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To go – or not to go – public

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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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MONDAY, FEBRUARY 14, 2005

To go – or not to go – public

Should I go public with my at-risk status?

That's a question I've thought a lot about since I discovered nine years ago that my mother had HD. The prospect of going public leaves me excited about the new ways in which I could help the quest for the cure, but it also makes me nervous about the many perils my family and I would face.

The other night my wife and I once again debated the pros and cons of my revealing my status. I always raise the topic and advocate my coming out.

I could give talks to local organizations such as Kiwanis that might be able to donate money or help the cause in some other way. I could write newspaper op-ed pieces in which I use my family's experiences with HD to describe the disease's horrors and its terrible social impact. I could openly invite acquaintances and friends to attend fund-raisers or to assist the campaign against HD in some other way. I could finally wear a "Cure HD" button for the whole world to see.

In short, I could do my small part to take HD out of the Dark Ages and give it the public prominence it needs and deserves. At last I could end the secrecy and be true to myself.

If and when I became sick, I would be able to look back on my efforts knowing that I struggled with every inch of my being.

My wife tends to see the broader implications of going public and urges caution and patience.

Do you want to give up your chances at career advancement so soon? she asks. What happens if you lose your job or if your employer uses your at-risk status to get rid of you? Will others interpret every tiny slip or miscue in public as the onset of symptoms? What happens if we lose our insurance and I am excluded from a new plan? A public declaration of my at-risk status will tinge every decision others will make about me.

My wife asks: will I be able to live with unmet expectations of going public? Most of our friends and acquaintances will at first show sympathy, but then how will I feel if they don't have the time or money to support the cause? What if my hopes for increasing donations do not materialize? Could the excitement and promise of going public later lead to depression?

And what about the impact of going public on my daughter? Insurers will want her to get tested. Employers might balk at hiring someone potentially at risk. There are numerous other ramifications as yet unimaginable.

I am always left in a quandary after these discussions.

I insist to my wife: if not now, then when should I finally go public? We have been dealing with HD for nearly ten years. As my potential age of

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onset approaches, the urgency of a treatment increases. I want to be able to fight for one while I still have all of my faculties.

You'll know when the time comes, she says.

Like the onset of HD itself, that moment is inevitable but can never be precisely known. Just as we have faced HD together from the start, the decision to go public will ultimately be one based on what is best for the family as a whole.

Posted by [Gene Veritas](#) at 4:47 PM



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