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Seeing Mom (Part II): a family's emotions

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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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FRIDAY, MARCH 25, 2005

Seeing Mom (Part II): a family's emotions

I previously wrote of the terrible difficulties resulting from the way Huntington's disease has immobilized my mother. During my visit to my parents many other aspects of HD also came into play, producing strong emotional repercussions for the entire family.

A heart patient, my father will soon turn 78. The strain of caring for a person with HD puts him at increased risk for suffering a health crisis. My mother's continued decline will only make the situation worse. My father is a stoic, but even he is moved to almost crying when my mother falls.

I was the one who ten years ago urged my father to take my mother to a specialist. It took him months to do so. That process led to her diagnosis with HD in 1995, just two years after the discovery of the HD gene made a definitive test for the disease possible. After my father's emergency triple bypass operation in 1998 I forced him to consider getting part-time in-home help for my mother. After much angry protest at my perceived meddling, he agreed. This visit I once again took the lead by calling an emergency family meeting and getting my father to focus on obtaining additional help in the home or moving my mother to a nursing home.

I could tell that my mother's worsening condition has softened his resistance: this time he did not protest what could be the biggest change in his life since their marriage in 1957.

The trip once again drove home for me that my mother's fate could be my own. Looking at her is like looking into a genetic mirror. It is a chilling experience. I especially noticed that her chorea – uncontrollable movements – had worsened since I last saw her in January 2004. Because of my fears, I didn't get too close to her. The only way I could be in the same room was to deny my own at-risk status and the deep fears associated with it.

As I returned home, I felt the added burden of taking on a new leadership role in the family. From a distance I will need to help with finding the best legal and medical help for my parents. I am inexperienced, and the task feels daunting. The prospect of my mother living alone deeply saddens me.

The visit brought an unexpected reunion with my sister, my only sibling, who had cut off contact with me because I insisted that our family deal more openly with Huntington's disease and that she help more with my parents, who live nearby. After three years of silence between us I called her to join my father and me in the meeting about our mother. In contrast to our last conversation, which she ended by hanging up on me, my sister thanked me for helping to press my father about our mother's health. The damage from our falling out may never be repaired, but we now at least have the potential for a businesslike relationship regarding our parents.

The most important, most touching moments involved my daughter's perceptions of her grandmother. Now four-and-a-half, my daughter

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consciously hugged her grandparents for the first time. She had fun being with them, and I was happy to see the joy that she brought to them. One time I asked my mother to hug her granddaughter, and, in a gesture that can be considered nearly miraculous for a person at this stage of HD, she moved her hands and arms down and over my daughter's back.

But more often than not, it was clear HD has devastated my mother's mind and body. During meals, as I coaxed my rambunctious daughter to eat by spoon-feeding her, across the table my dad cut my mother's food for her and spoon-fed her too. As my daughter was progressing towards greater social awareness and responsibility, my mother was regressing into a deeper dependence on those around her.

My daughter carefully observed the many ordeals that both her grandparents experienced as Grandpa helped Grandma with feeding, walking, and going to the bathroom. Later she asked about her grandmother's illness, which I had described as a "boo-boo on Grandma's brain." I was deeply proud to hear my daughter's intelligent inquiries, but I answered her slowly and with great measure.

"When did Grandma get a boo-boo on her brain?" she asked.

"She got it when she was born," I replied.

"How did Grandma get a boo-boo on her brain?"

"Sometimes people are born with a boo-boo on their brain because things did not go right when they were still inside their mommies' tummies."

"Why didn't Grandma get sick when she was younger?"

"Sometimes a boo-boo takes a long time to develop, to come out."

"Grandma is going to die from the boo-boo, right? We need to pray so that Grandma gets better. When Grandma dies, there will just be Grandpa."

"Yes, we need to pray for Grandma."

"Mommy and Daddy won't die for a long, long time!" she said to reassure herself.

Luckily, the moment has not yet arrived for my daughter to learn that I, too, am at risk for HD.

And, of course, there were my mother's emotions. Nobody can know what she really feels and thinks, because HD has stolen her ability to converse. But deep inside her being she struggles to express her desire to be human. If someone smiles at her, she can still smile back. She can also get out some light chuckles. On close contact with my father or with me, my mother uttered one of the few phrases that she can still eke out: "I love you." She said this about two dozen times during the four days that I was with her and my father.

I asked her, "What do you think of your granddaughter?" She was able to muster a response: "I like her." For all the sadness and tension that this visit generated, I will at least have this memory of a grandmother admiring and loving her granddaughter.

Posted by [Gene Veritas](#) at [10:26 PM](#)



3 comments:



~*[Daniella Bella](#)*~ said...

This comment has been removed by a blog administrator.

3:26 AM, October 02, 2005



❁ **~*Daniella Bella*~ said...**

OMG, your blog brought me to tears. My mother as well has HD. She has been sick for about 5 years now, but was not formerly diagnosed until the last two years. Everything you described is her too. It is the hardest and saddest thing to watch, but I will tell you it is the most amazing and rewarding thing that you will ever go through. I was 19 when my mom became ill and I had to start caring for her. At 20 I was hiring attorneys and going to court for conservator ship. I grew up very fast, but I would not change it for the world. Experiencing this with my mother and being able to care for her has given me a new light. It has forever changed my life, and with a lot of the bad I have experienced a lot of overwhelming love and compassion towards not only her, but everyone in my life. It taught me how precious life truly is, and what love means. It is amazing to me that you brought up the love part. My mother too could not talk, remember things, etc. But every time I would walk into a room she never forgot me and her eyes would light up. She would say I love you to me every few seconds, and till this day I am not sure if it was because she was just forgetting she just said it? Or if it was because she knew what was going to happen and she wanted to beat into my head that she LOVED me. This is a horrible disease and one that I'm at risk of as well. I pray that by time I am 40 there will be some kind of cure. Cherish every moment with your mother and stay strong. There is a light at the end of the tunnel.

4:04 PM, October 03, 2005



❁ **Tammy said...**

Your post brought me to tears. My sister-in-law is going through the testing process now-what a long process. Her mother had HD and passed away in her early 40's.

I am a social worker and getting ready to start grad school-I know my calling now! My brother and their two-year-old little girl are going through so much right now as well.

I, too, have a blog that I would like to share with you-
www.tammyladams.com

I will post things periodically regarding HD.

Take care!

6:18 PM, March 13, 2006

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