

Good News/Bad News about Alzheimer's

Nancy Valko, RN, June 16, 2018

First THE GOOD NEWS:

Alzheimer's disease [<https://www.nia.nih.gov/health/what-alzheimers-disease>] is a currently irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks.

However, a new study "Estimation of lifetime risks of Alzheimer's disease dementia using biomarkers for preclinical disease" [[https://www.alzheimersanddementia.com/article/s1552-5260\(18\)30098-0/fulltext](https://www.alzheimersanddementia.com/article/s1552-5260(18)30098-0/fulltext)] shows that "most people with preclinical Alzheimer's disease will not develop Alzheimer's dementia during their lifetimes", according to a mathematical analysis based on several large, long-term studies.

According to the Alzheimer's Association [<http://www.alzheimersblog.org/2016/10/27/preclinical-alzheimers-disease>], the term "preclinical" refers to "a newly defined stage of the disease reflecting current evidence that changes in the brain may occur years before symptoms affecting memory, thinking or behavior can be detected by affected individuals or their physicians".

Although biomarkers are still being investigated and validated, this new study can be reassuring to many people worrying that, for example, forgetting where they left their car keys means the beginning of Alzheimer's.

While the cause of Alzheimer's is still a mystery, research on the disease is massive and ongoing. Currently, there are drug and non-drug treatments [https://www.alz.org/alzheimers_disease_treatments.asp] that may help with both thinking and behavior symptoms. There is hope.

THE BAD NEWS

With the many negative stories in major media about Alzheimer's, it is no wonder that people are so afraid of it.

As Deakin University Professor Megan-Jane Johnstone says in her book "Alzheimer's disease, media representations and the Politics of Euthanasia-Constructing Risk and Selling Death in An Ageing Society" [<https://www.routledge.com/products/9781409451921>]:

"Alzheimer's has been portrayed as the 'disease of the century' that is poised to have a near catastrophic

impact on the world's healthcare system as the population ages...

This representation of the disease—along with other often used terms such as 'living dead', a 'funeral that never ends' and a 'fate worse than death'—places Alzheimer's as a soft target in the euthanasia debate because it plays to people's fears of developing the disease and what it symbolizes. It positions Alzheimer's as something that requires a remedy; that remedy increasingly being pre-emptive and beneficent euthanasia." (Emphasis added)

While countries like Belgium and Holland have long allowed lethal injections for people with Alzheimer's [<https://www.firstthings.com/web-exclusives/2017/09/euthanasia-for-alzheimers-patients>], this is forbidden in the US-for now. However, assisted suicide groups are now trying new "living wills" [<https://www.documentcloud.org/documents/4421347-dementia-advance-directive.html>] stating that if or when the person is diagnosed "with Alzheimer's or another incurable dementing disease", he or she refuses not only a feeding tube but also even assistance with oral eating and drinking to end their lives.

Compassion and Choices, the well-funded former Hemlock society, has long promoted VSED (voluntary stopping of eating and drinking) as a legal alternative to assisted suicide [<https://www.compassionandchoices.org/your-end-of-life-options>] in states without assisted suicide laws. But at the present time, people who cannot make medical decisions because of conditions like Alzheimer's cannot sign an advance directive.

So influential major media outlets like the New York Times often publish articles such as the May 30, 2018 article titled "Alzheimer's? Your Paperwork May Not Be in Order" [<https://www.nytimes.com/2018/04/30/well/live/an-advance-directive-for-patients-with-dementia.html>] that quote Dr. Judith Schwarz:

"People should at least understand what the normal process of advanced dementia is about," Dr. Schwarz said. "Feeding tubes are not the issue.... Opening your mouth when a spoon approaches is a primitive reflex that persists long after you've lost the ability to swallow and know what to do with what's put in your mouth." (Emphasis added)

Dr. Schwarz's advice?

“Complete her organization’s Advance Directive for Receiving Oral Food and Fluids in the Event of Dementia.”

But what Dr. Schwarz and others do not want to talk about is the often tragic reality of deliberate death by starvation and dehydration.

Although media articles portray VSED as a gentle, peaceful death, a 2018 Palliative Practice Pointers article in the Journal of the American Geriatric Society titled “ [https://www.medscape.com/viewarticle=894008] Voluntary Stopping Eating and [https://www.ncbi.nlm.nih.gov/pubmed/29532465] Drinking” [https://www.ncbi.nlm.nih.gov/pubmed/29532465] states:

“VSED is an intense process fraught with new sources of somatic and emotional suffering for individuals and their caregivers...The most common symptoms encountered after starting VSED are extreme thirst, hunger, dysuria (painful urination due to concentrated urine NV), progressive disability, delirium, and somnolence.” (Emphasis added)

Most chillingly, the authors state:

“Because an individual with delirium may forget his or her intention and ask for drinks of water, caregivers will struggle with the need to remind the incapacitated individual of his or her own wishes. This possibility should be anticipated and discussed with the individual in advance. While reminding the individual of his or her prior intentions may feel like coercion, acquiescing to requests for water will prolong the dying process for someone who has clearly articulated the desire to hasten death.” (Emphasis added)

The authors also state that if the patient’s suffering becomes severe, “proportionate palliative sedation and admission to inpatient hospice should be considered”. This is not the so-called peaceful death at home within two weeks that people envision with VSED.

Lastly, on the legal requirement of a cause on the death certificate, the authors state:

“the clinician may consider including dehydration secondary to the principle illness that caused the

individual’s intractable suffering. Although VSED is a self-willed death (as stopping life support might also be), use of the word “suicide” on death certificates in this context is discouraged because it incorrectly suggests that the decision for VSED stemmed from mental illness rather than intolerable suffering.

So, like assisted suicide, the real cause of death is basically falsified with the rationale that the deliberate stopping of eating and drinking to hasten death is just another legal withdrawal of treatment decision like a feeding tube.

CONCLUSION

Years ago, my mother told me that she never wanted to be a burden on her family.

I never told my children that-especially when they were teenagers and already thought I was a burden to their lifestyles! Instead, I told them that the “circle of life” includes caring for each other at all ages and stages. Such caring also eliminates future guilt and leaves a sense of pride that we did the best we could for each other during our lives.

When my mother developed Alzheimer’s in the late 1980s (and later terminal thyroid cancer), a friend asked if I was going to feed her. At the time, my mother was fully mobile and able to get ice cream out of the freezer and eat it. I was shocked and offended.

“Do you want me to tackle her?!” I asked my friend.

“Oh, no!” he answered, “I was talking about a feeding tube later on.”

I told him that my mother would die of her disease, not from deliberate starvation and dehydration.

Near the end of her life, we did spoon feed my mother and she enjoyed it very much before dying peacefully in her sleep.

For decades now, I have enjoyed caring for many people with Alzheimer’s [https://nancyvalko.com/2016/04/13/five-things-my-mother-and-daughter-taught-me-about-caring-for-people-with-dementia] or other dementias both personally and professionally. I can attest that such people can be sweet and funny as well as difficult at times.

Just like the rest of us!

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