



ALZHEIMER'S DISEASE AND DEMENTIA: MAINTAINING DIGNITY AND CONTROL OF THE END OF LIFE

Some of the most difficult questions we receive at End of Life Washington are asked by people who have been diagnosed with an illness such as Alzheimer's disease that will result in the loss of capacity to make decisions about their medical and end-of-life care.

Questions generally fall into three categories: How can I maintain dignity or ensure control over my dying after I become incompetent? How can I or someone else end my life if I become completely demented? How can I, as a caregiver or legal surrogate decision-maker, stop life-sustaining treatment or the force-feeding of my loved one?

Although many Americans believe people with Alzheimer's (PWA's) should have the right to voluntary euthanasia (defined as an action taken by another to end someone's life with their prior consent), this is illegal throughout the United States.

This leaves mentally competent PWA's who want to maintain control over their dying in the position of taking action while they still can or eventually losing capacity and relying on others to make treatment decisions that will result in a natural death at the first opportunity.

With regard to patients taking action while still competent, one of our former clients was a frail, elderly woman who had been diagnosed with early stage Alzheimer's. "Mary" was a very strong-willed person who had taken care of both her parents who died from Alzheimer's after long, debilitating illnesses. Her experience caring for her parents informed her decision to take action to end her life while she was still competent. After acquiring a pledge from her physician to refer her to hospice as soon as she was deemed eligible, she voluntarily stopped eating and drinking (VSED) and died peacefully in her home, surrounded by her family, approximately two weeks later.

While few PWA's will elect to end their lives as Mary did, many people are not aware that VSED in conjunction with palliative or hospice care can be a relatively quick, peaceful way to die.

Although some may question this choice or consider VSED to be drastic, the right of a mentally competent patient to decline medical treatment or VSED to permit a natural death is well established by law. And despite the policies of some religiously affiliated health care providers, neither of these choices is euthanasia – even when the patient's goal is to end his or her suffering or take control of the dying process.

However, these choices can be controversial or unsupported by family members and medical and long-term care providers who oppose them and who may even attempt to undermine them. For this reason, people who want this option may wish to contact End of Life Washington and/or a supportive, local geriatrician, geriatric social worker, elder law attorney or other professional with experience navigating Alzheimer's. Your local Alzheimer's Association may be a good source for referrals to these professionals. Additional resources include the National Association of Geriatric Care Managers and the National Association of Elder Law Attorneys.

If PWA's lose capacity, then they must rely on legal surrogate decision-makers to decline or discontinue life-sustaining treatment, including medically assisted nutrition and hydration, when the opportunity arises.

This path, however, requires patients to be very proactive in documenting their wishes, selecting an appropriate legal surrogate decision-maker, and then – most importantly – communicating these wishes to family, medical providers, the legal surrogate decision-maker, and others – and then acquiring their pledges to honor them. It also requires concurrent palliative or hospice care to prevent unnecessary suffering and enable a peaceful death.

Unfortunately, most Living Wills available or offered by estate planning attorneys or medical providers lack the clear, objective language necessary to communicate PWA's end-of-life wishes. For an example of appropriate Living Will language related to Alzheimer's, see section six and seven in End of Life Washington's combination Living Will and Durable Power of Attorney for Health Care. PWA's may also want to add a statement to their Living Will indicating their preferences about feeding. For example, "If I lose my ability to eat or no longer show interest in eating, such as not opening my mouth, spitting out food, choking, or turning my head away, I do not want to be fed."

PWA's who want to express their wishes about issues such as where they want to live, who provides their care, and when to stop driving, may also want to complete End of Life Washington's Alzheimer's and Dementia Mental Health Advance Directive. This first-of-its-kind advance planning document allows PWA's to document their wishes about the inevitable challenges related to living with the disease. In states where this directive is not legal, it can still be used to document wishes and provide a guide for families, health care providers, long-term care providers, and others.

PWA's who want to avoid life-prolonging medical treatments should also make a Physician Orders for Life-Sustaining Treatment (POLST), or – if POLST is not available – other nonhospital medical orders. Because it translates PWA's wishes into medical orders, POLST is the most effective way to prevent unwanted treatment. In Washington, a legal surrogate decision-maker is permitted to make a POLST on behalf of a person who is no longer competent.

Perhaps the single most important decision PWA's make is naming the right person to be their surrogate decision-maker in a Durable Power of Attorney for Health Care. Think of a Living Will as a roadmap; it can't get you where you want to go unless someone is driving the car.

PWA's often feel obligated to name their spouse, partner, or a child to be their surrogate decision-maker. The candidate for decision-maker is not a good choice if he or she does not fully support the person's decisions or is not assertive enough to confront medical and long-term care providers who disagree with his or her choices. PWA's should be encouraged to select their surrogate decision-maker very carefully. Alternatives to family include longtime friends or hiring a professional, such as a nurse, geriatric social worker, or elder law attorney willing to honor and carry out their wishes. Sometimes naming someone other than family can take the burden off a family member who is unwilling or emotionally unprepared to accept the responsibility.

Finally, a very important component of a peaceful, dignified death from Alzheimer's is to obtain palliative care through the use of hospice. Despite the appropriateness and significant benefit for PWA's and their families, very few receive hospice care.