

Alzheimer's and End of Life

Maintain Dignity and Control by Allowing A Natural Death

By Robb Miller, Executive Director, Compassion & Choices of Washington

At Compassion & Choices of Washington, we receive regular inquiries from both newly diagnosed people with Alzheimer's and the caregivers of those in later stages of the disease. Someone recently diagnosed with Alzheimer's asked: "How can I maintain my dignity or exert some control over my dying after I become incompetent?" A caregiver recently asked how to cope with her husband's wish to hasten death before he became completely disabled by dementia.

The question of how aggressive to be in treating late-stage Alzheimer's patients is one of the most difficult and controversial issues in medicine. Even when a patient's end-of-life wishes have been documented and discussed, it can be difficult to prevent a prolonged dying process. Refusing, withholding, or withdrawing treatment for life-threatening illness is not the same as assisted dying or euthanasia. In spite of the heated rhetoric during the Terri Schiavo case in Florida, refusing or removing artificial nutrition and hydration is not "starving a patient to death" or "killing." It is allowing a natural death to occur. Some contend that to withhold treatment is to hasten death, in effect, playing God. In some families, there is an unspoken concern that if they halt treatment, they will be judged—by their friends, others in the family, or their churches.

In the United States, preventing unwanted life-sustaining treatment and withholding or withdrawing life-sustaining treatment—in short, *allowing a natural death*—are medically ethical ways for a person with Alzheimer's or his or her caregivers to exert control over the dying process.

Early discussions about allowing a natural death should take place while people are competent, ideally soon after initial diagnosis. End-of-life wishes should be documented with advance directives, especially a Physician Orders for Life-Sustaining Treatment (POLST) form. The POLST form is the most effective advance directive because it translates your wishes into a physician's orders for medical care.

Making these documents is only the first step, however. Individuals must also talk to their families and medical providers about their choices and request a promise to honor them. Even without Alzheimer's disease or dementia, most of us won't be able to make all of our medical decisions at the end. One of the greatest gifts that we can offer our survivors is the peace of mind that results from having made our wishes known.

In the absence of advance directives and conversations, family members and doctors are left guessing. This means the patient will receive everything that medicine has to offer—including feeding tubes, intravenous fluids, antibiotics, and hospitalizations. Doctors treat medical conditions as they arise, putting off conversations about where, and whether, to draw a line.

It is important to understand that everyone has legal and ethical rights to refuse medical treatments, including artificial nutrition and hydration, or, if we become mentally incompetent, to have these treatments refused on our behalf by our legal surrogate. In Washington, legal surrogates are permitted to make a POLST form on a patient's behalf.

Finally, a very important component of allowing a peaceful, dignified, natural death is to obtain palliative (comfort) care through the use of hospice. Despite the appropriateness and benefit for people with Alzheimer's and their families, and their eligibility for the Medicare hospice benefit, very few people with Alzheimer's receive hospice care.

For more information, or a copy of the POLST form, call 206.256.1636 or 1.877.222.2816 or send e-mail to info@compassionwa.org

Accessing the Benefits of Hospice Care

by Rowena Rye, Director of Community Resources, Alzheimer's Association of Western and Central WA*

When planning your family member's end-of-life care, make certain you are informed about the benefits that hospice can provide. Facing the impending death of a loved one creates a variety of emotions in families: fear, sorrow, grief and relief are all natural feelings at the end of the long journey that is Alzheimer's disease. The comfort of the hospice patient, as well as the support of the family caring for the person who is dying, are the principal objectives of hospice care.

Hospice uses a multi-disciplinary team approach to providing care. The team is composed of a nurse, social worker, home health aide, volunteer and a chaplain who are supervised by the hospice team physician. The hospice team is available 24-hours a day and families can contact their hospice program at anytime when questions or concerns arise. Hospice can be provided in the home or in a long-term care setting.

Hospice benefits are available under most insurance plans, including Medicare (Part A) and Medicaid. In order to access hospice care through Medicare both the person's primary physician and the hospice program's director must give the terminally ill person a 6-month prognosis.

Potential Barriers to Hospice Care

End stage of Alzheimer's not always recognized. Hospice is an underutilized benefit for people with Alzheimer's. Unlike illnesses such as cancer, emphysema, kidney or heart failure the indicators for a person in the end stages of Alzheimer's are not always readily recognizable. In Alzheimer's patients, one will see a combination of functional problems and medical complications that indicate that it's time for hospice care.

Families accepting, coming to terms with impending death.

Choosing hospice care is choosing comfort care and quality of life. When the hospice care option is chosen, the choice is also being made to discontinue invasive and/or aggressive treatments intended to artificially prolong life and to instead focus on providing a pain-free, supported death that focuses on the quality of one's remaining life. Both the patient and the family are provided support throughout the process with preparation for death and loss. Family members also can make use of a 13- month bereavement benefit provided by Medicare available after the death of their loved one.

Functional Problems:

- Unable to walk
- Incontinent
- Needs assistance eating
- No longer recognizes loved ones
- Cannot speak or communicate well
- Unable to engage in purposeful activities

Medical Complications:

- Severe urinary tract infections
- Decubitus ulcers (severe bed sores)
- Fever over 100 degrees Fahrenheit (any cause)
- Difficulty swallowing
- Septicemia (spread of infection throughout the body's bloodstream)
- Organ failure

To obtain a copy of "Hospice: It's Your Right", a Late Stage Caregiver Booklet, or additional information about hospice care providers, contact the 24/7 Alzheimer's Association Helpline at (206) 363-5500 or (800) 848-7097 or email rowena.rye@alz.org.

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