

## DON'T PUT A FEEDING TUBE IN MY MOM

By Lenore Skenazy

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If I ever lose my mind and pretty much am wasting away with dementia (as is my mom, who would stand up and cheer this column if she could stand up anymore, or read – or cheer), do me a favor: Don't stick a feeding tube in me.

My sister and I are doing our mom a favor and making sure none gets stuck in her.

She's still able to enjoy a morsel here, a morsel there, and she's at home with a caregiver who has the time to sit by and help her eat. Thank God. That's the ideal: Slow, human feeding.

My mom is also in hospice care, which means no one is going to rush in and put her through a lot of medical intervention none of us wants. But the picture is becoming clear: That kind of high-tech intervention doesn't make sense for anyone in my mom's situation. Time to take it off the charts.

"We know from the medical literature that feeding tubes for endstage dementia, specifically, have not been shown to decrease mortality or increase the quality of life," says Joanna Martin, a geriatrician and medical director of Horizon Hospice and Palliative Care in Chicago.

In fact, when a person – not a body, a PERSON – is suffering from dementia and has a feeding tube put in, often this means that now the person has to be physically restrained from yanking the tube out. *Restrained*. As in tied-up.

Imagine being tied up AND not understanding what the hell is going on.

Now imagine going through all that and it not even HELPING you. It's almost a blessing that intubated endstage dementia patients don't live longer than their non-intubated counterparts, because who wants to live that way at all? I can't think of anyone.

So why are we doing this? Why are we putting tubes in patients who are inexorably on their way to death? Three reasons: Fear of liability. Fear of complications. And fear of The Conversation.

Liability fear is simply this: A patient who is allowed to gradually shut down is a patient who may look, to the authorities or to loved ones, like a patient who is not getting enough care. Nursing homes sometimes choose feeding tubes because that way their patients lose less weight, which looks good to the inspectors. You don't want to lose your funding, and you don't want to be sued. (Let's not even talk about the doctors who keep zero-quality-of-life patients alive to keep the payments coming.) In goes the tube.

Then there's the fear of physical complications. By the time dementia patients are forgetting how to swallow, there's the chance they could choke. But not with a feeding tube, right?

Wrong. Patients still can "aspirate" their saliva; it can go down the wrong pipe. And food pumped into the stomach can come up, too, like acid reflux. Without a good cough, it can settle in the lungs and cause pneumonia. So this is a war the feeding tube can't win.

But the third reason so many of our loved ones are on these things is simply this: We never had a conversation about what would happen at this point. Some doctors don't like to start these somber chats; some folks don't want to have them. But actually, they are the most important part of a patient's care. Death is inevitable. The path we take is not. On a tube or off it? Tied to the bed or not?

"Many people, if they were to diagram out their future, would say, 'I don't want any part of that,'" says Seth Tanenbaum, a cardiologist in Chicago, speaking of feeding tubes for late-stage dementia patients. But without The Conversation, that diagram never gets drawn.

The tube goes in.

The misery goes on, for no good reason. But several bad ones.

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