

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.” (Ralph Nichols)

In a 2008 study published in the JAMA, it was reported that clear discussions regarding end of life treatment resulted in “better patient quality of life near death” which “in turn was associated with better quality of life among surviving caregivers who experienced less regret and showed improvement in self-reported health, physical functioning, mental health, and overall quality of life during the bereavement process.”

Wright, A., Zhang, B., Ray, A., Mack, J., Trice, E., Balboni, T., et al. (2008).

Associations between end-of-life discussion, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA, 300 (14), 1665-1673. Retrieved from Academic Search Premier database June 29, 2009.

Early Conversations

Most people like to feel that they will always be in command of their own destiny but with a diagnosis of dementia a time will come when you will not be.

The sooner that you act and express your wishes about future arrangements the more likely it is that you will have the experience that you desire. It is best to do this planning while you still have the legal capacity to make decisions and sign documents.

Fortunately, with good planning, family members can honor your wishes once those desires can no longer be directly expressed.

Important things to cover in these conversations are future living/care arrangements, medical interventions such as CPR and tube feeding, and legal issues such as medical and legal powers of attorney. This is the time to prepare an advance directive and discuss it with your family.

It should be clearly understood that what may be appropriate for the first year or so may not be appropriate a few years from now. For example, a person with early stage dementia may be fine today living at home alone and driving, but that could change overnight. If a plan is in place, then the transitions will be easier for everyone.

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 ❖

After a diagnosis of Alzheimer's disease or other dementia, there are two times for important conversations. The first is soon after diagnosis, between the person with dementia and family members. The second occurs towards the end of the person's life. This conversation between caregivers and the primary care physician is based on those earlier conversations.

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 one's self. As difficult as it may seem, it is never too soon to start a series of conversations with your family about your desires for future living arrangements, medical interventions and funeral plans.

Ultimately, these conversations serve both the person with dementia and the family members. The goal is to insure that the patient receives the care that s/he wanted and that others have the information needed to carry those wishes out. Being able to follow the person's wishes relieves the family of a tremendous burden of trying to figure out what the person with dementia would have wanted and may eliminate conflicts among family members.

Maybe it's time to have a conversation?

Later Conversations

Let's fast forward a few years when it's time for the second type of conversation. Because of the earlier planning that was done, “mom” is now in a residential facility that specializes in dementia. Mentally, she is very impaired and can no longer walk on her own, speak clearly or feed herself. Overall, her health is deteriorating; she is increasingly frail and losing weight.

It is now time for the person who is responsible for “mom's” health to ask the physician about the future. This is the time to think about quality of life, not quantity.

How can she best be kept comfortable? Ask if it's time to revise her POLST form and lower the level of restorative care. Is it time to start hospice services? *Hospice is a special type of care that is designed to provide support and comfort to the patient and the family when the patient's life expectancy is estimated to be six months or less. The expense is covered by Medicare. More information can be obtained at www.hospicefoundation.org*

It is also appropriate to ask the doctor about the early signs of approaching death and what will happen when death occurs. Increased sleepiness, the refusal to eat or drink, changes in breathing and in skin coloration are all common and normal when death is approaching.

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



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In 1901, Dr. Alois 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 1906, 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 pathologic signature of the disease known as “Alzheimer's disease.”

Scientists continue to examine brain tissue to understand how Alzheimer's disease affects the brain. This is most 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 every year that will measure mental and physical symptoms and characteristics. After death, when a brain autopsy is performed, researchers evaluate this tissue against the earlier test results. This provides the opportunity to identify various dementia diseases at earlier stages. For family members of the deceased, the information from the autopsy may provide some closure about the disease that affected their loved one.

Research into Alzheimer's and other age-related neurodegenerative diseases is also significantly helped when brain autopsies are performed on normal, cognitively healthy persons. Scientists need a basis for comparison between healthy brains and diseased brains.

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Joseph Quinn, M.D., Ph.D.

Brain autopsy in Alzheimer's disease research . . .

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This is how they establish that something discovered in persons who suffer from a disease is truly unique to the disease. Further, by studying healthy brains, scientists attempt to identify what factors are working to protect the brain in those who age without developing brain diseases. Once these factors are known, we hope to develop ways to protect those who may be at risk for developing some form of dementia in the future.

Brain autopsy provides priceless tissue to researchers for anatomic, pathologic and neurochemical research.

One area of particular concern is that there are not enough people of color enrolled in these long term studies. As Dr. Steven Arnold, Director of the Penn Memory Center notes, "There is never enough brain tissue for research, especially from ethnic groups like Latinos and African Americans." This

is a concern because some studies suggest that African Americans have a higher prevalence of Alzheimer's disease than their Caucasian counterparts. A higher percentage of African Americans also have high cholesterol, high blood pressure and diabetes, all conditions that can affect memory. Scientifically this is important because current data from long term studies suggests that these diseases may play 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 diseases. Subjects and families who support 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 United States.

Major contributions to our understanding of these tragic diseases may come from single case studies.

Ultimately, autopsies help us all. They provide information to the family, improve the diagnostic skills of physicians, and help scientists develop preventative treatments and ultimately cures to a variety of serious diseases.

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

If you are a research subject and have questions about brain autopsies, please call: 503 – 494 – 6695. ❄

Advance Directive or a POLST?

Q: If I have an advance directive, do I need a POLST form?

A: It depends.

| Advance Directive | POLST |
|--|---|
| An Advance Directive (AD) is a form that you complete and have witnessed that tells your doctor what level of medical care you want if you are unable to express your own wishes. | 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. |
| Everyone over the age of 18 should have an advance directive that specifies what their preferences are for future medical care. | Every person with an advanced illness or who is very frail should have a POLST to guide their current treatment. (In addition to an advance directive). |
| An advance directive expresses a person's values and legally appoints a surrogate for health care decisions. | A POLST is a set of physician's orders that turns 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 advance directive. | Emergency medical personnel must honor a POLST. |
| Advance directives can help to guide medical treatment that takes place in a hospital setting, but if the advance directive is not available, then the person's wishes might not be respected. | Since 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 health care 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 |

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, bright pink POLST form for the person being treated.

Health care professionals will be required to send the new form to the Registry unless the patient or surrogate opts out. The new forms now include: home address, city, state, zip code; last 4 of your social security number; gender and surrogate information. For more information please call the registry office during business hours at 1-877-367-7657 or visit the website at www.ohsu.edu/polst. ❄

What Are The Steps Leading To A Brain Autopsy?

If you are a participant in a study sponsored by the Layton Aging & Alzheimer's Disease Center, we encourage you to discuss the prospect 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 also request information about your legal designee and your funeral home. When we receive the completed form, your legal designee will be informed of your decision and if you have indicated a funeral home, we will notify them as well. We will also provide them with instructions.

When death occurs, the next of kin/funeral home/hospice should call the Layton Center at 503-494-6695 as soon as possible after the death. After hours/weekends/holidays or on weekends, call the OHSU on-call operator at 503-494-8211 and ask that the neuropathologist on call be paged to facilitate a brain autopsy. Once the Layton Center is notified, someone will contact the legal designee to obtain authorization to perform the autopsy. This consent is obtained 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.

Autopsies are always performed with the greatest dignity and respect. In many autopsy rooms, you will find a sign on the wall that says "This is the place where death rejoices to help those who live."

Please note that the shorter the interval between death and autopsy, the more useful brain tissue is for research purposes. Nevertheless, families should never feel pressured to relinquish the body before they feel ready to do so.

Some important things to remember regarding brain autopsy: The body is not disfigured and an open casket is possible, the autopsy does not delay the funeral and all major religions support brain autopsy and research.

Thank you for your donation in the effort to find treatments and a cure for Alzheimer's disease. ❄

CONGRATULATIONS OPAR GRANT RECIPIENTS!

The Oregon Partnership for Alzheimer's Research Committee is pleased to announce the recipients of the 2009- 2010 OPAR grants. These grants are made possible through the Oregon Tax Checkoff program and support researchers who are entering the field of Alzheimer's disease research or who are pursuing new directions in Alzheimer's research.

Jadwiga M. Giebultowicz, Ph.D.
Oregon State University
"The Role of the Circadian Clock in Alzheimer's Disease"

Shawn K. Westaway, Ph.D.
OHSU
"Genes and Variants Associated with Late Onset Alzheimer's Disease"

Beth Wilmot, Ph.D.
OHSU
"Utilization of Genetic Architecture to Identify Candidate Genes for Alzheimer's Disease."

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