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Should Mom get a feeding tube?

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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)
 - ▶ November (1)
 - ▶ October (1)
 - ▶ February (1)
 - ▼ January (1)
 - [Should Mom get a feeding tube?](#)
- ▶ 2005 (17)

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THURSDAY, JANUARY 26, 2006

Should Mom get a feeding tube?

My HD-stricken mother was rushed from her nursing home to the emergency room last week because of dehydration. She spent almost a week there. The hospital staff also found a urinary tract infection.

As is typical with late-stage HD, my mother can no longer eat normally. The food gets into her windpipe, causing her to spit it out.

As I write she is on intravenous fluids because of another crisis of dehydration. She is in good spirits and still smiles when my dad and sister come to visit her.

But the nursing home people say that it's no longer possible to feed her through her mouth. She also cannot swallow her medications, which are necessary for alleviating the symptoms of HD such as chorea, or shaking.

My dad, my sister, and I now face one of the most difficult decisions we will ever make: should Mom get a feeding tube connected to her stomach?

It may be the only way to save her life.

But it would prolong her decline into the abyss of Huntington's disease. We don't want a Terry Schiavo-like situation, where Mom simply vegetates.

But we recognize that, despite HD's devastation, she maintains a part of her humanity.

Her living will says that no heroic efforts should be made to save her. But she signed that in 2000, when HD had already assaulted her with serious dementia. Did she really know what she was assenting to?

How can we possibly know her thoughts now, when she cannot hold the simplest of conversations?

"She still says constantly, 'I love you,'" my sister told me yesterday. "How could you let that go? That's what's bugging me now."

As the nurses have explained it, "You never know how long someone will live with or without a feeding tube," my sister added. She could go on for years, or just a few months.

And once the tube is connected, will we then face an even more terrible decision of having to disconnect it?

My dad and sister are scheduled to meet with hospice workers, who will give them the pros and cons of the different scenarios.

But no matter how much information we have, this decision isn't going to become any easier.

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Posted by [Gene Veritas](#) at [8:54 PM](#)

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1 comment:

Anonymous said...

The decision while a tough one is easy. It sounds like your mom can still communicate so ask her what she wants.

We are going through the same thing with grandma after her second stroke on saturday that has left her unable to communicate. We are following her wishes to let her go and remember the times we have shared. Grandpa is waiting for her so they can spend the rest of their lives together.

H.

[8:27 AM, December 10, 2007](#)

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