

Caring for a Loved One with Alzheimer's Can Be a Test

Guest Column by Johnny Burchett



Johnny Burchett by Vera's side — living the story behind the words

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No one should face Alzheimer's alone, guest columnist Johnny Burchett writes.

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June is Alzheimer's and Brain Awareness Month, offering an important reminder to focus on brain health and raising awareness for early detection of Alzheimer's and Dementia. Alzheimer's disease is devastating—not only for the more than 6 million Americans living with the disease, but also for the 11 million family and friends serving as caregivers. According to the Alzheimer's Association, there are more than 135,000 unpaid caregivers living in Oklahoma.

I am one of them.

My wife, Vera, is living with Alzheimer's disease. After six years of marriage and 12 years of knowing each other, we are on a journey we never imagined. Our lives took an unexpected turn when Vera was diagnosed with Alzheimer's disease in 2020. Vera's battle with breast cancer, which she faced with remarkable strength, was merely a prelude to our encounter with Alzheimer's. Initially, we attributed her memory lapses to the aftermath of chemotherapy or menopause, but it became clear that something more serious was happening.

The initial diagnosis came from a reputable doctor, but his lack of empathy and bedside manner compelled us to seek a second opinion. We hoped for a different outcome, but the verdict remained the same. Vera, a talented accountant, fought to continue working for a year after her diagnosis, but her cognitive decline eventually made it impossible for her to perform her job.

Many family caregivers like myself juggle competing priorities, including work and providing around-the-clock care for their loved ones. To ensure Vera's safety and well-being, I made the difficult decision to resign my job, which resulted in a devastating loss of income for both of us. Now, I have embarked on a journey to build an online business, determined to support us while also being her caregiver.

Navigating care for a loved one with Alzheimer's is hard enough and is made even more challenging when access to care is limited. Early detection and diagnosis of Alzheimer's and dementia offer individuals and families important benefits, including access to treatments, as well as clinical trials, but patients need to see a physician to get the diagnosis and get started.

When Vera had cancer, we were bombarded with appointments and phone calls, and the doctors knew exactly what to do. When she was diagnosed with Alzheimer's, it felt like no one quite knew what to do. After reconfirming her diagnosis, the doctor gave her some pills and said, "See you in six months." Once in Oklahoma, I called every neurologist I could find. All of them said they weren't taking new patients or did not provide care for Alzheimer's patients. It took about six months to find a physician.

My journey has inspired me to act. As an Alzheimer's Association volunteer advocate, I am working to change the narrative for caregivers and patients. I am advocating for better access to care, Medicare coverage for FDA-approved treatments, and public support for caregivers like myself. No one should face Alzheimer's alone. I don't know how much longer Vera and I will be on this journey, but I will do all I can to fight for her and make sure she receives the best care possible.

I implore others who find themselves caring for a loved one with Alzheimer's or dementia to remain calm, loving and patient. It is a test of endurance and devotion. I pray for my own health, knowing that I must stay strong in order to care for her. Together, we strive to embrace the present, cherishing the love we share in the face of adversity.

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