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A Huntington's warrior lays down his shield

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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SUNDAY, APRIL 26, 2009

A Huntington's warrior lays down his shield

My father, who is 81 and ailing, was one of those unsung Huntington's disease caregivers who quietly dedicate themselves to a spouse.

I think of him as a Huntington's disease warrior.

No matter how bad my mother's HD symptoms got, he met the challenge every day. He cared for her from the early 1990s until she went into a nursing home in the late summer of 2005, and he visited her at the home every day and fed her lunch until she breathed her last breath on February 13, 2006.

Complete dedication

In retrospect, my father might have learned more about HD and found many other ways to help my mother, but as a companion and caregiver in the home he was completely dedicated. As he watched HD inexorably destroy her body and mind, he gradually took over all the household responsibilities and stoically and lovingly saw to all of her needs. He got her up in the morning, dressed and groomed her, put on her lipstick, prepared three meals and spoon-fed her, assisted her in the bathroom, and bathed her.

My father told me once that she was the only woman he had ever slept with. Although he could be crotchety and domineering at times – what men in his generation weren't? – he showed her unquestioning love and loyalty.

Whenever he went out, he took her along, no matter how long it might take to get her ready or how difficult it might be to get her in and out of the car. One image forever burned into my memory is of the two of them leaving a restaurant that had a heavy entrance door. As she shuffled her way through, with him trying to guide both her body and the door, she lost her balance. Her body swiveled and then flopped to the ground, thumping on its side like a wrestler knocked to the mat. In the final months, she was in a wheelchair.

My mother was only 68. Had it not been for HD, she might have lived well into her eighties, as had both her mother and maternal grandmother. And she could have helped care for my father, who was ten years older.

Signs of decline

In the last few years before her death, my father started to show some of the usual cognitive decline that comes with aging such as forgetfulness and confusion, but he kept both himself and my mother going.

Not long after she died, however, he told me, "It won't be long before I follow your mother."

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[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

My father had lost his reason for living. Last year, as his decline accelerated, he moved into an assisted living facility ([click here](#) to read my entry about the process).

Rapid descent

Since then, he has gone downhill even more rapidly. One day in late February he walked out of his room looking for my mother. The head caregiver had to take him aside for a long talk and explain patiently that his wife had died.

In March I flew to my hometown to spend a few days with him at the facility. He was in a so-called “memory care” unit for people with severe cognitive loss. He cannot leave the unit without a family member or caregiver.

It took my father a while to grasp fully that I was his son. He now has no memory of my mother’s death from Huntington’s disease. In fact, he no longer knows what HD is. Perhaps that is a blessing. Walking just a few yards tires him. Once it took him several minutes to lift himself up from the couch. I had to coax him to eat and drink.

Glimpse into the future

As I spent time with my father and tried to improve his care, I was reminded painfully of my mother’s demise. And I got a probable glimpse into my own future in a care facility if an effective treatment or cure for HD is not found soon. I tested positive for the HD genetic defect in 1999, and I am now at the very age when my mother’s symptoms started.

On April 18 my father became severely dehydrated and was admitted to a hospital. When I called on the phone, he could barely speak. On April 23 he was transferred to a rehabilitation facility, where physical, speech, and occupational therapists will attempt to revive his health to the point where he can return to the assisted living home.

I had a difficult time this past week thinking of my father. For a couple of nights I slept poorly because while I thought his death might be imminent.

A stroke and painful transitions

I’ve thought about how lonely it must be for my father in the rehab facility. The transitions have been many and brusque: from losing his wife to losing his car and home to losing now the last semblance of a home life, with yet another group of strangers in charge of his care. The rehab nurse told me on April 24 that he had trouble remembering his name and mentioned that his doctors had listed a stroke as a possible diagnosis.

Today my cousin and uncle visited my father and were told again that he had had a stroke. My cousin wrote in an e-mail: “I fed him a cup of ice cream. No way he could have fed himself.”

On the night of the 24th I opened several e-mails from the real estate agent hired to sell his condo so that he has sufficient funds to pay the very expensive monthly fee at the assisted living. In one of the messages, I clicked on a link that took me to a virtual tour of the one-floor condo, where my parents had moved when my mother’s symptoms made it too risky for her to continue in the split-level home where I grew up.

The video camera zooms in and out as it travels through each room of the condo. I can see the bathroom where they spent so much time together struggling to overcome what HD had done to my mother’s mind and body. I see the bedroom where he slept alone, the kitchen counter where he fed her, the family room where he spent countless hours reading the paper, watching TV, and talking to her as she sat silent and motionless in a chair.

I also see the bed where my mother slept – the bed where HD ravaged her brain. Whenever I visited my dad after my mother's death, he offered that bed to me. I shuddered at the idea of lying down in the same spot where my mother slowly lost the last of her cognitive abilities. I could not bear to think that I might become like her. I refused to sleep there.

Watching the video was an eerie and completely unexpected experience. Nobody is in the picture, and some of the furniture is gone. Everything is tidy.

The cycle of life continues. The old Huntington's disease warrior who fought so many battles for his beloved is now laying down his shield.

Posted by [Gene Veritas](#) at [10:28 AM](#)



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