock nursing was prohibitively expensive and hadn't solved the problem, so I brought him home. When I say that I (and a trusted team of aides) have cared full time for Harvey in my Maryland home ever since, many ask me why. Even now, there is always an initial reflex that makes me want to say, "Do I really need to explain myself after all I've been through?"

I realize that the question is a natural one, a human one, a social one. The interlocutors are not judging me but rather vicariously checking themselves. In questioning me, they are testing their own capacity to deal with a diagnosis of Alzheimer's disease and the potential impact it might have on their relationship with a partner or parent.

For Alzheimer's distorts and destroys the memories upon which intimacy is built. Birthdays and anniversaries become forgotten, irrelevant dates. Losing this shared history can create a deep emptiness in the person who

remembers; often I have felt as if I didn't even exist. We caregivers are like hurricane survivors, sifting through the rubble to rescue storm-drenched photos.

When people hear my story, they sometimes tell me they wouldn't keep their loved one at home. I never hold myself up as an example to follow. No one who has been on the front lines of care ever questions when someone says, "I can't do this anymore."

But I do want to be part of the last generation of caregivers trapped by a loved one's diagnosis, no disease-modifying therapies and a troublesome lack of quality-care options. Alzheimer's disease today affects a reported 5.2 million people in the United States; every 67 seconds, another of us falls victim. My greatest fear is that by mid-century my family's story will be the norm.

Sometimes I think we would be better off if Alzheimer's disease were a brand-new emergency instead of a century-old threat. Perhaps people would understand that when it comes to this disease, everyone is a stakeholder, because everyone is at risk. Those of us 50 or older must stop viewing ourselves as ageless. Denial won't protect us from Alzheimer's.

Researchers must get ahead of the disease by studying adults who do not yet show symptoms. People like you and me. And, as exhausting as it is to take care of someone with dementia, caregivers must gather the strength to tell our stories and demand the funding and research focus needed to finally generate some treatments that work.

Our sons and daughters deserve better options than the ones we have faced. They shouldn't be bankrupted by caring for the coming legions of Alzheimer's patients. Nor should their grandchildren remember their homes as blan-

keted by sadness, the way my own beloved grandkids will surely remember mine.

As I write these words, a faint glow fills the room I share with Harvey. He is always present, even though he is absent. There is an intimacy in our isolation. Nonetheless, I have opened the door to our room in the hope that you will find a way inside. Only then will our story be worth the pain of its telling. ■



"I want to be part of the last generation to be trapped by a loved one's diagnosis."

—Meryl Comer, Alzheimer's advocate

Meryl Comer, a former broadcast journalist, is president and CEO of the Geoffrey Beene Foundation Alzheimer's Initiative. This essay is adapted from Slow Dancing With a Stranger: Lost and Found in the Age of Alzheimer's by Meryl Comer. Copyright © 2014 by Meryl Comer. Reprinted by permission of Harper One, an imprint of HarperCollins Publishers.