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Seeing Mom (Part I): falling down

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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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THURSDAY, MARCH 24, 2005

Seeing Mom (Part I): falling down

My mother cannot walk anymore.

That was one of the stark outcomes of Huntington's disease that I witnessed during a four-day visit to my hometown to see her and my father.

When I visited in early 2004, she could still shuffle her way for a few yards. But this time my father had to help her with every step. Each movement was painfully deliberate and slow. Sometimes she used a walker, but it did not help much.

When my father, my four-year-old daughter, and I went to another room for just a minute, my mother got up from her chair. We heard her fall and rushed to check on her. My father nearly broke into tears in a fit of anger and frustration as he bent over her and asked why she had tried to leave the chair on her own. Silenced by HD, she could not explain. She wanted, of course, to be near us. A few seconds later she nearly fell again as my father maneuvered her to a couch.

The next day my father was helping her out the door of a restaurant. Her 160-pound body went twisting to the ground. My dad and I had to help her up and into the car.

The strength and coordination have completely left my mother's legs, now flimsy as rubber. She can no longer stand on her own two legs, that most basic part of humanity. I had to help my father get my mother in and out of the car and in and out of her wheelchair. Every couple hours my father asked my mother if she needed to use the bathroom. My dad asked people to stand guard at the bathroom door while he and I guided her in, took off her coat, and positioned her in the stall. It took my mother a long time to understand that she should put her hands on the grab bars.

As I looked at my mother, I feared the terrible impact this scene was having on my daughter. I worried about my dad, who struggled to maintain his patience as he gave instructions to my mom in the way he might speak to a child. I was angry and horrified at her total dependence on others for the simplest tasks. She could not even do what a two-year-old could.

Last year my mother broke her wrist after a fall. A couple months ago my mother fell during the night and hit her head on a nightstand. With blood running from her scalp, my father called 9-1-1. At the emergency room she received seven metal staples.

All of this immobility and falling convinced me that next time my mother could die. I had planned this trip as a vacation for my daughter to see her grandparents. But it now took on a different character. I immediately called an emergency family meeting to discuss my mother's situation. My sister and brother-in-law, who live nearby, and I gently but firmly told my

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father what was obvious for us but unthinkable for the man who has spent nearly a half century at her side: the time had come to hire full-time help or to put my mother in a nursing home.

The next few months will bring a huge transition in my parents' lives. First will come the quest for help, so difficult to find because of the lack of awareness about HD and because so many nursing homes are believed to charge exorbitant fees without caring adequately for their clients. Then the financial burden will become enormous as my father, my sister, and I try to figure a way to pay thousands of dollars per month in fees. My mother does not have long-term health care insurance, and Medicaid will not be available until my parents spend a good chunk of their assets. Finally and most serious of all will be the emotional adjustments both of my parents will have to make, either to having strangers in their home or to living separately.

As I said good-bye to them, I realized that it would probably be the last time I would see my mother at home. I imagined seeing her bed-ridden in a cold, impersonal institution, living her final years alone, misunderstood and unloved, away from her husband and no longer able to talk to the son she bore with such affection. The next day the sadness and apprehension about my mother's future caused me to have several dizzy spells. Huntington's disease, which has been slowly killing my mother, was victimizing the rest of our family too.

Posted by [Gene Veritas](#) at 9:47 AM



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