

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

3-23-2011

Huntington's disease, loneliness, and love

Kenneth P. Serbin
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

Digital USD Citation

Serbin, Kenneth P., "Huntington's disease, loneliness, and love" (2011). *At Risk for Huntington's Disease*. 90.

<https://digital.sandiego.edu/huntingtons/90>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.


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)
 - ▶ December (2)
 - ▶ November (4)
 - ▶ October (4)
 - ▶ September (2)
 - ▶ August (1)
 - ▶ July (2)
 - ▶ June (2)
 - ▶ May (4)
 - ▶ April (4)
 - ▼ March (3)
 - [Huntington's disease, loneliness, and love](#)
 - [A cascade of emotions about Huntington's disease](#)
 - [Huntington's support group: seeking solidarity, fi...](#)
- ▶ February (3)
- ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 GENE VERITAS

[View my complete profile](#)

WEDNESDAY, MARCH 23, 2011

Huntington's disease, loneliness, and love

Imagine how lonely you would feel if you were a young person who knew you might never get married and have children because you faced a cruel and deadly genetic disease.

This is the harsh reality of many young people affected by or at risk for Huntington's disease, which robs individuals of their abilities to walk, talk, think, and swallow. In the case of an affected male father, the children can inherit a far worse form of the disease, known as juvenile Huntington's, with onset as early as infancy.

Starting in the teen years and extending into their mid-30s, dating for these people can become an incredibly difficult affair, instantly laden with fear and complex calculations about the future. Even though most standard testing centers won't allow testing before age 18, those calculations can begin as soon as teens develop an interest in sex and procreation.

When will my symptoms start or worsen?

Should I opt for preimplantation genetic diagnosis to assure my children don't have HD?

How will I be able to raise my children?

How will my spouse care for me, and for how long?

Why would anybody want to enter a relationship charged with such huge health and emotional challenges?

Will I end up alone?

Will anybody ever love me?

Understanding the pain

These are just some of the many questions that pass through the minds of young people in HD-affected families. The implications can become more serious as a person passes from at-risk to gene-positive status and ultimately on to the early symptoms.

As an HD-positive but currently asymptomatic person, I viscerally understand the emotional pain of young people in this predicament. Even though I have been fortunate to have a supportive wife, I have heard numerous depressing stories of the break-up of marriages and relationships where the mate could no longer handle the responsibility of caregiving.

And, as I await effective treatments to stave off the disease and advocate for the cause, I have experienced my own cascade of difficult emotions.

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[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.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

After writing about this in [my last blog article](#), I received a comment from Nancy Hess, who tested negative for HD, about the deep loneliness we in the HD community can feel: "So often we find ourselves helping others comfort us when talking about HD. This can bring on an unexpected loneliness but then, as one might say to one's self from time to time, 'Get over yourself!' The truth is, there are only going to be a few in our lives who get it, and can stick with us through the dark passages."

Fear of a lonely and love-less life dominate the stories of young people. Watch, for example, the short video "Five Women Speak from the Heart" on the homepage of the [San Diego chapter of the Huntington's Disease Society of America](#) (HDSA-San Diego).

"I felt like having kids was the number one thing in my life," says Whitney, an at-risk woman whose father developed HD. "I felt like: is my life over?"

"The only thing I fear is just being alone, not having somebody, because I wouldn't want to put anybody through what I've gone through," says Kristen, whose mother was stricken with the disease. "So I couldn't expect anybody to love me like my father loved my mother."

Crying all day long

Recently, Jiyeon Kwon, a 19-year-old man with Huntington's, wrote in an HD group on Facebook about the social burdens of the disease.

Sometimes I regret telling anyone about my diagnosis. Now I know that some of my friends pretty much define me by it. They probably look at me and see "the guy with Huntington's disease" or "the guy that's going to be dead in ten years." And some people treat me differently and let me get away with stuff they wouldn't let anyone else get away with. It's just frustrating, I guess. It's funny how people who you thought were good friends make a totally different image of you just because of one disease you happen to have. [quoted with Jiyeon's permission]

We can gain even deeper insight into the emotional impact of HD on relationships by listening to words of the unaffected partner, as in this message that I recently received from a female college student:

I have an amazing and wonderful boyfriend who I plan on spending the rest of my life with. I found out a while back that his mother has Huntington's disease. To be honest, when I found out I didn't research much on what this disease was about. (I have also never met her.) So I didn't realize until today (from my science teacher) that my boyfriend has a 50 percent chance of inheriting this. I've never been so heartbroken and confused in my life. I don't know what to do. I don't know what to think. He's not one to really talk much about this so I don't even know the right way to bring it up. I've done nothing but cry all day long....

I'm so new to all of this, and all I know is all the negative things I've read on the internet. I'm scared for my boyfriend so much but I don't know if it's wrong to show my fear in front of him.

True, enduring love

Indeed, in these circumstances, love must be *true* to thrive and later endure.

My father and HD-stricken mother's marriage was far from perfect, but they held on through the fifteen-plus years of her illness. My dad, the "[Huntington's disease warrior](#)," fed, bathed, and clothed Mom daily until she went into a nursing home in mid-2005. He visited her each day at the home until her death in February 2006.

Because Mom was falling ever more frequently, Dad probably should have relinquished his caregiver role even earlier. But then she may have died even sooner.

In this era of instant hero status, heroism has lost its meaning. Everybody, it seems, can be a hero for the proverbial 15 minutes. But Dad – and the millions of other caregivers in America looking after HD, Alzheimer's, and other neurologically disabled people – are the real heroes. Nobody knew about him, but he got into the HD trenches every day for 15 years.

In my case, I am greatly blessed with the unbending support of my wife. We learned of my mother's diagnosis just three years into our marriage and before attempting to have children. As a recent immigrant and still without an established career, she could have responded to the daunting prospect of caring for an HD-stricken husband and having affected children by taking the easy way out: returning to her home country of Brazil and her old job.

But she stuck with me then – and after I tested positive in 1999. The lasting bond we forged was further cemented by our good fortune in having our “miracle baby,” who tested negative in the womb. We know all too well the fear of passing on the defective gene.

In 2009 and 2010 she ran in a half-marathon to benefit HDSA. ([Click here](#) to read more about us.)

Support for families

I have gained an important lesson from my parents' experience and my own family's situation, as we face my inevitable incapacitation: HD families need greater support from HDSA, physicians, and local social services and clinics. As so many have stated before, HD is a *family disease* affecting everybody within the nuclear unit and often reaching far into the extended family.

Despite the immense health and social challenges of HD, many families and caregivers steadfastly support young people with the disease. The family of Terry Leach, a San Diego teen who first developed HD as an infant, has shown great love and togetherness in caring for him ([click here](#) to read more).

Many spouses and caregivers accompany their loved ones to the local support group. Some caregivers even attend after the patient has gone to a nursing home and can no longer join the group. In other cases, at-risk individuals are unwilling to participate in the group, but their potential caregivers attend anyway.

Doing the right thing

It's also encouraging to see the young people who are standing by their partners and spouses. I was touched to read the comment to the Facebook HD group by one young woman who was “having the best week. I just got home from Disney World with my amazing boyfriend. We had the best time together. He takes such excellent care of me. I used my wheelchair at Disney World. It worked out great. I love my boyfriend with all my heart. I am so blessed that he is in my life.”

With such stories of commitment and my own years of experience in mind, I wrote back to the young, heartbroken girlfriend of the at-risk college student:

I think the best advice I can give is to be completely honest with yourself and your boyfriend. Do NOT hide or avoid or deny the subject of HD. It's best to meet it openly and head-on, although always with patience, gentleness, and kindness. I am a firm believer that hiding the truth can be

convenient and easy in the short run but ends up doing very serious damage in the long run. You're doing the right thing by learning about the disease and all that it could mean for your boyfriend. And it's important for you to stand by him as a girlfriend and as a friend. We cannot predict the future, but even if you end up not being in each other's life down the road, you will have done the right thing by supporting him at this point.

Posted by [Gene Veritas](#) at 4:31 PM



Labels: [at risk](#) , [at-risk](#) , [caregiving](#) , [diagnosis](#) , [gene-positive](#) , [genetic](#) , [Huntington's](#) , [juvenile Huntington's](#) , [love](#) , [nursing home](#) , [support group](#) , [symptoms](#) , [Terry Leach](#) , [tested positive](#) , [warrior](#)

8 comments:

Anonymous said...

Thanks for this blog post. Before marrying the love of my life since age 15, it never once occurred to me not to be with him because he was at risk for HD. His at-risk brother (who later tested negative) had a serious girlfriend leave because of the same issue. I guess it depends on the person.

After my husband tested positive in our second year of marriage, we had to deal with the whole "kids" issue.

Fortunately for us, since we had the "dad" jhd concern, our accidental pregnancy gave us an HD gene-free baby. The prenatal testing was stressful, and I did feel I was judged here and there, but all turned out for the best.

Life does not end with and HD + result. We all know that life can turn on a dime for everyone. Live it like it's the best life you have. :)

8:12 PM, March 23, 2011

Jessica said...

Thank you so much for writing this! I'm so happy you included my message to you as well. You're such an amazing person, and you continue to give so many people so much positive encouragement day in and out. I hope anyone who is HD positive, or know someone who is, or know anything whatsoever about HD never give up the fight to end this disease. With your encouragement, we won't.

3:41 PM, March 24, 2011

Ji Kwon said...

Thank you for writing this. It really means a lot to me, and I'm sure the same goes for a lot of people who can just relate to what was said in it.

I actually got a boyfriend not too long ago, and right before it was official, he was telling me about how he'd be happy to be my caregiver if I'd let him, for when the time comes when I can't take care of myself anymore. It must take a strong person to commit to that sort of thing, and what I would think would be true love for a person.

3:45 PM, March 24, 2011

☼ Anonymous said...

Thank you for this blog.

I remember when me and my love started dating. About a month in he told me about his family's HD experience - and the possibility that he too may have it. (He is still coping with getting tested.) I quickly took out my pda and googled HD. Watched youtube footage and researched. I told him it didn't matter. It does matter - but not in the way that will keep me away from him.

I grew up in a household where - no matter how tough things get - we follow through - because we are family and we love eachother. That's how I was raised. That's the way I know. Sure, it's scary - but life is scary...and I haven't left "life" yet... He is my love - and I won't ever give up on him. Having been in and out of hospitals myself (as a child and adolescent) I know how tough it is to think of oneself as a burden to others. My love's concern is that he will not be able to take care of himself and doesn't want to be a vegetable in a care center...alone. I assured him that I wouldn't leave him alone. It took a long time for him to understand this concept. But he understands it now. And we are both prepared to move forward together - still knowing that there is the possibility of him testing positive. But we will jump that hurdle as we approach it.

Good luck to all out there who are in some way or another affected by HD. My heart goes out to you sincerely. God Bless <3

9:42 AM, March 25, 2011

☼ Anonymous said...

I just wanted to say thank you very much for posting this blog. I am a college student who is at risk for HD and it's not easy. There's a part of me who just wants to know if I have it. Also, my dad is currently trying to live through it, but he's getting to the later stages of it so soon. It's hard knowing that he could die at any time because I had two others in my family die from it too, my grandpa and my aunt, but I have faith and hope that everything is going to be ok. Thanks again and God Bless.

11:44 PM, May 17, 2011

☼ Anonymous said...

Hi I am a 19 year old female who is at risk and very scared. I will going through the process of genetic testing in the next four to five months... If anyone feels like making a friend or is just scared like I am ill be your friend. My email is mjjmlover@yahoo.com don't be afraid to contact me, I want to meet people who share the same feelings as I do

7:37 PM, March 10, 2013

Anonymous said...

I am the father of a young woman who is dating a young man who is at risk, but has so far refused to get the predictive test, and is in denial of the reality of what this could mean to my daughter.

In love or not, my feeling is that a refusal to get the test, before they might marry, is selfish and unfair and cowardly by the person at risk.

Say I am heartless and emotionless, but I think the fact that this person does not realize the importance of his partner knowing, is both immature and the most cowardly act imaginable.

How dare he act this way?

6:56 PM, October 26, 2016

**Unknown said...**

I agree, asked that my daughter have her husband tested before marriage so she could make an informed decision and both refused. A few kids later and I think he is the most selfish person on the planet. I couldn't look at my kids knowing I rolled the dice and destined them to a horrific early ending. Then I remember life is lived in moments, little or big, whether our time here is predestined or not. Some people live more in 30 years than others that have 70 years. Maybe our children being caretakers scares us more than it does our children because they are still children to us. I suppose character is decided by when we stand and fight. It is better in life to love deeply, than not to have found that love. Truth is we made our life choices and lived with the outcome. It is their time to do the same.

6:20 PM, December 17, 2016

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)
