Dementia and Conversations About the Future

“The most basic of all human needs is the need to understand and be understood. The best way to understand people is to listen to them.”

― Thomas Szasz

In a 2018 study, published in the JAMA, it was reported that individuals discussing end-of-life treatment resulted in “better patient quality of life near death” which “may have been associated with better patient quality of life among participating caregivers.”

This goal is experienced less and deemed important in self-reported health, better emotional functioning, mental health, and overall quality of life during the bereavement process."

We are surrounded by this data but do you really know how to discuss it with your family? And if you do discuss it with your family, the more likely it is that you will have the experience that you desire. It is best to do this planning while you are still able to think through the options. In fact, recent research suggests that the earlier the diagnosis, the more likely it is that you will have the experience you desire.

For the family member and the individual, the purpose of end-of-life conversations is to understand the preferences of the individual and the family members. The discussions serve both the person with dementia and the family members. They serve to figure out what the person with dementia would have wanted and may eliminate conflicts among family members.

Most people like to feel that they will always be in command of their own destiny but with a diagnosis of Alzheimer’s disease or other dementia, there are too many important conversations the person with dementia and family members must discuss in order to make decisions that are in the best interest of the person with dementia.

When a person first receives a diagnosis of Alzheimer’s disease, there is an uncertain future ahead. How quickly the disease will progress is unknown. Life is going to change and with this diagnosis, at some point in its relentless progression, one will be unable to make decisions for oneself. At that point in time, it may be too late to realize a conversation with your family about your desires for future living arrangements, medical interventions and future plans.

Ultimately, these conversations serve both the person with dementia and the family members. The goal is to ensure that the person receives the care that she wanted and that her wishes are considered and honored. Being able to follow the person’s wishes allows the family of a loved one to provide end of life care for the person.

Maybe it’s time to have a conversation?

By: Layton Aging & Alzheimer’s Disease Center

An excellent document that can be used to initiate these conversations and assist in planning is Your Life Your Choices: Planning for Future Medical Decisions. This is produced by the US Department of Veterans Affairs and can be found at: www1.va.gov/pugetsound/docs/ylyc.pdf

For more information, contact Linda Boise, Ph.D., M.P.H., education director at 503-494-7197 or linda@layton.org

The Aging & Alzheimer’s Disease Center

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A National Institute on Aging Alzheimer’s Disease Center

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In 1991, Dr. Alan Alzheimer, a German psychiatrist and neuropathologist who worked in an asylum in Frankfurt, observed a 51-year-old woman who had short-term memory loss and other symptoms. He was fascinated with her disease, and when she died in 1996, he used newly developed laboratory techniques to examine her brain. He identified two peculiar lesions which he named "amyloid plaques" and "neurofibrillary tangles." They are still recognized today as the pathological signature of the disease known as "Alzheimer’s Disease."

Scientists continue to examine brain tissue to understand how Alzheimer’s affects the brain. This is more helpful when scientists have good information on the person’s health and symptoms over a period of months or years. When individuals suspected of having Alzheimer’s disease enroll in a long-term clinical study, they will undergo a series of tests every six months or even more often that will measure mood and physical symptoms and characteristics. After death, when a brain autopsy is performed, researchers evaluate the brain’s structure to provide more information about the disease.

Research into Alzheimer’s and other age-related neurodegenerative diseases is also significantly helpful when brain autopsies are performed on normal, healthy patients. Scientists used a brain for comparison between healthy brain and diseased brains.

Why is brain autopsy so important for Alzheimer’s disease research?

A National Institute on Aging Alzheimer’s Disease Center

EDITORIAL COMMENTS

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Advancement in Alzheimer’s disease research... Continued from front page

How they are that something discovered in a person who suffers from a disease is truly unique to that disease. Further, these studies are ongoing, scientists attempt to identify what factors are working to protect against disease and dementia. Once these factors are known, we hope to develop new therapies that these may be a role in therapies that develop for specific conditions in the future. Brain autopsy provides priceless tissue to researchers for anatomic, pathologic and neurochemical research.

One area of particular concern that suggests that these diseases may play a role in development of dementia is that of Alzheimer’s disease. Many of our clinic staff are nurses, and psychologists who have experience in Alzheimer’s disease research or related to aging or Alzheimer’s disease. Our Center is one of 30 NIH Alzheimer’s Disease Centers in the United States and the only one of its kind in Oregon. Our Center is recognized as a national leader in dementia care and research, and is committed to serving the needs of people throughout the Northwest.

Patient Services
Our staff is staffed by neurologists, nurses, and psychologists who have expertise in aging and dementia. Many of our clinic staff are also actively involved in Alzheimer’s disease and dementia research. We work together with other research partners and the service community to carry out studies in several areas, with particular focus on the elderly of our community over 85 and on those with early-stage dementia.

Advance Directive or a POLST?

If you are a research subject and have questions about brain autopsy, please let us know. For more information go to www.ohsu.edu/polst.

If you are a participant in a study sponsored by the Layton Aging & Alzheimer’s Disease Center, we encourage you to discuss the pros of brain autopsy with your family. This conversation is important because after death, the decision regarding whether an autopsy will be performed rests with the next of kin, usually the spouse or another immediate family member.

If you make a decision that you want to donate your brain to science, you will be asked to complete an “intent to donate” form that must be witnessed by two people. We will ask to verify your information about your legal designee and your written wishes. When we receive the completed form, your legal designee will be informed of your decision and if you have indicated a family nurse, we will notify the family as well. We will also provide you with instructions.

When death occurs, the next of kin/family member or hospital should call the Layton Center 503-494-6974 as soon as possible after the death. After hours/weekends/holidays or if the next of kin/family member or hospital is not available, call operator at 503-494-8213 and ask the neuropathologist on call to be paged to facilitate a brain autopsy. Once the neuropathologist is notified, someone will contact the legal designee to obtain authorization to perform the autopsy. This consent is offered over the phone. The Layton Center asks the next of kin to allow the use of the brain tissue for both diagnostic and research studies. If you are a Layton Center research subject, there is no charge to the family.

Major contributors to our understanding of these large data sets come from single case studies.

Contact your health care provider if you have more questions.

Oregon Now Has An Electronic POLST Registry

The Oregon POLST program has created a new electronic Registry for POLST forms. This is a resource for emergency healthcare professionals to call during a medical emergency if they are unable to locate the original, pink POLST form for the patient being treated. A POLST (Physician’s Orders for Life Sustaining Treatment) form provides additional specific treatment options. This form is completed in conjunction with you by your medical provider.

Each person with an advanced illness or who is very near death may have a POLST to guide their current treatment. (In addition to an advanced directive.)

A POLST is a set of physician’s orders that turn a person’s values into medical actions.

Both of these documents should be discussed with the person responsible for carrying out your medical wishes and advance directives.

Emergency medical personnel do not have to honor an advanced directive in a role in the development of dementia.

Since 2006, autopsy tissue supplied by the Layton Center has supported approximately 50 projects investigating the causes and consequences of age-related brain disease. Family members and subject who have the Layton Center through their interest in brain autopsy have helped to create one of the most active and scientifically productive repositories of human brain tissue in the world. Ultimately, autopsies help us all. They provide the information to family, improve the diagnostic skills of physicians, and help scientists develop treatments and ultimately cure to a variety of serious diseases.

If you are interested in inquiring about clinical studies, please contact Joyce Laraor Darren Larson at the Layton Center: 503 - 494 - 7615.

If you are a research subject and have questions about brain autopsy, please contact Joyce Laraor Darren Larson at the Layton Center: 503 - 494 - 7615.

To A Brain Autopsy?

An advance directive (AD) is a form that you have completed and witnessed that tells your doctor what level of medical care you want if you are unable to express your own wishes.

Everyone over the age of 18 should have an advance directive that specifies what your preferences are for future medical care.

An advance directive ensures a person’s autonomy in medical decisions.

A POLST (Physician’s Orders for Life Sustaining Treatment) form provides additional specific treatment options. This form is completed in conjunction with you by your medical provider.

A POLST is a set of physician’s orders that turn a person’s values into medical actions.

This form can be obtained through your healthcare provider, your attorney, or at www.oregon.gov.

Your health care provider can provide the form. For more information go to www.ohsu.edu/polst.

An advance directive is not available, then the patient’s wishes might not be respected.

Advance Directives can help to guide medical treatment that takes place in a hospital setting, but if the advance directive is not available, the patient’s wishes might not be respected.

Emergency medical personnel must honor a POLST.

A POLST is a set of physician’s orders, the expressed wishes must be honored. With the new electronic registry in Oregon, all doctors, hospitals and emergency personnel will have access to an electronic POLST.

This form can be obtained through your healthcare provider, your attorney, or at www.oregon.gov.

Your health care provider can provide the form. For more information go to www.ohsu.edu/polst.