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A Thanksgiving visit: a time to reflect on HD

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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)
- ▶ 2006 (4)
- ▼ 2005 (17)
 - ▼ December (2)
 - [A Huntington's Christmas story: ten years of wonde...](#)
 - [A Thanksgiving visit: a time to reflect on HD](#)
 - ▶ September (2)
 - ▶ July (1)
 - ▶ May (1)
 - ▶ April (1)
 - ▶ March (4)
 - ▶ February (3)
 - ▶ January (3)

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FRIDAY, DECEMBER 02, 2005

A Thanksgiving visit: a time to reflect on HD

My dad traveled to visit for Thanksgiving, bringing the stark reality of my mother's affliction with Huntington's disease into our household.

I have seen my father, now 78, become tearful only a few times. But he cried when he first talked about my mother, whom he left for the first time in 47 years of marriage in order to spend ten days with us. He has been doing a lot of crying since putting my mother, 68, into a nursing home in August, he explained.

"I ask God, 'Why our family?'" my dad said. A devout Catholic who believes in accepting God's will, he added quickly: "I suppose I shouldn't ask that question."

Later I decided to ask him: "Why do you think God would choose our family?"

"Maybe he's testing us," my dad responded.

"That's quite a big test he's putting us through," I rejoined.

I asked myself that same question – "Why us? Why must I be at risk for HD?" – over and over again during his visit. I don't discount the possibility that in some odd way there might be divine purpose in Huntington's disease. But mainly I believe that our creator – whatever it may be – has placed us in a universal struggle for perfection and justice. Curing HD is just one of the great challenges that humanity faces. At-risk people like me who are fighting to ward off onset and striving to support those who research treatments are front-line fighters in that great struggle. We try to set an example for others, raising awareness about genetic diseases and pointing out the need for compassion.

I also don't discount my father's faith. Over the past fifteen years, it has helped him care for my mother day after day and to accept her gradual but inexorable decline into the infant-like helplessness HD causes.

"You've shown a lot of strength," I told him as we went out for a drive one night.

"I didn't know how much I loved your mother until these past few years, taking care of her and seeing how much she has lost," he said.

The transition of the last few months – Mom into the nursing home and Dad living alone for the first time– has been tough. But that same strength is there. He visits her every day for several hours, taking her favorite fruits and talking patiently with her even though she can no longer speak.

For the first time since August, he and I talked to her together on the phone, because at my house we have two extensions. I have sorely missed these three-way conversations in which my dad and I did all the talking

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and my mom simply listened. Whenever I call her at the nursing home, I am at a terrible loss for words. I usually speak for just four or five minutes, telling her about her five-year-old granddaughter and other things in our life.

“Whenever I arrive at the nursing home, her face just lights up in a big smile,” my dad said many times during his visit. “That makes me feel so good.” He added, “I know I made the right decision putting her in the home. I know she’s happy there.”

One of the hardest parts of my dad’s visit was seeing him so frail. Seeing the man I might become has made me think a lot about my own mortality.

But I fear most my mother’s fate, because I, too, am gene positive for HD. More difficult than seeing Dad was looking at pictures he had taken of my mother at the nursing home. These were the first photographs I’d seen of her since the move. My dad pays a woman to do Mom’s nails and set her hair, but he still needs to coach the nursing home staff on how to use a shower cap to keep her hair nice. It was hard knowing that she can’t receive the same loving care that my father provided (but can no longer provide). There were also photos of her in a wheelchair and with the grimace HD people typically express.

My dad left me some of the pictures. My wife, my daughter, and I looked at them very briefly. My wife and I didn’t say anything, and we quickly put them away. I’ll let them sit a few days until I can collect my thoughts about the flood of emotions that came with my dad’s visit.

When I get the courage to look at them again, I think I’ll take out my favorite picture, the one in which Mom has that big smile that Dad likes to describe. Despite all that HD has done to her, it reminds me that she is still alive and human!

I think I’ll frame that picture.

Posted by [Gene Veritas](#) at 9:59 AM



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