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Pondering an exit from the HD closet

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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, AUGUST 20, 2009

Pondering an exit from the HD closet

Huntington's disease forces gene-positive people like me to live many paradoxes. One of the most difficult involves the challenge of going public with my status, a challenge far more difficult than those faced by people with cancer, AIDS, and other devastating but more common and better-understood diseases.

To help end this deadly brain disorder, HD people and their families must come out of the closet to act as public advocates and participate in research experiments. But doing so carries the enormous risk of discrimination and profound misunderstanding at work, with insurance companies, and even within extended families such as my own, [as I revealed last year](#).

Ever since I discovered in late 1995 that my mother had HD, I have hidden the fact from all but a handful of trusted friends and relatives. I have mainly feared discrimination at work and the potential loss of opportunities for a better job, as I have described in previous entries ([click here](#) to read more). Even though HD and other diseases are considered disabilities, the reality is that employers can often find a legal pretext for dismissing an individual expected to decline someday.

In my field, which involves writing and other demanding intellectual tasks, few people would want to risk hiring someone who tested positive for a brain disorder and had a 100-percent chance of developing it.

And once gene-positive status emerged, it could spread rapidly via the Internet.

Family concerns

I am also wary of exposing my family to the many challenges of living with a husband and father on his way out of the HD closet. My nine-year-old daughter knows her grandmother died of HD, but we have not yet told her about my status nor that she tested negative in the womb.

Recently I discussed with my wife how to continue this blog in the likely event that my symptoms prevented me from writing. I suggested that she and my daughter could post videos of me – to show the onset of symptoms and my struggle to overcome them – but she adamantly opposed the idea as an invasion of family privacy. She understandably sees the immediate burden on her and our daughter as outweighing the potential good for the cause.

I have frequently mulled over the process of coming out but have always pulled back. This has been a long struggle, and a very difficult one. It was especially painful to hide the real cause of my mother's death from people at work or individuals who were curious but whom I did not trust.

She died of HD in 2006. I told these people that she died of respiratory difficulties. Most accepted this without questioning. One person, perhaps a

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HD Blogs and Individuals

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bit of a busybody, wanted to know more details. When I refused to elaborate, he became testy. I felt annoyed and angry at this person, but also because of the need to brush him off.

Since then, nobody has touched on the subject. I know, however, that if I had revealed HD as the cause, people would have felt shocked. And many would sooner or later have learned that HD was a genetic condition with dangerous implications for me and my family.

A sheath of anonymity

I'm not the kind of person to seek sympathy, but at the time of my mother's death I certainly needed it. I received support from readers of this blog and others who know about the existence of HD in my family. But by downplaying the death of my mother to those who didn't know about HD, I denied myself access to the reservoir of human solidarity that people need in a time of grief, in this case multiplied by the devastation of HD and the threat to my own well-being.

I have hidden a crucial dimension of my life, and, as a result, feel distant from friends and co-workers. Sometimes I even get angry at them for not knowing, for not sharing the burden with me. It's the human tendency to blame others for misfortune. This tangle of feelings makes it difficult for me to be myself.

My self-imposed sheath of anonymity inevitably involves an aspect of denial. By not revealing my status to others I feel safe, and I can avoid all of the painful feelings associated with explaining to people HD, its impact on my family, and the seemingly inevitable course ahead.

HD is not like cancer or AIDS or heart disease, where the mention of a single sentence or even just a word telegraphs a wealth of information. It is not only a little-known, orphan disease. It is a devastating, multi-symptom disease that requires a detailed explanation of its medical aspects and an even more detailed discussion of its social implications such as genetic testing and discrimination.

Trying to tell a friend

When [I turned down a wonderful job offer](#) two years ago because of the threat of HD to my family, I decided to start coming out of the closet gradually and carefully. I became involved in stem-cell advocacy here in California, and I started revealing to more people my gene-positive status and my authorship of this blog. During a recent visit to CHDI Management, Inc., which seeks treatments and a cure for HD, I was introduced as a gene-positive person to strangers for the very first time.

The other night I wanted to experiment yet further with coming out. I went to a coffee shop to chat with a friend I have known since 1987. A few years ago he went through a painful divorce, and now he faces financial troubles. He needed a shoulder to lean on and somebody to brainstorm with about his future.

In the days before our meeting, I built up the resolve to tell him about my struggle with HD. I too wanted to lean on someone who knew me long enough to be able to sympathize and even discuss with me a strategy for coming out locally, since we have so many common acquaintances.

I kept wondering, "How can I bring up a huge new problem out of the blue, one that I have hidden from him for more than a decade, especially when he's going through a crisis of his own?"

We hadn't seen each other in about a year, so it was a warm and heartfelt evening for both of us. I gave him some tips on landing some work, and I told him about some of my difficulties at work and even about the big job I

turned down a couple of years ago.

A couple of times, when the conversation briefly paused, I thought of seizing on the moment.

Emotional paralysis

But I couldn't. All I could do was make vague references to "other factors I'll tell you about sometime" or "something I won't get into now." I've become so good at hiding my worries about HD that he had no inkling of the anxiety I was feeling.

I didn't want HD to ruin our evening. And I felt very guilty about burdening my friend at a time when he's struggling to pay the rent and buy groceries.

And I couldn't find a way to talk about such a devastating situation when I currently do not have the overt symptoms of Huntington's disease. I kept feeling that it would all seem so abstract and hypothetical in comparison to his predicament.

I felt this even though I knew that my situation is one of life and death.

But it is a death that would come very slowly, like my mother's 20-year struggle with HD.

I felt emotionally paralyzed. It was easier to keep on my protective sheath.

No ritual for discussing HD

My terrible hesitation stemmed in part from the lack of a societal ritual for coming out about two conditions: the results of a genetic test and at-risk status for a neurological disorder. People are used to hearing about patients suffering from heart disease, cancer, or AIDS. Actress Farrah Fawcett shared her demise from cancer with the country by appearing in a reality TV show. Just a few days ago Secretary of State Hillary Clinton stood shoulder-to-shoulder with AIDS patients at a clinic in South Africa and helped once again to give the victims of that disease a public voice. People with AIDS were once enormously stigmatized.

But in the new era of the Human Genome Project and the burgeoning of neurological disorders such as Alzheimer's, few people have yet to pioneer the act of coming out with HD and other similar conditions. Former First Lady Nancy Reagan came out with her husband's Alzheimer's, and actor Michael J. Fox went public about his battle against Parkinson's. But these are exceptional cases.

For HD the situation is even worse, because its symptoms are more devastating. And since the death of Woody Guthrie in 1967, no famous American has come out with HD. Public understanding and our collective consciousness about these conditions are still at the level of a hush.

Over the years many television programs have portrayed people at risk for HD. In the current program *House* one female character wrestles with the decision to get tested and then struggles with being gene-positive.

This may signal that HD is moving closer to the mainstream, but TV is not reality. Real at-risk and gene-positive people don't go public. Many hide their status just as I do. Many, many more won't even get tested.

It could take years – if not decades – to change this situation.

Confiding in others

Around 11:30 p.m., my friend and I decided to say good-bye. Our

friendship was renewed. We both had a sense that the conversation wasn't over, and we agreed to meet again soon.

My friend, who is a highly capable and proud man, had confided a lot in me by sharing personal difficulties.

I believe that next time it'll be easier to raise the subject of HD.

The time has also come for *me* to confide in others. I've already begun that process through this blog and my eleven years as an activist for the Huntington's Disease Society of America. Now I'll be taking my activism to a new level by personally speaking to more people about HD.

There are no guarantees of assistance or even sympathy. Indeed, coming out could backfire and bring serious consequences.

But each experience of coming out can only strengthen my courage and prepare me for the next one.

At the very least I will be increasing one by one the number of people who know about the challenge of Huntington's disease. It's time for the stigma about HD to end, enabling gene-positive people like me to speak openly and without fear.

Posted by [Gene Veritas](#) at [11:00 AM](#)



1 comment:

 **HDSocialWorker said...**

Gene, Your writing always resonates with me and I appreciate the candor with which you share your thought processes with others. I hope you find peace in whatever you choose to do. It is quite a shame that you would even have to expend so much energy on decisions about disclosure, but unfortunately the reasons you struggle with this are real and significant. Best wishes - now, and in the future.

[8:09 AM, August 21, 2009](#)

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