



ALZHEIMER'S ASSOCIATION CONNECTICUT CHAPTER AUTOPSY INFORMATION

It is becoming more important than ever before to establish a definite diagnosis of dementia. Alzheimer's disease is a common, progressive degenerative disorder that affects more than 5.3 Americans. While Alzheimer's disease is the most common neurological disease causing dementia, it is only one of numerous diseases that can cause dementia. Physicians are becoming better able to diagnosis the cause of dementia in their patients but an individual may present symptoms in a manner that makes clinical diagnosis difficult. A definitive diagnosis of Alzheimer's disease or another brain disorder causing dementia can only be firmly determined by brain autopsy outcomes after death. Currently there are no cures for most dementias but research advances are developing that may soon offer hopes of treatments that are specific for particular types of dementia and that may delay or even prevent its development.

Answers to Concerns about brain autopsy:

- **Does not disfigure the body and an open casket is still an option.**
- **Does not delay preparation for burial.**
- **Most Religions and cultural traditions recognize the value of autopsy and of organ donation. Specific concerns should be discussed with your religious advisory**

Benefits of Autopsy:

- **Family members learn the exact cause of their loved one's decline and death. Knowing this often brings some sense of relief that the diagnosis and treatment given in life was accurate.**
- **Findings can help family members better understand their own risk factors and may help in prevention or treatment if they develop similar problems.**

- In some cases, the autopsy results may indicate that family members should undergo genetic testing and counseling for the familial form of Alzheimer's disease or other dementias.
- Autopsies provide information establishing more accurate statistical data about the prevalence of dementia and provide information to those who advocate for laws and programs to support the care of patients with dementia and their families
- Autopsies done through research programs enhance scientific knowledge about dementia, its treatment and, hopefully its prevention.

Planning for an Autopsy:

- **Plan ahead** and prepare needed paperwork which will prevent having to make arrangements during the stressful time of death.
- **Discuss the autopsy** decision with involved family members, legal next-of-kin and, if needed, your own religious advisor.
- **Discuss the autopsy services** that are available in your area with your doctor or member of your health team. The Connecticut Chapter of the Alzheimer's Association also has this information . www.alz.org/ct or call 1-860-828-2828
- **Decide on where** the autopsy is to take place, **enroll** and complete needed paperwork. There are two major methods for obtaining a brain autopsy:
 - 1) Brain donation through a research center can include an Alzheimer's Disease Center (ADC), a Brain Bank, or through research programs at some hospitals. For a directory of ADCs go to: www.nia.nih.gov, click on Alzheimer's Disease information and then on AD research center. For a directory of Brain Banks go to www.BrainBanks@ninds.nih.gov. In the search box at the top of the page insert "brain banks Alzheimer", then click on the first offering listed "Regional Brain Repositories". Information can also be obtained through ADEAR at 800-438-4380. If brain donation is decided, most hospitals and research programs offer those who qualify the neuropathological services free of charge.
 - 2) Privately arranged brain autopsy ranges costs vary from no cost to as much as \$1500 plus the cost of transportation to the facility. Fees may be waived if the deceased individual received medical care from the institution carrying out the autopsy. If the brain is donated to research these costs may be reduced. Your doctor or the pathology department of the hospital

where your doctor is affiliated often will offer help with arrangements and should be called in advance of death.

- **Complete the consent process** as much in advance as is possible. Permission for autopsy is required from the legal next-of-kin. If the spouse is deceased the eldest child is considered next of kin. ADCs or Brain Banks will provide the necessary documents. For privately arranged autopsies, the facility performing the autopsy or your lawyer can advise you.
- **Prepare contact information to be used at the time of death.** A copy of the autopsy consent, procedures and contacts that will be needed at the time of death should be given to your physician and to the facility where the patient resides. To be most valid, an autopsy should be performed as soon as possible after death.
- **Inform** both the funeral director and the facility performing the autopsy of any requirements or pertinent religious considerations.
- **The report** of a brain autopsy explains the final diagnosis, including whether Alzheimer's disease was present and major changes in the brain. If a whole body autopsy is performed, additional information may be obtained about other contributing health problems. Usually the report is available several weeks to 2-3 months after death.