

The Quiet Rage of Caregivers

Looking after a sick family member can mean putting your own life on hold, often with little recognition or outside support.



By Catherine Pearson

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Ann Brenoff didn't worry when her dogs returned from a walk without her husband in 2015. He often dropped their leashes and let them race up the steep driveway to their home in the canyons of Los Angeles. "But after 20 or 30 minutes, we said 'OK, where's Dad?'" said Ms. Brenoff, 73, whose two children were then teenagers.

They found him lying at the bottom of the driveway. He had collapsed walking up the street and crawled home. Ms. Brenoff's husband was soon diagnosed with acute kidney failure and needed round-the-clock care.

Three times a week, she made the hourlong drive to his dialysis appointments or arranged for someone else to take him. She cooked separate meals so he could follow a special diet, and squared off daily with their health insurance company. She learned that a bit of Vicks VapoRub under her nose helped mask certain odors as her husband's condition deteriorated.

"You wake up one day and realize you're not a partner and a wife anymore," Ms. Brenoff said. "You're a full-time medical case manager." She stopped seeing friends and gained 20 pounds. Her blood pressure climbed.

And she got really angry.

Around 53 million Americans are caregivers for a family member or friend with a health issue or disability, and nearly a third spend 20 or more hours a week in that role. The Centers for Disease Control and Prevention, which calls caregivers the "backbone" of long-term home care in the United States, has warned that caregivers face many risks — anxiety and depression, chronic health conditions and financial strain, to name just a few. Yet experts said many caregivers feel they cannot speak openly about their frustration and anger.

"The stress is just monumental and constant," Ms. Brenoff said. "I was pissed off."

Ms. Brenoff's husband needed to travel to kidney dialysis three times a week and eat a special diet. It fell to his wife to juggle it all. Mark Abramson for The New York Times

"There's this myth of the loving caregiver," said Allison Lindauer, an associate professor of neurology with the Oregon Health & Science University School of Medicine. But she and other experts said that anger and frustration are inevitable parts of the caregiver experience, and that it is important to normalize those feelings.

"There is a lot of stigma," Dr. Lindauer said.

A loss of control

Allison Applebaum, the director of the Caregivers Clinic at Memorial Sloan Kettering Cancer Center and the author of the forthcoming book "Stand By Me," said that among the 4,000 or more caregivers she has worked with, she has yet to meet one who has not expressed some form of anger.

Often just beneath that anger is a "deep well of sadness," Dr. Applebaum said. Many caregivers feel powerless, she said, and take on the role out of necessity or a sense of duty. They have little control over what happens to the person they are caring for, or to themselves.

"Many caregivers can't plan for the next day or week, let alone the next month or year," she said. "And that's maddening."

That has been a source of frustration for Heidi Warren. For more than eight years, Ms. Warren, 48, has been a full-time caregiver to her mother, whom she lives with in Greenville, Pa. Her mother, 76, had complications from spine surgery in 2015 and developed chronic pneumonia, which has landed her in the hospital more than 30 times.

Recently, her mom has been doing better. But when Ms. Warren was in her early 40s, her mother's needs were unpredictable. "I essentially had no social life," she said. She would make plans to see a friend in the evening, only to come home and find her mother in respiratory distress.

"No two days are the same," Ms. Warren said. "There are times when it's like, OK, well, I planned to do this today, but now we're at the E.R."

The pair are best friends, "so it's a labor of love," she added. But many caregivers don't share that bond.

"Not everybody loves the person they care for," Dr. Lindauer said.

Making an unrecognized sacrifice

John Poole, 39, became a caregiver in 2014 when both of his parents had strokes within a month of each other. One of his main sources of frustration was the feeling that the health care system did not always take the work he did as a caregiver seriously — even as he took on some of the tasks a skilled nurse might perform, like administering medication and managing tube feedings.

"The first year or so was very chaotic in the sense that I was just learning as I went," said Mr. Poole, who lives in Sicklerville, N.J., and had to leave his job in state government because of the demands of caregiving.

He did not qualify for state Medicaid programs that would allow him to get paid for his caregiving work. And though he had family help with some of the practical, day-to-day responsibilities, he sometimes felt as if well-intentioned outsiders suggested fixes without understanding the complexities of caregiving in the United States.

"A lot of people's frustration — I know mine — was that you're doing very valuable work that is really not recognized by the outside society," Mr. Poole said.

Finding support through connection

Long-term caregiver stress has been tied to health issues, like diabetes, arthritis and heart disease. Given that, Dr. Applebaum advises caregivers to address the physical effects of anger, whether through breathing exercises, a hot shower or a run — whatever helps. Sometimes, she said, caregivers need a private place where they can just scream.

Every person interviewed for this story mentioned the power of peer support as well.

Jennifer Levin, 42, started a Facebook support group for millennial caregivers seven years ago, after caring for her father. He had progressive supranuclear palsy, a degenerative condition similar to Parkinson's disease.

"You have the baseline of a common experience, and so you don't have to explain where you're coming from with this anger," Ms. Levin said. "A lot of times, I think people worry if they express it to somebody who doesn't totally get it, that it will overshadow the totality of their experience."

Still, she said, there is a limit to how comfortable some people feel sharing, even in a closed forum of peers. "A lot of caregivers are afraid to express their anger, because they feel guilty."

Ms. Brenoff's husband of 15 years died in 2017, after 18 months of "misery." Before he died, she found solace in another Facebook group for caregivers, which observed Throat Punch Thursdays. "That was the one night that you could sign on and say you wanted to scream at somebody," she said. She has since remarried and written a book about her experience:

“Caregivers Are Mad as Hell! Rants From the Wife of the Very Sick Man in Room 5029.”

Though most people have responded positively to her speaking and writing about her anger so openly, it has not always been easy.

“There’s a lot of shame if you dare to say to somebody: ‘No, this actually isn’t rewarding. This isn’t what I signed up for,’” she said.

Audio produced by Kate Winslett.

Catherine Pearson is a reporter for the Well section of The Times, covering families and relationships. More about Catherine Pearson