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Planning for Mom's move to a nursing home

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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, JULY 19, 2005

Planning for Mom's move to a nursing home

My family faces a moment almost as difficult as an impending death: My sister, my father, and I are about to make the wrenching decision to put my mother in a nursing home.

Mom has had HD for at least fifteen years, since she was in her early fifties. As a caregiver, my father has been saintly. However, she has declined rapidly over the past few years, losing the ability to talk and walk. Last year she broke her wrist during a fall, and earlier this year she suffered a large gash to her head after hitting a piece of furniture.

In just one day this past week she fell three times. Once again my dad had to call 911 for help in lifting her off the floor. She now has bruises on her chest and back. At 77 and suffering from a heart condition, Dad can no longer provide Mom with adequate care.

Over the past few weeks my family has experienced a whirlwind of plans and emotions. First my sister, Mom, and Dad met with a lawyer to prepare my parents' finances and legal matters for a Medicaid application. (I live in another state and could not attend the meeting.)

Nursing homes in their area cost more than \$5,000 per month for a semi-private room. At that cost, my parents' savings will run out in a few months, leaving them no choice but to depend on public assistance. Before they can qualify for Medicaid, they must spend practically all of my mother's savings and about half of my Dad's.

My sister and I have had emotionally draining phone calls about the legal, health, and logistical aspects of this big change in our lives. Just talking about HD reminds us of the disease's threat to our families. Like me, my sister has a 50-50 chance of having inherited the disease from Mom, and she has three sons who could also be at risk. Mom's departure will disrupt my parents' lives and deeply sadden all of us. As I thought of my mother's illness, I saw our family's history pass before my eyes, from the time Mom used to smile at us children to the cruel cognitive loss that has stolen her ability to speak. I was gripped with anger, confusion, guilt, and doubt. How could this happen to my mother? Are we doing the right thing for her?

We have no experience with nursing homes and are learning as we go. The process feels utterly haphazard. There are so many variables involved, and each time we speak new ones arise. What's better, a big facility or a small one? What are the nurse-patient and aide-patient ratios? Do we put her in a private room, a semi-private one, or a quad? Which home would be most convenient for my father to drive to? What kind of physical therapy will be available? How will Mom interact with the other patients?

And the biggest questions of all: how familiar is the staff with HD, and will they be able to adapt to the unique disease profile that HD has characteristically produced in my mother? Will they be able to keep her from falling and injuring herself without having to strap her down or drug

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her? Most nursing homes do not have staff trained specifically for HD patients. In fact, some reject HD patients because of prejudice or the perceived difficulties in caring for them.

"If we were millionaires," I said to my sister, "we could build a special home for Mom and Dad with all the necessary protections for Mom, and we could hire around-the-clock help to make sure she didn't fall any more. But we are not millionaires. The only choice we have is to put her in a home."

The other night I cried as I realized that Mom's transition to a nursing home will leave an emptiness in all of our lives. I imagined her and my father separated for the first time. I thought of her being alone for many hours without anybody to love her. I felt a premonition of the shock I will experience when I visit her there for the first time. I wondered about the impact on my five-year-old daughter of seeing her grandma in a place with many old and disabled people.







And I remembered that I myself run the risk of ending up in the same lonely circumstances as Mom.

The hardest part of this decision is convincing Dad that the time has come to move Mom. He is dedicated and stubborn – and afraid. Whenever I broach the idea, he changes the subject. The weather, meals, his tomato plants, the birds and animals in his yard, the church bazaar – anything is easier to talk about than a nursing home.

A couple days ago I put the matter directly to my mother for the first time. HD makes it impossible for her to converse but she can listen, and I wanted her to start getting accustomed to the idea of living away from my father. As I said, I want them to have to a heart-to-heart conversation about this.

"It's not easy to do this after you've been in a good relationship with a person for almost fifty years," Dad said.

Our whole family is starting a new phase. The transition to the nursing home is just the start. We will have to be vigilant about her care. Each visit will generate new emotions. The most important thing we can do is to make Mom feel as comfortable as possible and to continue to show our love in the final years of her life.

Posted by [Gene Veritas](#) at [11:59 AM](#)      

5 comments:



Gene Positive said...

so it seems we share the same blogging name and the same sort of fate. i don't know what to say, but it's kinda neat!

It is really tough watching a parent die...especially when it takes so long, and we know they're suffering. then to think it will happen to us!

My thoughts are with you. Bless you!

[3:14 PM, September 14, 2005](#)

Anonymous said...

I had to put my mother who is declining with Alzheimer's and we suspect suffered a mild stroke several weeks ago into a

nursing home a week ago. I empathize with you. I visit her every day to make sure she doesn't feel I stuck her in there and left her. I had to do it for her safety and she is getting much better care than I can give her. It isn't easy though. I know she will adjust with time but she is finding it very different. Breaks my heart.

10:19 PM, December 10, 2008

⊗ **Kim I said...**

Kim I said...

I myself am living with this my daughter is 26 years old and she got it from her father she has had it for about 13 years and she dieing slowly right before my eyes and i too have to think about a nursing home and i dont have a clue what to do so i know what u are going through its terrible

10:22 PM, January 22, 2011

⊗ **Anonymous said...**

My brother to. The day is today, Monday, Feb. 6, 2012. My brother had to leave work in Queens NY to go home to NJ to take his wife to hospital. There is a special committee meeting tomorrow to determine her fate. I feel very frustrated living in Florida not being able to help much. However, the internet does allow me to help in ways I never would have been able to 10 or 20 years ago. I'm trying to put together a list of Nursing Homes that specialize in HD that I can email to him that are not further than 50 miles from Ringwood NJ where he lives. I'm finding that very few facilities are familiar with HD and therefore Google results are few. Is there anyone out there who can tell me what i need to look for and if they know any good facilities around Ringwood??? Any help would be appreciated, including prayers for my family. Thank you. Chris at electroletter@aol.com.

5:22 PM, February 06, 2012

⊗ **shayne said...**

I too share your pain. I am about to put my 40 year old, little brother into a nursing home. After watching our mother die, he gets to repeat her fate while I get to rewatch. I can believe this is happening again.

We are all related, those of us with HD. Good luck to you my cousins...

God help us all

1:46 PM, December 11, 2012

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