

Teen Caregiver

*By Lindsey Jordan,
who is 16 years old and lives in Southern California*

My childhood is filled with so many wonderful family memories. My dad was a health-care professional and taught at various colleges. My mom worked part-time, and I was blessed and lucky to be a working actor and singer. My mom and dad introduced me to volunteerism when I was very young. Over the years, I learned the importance of bringing hope and happiness to others and feeling very fortunate every moment for all that I had. I learned and believed that together ordinary people could do great things.

But nothing in my life prepared me for Alzheimer's, the unforgiving and relentless disease that stole my dad's memories and robbed us of a lifetime of adventures.

Dad began showing signs of dementia in his late 40s. In 2002, when he was only 51, he was diagnosed with younger-onset Alzheimer's disease. I was 8 years old when Alzheimer's chose me to be a caregiver. (I'm 16 now.) It didn't care how old the patient or caregiver was.

Caregiving is a 24-hour-a-day job, and I helped Mom wherever I could. As a young child, I remember helping Dad get dressed, tying his shoes and preparing his breakfast, all before I went to school. I often held his hand so he wouldn't wander and get lost. I worried when he did. To calm both our fears, I often read and sang to him. All the simple things we took for granted became much more difficult.

When I was a child, Alzheimer's meant my dad was sick. Now as a young woman, my knowledge of Alzheimer's has led me to understand the harsh reality of this disease. My biggest sadness comes from knowing that this Alzheimer's has already taken my dad from me. Although I know he will always be with me in my heart, the reality is that my father will never see me reach those special milestones in my life, and I will never get to see the love and pride on Dad's face as I realize my dreams. He won't see me graduate

from high school or college. He won't be by my side walking me down the aisle or smiling as his grandchildren take their first steps.

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Although I try to be strong, it has been extremely stressful and absolutely devastating to watch what this disease has done to my dad, my family and our friends. I wish no one ever has to learn firsthand what it's like to struggle financially because of this disease or shed tears of frustration and pain because they are worried about their loved ones and their own future.

As for me, I find comfort in being an Alzheimer advocate. I participate in Alzheimer's Association Memory Walk®, give speeches and coordinate Alzheimer awareness events. I have had the opportunity to travel to Sacramento, Calif., and Washington, D.C., where I've shared my story with our elected officials and have asked for their continued support in the fight for a cure.

Sadly, my dad is in the final stages of Alzheimer's. His once warm eyes stare blankly at me now. He's unable to remember I am anyone he knows, let alone his daughter.

My dad's legacy of goodness and compassion live within me. Although his memories are long gone, I still remember.



Lindsey Jordan with her dad Charles.

afraid to take him too far from home. Friends visited. They came to Daddy when he could no longer come to them. That's one of the luxuries of living a long time in a small town. Still, their world shrunk as Daddy became more and more housebound.

Watching Mother look after Daddy, it was clear to me that caring for a loved one suffering from Alzheimer's is a burden that cannot be carried alone. My mother was fortunate she was able to hire help. Friends and acquaintances would call with the name of someone who had assisted one of their relatives, and so she found a man to come in each morning to help Daddy bathe and dress, and she had other people who came through during the day to help.

I always felt bad that I wasn't able to pitch in more, especially in the last months of Daddy's life, because they fell during George's campaign for governor. Looking back now, I see other things I wish we had done. Daddy always loved music. He loved Glenn Miller, Glen Campbell and Jerry Jeff Walker's "London Homesick Blues." I wish we had played more music for him during those last few years. Brain researchers say that songs are imprinted in our memories longer than many other things.

It wasn't until after Daddy was gone that we realized what a weight his illness had been. About a year after Daddy died, Mother told me that she felt well again. She said she realized then how the constant vigilance of caregiving had left her feeling almost physically ill. As the burden of caring for Daddy was lifted and her own sense of well-being returned, Mother was able to focus on parts of her life that had been on hold. She began to tend to the house Daddy had built for her: reupholstering the chairs, replacing the drapes and fixing the myriad things that had gone unrepaired while Daddy was in decline.

Alzheimer's and dementia in general are often called "the long goodbye," but to me they are "the sad goodbye." So often, as with our family, we don't say goodbye when we can. We don't recognize that moment when the person we love still knows enough, still comprehends enough to hear our words and answer them. We miss that moment, and it never comes again.

I'm grateful for ongoing efforts to bring about a future in which our children and grandchildren will not have to worry about missing that moment. Without action, it's expected that Alzheimer's will claim the lives of more than 16 million Americans by 2050, and someone will develop a new case every 33 seconds—twice as often as today.

We've seen so much progress in our battle against stroke, cancer and heart disease. The same can be true for treating and curing Alzheimer's. Greater dialogue will lead to greater awareness. Purposeful investments can stimulate successful research. And together, we can help bring an end to heartbreaks caused by the sad goodbye.