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At Risk for Huntington's Disease

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## What is wrong with Grandma?

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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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[Huntington's Disease Society of America](#)

SATURDAY, MARCH 12, 2005

## What is wrong with Grandma?

Because my mother has HD and is incontinent, she can no longer travel on an airplane to visit me and my family. So next week I'm taking my 4-year-old daughter to my home state to see her grandma.

This trip will not be easy.

My mom knows she has a granddaughter, but she cannot talk to her. She cannot play with her or take her to the park or teach her how to sew (an activity she thoroughly enjoyed in her better years). She cannot even hold or hug her.

When we saw my parents in January 2004, my mother spent a good part of the time in a wheelchair. As my daughter romped around the museum and arboretum we visited, my mother simply sat and looked into the distance with the sad stare that seems like a slumber she cannot awake from.

We had to plan our outings based on my mother's immobility and inability to spend long periods away from home. Moreover, getting in and out of places can be a serious logistical challenge. At the museum my daughter seemed intrigued at the fact that Grandma had to ride a special elevator alongside the stairs. As my daughter watched silently, I wondered what kind of meaning this image was leaving on her impressionable mind.

My daughter has not yet been too inquisitive about my mother. Until now I have simply explained that "Grandma has a boo-boo on her brain." She understands.

But lately my daughter has been asking big questions. "Why do we have policemen?" she asks. "Why are some people bad?" No longer a toddler, this time my daughter will want to interact more with her grandparents and learn about their lives. I am bracing myself for even more difficult questions about my mother such as "what is wrong with Grandma?" or "why does Grandpa have to feed Grandma?" or "why can't Grandma play the game with us?"

I don't want to alarm my daughter about HD, but I also don't want to shelter her from it. Someday she will have to learn that her very own daddy is at risk for the disease. I'd rather gradually accustom her to the idea than spring it on her suddenly when she's a teenager.

So as our trip approaches, I am preparing myself to have my first serious conversation with my daughter about HD. It will be particularly wrenching for me because whenever I see my mother, I see what my future could very likely hold for me. I am thankful that for now I won't have to tell my daughter that her dad could follow in her grandmother's steps. But I also know that her intelligent mind will continue to form new questions about her family and life. My hope for now is that she can bring some joy to a grandmother who can no longer express such a feeling. And I would like

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## HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)  
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her to have good memories of this trip.

It's all such a big lesson for such a little girl to learn. And it's equally hard for her dad to think of how he's going to help her with it.

Posted by [Gene Veritas](#) at [9:11 AM](#)

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