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At Risk for Huntington's Disease

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No time for fear

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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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▼ 2009 (21)
 - ▶ December (1)
 - ▼ November (2)
 - [Smelling the flowers at Thanksgiving](#)
 - [No time for fear](#)
 - ▶ October (3)
 - ▶ September (2)
 - ▶ August (3)
 - ▶ July (3)
 - ▶ June (1)
 - ▶ May (2)
 - ▶ April (4)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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 GENE VERITAS

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SUNDAY, NOVEMBER 15, 2009

No time for fear

Knowing that I will almost certainly develop a devastating brain disease, how do I deal with fear?

A good friend posed that question to me on the afternoon of Halloween. He called just as I was settling down into my comfortable recliner to relax a bit and watch some television before my daughter, accompanied by my wife, went out trick-or-treating and I prepared to man the front door.

I can't remember anyone ever asking me that question so bluntly in the ten years since I tested positive for Huntington's disease.

The question took on special urgency, because my friend, who had nearly died of lymphoma in the 1990s, would find out in a couple of days whether his recurring symptoms, including intense headaches, signaled a return of his cancer. His anxiety had become unbearable, and he needed help.

Many strategies

For an hour and a half I described some of the strategies I had employed over the years to confront my many worries about Huntington's: working with a psychotherapist, taking various drugs for anxiety and depression, and reading the book *Don't Sweat the Small Stuff ... and it's all small stuff* as well as some writings by the Vietnamese Buddhist Thich Nhat Hanh. I also try to exercise, live in the moment, and to connect with my spiritual dimension, for example, by attending Mass.

I spent most of the time explaining the positive and negative reactions I had to different medicines and how it had taken me years, with the help of my therapist and several psychiatrists, to find a combination that kept me emotionally stable.

I also emphasized the importance of building a trusting, long-term relationship with a therapist – a person I can call upon to discuss difficult feelings and help me maintain stability. I like to refer to my therapist as my “mind coach.”

Personal trainer for the mind

“Doesn't LaDainian Tomlinson have a personal trainer?” I asked my friend, a big football fan, in referring to the star running back of our local team, the San Diego Chargers.

“Sure!” he replied.

“My therapist is like a personal trainer,” I continued. “She's my mind coach. She helps me keep my mind working at its best to meet the challenges of living at risk for HD, just as a personal trainer or coach helps a professional athlete keep his body in top shape.”

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Paralyzing memories

When I hung up, however, I felt distraught. I was deeply worried that my friend's cancer had returned and that he might die.

And I was faced once again with my gene-positive status for Huntington's. I found it especially troubling to recall the last weeks of my mother's life, when, seeing her completely debilitated by HD, I felt as if I were looking into a genetic mirror – my own future as a Huntington's patient unable to walk, talk, or even swallow. After she died in February 2006, it took me months of mourning and a new combination of drugs to stop the panic attacks I was suffering, bowing down low, over and over, mimicking my mother's symptoms ([click here to read more](#)).

I immediately took down some notes, thinking that I would blog in the next day or two on the subject of dealing with fear.

But the memories of my own deepest fears emotionally paralyzed me, and I decided to wait.

No "magic bullet" for fear

It also struck me that I hadn't really answered my friend's question. I had described to him my coping mechanisms, but I hadn't even scratched the surface of my feelings about HD.

My friend has read much of this blog over the years, so he had a general idea of my struggles in living at risk. But even in writing more than 50 posts over nearly five years, I still hadn't fully described for my readers – or for myself – how I was confronting my gene-positive status.

The more I thought about it, the more I concluded that I had no single, simple answer for "dealing with fear."

Some excerpts from my notes reveal the jumble of thoughts that came to mind and the lack of a "magic bullet" for overcoming fear:

Wife. Distractions.... Finding right pills.... Deep breathing. Letting water run on my head in shower. Spirituality, attending church, thinking about the larger questions of humanity. Feeling part of the HD movement. Sharing with others. The blog.... Exercise, swimming, walks. Work as a distraction. Denial.... Hope for treatments, research. Pretending I'm immortal. Remembering how at age five I decided I would never die. Pretending that it's all a bad dream. Pretending that I'm a child again. Focusing on [my daughter] and her development. Many times I tell myself that I will beat the disease.

Every reminder of HD – and they come at least once each day – leads me to select one or more of these strategies.

Making sense of the struggle

Next month will mark 14 years since I learned that my mother had HD. In retrospect, I have fought hard to stay healthy, stable, upbeat, and, as an activist for the local chapter of the [Huntington's Disease Society of America](#) (HDSA), engaged in the campaign for treatments and a cure.

My friend's question about "dealing with fear" forced me to analyze once again my quest for survival. Fortunately, his cancer test results came back negative. But his own deep fears, and a bit of my advice, have prompted him to take greater care of his emotional health as he continues to live at risk for lymphoma.

In my case, I now see more clearly that I have conscientiously strived to devise my own unique strategies for confronting fear and to construct a

network of human support via my family, friends, and HDSA.

Constructively confronting fear

So how have I dealt with fear? As I live at risk for Huntington's disease, fear shadows me constantly. But I know the fear of HD well – so well, in fact, that dealing with it is now part of the routine of life. I try as much as possible to keep it in perspective and not allow it to stop me from focusing on my family and my activism.

I have *constructively* confronted fear. And this is a *daily* task.

It struck me that, as Jackson Browne put it in his song "The Pretender," in the evening I lay my body down, "and when the morning light comes streaming in, I'll get up and do it again. Amen."

These past few days I have perceived yet another facet of living at risk for Huntington's disease.

"I have no time for fear," I concluded. Acknowledge it and move on.

Posted by [Gene Veritas](#) at 6:03 PM



3 comments:

Michelle R said...

That's amazing, Gene. I appreciate your use of acknowledgement, acceptance and mindfulness to get through it and your reflection on the subject. Sometimes people ask me things that stop me in my tracks. They may not know it but reflection on these things that so trouble me at the time help me to grow. I totally agree too on your therapist being a personal trainer. I could not live without mine. Keep up the great work.

[11:28 PM, November 15, 2009](#)

Anonymous said...

Hi Gene. I try to read as often as I can - today this really hit home with me. It made me think of my sister and how she is coping with her own fear right now as she's experiencing HD and raising her son. I am at risk and reminded daily about my fears, especially today. The blog was a good thing for me to read today. Thanks.

[10:16 AM, November 16, 2009](#)



[wayne.greenway](#) said...

Hello

I was wondering if everyone who reads this blog could have a look at a very important project for youth in the HD community that we are trying to do in Canada by reading:

<http://www.avivacommunityfund.org/ideas/acf1853>

Anyone anywhere in the world can vote on this project and people can votes every day.

If we can get in the top 20 projects in terms of votes we can really make a huge difference for youth living in the HD

community.

Please have a look at this project and vote everyday if you think it is worthwhile

Thanks Wayne

5:48 PM, November 24, 2009

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