



My journey from darkness to light

Caring for my dad for 14 years was the toughest thing I've ever done. But I'd do it all over again

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My father, Ralph Henderson, was always a difficult, controlling man who became even more so after my mother died in 1986.

He treated me badly, abusing my love and my time. His spinal arthritis, which would eventually cripple him, was progressing quickly, frustrating him even more.

In response I did the only thing I knew how at the time to preserve myself: I raged at him, but I raged in silence. I knew I was being hurt unjustly and I resented it.

Finally, my father was diagnosed with vascular dementia and probable Alzheimer's disease, which helped explain his increasingly erratic behaviour. No one sat me down and told me what this was going to be like. Was I lucky not to know?

After suffering a broken hip, surgery and then a major stroke, Dad was at war with everything and I was caught in the middle. The telephone became an instrument of torture. His verbal and emotional abuse wore me down completely.

The next two years were a blur of rushing to my father's home, where he lived with a housekeeper, to reassure him I had not abandoned him. I didn't understand dementia then – how it was changing my father's view of the world and how it would completely change my reality.

Finally his condition became too difficult to manage. After yet another major stroke, he waited in hospital for three months to be placed in a nursing home.

As his dementia progressed, he smiled more, he cried more. He softened. Now I better understood who he was becoming. When he had his first major stroke – likely after many smaller ones – I was the only one who could approach him and calm him in the hospital, as he suffered from terrible confusion and fear.

Later, when I'd walk into his room, his face would absolutely light up. It lit up only for me. I had become his whole world, his protector, his security. It was an incredible responsibility but also an unbelievable gift.

Caregivers are fortunate because we have the opportunity to learn how deep love can be.

I finally did and I started to change. For some reason, God gave me the strength to move beyond the old hurts and become the person my father needed me to be. Somehow all that mattered to me was that my father knew he was loved absolutely; that he was secure.

I learned that it was not worth it for me to remain angry or bitter. I saw an old man suffering more than any person should and I was lucky enough to be able to respond. I reconciled with my father. I forgave him and I forgave myself.

And I learned one wonderful lesson with the help of Oreo, a dog I rescued her two years before my dad died. As I got to know her, I realized that there were similarities between my dad and my dog.

The most outstanding: Oreo lives for the moment: for the walk she sees coming, the treat in my hand. She has no concern for yesterday; tomorrow does not exist. And I realized that people with dementia also must live in the moment. And so we caregivers, too, must live for the now, not for yesterday's sorrows or tomorrow's losses.

Shortly before my father died, I began to relate to him in a different way, on a different level. I brought my Bible with me on visits, the Bible he had given me when I was 12. I read hymns and psalms, especially the ones I knew and had grown to love.

I began to understand what walking through the valley of the shadow of death meant. I was walking there with my father and somehow he was leading me without words to a place where both of us could find comfort.

But as I sat beside his bed near the end, I was panicking. When would he die? How would I know when it was time? What should I do? Could I do it?

Hours before he died, I walked home for a brief break and went to my computer for answers. I found a small hospice's website that listed in plain language the signs and symptoms of approaching death. Tears poured as I read about how the body of the dying person begins to shut down; how the spirit begins the final process of release from the body in readiness for the next dimension of life.

I began to understand what I had already witnessed in my father – the change in skin colour and temperature, the changes in his breathing. The words were simple and beautiful. They comforted me as no person had done.

Even though my father once admitted he was not afraid to die, I didn't want to hear about death. I didn't let him tell me what he needed to say, what he wanted me to know. I thought there was lots of time to discuss what I did not have the courage to face.

I said to myself: "It's too early. We don't need to talk about death. Don't alarm him."

I was wrong. It wasn't too early. I didn't understand dementia then or how insidiously it claims its victims. I ran out of time.

Caregiving until the end of life leaves few untouched. In most cases, the death of a loved one allows caregivers to heal and move forward, wiser in the knowledge that the circle of life continues as it always has.

Dementia, however, imposes its own set of unique sorrows upon caregivers because when the dementia journey is supposed to be over, it's not over.

After this unspeakable injustice has robbed us, daughters and sons, of those we love, after we are finally able to shake off the shock, the fatigue and the disbelief over what we have managed to live through, what remains is the dark terror that we will follow in our parents' genetic footsteps.

If a little knowledge is a dangerous thing, what will too much knowledge do to us, year after year after year?

My regrets: I wish that my father and I had talked about things like doubt and despair and missing the ones we loved and lost. Parents need to talk about the loved ones they have lost – a spouse or a child. It helps us all heal.

The 14 years I spent caring for my father changed me forever. It was the toughest thing I've ever done.

But I would do it all over again because it allowed us to journey from rage, hopelessness and despair to understanding, acceptance and forgiveness – from darkness to light.

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