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Overcoming HD's tyranny of time

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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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THURSDAY, JANUARY 27, 2005

Overcoming HD's tyranny of time

It's been more than two weeks since I've written here. The reason I've taken so long to return is, quite simply, time.

After death, time is the thought that most frequently comes to my mind when I'm worrying about HD.

How much time do I have before HD strikes?

Will I have enough time to accomplish all that I had planned for my life?

How can I manage my time more efficiently to get all that I want out of life? And how do I prevent the striving for efficiency from tyrannizing my life?

How do I balance the many commitments that demand my time – commitments compounded by volunteering in the campaign against Huntington's and writing here?

Last Saturday night my family and I went to a dinner party. It was supposed to be a relaxing evening, but all I could think about was leaving early so that I could get to my HD volunteer activity.

This hyper-awareness of time often saps the joy out of my life.

What terrible decisions I often have to make! Should I play with my daughter or do something to save my life, like volunteer work or extra exercise or writing about HD?

I occasionally used to ask myself: what do I want to look back on when I'm on my deathbed? It's a question that I now ask myself more often to help me put things in perspective and use my time more wisely.

Wisdom, I'm discovering, does not necessarily mean greater efficiency. In the process I'm starting to learn to give up things that I've held dearly for so long. For years I've strived to be at the top of my profession. But as I become more deeply involved with the fight against HD, I see that work is no longer so important. (Read more on HD and career in another entry to be posted here soon.)

I'm also struggling to learn how to enjoy the moment.

I must learn that time is not my master.

As a Vietnamese Buddhist put it so well, all time is our time if we choose to see it that way. Whatever we are doing at any particular moment is our own experience, whether it be some great and courageous action in the fight against disease or something as simple as helping my daughter learn to brush her teeth.

- [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.](#)

I look forward to a time when HD will be conquered. I hope it comes in my lifetime. I would love to experience once again the freedom of not thinking so much about time.

Posted by [Gene Veritas](#) at [7:44 AM](#)



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