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Saying good-bye to Mom

Kenneth P. Serbin

University of San Diego

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Serbin, Kenneth P., "Saying good-bye to Mom" (2006). *At Risk for Huntington's Disease*. 19.
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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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WEDNESDAY, FEBRUARY 01, 2006

Saying good-bye to Mom

My father decided last week that he did not want my mother, who has had Huntington's disease for about 15 years, to have a feeding tube. My sister and I reluctantly agreed. Mom can no longer swallow properly – one of the final symptoms of HD before death. She runs the risk of taking food into her lungs. My father and my sister contacted a hospice, which will assist with my mother's care until her death, attempting to make her passing as painless and as comfortable as possible.

On Thursday night I called the nursing home where my mother is living. The nurse suggested that I visit as soon as possible, because death could come quickly. Mom has had two incidents of serious dehydration in the past couple weeks and, without a feeding tube connected to her stomach, she might not last much longer. The nurse bluntly revealed an emotional bombshell: Mom had said that she was "not afraid to die."

I decided to travel on Friday for a weekend trip to my hometown to visit Mom for what could be the last time. I dropped everything I was doing, frantically packed, and reserved a last-minute flight. Throughout the long, emotionally-draining trip across the country I could not stop thinking about our family's decision about the feeding tube, my Mom's illness, and my own at-risk status.

After my father and sister picked me up at the airport and we got a quick dinner on Friday night, Dad and I drove to the nursing home. I insisted that we go, even though it was already a couple of hours past her bedtime. I had come on a mission to see Mom, and I did not want anything to prevent me from doing so. My adrenalin flowed as I braced myself for what I knew would be a depressing scene in the nursing home.

Mom was asleep when we entered the room. She lay in a simple bed with two railings to stop her from falling out. On the other side of a curtain slept another woman, a paraplegic who can only whisper her words. But, as if Mom sensed our presence, she suddenly awoke. I bent down over her in the dark and asked her if she knew who I was.

Mom did not recognize me. At first she referred to me as her "husband," then as "Grandpa." HD-driven dementia has clearly taken its final toll on her mind. When I saw her nearly a year ago, she had no difficulties in recognizing me. Only a couple times throughout the nearly six hours that I spent by her side over the weekend did she really seem to understand who I was.

I hugged her and kissed her and then bade her good night, as we would be returning to see her again the next day.

That night I dreamt nervously of visiting Mom and walking through the somber halls of the nursing home.

On Saturday we arrived around 12:30. Mom was sitting in the hallway in a

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special padded lounge chair provided by the hospice. Dad called it the “Cadillac,” because it was much nicer than the chair she had used earlier, and certainly more comfortable than a wheelchair. It had wheels, so we could roll Mom around the nursing home.

Mom again had trouble recognizing me. She just sat immobile in the chair, turning only her head and moving her legs a little from time to time.

But when I showed Mom a picture of a little girl, she immediately called out her granddaughter’s name. I felt good.

Dozens of times Mom said, “I love you,” to us, to the nursing home personnel, and to the lady who comes to fix her hair, a person who has helped care for her the past eight years. She still understood the essence of life and wanted us to know what she felt for us.

My sister, my dad, and I conversed about HD and my Mom as we contemplated her in the chair. HD people have a hard time focusing their eyesight, but Mom was able to fix her gaze to meet up with mine a number of times. I felt close to her. And I felt as if I were once again looking into a genetic mirror, seeing how I myself could end up if a treatment or cure for HD is not found soon.

That was the most unnerving aspect of the whole visit: having to see Mom in such a deteriorated situation and knowing that I carry the indelible mark of a defective huntingtin gene.

I also learned how difficult her swallowing has become. An aide brought over a glass of water with a thickening agent in it that is supposed to facilitate swallowing. My sister and I patiently helped Mom take sips from the glass. She had difficulty keeping the liquid in her mouth, so we put a towel across her chest. Over ten minutes she barely got down more than an ounce or two.

I now understood why the doctor had extended the possibility of a feeding tube, although we were also told that such a tube was no guarantee that Mom would not get food into her lungs.

Sunday would be the final day of my visit. I wanted to get to the nursing home as early as possible to be able to spend quality time with Mom.

I was very nervous and fidgety, thinking the whole time of how my life could become transformed by my genetic destiny. I kept sitting down and getting up from my chair as I looked at Mom and tried to concentrate on the conversation going on around me.

Mom’s caregiver friend washed, cut, and curled her hair to make her presentable for her visitors.

During the hairdo, an aide came into feed Mom. Because of her inadequate swallowing, she is now getting only “pleasure foods” that ostensibly go down easier. On the tray were a small bowl of mashed potatoes with gravy, some pureed apple pie, a small glass of milk, and a glass of water. Again both liquids contained a thickening agent.

Her swallowing difficulties became even more apparent. The aide had to tell Mom to get ready for each spoonful, then quickly stick it into her mouth, and then massage her throat to help her with swallowing. The aide also had Mom open her mouth to make sure that the food had gone down.

After 45 minutes of patient feeding Mom had eaten only about half her food. She drank most of the milk but practically none of the water.

It was no wonder that she easily became dehydrated.

We then wheeled Mom to a reception room with more comfortable furniture. There we took some pictures.

Then I asked my sister and father to leave the room briefly so that I could say my final farewell to Mom.

I told Mom that I was saying goodbye and that I might not see her again. I told her what an excellent mother she had been, and I apologized for all the times that I had not been the best of sons.

I looked her in the eyes.

I hugged and kissed her.

I put her hand on top of mine on top of the tray that was part of her special chair.

I told her I loved her. She said she loved me too.

In the past couple days Mom had not moved her hands at all. When we asked her to point out things, she had been unresponsive. But then, inexplicably, Mom started to move her left hand upwards. Slowly it moved until it touched my face.

I took her hand and pressed it against my face.

Miraculously we had touched each other's hearts.

I felt a warm glow of love and relief.

Now, back home, I have nagging feelings about the feeding tube. Are we doing the right thing? Mom could be gone in a flash, whereas the tube might give her months or even years more. The problem is that it is all unpredictable. I am anguished and disturbed at the thought of her dying.

But part of me has a sense of peace. It was good to become close to my mother again. For so many years the dementia prevented her from expressing her feelings, and my fear of HD kept me from sitting down with her and attempting to converse.

At least we were able to say good-bye.

Posted by [Gene Veritas](#) at [10:53 AM](#)



3 comments:



Angela_F said...

Reading your blog really did bring tears to my eyes. I can't imagine what it is like to face those kinds of decisions.

Best wishes during a difficult time

Angela_F

[6:25 AM, March 15, 2006](#)

Anonymous said...

Thank you so much for sharing that moving account of your visit with your mother. I share your hope for a cure for HD. As a nurse at Lowell Healthcare Center in Massachusetts, I have met so many wonderful people living with HD, and their families who struggle along with them with tough decisions,

anguish and hope for a cure. Keep on hoping.

Micky

7:42 AM, May 15, 2006

⌘ **Anonymous said...**

Well I don't know you and less I can't tell if you can handle the truth, but what you think your mother want you to do ? in my case I will save her from her misery, you know what I mean.

9:06 AM, May 17, 2011

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