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Uncertainty and a steadfast spouse

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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)
- ▼ 2007 (7)
- December (1)
- September (1)
- April (1)
- ▼ March (3)

<u>Huntington's makes</u> <u>page one</u> <u>Testing a new service</u> <u>Uncertainty and a</u> <u>steadfast spouse</u>

- February (1)
- > 2006 (4)
- 2005 (17)

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HD Links

Huntington's Disease Society of America International Huntington Association Huntington's Disease Drug Works Huntington's Disease Lighthouse Hereditary Disease Foundation

TUESDAY, MARCH 13, 2007

Uncertainty and a steadfast spouse

The forgotten people in the story of Huntington's disease are the spouses and potential spouses of those at risk. Practically all of the energy of the HD movement goes into finding a treatment to alleviate the suffering of the ill and preventing the onset of the disease among the at-risk. Fundraisers, publications, and meetings seldom address the pain of the caregivers-to-be.

A recent e-mail from one of my readers painfully reminded me of this reality. He agreed to let me discuss his situation but wants to remain anonymous. I'll call him Ed.

A love story

Several years ago Ed fell in love with a woman whose mother died of HD. However, the pressures of living with her at-risk status led them to argue frequently. Ed feared that his girlfriend might someday test positive for HD. Their relationship soon fell apart. She did not believe that Ed could really love her, and Ed found it difficult to manage the huge uncertainty of a life with an at-risk person.

Recently they bumped into each other and had their first serious conversation in two years. Still untested for the disease, Ed's friend had gone on with her life and achieved many of her goals. "She seemed really happy," Ed wrote. "I tell you all this, Gene, because I want you to understand that she does captivate me and, if I am being honest, my life over the past two years has been boring without her."

Ed's friend hinted that she wanted more than friendship. Ed again became scared. "My greatest fear is that one day the woman I love will be transformed and will be unrecognizable," he wrote. "I don't know if I can commit to this life. More importantly, I cannot let her down again."

Ed's predicament is one shared by all couples in the HD community – intense love challenged each and every day by the harsh reality of a fatal brain disease. "I just feel muted by the situation," Ed confided to me. "I can't share my fears with the person that I want to. If we can't discuss the situation and our fears, those fears will fester and prove insurmountable, even in the short term."

Just today I received another message from Ed stating that they had once again broken up.

A special person

There are no easy answers for Ed or anybody else in a similar quandary. Many people break off a relationship when they learn that the other person could get Huntington's disease, and some marriages end in divorce when the at-risk person becomes ill. Caring for a person with HD becomes an ever more trying and time-consuming process. Sometimes the stress Huntington's Disease Advocacy Center Thomas Cellini Huntington's Foundation HDSA Orange County (CA) Affiliate HD Free with PGD! Stanford HOPES Earth Source CoQ10, Inc.

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severely debilitates or even kills the caregiver first.

Only a very special person can successfully navigate through the treacherous swamp of uncertainty presented by HD. That special quality includes more than love and commitment. It requires the ability to plan each day for the worst but to maintain eternal optimism about the hope for a treatment, a cure, or simply a delay of the disease's onset.

I am thankful every moment that my wife is that person. We had been married for only three years when HD intruded on our lives. We did not yet have a child, so it would have been very easy for my wife to ask for a divorce. But I don't think the thought ever crossed her mind. Somehow we knew we were together for life, and she remained loyal. For her the biggest challenge was not about deciding whether to stay with me, but learning how to adapt to a new reality and to make life as normal as possible in a highly abnormal and difficult situation.

Inner strength

My wife has an inner strength that comes in part from having grown up poor. When she was young her family had to sell their home, and many days there was no meat on the table. The worst part was the *certainty* that the next day would bring the same misfortune. She postponed badly needed dental treatments, and she started working in her late teens to help balance the family budget. She attended college at night while working full time.

Living on the edge of survival has prepared her to accept a lot of adversity – especially my positive test for HD – with great determination. Knowing that I will lose a good part of my income after I become disabled, she works full-time so that we can try to pay off our mortgage earlier and increase our savings. She knows that she will not be able to take early retirement and will have to see our daughter through college.

Every week she cooks a menu of healthy meals for me, and she takes on the burden of extra housework and childcare when I become immersed in writing for this blog or working as an activist for the Huntington's Disease Society of America (<u>www.hdsa.org</u>). Every weekend she observes me as I perform cognitive tests on the Huntington's Disease Drug Works computer program (<u>www.hddrugworks.org</u>). Every year we plan together how we will donate money for HD research. Whenever she hears or reads a report about breakthroughs in neurological research, she immediately notifies me.

Right after our marriage started, our lives had taken a turn for the better. We were both establishing ourselves in our careers, and we had many exciting plans for the future.

But my wife has had to postpone or simply erase from her mind the hope that we will achieve many of those goals, for example, having a larger family. Our daughter tested negative for HD in the womb. My wife has badly wanted another child, but going through the trauma of testing another child or the expense and challenges of preimplantation genetic diagnosis (testing embryos for the disease) led us to cut off that possibility forever.

My wife has given up a lot of other dreams, like buying a summer home or moving to a less expensive city. We need to invest in *her* future *here*, because this is where she has job security and a salary that probably could not be matched elsewhere.

Worry: a constant companion

More than anything else, HD has robbed my wife of the chance to live peacefully. After so many years of struggle, she now faces the biggest At Risk for Huntington's Disease: Uncertainty and a steadfast spouse

challenges of her life. Worry is her constant companion. Once my symptoms commence, how will she continue to work full-time, manage the household, raise a daughter, handle all of the other tasks that I have taken care of over the years such as our financial paperwork and house repairs – and care for *me*? How will she and I decide when it is time for me to enter a nursing home?

As my wife said after reading a draft of this article, the worst thing about HD is its *timing*. It hits people in the prime of life, *and* it robs victims of their abilities to walk, talk, eat, and think over a period of 15 to 20 *years*. That is a very long time for both me and my family to endure.

We don't talk much about Huntington's disease these days. But HD is always looming in the shadows of our life. We *should* talk more about it, but we don't. We're trying to enjoy our lives and our daughter as much as possible before the pain begins.

Deep inside, I know my wife will prevail. She is always at my side, and she will remain there as long as possible. She'll get by somehow. But it will be lonely and arduous, because she faces losing her closest companion and her daughter's devoted father.

Posted by Gene Veritas at 8:07 AM 💽 M 🖪 💽 🛐 🕥

6 comments:



Staysea said...

Thank you so much for sharing your story about the struggles couples go through with HD. I was with my boyfriend for 4 years , we had a great relationship and loved each other very much. Time went on and as he grew older he started to push me away he felt it wasnt fair to put me through all the hard times that were ahead. We started to fight a lot about it , I told him it was my decision and that I was in it for the long haul. Well I am sad to say that it didn't work out and we did finally break up. The ironic thing is that we are still very close friends so he hasnt saved me from the hard times because I will always be there for him till the end. I commend your wife for all she does and I also commend you for letting her love you. many blessings to you and you family.

staysea

8:33 AM, March 17, 2007



Angela F said...

Your article has highlighted a really important part of the HD story. Children, partners, siblings, parents, friends etc sometimes are all too often forgotten about but they go through so much.

Some do not have the enormous amount of strength required, and some do. I am so very lucky to be with the man that I am. He amazes me everyday in his unwaivering support. I know now that I would never have coped this far without him and I am a strong person. I guess we are stronger. At Risk for Huntington's Disease: Uncertainty and a steadfast spouse

I don't know how I found him or how I managed not to mess it up - I was always a bit of an expert at that before. I really wish people who find themselves in such difficult situations (whether it's HD or something else) have someone like him. 1:10 PM, March 28, 2007

Anonymous said...

Thnaks for sharing. I am the spouse (35 years of marriage) of a pHD. The physical problems (chorea, coordination, swallowing) are much easier to deal with than the psycho-social issues. Behavior of the pHD may result is isolation and alientation from family and friends- and as the caregiver, you may be the closest target. The people that will become involved in interventions, such as Adult Protective Services, tend to be poorly informed, and pretty much uninvolved.

<u>11:20 PM, January 03, 2009</u>

Anonymous said...

I just read this... I am going through a dicorce right now becuase my hub could never get past my gene positive results, Everything we did revolved around HD once we found out it was in our family. I couldnt handle being that person that always let him down anymore.

7:20 PM, October 21, 2012

Anonymous said...

my wife of 28 years recently filed for divorce for no reason, she has test positive for the hd gene. she has now started casual dating another man who she has not told of her issue. she is in the beginning stages of onset but is in denial. I knew from the beginning of our marriage that she would develop the disease. I always supported her and wish to do so till the end. she wrote off our children and grand children. I cant seem to get any help for her and worry for her as he personality has changed as well as her reasoning skill she does things without reasonable thought it breaks my heart and that of our children what she is doing. we need some support for her. also the rest of us. is there any place out there that can help us to help her? 9:52 PM, March 22, 2015

B

🛞 <u>Unknown</u> said...

My name is john, my story as it begins with my wife,it's a wintery night, 1985 going to a club after we (my friends), and I go to a friend's birthday.there I see my wife for the first time.what can I say, I was in love whole heartly.I remember my heart was afire.we talked for hrs, she came from a strict family.no contact or her po aren't that where there , at party would had put a end to it right there!she left but I had no number, but I knew I would never go out as a single man again.that night I walked home 5 moles in snow, because all I

At Risk for Huntington's Disease: Uncertainty and a steadfast spouse

could do is think and hold her face in my mind. My friends believed I would have been the last guy to ever get married,but I said to them I had found my wife, not to get to much Der per we where married 1987!knowing what I know of this disease, and all we went through , I do it again, she is my soul mate, my air, my everthing, I love you josephine!

<u>6:27 AM, October 25, 2015</u>

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