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Keeping calm in the face of Huntington's

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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)
- ▼ 2008 (7)
 - ▶ September (1)
 - ▶ August (1)
 - ▶ June (1)
 - ▶ April (3)
 - ▼ March (1)
 - ▶ [Keeping calm in the face of Huntington's](#)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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SUNDAY, MARCH 16, 2008

Keeping calm in the face of Huntington's

Living at risk for Huntington's disease often causes me to try too hard to take care of myself. I've always been a bit of a hypochondriac and face the possibility of other health problems, so living with a positive test for HD can greatly magnify my concerns.

Just recently a chain reaction of self-inflicted and misunderstood incidents landed me in the operating room.

Weighing the risks of supplements

About three years ago, I started taking the supplements recommended by the [Huntington's Disease Drug Works](#) program. They are tolerated well by humans and have shown positive results in animal tests, and, significantly, those people with early or mid-stage HD who consistently take them have stabilized or improved. I am hoping that they will delay the onset of my symptoms, which are inevitable because of HD's 100-percent genetic nature.

As one should do with any supplements, I have carefully followed the instructions. With creatine, for example, I get periodic blood tests to check for possible harm to the kidneys.

Another of the supplements is trehalose, a natural sugar. I take it mixed in water, plain yogurt, or cereal.

Trehalose seemed harmless and I didn't think it would cause any side effects. In contrast with my concerns about creatine, I took it without thinking about the possible consequences.

But then early last fall I got a call from a nurse at my health plan stating that I should see my physician because one of my blood tests showed a glucose reading of 109 – nine points above the recommended maximum. I learned pretty quickly that 109 put me in a category known as “pre-diabetic.”

“Diabetes?! I have enough to worry about with HD!” I told my wife. There is no history of diabetes in my family, and I usually keep very close to my recommended weight range.

Dr. LaVonne Goodman, the founder of the Huntington's Disease Drug Works program, reminded me that the instructions for taking trehalose include reducing my carbohydrate intake. After all, the nine standard-size packets of the sugar were the everyday equivalent of three soft drinks.

Panicking about carbs

For the first time I started paying attention to the carbohydrates in my diet. “Carb counting” is a big new fad in our culture. My wife did it when she took part in a weight reduction program. These days carb stats seem to

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be on every food label and every restaurant menu.

I did not know the actual cause of my glucose reading. Was it the trehalose? Was it the fact that I had gained twelve pounds over the summer and had gotten out of my exercise routine? Was it a lab mistake or maybe just a fluke reading? Had I crossed some artificial barrier established by a drug company interested in classifying more people as diabetic? Did the reading result from some combination of factors? Both Dr. Goodman and my own physician actually expressed little concern about the number.

Whatever the cause, I panicked. I simply could not accept having another major health threat to worry about. I wanted to cut my carbs and lose weight.

I immediately eliminated practically all carbs from my diet – no bread, no dough, no candy, no corn, no potatoes. I tried to eat just proteins, vegetables, and salads. I had an especially hard time turning down pizza. But I was determined to escape from the “pre-diabetic” range.

From bad to worse

In my worst imagination I could not have imagined the terrible result of this strategy. My stools became rock-hard, and my bowel movements, which have worked excellently throughout my life, turned into an ordeal. Blood started showing up on the toilet paper. I figured the cause was hemorrhoids that occasionally flare up, which I usually treat with some over-the-counter suppositories.

Then one night a large amount of blood came out, leaving a very long streak in the toilet bowl. It must have been close to a tablespoon's worth. The doctor at the proverbial urgent-care clinic examined me, saw hemorrhoids, and prescribed a medication. It did not work. The bleeding continued, and now I had pain. Several weeks later I returned to the clinic. This time I heard another diagnosis: the doctor said I probably had an anal fissure produced by the hard stools and that it might require surgery.

Anal fissure?! That was a completely new term for me. Surgery?! My fears multiplied. I quickly learned that anal fissure surgery had a high success rate, but in some cases the patient ended up with uncontrollable flatulence or, worse yet, had to wear diapers the rest of his or her life because of anal dripping.

And, I was told, surgery involved general anesthesia. I wanted to avoid this option at all costs, because I had heard stories over the years of people at risk for HD suddenly experiencing their first serious symptoms or seeing their symptoms worsen because of shocks to their bodies such as car accidents.

Staving off surgery

I tried a cream on the fissure with no luck. A surgeon prescribed stool softener, several warm baths per day, and nitroglycerin ointment, used to promote blood circulation and healing in the anal area. He told me to try this treatment for two months.

The pain became excruciating – like a knife cutting into my anus. The doctors I spoke with said it was one of the worst kinds of pain. Every bowel movement caused the fissure to reopen. The pain usually lasted for hours and sometimes as long as half a day. I could not sit comfortably. I did not feel like talking to anybody, and I couldn't find the energy to blog here except for one important entry in late December ([click here](#) to read it). One night I had to eat dinner standing. I became very irritable towards my wife and daughter. Sometimes I felt on the verge of fainting.

The nitroglycerin did not help. I sought a second opinion from another surgeon, who sometimes did Botox injections into a patient's anus as a way of relaxing it and allowing the fissure to heal. But she recommended I have the surgery. And – very important for me – she said I could do it as an outpatient and with local anesthesia.

The procedure, which took place on February 8, immediately relieved the pain, and my recovery went well. Now, for the first time in five months, I am no longer afraid to go to the bathroom.

Valuable lessons

I have learned some valuable lessons from these past few months.

The terrible pain and my subsequent recovery have reminded me once again to savor every moment of life.

It also reminded me that living at risk for or having HD does not exempt people from other health challenges. I know of at least two women who have also had to battle breast cancer.

Just as with standard medications, taking supplements is a serious matter that requires extra vigilance regarding diet and other habits. It actually took me a year to start taking the supplements, and I phased in one after the other.

However, in my case, because I have not revealed my at-risk status to my health plan for fear of genetic discrimination, I do not have a local physician monitoring my body's reactions as recommended by the Huntington's Disease Drug Works. If I had, I likely would have avoided the crisis. The crisis, in fact, led me to seek out a naturopath, who has helped me take a more holistic approach to my situation of risk. Thus I am constantly juggling information from Huntington's Disease Drug Works, my health plan, my psychotherapist, and now the naturopath.

An uncomfortable place in the system

It's obvious that our health system is failing me. If I could give full disclosure, I could get the proper care locally. Had the system not taken weeks to properly diagnose and treat my anal fissure, I very likely could have avoided the pain and the surgery. Had the system guided me to a dietician after I tested high for glucose, I could have avoided the fissure altogether.

I'm learning not to rush into solutions. Had I not cut my carbs so quickly and drastically, the crisis would not have started. The naturopath put me on a vegetarian diet for a couple of weeks in order to help soften my stools and relieve the pressure on the fissure. That was good short-term advice. But then my wife pointed out to me that, if I stayed on a strict vegetarian diet without further consultation and study, I could be heading for a new crisis.

On a follow-up visit, my naturopath agreed and said, "Listen to your wife." Health care – especially when one is at risk for a serious disease – is a family matter, not just an individual one.

Managing anxiety

I believe that my crisis provides me and others at risk for Huntington's disease with one final message: keep anxiety at a manageable level. At the end of my last conversation with the naturopath I concluded that I was trying to "maintain equilibrium." By equilibrium I mean a balance in activities and diet and proper attention to the mind and soul. Only with that approach can we muster the energy and level-headedness needed in the fight to avoid Huntington's disease symptoms.

I recently had a new blood test. My glucose is back in the normal range. The months of pain were a high price to pay for my few days of panic. I should have acted more slowly and calmly. But that's so hard when you face a disease like HD. As I felt relief after my operation, I yearn for a cure for Huntington's disease so that I and so many others can lead more peaceful lives.

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



1 comment:

 **Anonymous said...**

Gene -- Keep up the good work. I am also at risk for HD and so glad to read other's comments. It is a tough road.

I have also started a blog... a more fictional approach if you will at www.standingcrazy.blogspot.com. It has been very therapeutic... Check it out if you have time. If you like it, I would be very happy for you to add mine to your blog list.

We WILL beat this!

[12:20 PM, March 25, 2008](#)

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