

When it's Time to Stop

By Helen Hinchliff

“Are you here to see my mother?” I asked the hospice care nurse walking down the corridor of an assisted-living residence in California. “Her name is Joanne.”

“No, I’m here for Bonnie.” He paused, studied my face, and said, “Let me guess.”

“Okaaaay . . .”

“Your mother has stopped eating and drinking.”

My eyes widened as I blurted out, “How did you know?”

“Because it’s part of the process.”

The particular process he was talking about is “dying,” and, unless we die from a heart attack, stroke, or a fatal accident, then the process is likely to be a lingering one during which time the body slowly shuts down. The process takes little energy, so desire for nourishment and fluids slows down markedly. In the case of Alzheimer’s Disease and other dementias, the body usually forgets how to swallow.

If we live long enough, this is how we might well die. In 2014, the Alzheimer’s Association released a detailed report (www.alzorg.org/downloads/Facts_Figures) on the current state of dementia in the United States. Among other sobering items, it reported that one in three senior Americans who die this year will die from Alzheimer’s or a

related dementia. Deaths from diseases such as cancer, heart attack, and stroke are trending downward; however, deaths from Alzheimer's disease increased by 68% between 2000 and 2010.

In 2011, as a condition of my mother being admitted to her residence, she and I completed an advance-care directive. "I don't want any life-saving measures," she said. "When the time comes, just let me go."

But when does the time come to stop trying to spoon feed a dying person?

After having grown quite frail and having suffered three falls in as many weeks, my mother announced her desire not to eat anymore. At first, I tried to encourage her: "Look, Mom," I'd say as if talking to a one-year-old, "here's some puréed lasagne. It's good for you. Take a spoonful." Then I'd put the spoon to her lips.

Sometimes, she opened wide; often, she'd spit out the lasagne. I tried vanilla pudding, but she'd wrinkle her nose at that too. I kept trying to feed her for several days, but she began to resist, sometimes closing her eyes, clenching her teeth, pursing her lips, or turning her head away.

I'd seen this movie before: my father died from liver failure; Donald from a massive stroke; and Murray from dementia, but in each case they stopped eating and drinking fluids days or even weeks before they died. In each case, I felt uncomfortable trying to prompt them to eat when it was clear they didn't want to anymore. In Murray's case,

particularly, his body had forgotten how to swallow, thus he could have developed aspiration pneumonia if anything went down the wrong way.

My experiences have led me to view the active promotion of nourishment and liquid to a dying person as the equivalent of “force feeding.” And I believe it is wrong. However, the B. C. Court of Appeal does not agree. On March 3, 2015, it held that prompting Margot Bentley, a former dementia care nurse, to accept purées and liquids is providing her with “basic care.” Moreover, that care should continue despite Mrs. Bentley’s wishes stated in her living will, now called an advance-care directive (www.dyingwithdignity.ca). It specifically named her desire not to be provided nourishment or liquid if she were ever in an advanced state of dementia. The Court of Appeal declared her directive irrelevant because, under B.C. law, such a directive can only deal with medical care and not “basic care.”

Finally, the Court held that if Mrs. Bentley opens her mouth when prodded, she is thereby indicating that she wants nourishment. Mrs. Bentley’s family, who are considering an appeal to the Supreme Court of Canada, say that she sometimes opens her mouth as an automatic reflex, that she swallows with difficulty, and that prodding her as many as seven times per spoonful amounts to unwelcome touching equivalent to assault and battery.

We humans are obsessed with immortality. Generally, we want to live as long as possible, preferably as our younger

selves. Certainly, we don't think about having someone assisting us with all our bodily functions.

But we have to face facts. We're all going to die and many of us will find ourselves caring for someone who is dying or having someone care for us when we're slipping away. I recommend Atul Gawande, *Being Mortal* (available at Salt Spring Books), for a personal, sensitive, and highly informative read on this subject.

If, as a society, we can figure out how we can legally direct our loved ones (or paid care aides) to care for us as we wither away, then we'll be free to spend those last days in peace.