

# The Alzheimer's Association Autopsy Assistance Network

**An information and assistance network serving families of patients with Alzheimer's disease and related disorders**

**Alzheimer's Association** Western and Central Washington State Chapter  
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## QUESTIONS AND ANSWERS ABOUT AUTOPSY

Q. Who may request an autopsy?

A. Legally, the next-of-kin or guardian is the person to make that decision. If the spouse is deceased, the oldest child is considered next of kin.

Q. Is a complete autopsy performed?

A. No. In instances where Alzheimer's disease is suspected, only the brain tissue need be examined for diagnosis; however, a complete autopsy is recommended.

Q. Where is the autopsy performed?

A. If death occurs in a hospital, the autopsy may be performed in that facility; if death takes place in a nursing home, other arrangements will have to be made with a pathologist.

Q. Can I have an open casket?

A. Yes. Brain tissue removal leaves no apparent disfigurement.

Q. Will my relatives know the brain has been removed?

A. Only on close inspection would anyone

know an autopsy had been performed, because tissue is removed from a non-visible area.

Q. Hasn't the patient suffered enough? Why put him/her through anything more?

A. It may appear callous to discuss a need for autopsy when dealing with those emotionally burdened, but a refusal based on "they have suffered enough" is the result of an emotional state of mind. Only through autopsy can the diagnosis be certain.

Q. Is it important for children of Alzheimer's disease patients to have confirmed diagnosis through autopsy?

A. Yes. As our knowledge increases, it becomes more important for families to have complete medical records. If other family members develop dementia, an autopsy confirmed diagnosis of previous cases will be essential for any early treatment the future may bring.

<p style="text-align: center;"><b>PROCEDURE AT THE TIME OF DEATH</b></p> <ol style="list-style-type: none"> <li>All states require a signed autopsy permit. In some states, it is possible to pre-sign an autopsy permit, but the decision for brain autopsy must be confirmed verbally at the time of death. Autopsy permit forms are available from your pathologist or hospital.</li> <li>The pathologist will arrange the details of the autopsy.</li> <li>Families can expect a written autopsy report from the pathologist, neuropathologist, or research center within a reasonable time after the death of the patient.</li> </ol> <p><b>NOTES:</b></p> <hr/> <hr/> <hr/> <hr/> <p><b>IMPORTANT TELEPHONE NOS.</b></p> <hr/> <hr/> <hr/> <hr/>	<p style="text-align: center;"><b>ABOUT ALZHEIMER’S DISEASE</b></p> <p>Alzheimer’s disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. Approximately 4 million Americans are affected. Its symptoms include loss of recent memory, decline in ability to perform on the job or at home, difficulty in learning, impairment of judgment, personality change, and difficulty with movement and speech. The disease eventually renders its victims totally incapable of caring for themselves.</p> <p>Alzheimer’s disease is the leading cause of dementia among the elderly and the fourth leading cause of death among American adults. At this time, there is no known cause or cure for Alzheimer’s disease.</p> <p style="text-align: center;"><b>ABOUT THE ALZHEIMER’S ASSOCIATION AND ITS MISSION</b></p> <p>The Alzheimer’s Association is the national voluntary health organization dedicated to research for the prevention, cure and treatment of Alzheimer’s disease and related disorders, and to providing support and assistance to the afflicted patients and their families.</p>	<p>The Alzheimer’s Association’s mission is carried out through:</p> <ul style="list-style-type: none"> <li>Research into the cause, prevention, treatment and cure for Alzheimer’s disease and related disorders.</li> <li>Education of the public and information for health care professionals.</li> <li>Chapter formation for a nationwide family support network and to implement programs at the local level.</li> <li>Advocacy for improved public policy and needed legislation.</li> <li>Patient and family services to aid present and future victims and caregivers.</li> </ul> <p style="text-align: center;"><b>THE ALZHEIMER’S ASSOCIATION AUTOPSY ASSISTANCE NETWORK</b></p> <p>The Network was established because families were increasingly aware that diagnosis of Alzheimer’s disease or a related disorder can be confirmed only through brain autopsy after death. Planning ahead helps families in making the difficult decision for autopsy; families need support and guidance in making the decision and planning for autopsy.</p>
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Obviously, there is an ongoing need for tissue for research. But equally important is the listing of Alzheimer's disease or related disorder on the death certificate. If the autopsy diagnosis shows a type of dementing illness other than Alzheimer's disease, death certificates should be corrected through the attending physician. This will eventually provide the basis for more reliable studies and statistics on the prevalence of dementia.

The primary purposes of the Autopsy Assistance Network are:

- To provide families with information regarding autopsy.
- To assist in obtaining a confirmed diagnosis.

Additional benefits of the Autopsy Assistance Network include:

- Providing issue for Alzheimer's disease research.
- Establishing diagnosis for purpose of clinical and epidemiological studies.

NOTE: The Alzheimer's Association Medical and Scientific Advisory Board recommends that the body organs of the patient with Alzheimer's disease *not* be donated for transplant purposes.

## **PROCEDURE FOR PREARRANGING A BRAIN AUTOPSY**

1. Meet with the entire family to make the autopsy decision and preplan for the autopsy.
2. If the patient is in a hospital, nursing home or Veteran's Administration Medical Center, contact the doctor in charge and state your intention that an autopsy be performed.
3. State your intentions for autopsy to the nursing home, care center and/or attending physician, along with a written statement requesting an autopsy to be placed in the patient's medical record.
4. If the family wishes to donate brain tissue for research, contact your regional Autopsy Assistance Network Representative for further details.
5. It is advisable to plan in advance with the funeral director for the autopsy procedure. Inform the funeral director that an autopsy is to take place. Work with the funeral director to make the autopsy arrangements.
6. There may be costs associated with the autopsy. For information concerning those costs, contact your local Alzheimer's Association Network Representative (your local Chapter of the national office can give you the telephone number).