


# 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, JUNE 12, 2008

## Huntington's disease, destroyer of families

When my mother died of Huntington's disease 28 months ago, she became but the first victim of the disease in our family.

The stark truth of HD's reach into our lives came down like an anvil on my head when I received a surprise phone from a social worker, who told me that my 80-year-old father might have to be admitted to the geriatric psychiatric ward of the hospital back in my hometown. Someone at the Veterans Administration, where my father has occasional medical appointments and picks up his discounted medicines, had filed a complaint with Adult Protective Services, the agency that looks after adults who are neglected or unable to take care of themselves.

When the social worker looked in on my dad, she saw him talking to my mother's wedding picture, turning on the television for it, and checking frequently to make sure that "she" was okay.

My father started caring for the picture around the first anniversary of my mother's death, about 16 months ago. He sometimes takes it with him in the car and to my sister's and friends' homes, and he hangs a decoration on it.

"You know that it's just a picture, don't you?" my relatives and I always ask him. He readily responds yes.

## HD wiped out the 'golden years'

After 48 years of marriage and 15 years of caring for my mom after her HD became full-blown, it's understandable that my dad would develop an attachment to her photo. He's especially lonely because I live thousands of miles away and because he has relatively little contact with my sister, her husband, and their three sons. According to my sister, he became alienated from them in part because he had dedicated himself fully to caring for my mother and had no time for them. He has nobody to help him with the grieving process.

My father had remained quite alert while my mother was alive, but he has declined physically, mentally, and emotionally since her death. He does not eat properly, has lost weight, and has several serious health problems.

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In addition, his short-term memory has severely deteriorated, and he often becomes disoriented. He refuses to even discuss an assisted living facility, so as a stopgap measure late last year we arranged for caregivers to come into the home for a couple hours three times a week. Early this year he fired them, claiming they were too expensive. He is stubborn, proud – and unaware of his changing circumstances. When I continue to press upon him the need for assistance, he becomes angry and defensive and says, “I don’t need any help!”

My mother was only 68 when she died. I had always assumed that she would be *his* caregiver someday, and that he would die first. Huntington’s disease reversed their roles and robbed them both of their “golden years.” Instead of trips and time with the grandchildren and friends, they struggled together with her decreasing ability to walk, talk, and eat. Slowly my mother became but a faint shadow of her once vital self.

### Avoiding the lock-down

The social worker arranged for counselors to come to my father’s house to evaluate him. It was a Friday afternoon, and they would arrive at 10 a.m. on Monday. Because I was preparing to hire a geriatric care manager to keep watch on my dad and his health, I tried to negotiate with her to postpone the meeting for at least a few days. But she was adamant: she was concerned about my father’s safety. A lawyer urged us to “play along” with Adult Protective Services, because it has lots of “authority and clout.” I finally convinced her to hold the meeting at 3 p.m., when my sister and others could be present.

I learned that my dad could be in the hospital for as long as ten days. Worse yet, the geriatric psych ward was a so-called “lock-down” facility: he would not be allowed to leave. If they found him incompetent, he would go immediately to a nursing home or similar facility. Depending on the availability of beds, we might not even have a choice of location.

I feared a devastating shock to my father’s fragile emotional state. The first night of the crisis I stayed up until 2 a.m. on the computer researching the law and potential solutions to my dad’s plight.

That night I had a vivid dream in which my father – the man who had guided me through so many of life’s challenges – led me through a desert filled with vipers, a white bobcat, and other threatening animals. I in turn helped him navigate the same dangers.

### Rallying the family

I considered flying home but, given the precious little time before the meeting, decided it was best to work the phones to rally family members (including a cousin who’s an attorney) and discuss the predicament with a geriatric care manager, who was already familiar with my dad’s situation.

My sister and five other people representing our family attended the evaluation. I believe that the show of solidarity with my father convinced the counselors that he did not need immediate hospitalization.

But there is no doubt that my father needs immediate help in many other ways. The counseling agency will arrange to spend several hours with him three times a week, and he will start getting Meals on Wheels. We need to stop him from driving and start making plans for an eventual move to an assisted living facility.

### **HD's many victims**

Like my dad, my sister and I are stoic about life and really good at denial, too. But we're forced once again to stare Huntington's disease in the eye. Instead of enjoying our father's final years, we're constantly reminded of my mother's illness and his loving, heroic, and tragic attempts to deal with it. We see how sad and run-down he has become after the long fight against HD.

So we are victims too. My father's episode reminds me of my own gene-positive status and the likelihood that I will follow in my mother's footsteps. My sister, who is 46, is untested, and she and her husband wonder about the status of their sons. My wife stands by helplessly as she worries about me and what her own life will be like when my inevitable symptoms start and I can no longer be the dedicated father I have been to our daughter, now eight years old.

HD is more than a disease. It is a destroyer of families. And that is all the more reason why we must stop it.

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Posted by [Gene Veritas](#) at [7:46 AM](#)



4 comments:

#### **Anonymous said...**

Gene,

I happened upon your blog while doing some internet research on Huntington's. You might want to check out the information on [www.endowmentmed.org](http://www.endowmentmed.org) regarding a saccharide called Trehalose and Huntington's disease. While I don't have Huntington's (I have MS), this looks promising to me, and definitely worth a try. Best of luck to you.

[12:14 PM, June 24, 2008](#)

#### **Anonymous said...**

Gene - with significant experience with HD, I am genuinely sorry for the pain and sorrow it has caused you and your family. One unspoken feeling, however, is that the late onset of HD is kind of a blessing, compared to the more common early onset -

I know so many families in the throes of HD where parents and young people and children ALL have it - they generally have a tougher time with basic life expenses, due to primary breadwinners unable to work, and caregivers too young for any retirement or social security. I hate myself for pointing out at least your parents had the chance to have a fairly lengthy marriage together and didn't have to try to parent you and your sister at the same time your mother was stricken with HD. Not a popular comment and I do not mean to diminish what you are all dealing with, since HD's a really ugly disease in any case. I just hope you can be thankful that the late onset allowed your family to have a fairly normal existence, by comparison. Thanks for writing.

2:21 PM, April 27, 2009

**Anonymous said...**

Hi Gene,

Your blog is very moving. As an English teacher, I also want to say that it is a pleasure to read your writing.

My fiance also has 40 CAG repeats. He's 63, still working, and doing very well. Our neurologist told us that with this late onset and low number of CAG repeats, we have reason to hope for, and I quote, "a relatively benign course of the disease." I know "relatively" is a loaded term, but Gene, let's hope that you and my fiance remain healthy until those hard-working scientists come up with the cure we all know is ahead.

Signed,  
Hopeful 1

1:38 PM, April 29, 2009

**Anonymous said...**

Who knows where to download XRumer 5.0 Palladium?  
Help, please. All recommend this program to effectively advertise on the Internet, this is the best program!

11:18 AM, November 20, 2009

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