

## **Brain donation is one of the most important contributions to research on memory and aging**

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 within three months of the autopsy. 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**

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*If you and your family choose to donate your brain, it is important to understand what will happen:*

- As soon as we are notified, we will arrange for transportation for the deceased to Northwestern Memorial Hospital for brain removal.
- The next-of-kin will be asked to speak to our Office of Medical Records to give verbal permission for a brain-only autopsy.
- Following the procedure, our staff will arrange for transportation of the deceased 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. The family will receive a report after about 3 months, detailing the findings. The autopsy provides information about the brain. The tissue is stored for future distribution to approved research projects. In this way, the tissue can support numerous studies now and in the future.
- Northwestern will cover all costs associated with the brain donation process (about \$2500) through our Center's research grant.

## **Making the Decision**

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*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.
- Even though you may have indicated your intent for the brain autopsy on the research consent form, this form is not a legally binding document and consent is always requested at the time of death from the next-of-kin.
- We will call you every 6 months once you can no longer make visits to our office for an update and to record any changes in plans.

## Frequently Asked Questions

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

Research funding covers the costs of brain autopsy and round trip transportation to Northwestern Memorial Hospital

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

Brain autopsy procedures are performed 7 days a week. At the time of passing, your family should call our 24-hour line. The Autopsy Coordinator will return the call within 30 minutes.

### Will the brain autopsy affect our funeral plans?

The procedure 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 brain autopsy report?

Your family may call the Autopsy Coordinator at (312) 926-1851 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.



*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 at:

**Phone:**  
(312) 926-1851

**Email:**  
[memoryresearch@northwestern.edu](mailto:memoryresearch@northwestern.edu)



## BRAIN DONATION

Information for you  
and your family

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