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To flee or to fight

Kenneth P. Serbin
University of San Diego

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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.

MONDAY, MAY 25, 2009

To flee or to fight

People respond to a diagnosis of Huntington's disease in many ways, ranging from complete denial to optimism about the research for a cure. Indeed, in order to cope, a person with HD or at risk for the disease can experience the entire range of feelings within his or her own life – perhaps in just one day.

In the last decade, I myself have gone through dark moments of thinking that my symptoms had started and also felt near euphoria after learning of potential breakthroughs towards an effective treatment. I tested positive for Huntington's in 1999, and my mother died of the disease in 2006 at age 68.

But some reactions, falling into a category all by themselves, stir up the deepest of emotions.

Changing her identity

I got that feeling this past week when I read the following anonymous comment on my previous blog posting (click here to read it). It reads:

"Thank you, Gene. I am new to this forum and my connection with HD is an in-law who has begun showing signs. I have wept much since she first confided in me (only five people in the world know as she changed her identity and left home long ago to escape the horror). She is the bravest person I have ever met. I do not know how you live with the time bomb, and I pray for her continually to know a measure of peace. I am adding you to my prayer list as well."

Reading about this person's decision to change her identity and move away sank my heart. I felt deep sadness and empathy for this person. I know nothing else about her, but I believe I know exactly what she is feeling.

Like an injured animal that knows it will not survive, she has gone off into the wilderness to die.

She reminded me of Phebe Hedges, a 40-year-old woman with HD who walked into the sea in an act of suicide, as described in Alice Wexler's book about Huntington's, *The Woman Who Walked into the Sea* (click here to read about the book).

The instinct to protect

The woman who fled acted on instinct, seeking to remove herself from all of the social horrors often experienced by the affected and their families, including denial, stigma, and discrimination.

Her instinct also led her to preserve those around her from witnessing the terrible symptoms of HD such as the inability to walk, talk, think, swallow, and remember. As her brain dies and her humanity disappears, their lives

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will go on in relative tranquility.

I remember visiting my mother for the first time after her diagnosis. I had not seen her since her and my father's trip to visit my wife and me in California. I had urged my father to seek out a specialist to get to the root of my mother's unexplained strange behavior. Now, speaking about her diagnosis, she appeared very sad and depressed. She was upset because she could not stop saying "yep." Her self-control was disappearing. She appeared helpless and bewildered.

Looking back on that moment, I think she must have had those same deep, instinctual feelings about her impending decline.

Thoughts of suicide

The story of the woman who fled evoked my own thoughts about suicide. In the first years after my positive test for Huntington's disease, I told my wife and some close friends that I would prefer to die with my health relatively intact than to be forced to watch myself lose my ability to write, work, and enjoy my family.

I fantasized about organizing a farewell ceremony at which I would announce my decision to my friends and family and then privately take my leave of the world. This, I thought, would be better than flailing about lonely and mindlessly while being tied down to a chair or confined to a room in a nursing home, the fate of some HD patients.

As I became deeply involved in raising of my daughter and in the local chapter of the Huntington's Disease Society of America (HDSA), I repressed these thoughts and channeled my energies into the movement to find treatments and a cure.

I am hoping that the memory of those dark thoughts has come alive again only for a short time.

I will need complete focus as yet another stage looms in my personal battle against HD: the need to become more public in my activism.

We must speak out

I would never criticize the woman who fled, for I saw her pain in my mother's face and have denied my own at-risk status in numerous ways. As my readers know, I use a pseudonym on this blog – my own self-protection because of the horrors of HD. And if I develop full-blown, highly debilitating symptoms, suicide might once again look like the only way out.

But at this juncture I want to go down fighting. And I have come to believe that, despite whatever happens to me because of HD, my life can still have deep meaning and significance.

As one caregiver stated angrily at a Huntington's disease support group meeting that I attended last month, nobody will notice – or help – affected individuals and their families unless we speak out and let the world know about the enormous challenges posed by HD.

A dream about going public

Two nights ago, after I had started writing this entry, I dreamt very clearly about Huntington's. In the dream my co-workers – who in reality and in the dream do not know about my situation because of my fear of discrimination, and of losing my job or not getting a better one – are speaking enthusiastically about a new and deeply worthy cause: HDSA. They are planning to attend an exciting fundraising event that the organization is putting on in a few days (click here to read more).

Huntington's Disease Lighthouse
Hereditary Disease Foundation
Huntington's Disease Advocacy Center
Thomas Cellini Huntington's Foundation
HDSA Orange County (CA) Affiliate
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Earth Source CoQ10, Inc.

HD Blogs and Individuals

Chris Furbee: Huntingtons Dance
Angela F.: Surviving Huntington's?
Heather's Huntington's Disease Page

Near the end of the dream I decide to reveal my story to this warm and understanding group of people.

Like the woman who fled, I cannot escape the horrors of Huntington's disease. But, unlike the animal that dies alone in the wilderness, I can tap into a community for help – a community of HD families, activists, and supporters who are working to find treatments and a cure.

As I often write to others in the community, *together we can beat this disease.*

Posted by Gene Veritas at 10:09 PM

5 comments:

Anonymous said...

I am the anonymous writer and first I want to say I'm so sorry if my commment stirred up more pain for you. But I also want to say thank you. Thank you for your courage, for giving yourself away the way you do. No one can know the gamut of emotions you go through unless their experience is the same. When someone watches the disease and its effects first hand, they enter into an entirely different place of struggle. I know that those dark moments of wondering whether it is worth it must come, but again -- I thank you for pressing on. Your contributions are an encouragement and hope to people you may never know personally. You have already helped me understand in a way I couldn't have before. Thank you and I will continue to pray for you and your family.

5:45 AM, May 26, 2009

Anonymous said...

As a sister watching my older brother suffer from HD at the age of 39...I wish he had some kind of hope. He rarely will even acknowledge this horrible disease. My brother ran away atleast 3 times and lived as a homeless person in Seattle. He has been back home now for several years but lives as a hermit. I am so angry that this has happened to my once lively, funny, smart, fun-loving brother. There is a beautiful picture of my brother and daughter with sunflowers in their hair in this years HD calendar. That is the way I love to remember him. I pray for every family struggling with HD. I will never give up hope!

8:34 AM, May 26, 2009

Anonymous said...

Gene,
I left the last comment on your previous post. Despite the optimism of that comment, I too struggled with feeling alone and desperate prior ot discovering my test result.

The anxiety was so great that I actually thoroughly thought out the "best" way to end my life in my own hands. To me, it wasn't about my escaping pain or hardship, it was about sparing my family the pain and burden of seeing me battle HD.

I needed to visit that dark place, that worst case scenario, to come to the place I am today--a place of immersion in the now. I needed to confront my worst enemy in order to become at peace with it. I, like you, hope that despite that which may be out of my control, I still have value to impart on my family, my friends, and my community.

I whole-heartedly agree that we, the HD community, must unite, and in so doing, there is such a huge potential for a cure. Like you, I remain annonymous in my at risk status, aside from a few friends and close family members. However, I too am contemplating the immense benefits of becoming vocal in regards to furthering the fight against this disease.

A month or so ago I attended my first HDSA event in a neighboring state. It was a fundraising walk. A walk at which over $100,000 was raised for HD research. A walk for which I myself raised thousands. But for me,so much more valuable than the money raised, was the sense of community that I came away from that event with. As my HD-positive mother and myself (also gene-positive) were briskly walking side by side, she turned to me and said, "it is so amazing to feel like I'm not alone in all of this." Truly, we must remember, we are not alone, and together we can beat this disease.

Thanks for being a sense of support and strength in the fight .

8:42 PM, May 26, 2009

Angela_F said...

Together we can beat this disease. I wholeheartedly agree. We can do it, all of us together.

8:07 AM, May 29, 2009

Anonymous said...

Gene - I urge you to discuss those gene results with your 9-year-old! I was her age when my father died, and I'll just tell you that in the fifth grade, I was already digging through the library for anything I would get my hands on about HD. So if she has the blessed news of not having inherited the gene, you can save her all that angst, over even the perception of being at-risk...!

10:09 AM, August 24, 2009

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