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At Risk for Huntington's Disease

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Preparing for a lonely day

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Serbin, Kenneth P., "Preparing for a lonely day" (2005). *At Risk for Huntington's Disease*. 12.
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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, MAY 05, 2005

Preparing for a lonely day

One of my deepest fears about Huntington's disease is knowing that there could come a day when my wife cannot take care of me. If I follow in my HD-stricken mother's footsteps, I will need help starting in my mid-50s. My wife and I have had several conversations about this.

I want to stay home as long as possible. I don't want to go into a nursing home or similar facility. I have seen HD patients in such conditions, and it frightens me to see how they receive so little attention or stimulation.

At one place I saw a woman belted to a special chair. She writhed uncontrollably. I wonder: "What kind of life is that?"

Other patients lived in cubicles. One had a padded floor on which the patient lay.

I am hoping that caregivers can be hired to take care of me at home. Our insurance would likely cover only part of the costs, so we're saving to try to cover the difference. But this might be only during the day. Who will take care of me in the evenings?

My wife points out that she will not be able to work full time during the day and then take care of me during the evenings, when she will have to be managing the household and helping our daughter with schoolwork and other things.

The day my wife told me that I'd have to go to a care facility when home care was no longer possible, I felt abandoned and utterly lonely.

Sometimes I tell my wife that I prefer suicide to going into a nursing home. In fact, suicide rates among HD people are higher than average. In a notorious 2002 incident a Georgia mother shot her adult sons, who had advanced HD, to help them escape their misery.

I need to plan now, while I'm healthy, to make sure that I can stay at home as long as possible. I must find professional caregivers who know about HD.

That's a difficult task, as my family has discovered with my mother. So few people know about HD, and many doctors have never seen a case of it. The lady who cares for my mother a few hours per week mainly bathes her, does her hair and nails, and helps clean the house. She has no HD-specific training and cannot give my mother the physical and psychological stimulation she needs. I am convinced that, if my mother had gotten better help a decade ago when the disease first struck, she would be better off today. Sadly, our health care system fails to train people to work with HD patients.

To me, life is action. I want to be cared for by people who will recognize the remnants of that impulse in me once HD has erased many of my faculties.

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HD Blogs and Individuals

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Struggling with HD is not just about ameliorating symptoms. It's also about building a support team that can preserve the patient's humanity as much as possible.

Posted by [Gene Veritas](#) at [5:28 PM](#)



2 comments:



Unknown said...

You say you are "at risk," as am I, yet you speak with a certainty of having the disease. If you are untested and don't know you have HD, you spend an awful lot of time obsessing about the worst case scenario. The idea that "this could happen to me" is frightening and lonely, but from what you post here, you never spend any time with the "glass half full" side of the equation. Life is pain. Life is beautiful.

[5:21 AM, May 07, 2005](#)



steinre1 said...

Gene-

I have to agree with the previous post. I am 29 years old and got my test results a couple of months ago. My father is in the mid stages of HD at 63. I have been forgetting names, facts, figures, passwords, etc. I also found that I tripped on the carpet when there was nothing there, and choking on food when I ate. My test results came back negative. I was shocked. Sometimes our mind just plays tricks on us...either that or just old age ;). I'm sure you've spent a long time thinking about being tested, and the solution is not an easy one. However, you sound like me - while you still hold out hope, you just kind of assume you are positive. If you take the test and you are positive, will your outlook change much? But what if you tested negative????? I am not trying to tell anyone what they should do, just shedding some light on my own thought process when deciding to test....

[8:19 PM, May 08, 2005](#)

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