



End of life issues not easily solved

By Ellen Waldman

October 18, 2016

You might have recently read about a very difficult situation affecting a person with dementia. She had made her wishes known that she did not want to be fed when the dementia progressed. When the time came, her caregivers and family were required to do this anyway.

Long-term care and dementia care facilities have a mandate to offer food to their residents. This is not an isolated incident and people struggle with this, often in a quiet and private way. Dementia is challenging in itself for families, and when it gets toward the end of someone's life, this issue of offering something to eat and drink, or not, often arises.

If you've ever been around a person with dementia, you will know that they might reply yes or no when asked a question, while those close to them realize their response was incorrect. For instance, they might have just eaten a full meal, but if you ask them if they're hungry, they will reply "yes." It's often a case of "out of sight, out of mind." If the food is not in front of them, they might think they have not yet eaten.

When providers of care are required to offer food and drink, people often accept it, either because it's in their pattern to do so, or because they can't determine if they are really hungry and so answer in the affirmative.

The best response to this challenging and complex problem was a guest opinion in the Medford Mail Tribune on Sept 25. Here's the link to read in its entirety:

<http://www.mailtribune.com/opinion/20160925/guest-opinion-such-irony-in-end-of-life-care>.

The opinion was written by Dr. John Forsyth, who among other positions, has been the head of the organization Choosing Options Honoring Options (COHO). The organization's mission is to help people put all their advance care planning in place, which primarily included the Oregon Advance Directive for Health Care and the Physician's Orders for Life Sustaining Treatment (POLST). This has been a very successful endeavor.

Nonetheless, the subject of how to have your wishes honored in the case of dementia is perplexing. Dr. Forsyth addressed this with his great, good heart, and provided additional suggestions for strategies for the future.

At this point of time in Oregon, what can a family do to advocate for and support their loved one, whose wishes might well be overturned by the system that provides care for people?

There is a national organization called Compassion and Choices. Its website will allow you to access not just info for preparing for the end of your life, but something they call the "Dementia Provision." Here is how to find it: <https://www.compassionandchoices.org/eolc-tools>, under "Step 3: Enhance Your Advance Directive."

In this document, you can state that you do not wish to be given food or fluids at the advanced stage of the disease process. The problem seems to be that, even with all these signed documents in place, facilities that provide this care are still mandated to offer sustenance.

When people are coherent and cognitively competent, it's a straight-forward matter of choosing not eat and drink on their own. It's known by the acronym VSED, which stands for "voluntarily stopping eating and drinking." When someone is at the end stage of dementia, they cannot remember why they might not want to eat and/or drink any longer, even if they had documented this wish earlier in their life.

What other options are available? Some actually elect to take their loved one out of a facility back to their own home. There, they must continue to provide round-the-clock care, but can follow the wishes to not provide food and fluids.

This is not a simple decision. We are wired to take care of those we love by feeding them. Even if someone has no dementia and at the end stage of life declines food and drink, we still want to keep offering them. It's in our nature to do this, so withholding nutrients, even to follow their wishes, is often very difficult.

Right now, there are no great answers. Taking someone out of a facility is one way. Hoping these facilities will take another look at their legal mandates may happen down the line, as will hopefully a change to the advance directive allowing this choice.

Adding language into your own advance directive is good, but you must know it has a limited effect on the wider world at this point. There are even a few people who, upon diagnosis of dementia, do not wait until they can no longer remember their decision to withhold nutrients, and decide to apply VSED at that point. These are heart-wrenching decisions with no simple answers.