

You can help us combat dementia

We are asking for your help in the struggle against Alzheimer's disease and other dementia-causing diseases. These diseases often leave us feeling helpless and frustrated as we witness the decline of a relative or friend. Much more must be learned about these disorders before effective treatments are discovered to prevent or retard mental decline. Brain donation at the time of death is one of the most important and generous gifts a patient with dementia and his/her family can make. Brain donations from older individuals who do not suffer from dementia are also critical for comparison with Alzheimer's disease.

Brain autopsy provides a definite confirmation of a diagnosis of dementia, since there are many possible causes.

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

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

Facts about the autopsy procedure

The body is not disfigured. You will be able to have an open casket funeral if you choose.

The funeral will not be delayed due to the autopsy. The brain autopsy requires only a few hours and will be conducted as soon as possible.

Most religions support brain autopsy and tissue donation. In fact, none of the major religions absolutely prohibit a brain autopsy.

BRAIN AUTOPSY: The Decision and Process

Information for you and your family

*Cognitive Neurology &
Alzheimer's Disease Center
at Northwestern University*

MAKING THE DECISION

Brain autopsy is a decision that individuals and their families can make only after thoughtful consideration. The decision has important emotional and practical implications. Members of the professional staff at the Cognitive Neurology and Alzheimer's Disease Center at Northwestern are available to talk with you and answer your questions.

The bereavement period is not the optimal time to begin thinking about an autopsy. The time to start thinking about brain autopsy is now, even though death may be years away. Early discussion reduces the stress of such decisions at the time of death. Your decision may be influenced by a variety of factors.

? Diagnosis -- At present, Alzheimer's disease and other forms of neurodegenerative dementia can only be diagnosed with 100 percent certainty through a brain autopsy.

? Concerns about genetic factors -- If other family members develop dementia in the future, confirmed diagnosis of previous cases is important, especially if treatment becomes available.

* Religious or cultural factors may influence attitudes towards brain autopsy, and individuals may feel the need to consult with religious leaders in their community.

* Benevolence -- Brain donation often helps family members feel that they have provided a gift of hope to future generations, thereby diminishing the sense of hopelessness and despair.

FOR RESEARCH PARTICIPANTS

The Intent Form

In order to assure that arrangements are in place well in advance, we ask brain donors and family members to be familiar with the contact procedures and to sign the necessary forms so that we have them on file and can activate them when needed. Your signature on the forms implies that you intend to have a brain autopsy at the time of death. When death occurs, the family will need to provide legal permission for brain donation.

The Brain Autopsy

The brain autopsy is done by experienced staff of the Northwestern University Feinberg School of Medicine for the purpose of obtaining tissue for research. Certain diagnostic criteria may preclude brain donation at the time of death, in which case the family will be notified by the autopsy coordinator. The family will be informed of the brain autopsy findings within 2-3 months after brain donation.

Steps for Arranging Brain Autopsy

Notify the staff at the Neurobehavior and Memory Health Services clinic several days in advance if the donor's condition appears terminal. This will allow us to better coordinate efforts at the time of death. Please call us weekdays between 8:00 am and 5:00 pm at 312-695-2343.

For research purposes it is important that the autopsy be performed as soon as possible after death. As soon as you are informed of the death, you should notify us as follows:

* Please call our 24-hour line at 312-915-8021 and ask for the "Alzheimer Pathologist on-call." Leave your name, telephone number and the name of the deceased. The autopsy coordinator will call you back within 30 minutes.

* ***Legal autopsy permission.*** The autopsy coordinator will ask for a "**legal telephone consent for brain autopsy**" and will arrange for you to speak with someone from the Office of Medical Records at Northwestern Memorial Hospital to give this consent.

* ***Death certificate.*** The Illinois Medical Examiner requires us to have a *death certificate* signed by your Family MD (or we must contact him/her) before the autopsy. Your funeral home will work with you to expedite obtaining a completed family doctor's death certificate.

* ***Cost.*** The total cost of a brain autopsy is \$1,500. This cost is fully covered by our research grant and you **WILL NOT** be responsible for these charges

* ***Transportation.*** The Autopsy Coordinator will work with your funeral home to arrange transport to and from the hospital. The cost of the transportation of the body to and from the hospital will be the responsibility of the family of the donor. The costs can vary depending on distance, and families are urged to obtain this information from the funeral home. In cases of financial hardship, special arrangements may be possible and can be discussed on a case-by-case basis. If a patient expires at Northwestern Memorial Hospital, the procedure will be conducted at the hospital.

Because it is important that this process be done in a timely fashion, we suggest that you choose a funeral home in advance, if possible.

A Closing Note

Brain donation is a private matter. Each individual's and his/her family's decisions will be respected. Clinicians at the Neurobehavior and Memory Health Services clinic are available to assist families in making this decision. Please save this brochure. Thank you for your consideration.