

Brain donation is one of the most important contributions to research.

As researchers work to better understand disorders that affect mental function with aging, brain donations are essential to their progress.

By studying the anatomy, pathology, and chemistry of the brains of people with memory problems or cognitive disorders, we are able to expand our knowledge of diseases such as Alzheimer's and Frontotemporal Lobar Degeneration and take steps toward prevention and treatment.

While major advances have already been made possible through the generosity of brain donation, there is still much more to be learned and a need for continued support.

Brain donation provides a valuable service to families.

A comprehensive brain autopsy is performed on each person who makes a brain donation to our Center. The family of the donor receives a full report detailing the neuropathologist's findings. At present, neurodegenerative diseases can only be diagnosed with 100% certainty through a brain autopsy, so families are provided with a definitive diagnosis.

Such information is useful if other family members develop a problem with memory or thinking in the future or if there is a known family history.

Making this generous donation provides the family with a way to potentially help others, which can create a sense of hope and power over the illness that affected their loved one.

Understanding the Process

If you and your family choose to donate your brain to Northwestern's Cognitive Neurology Center, it is important to understand what will happen.

- As soon as we are notified, we will arrange for transportation to Northwestern Memorial Hospital for brain removal. The cost of transportation to Northwestern Memorial Hospital will be paid by our Center.
- The next of kin will be asked to speak to our Office of Medical Records to give verbal permission for a brain-only autopsy.
- Our staff will arrange for transportation from the hospital to the funeral home the family has chosen. Funeral services may then proceed according to the family's wishes.
- If you live far from Northwestern, we will find a local facility to do the brain removal and send the brain to our laboratories. The instructions in this case differ from this flyer and will be handled on a case-by-case basis.
- The experienced pathology staff of the Northwestern University Feinberg School of Medicine will perform the brain autopsy in the next few weeks. The full cost of the autopsy (about \$2500) will be paid through our Center's research grant. The autopsy provides a detailed examination of the brain to diagnose the abnormalities that caused the dementia. The tissue is stored for distribution to researchers who request resources for studying cognitive aging and dementia.

Making the Decision

The decision to become a brain donor requires careful thought and planning. As you and your family consider making this important contribution, please keep in mind that the bereavement period is not the optimal time to begin planning for a brain autopsy. It is best to make arrangements as far in advance as possible, even though death may be years away. There are several things that you and your family can do to prepare in advance.

- Begin talking about brain donation with your family now. Early discussion can reduce stress at the time of death.
- Choose a funeral home and inform them of your plans for brain autopsy. This will give the funeral home an opportunity to contact us with questions and ensure that all parties understand what will happen when the donor passes away.
- Complete the "Autopsy Intent" form provided at your yearly research visits. This form is not a legally binding document, but it helps to keep our staff aware of your plans and to update your contact information.
- We will call you every 6 months once you can no longer make visits to our office to update the condition and to record any changes in plans.

Frequently Asked Questions

Who will pay for the autopsy and transportation to Northwestern Hospital?

Northwestern University will pay for the brain autopsy and the cost of transportation to Northwestern Memorial Hospital.

What happens if death occurs at night or during the weekend?

Brain removals are performed 7 days a week. Outside of regular business hours, your family should call our emergency line at (773) 495-2982. The Autopsy Coordinator will return the call within 30 minutes.

Will the autopsy affect our funeral plans?

The removal only takes a few hours and will be conducted as soon as possible, so it will not delay the funeral. Procedures do not alter the donor's body in any way that would affect the option of having an open casket service.

Who can my family talk to about the autopsy report?

Your family may call the Autopsy Coordinator during regular business hours to discuss the report and ask any questions. An in-person feedback session with a clinician from our Center is also available at no cost to your family, if desired.

Do some religions prohibit brain autopsy?

None of the major religions prohibit a brain autopsy, but we encourage you to discuss your plans with a leader from your particular faith.

CNADC

Brain donation is a private matter. Northwestern's Alzheimer's Disease Center respects the decisions of each individual and his or her family. Our Autopsy Coordinator is available to assist you and your family during the decision-making process.

**Our staff can be reached
Monday through Friday,
from 8am to 5pm.**

Phone: (312) 926-1851

Email: memoryresearch@northwestern.edu



CNADC

BRAIN DONATION

Information for you
and your family

*Individuals With A Diagnosis
of Dementia or
Mild Cognitive Impairment*

**Cognitive Neurology &
Alzheimer's Disease Center**
of the Northwestern University
Feinberg School of Medicine