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HD's financial devastation

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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.

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TUESDAY, MARCH 01, 2005

HD's financial devastation

HD is not just a threat to my health. It colors practically every decision my wife and I make about our finances.

The other night an acquaintance who is a real estate agent suggested to me that we take advantage of the large amount of equity in our home to buy another property, travel, or do anything else that we've wanted to do for a long time. My wife and I are still pretty young and in the long run could handle the extra payments on another loan.

It all made sense, I told her, until you factor in my at-risk status. If I become ill in a few years, disability insurance will cover only part of my income, and then only until I reach my mid-60s. The enormous loss in income would put a triple burden on my wife: handling the mortgage in the present, saving more for retirement, and finding money to help pay for my care. In addition, she would be supporting our daughter throughout high school and college. We're already spending extra money on added insurance to cover my expected illness. And we donate a sizeable amount to HD research each year.

So instead of spending more, each month we pay off an extra \$500 of the mortgage principal. We're thinking of increasing the payment by several hundred more. Our financial advisor, who doesn't know about HD in our family, urges us to stay in the market for the long haul. But if the stock market rises again, we have vowed to put take the profits out to pay off as much of the mortgage as possible.

Our dream of buying a vacation home has remained just that – a dream. We take short, modest trips. We've scaled down our current project of home remodeling.

A couple years ago we turned down a chance to co-sign a loan on a very promising business venture because we feared losing our good credit rating. The more my risk for HD approaches the probability of symptoms, the less we expose ourselves to financial risk.

Whenever we think of money, the question inevitably rises: "What if HD kicks in?"

"If it weren't for HD" is a regular part of our vocabulary.

HD is like a big "no!" that screams at us every time we think of being adventurous.

Before I learned about HD I had always imagined myself working until well into my 60s and maybe even into my 70s. Now I will consider myself lucky if I can reach age 55. That's a decade or two of lost income – about a quarter of my working life.

HD is medically –and financially – devastating. We were fortunate enough

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to learn of my risk early enough to plan for the future. Even so, the consequences are not bright. For families with less warning about HD or with multiple members affected by the disease over one or more generations, financial ruin is a harsh possibility.

Posted by [Gene Veritas](#) at 8:57 PM      

1 comment:



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I didn't see where you mention your CAG repeats. Care to share?

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8:49 AM, March 08, 2005

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