

FREQUENTLY ASKED QUESTIONS

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

Northwestern University will pay for the brain autopsy. The family will be responsible for the cost of transportation to Northwestern Memorial Hospital.

- **Will the autopsy affect our funeral plans?**

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

- **Do some religions prohibit brain donation?**

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

YOU CAN HELP US

We are asking for your help in the struggle against Parkinson's disease and other movement disorders. These disorders often leave us feeling helpless and frustrated as we witness the decline of our patients. Much more must be learned about these disorders before the causes can be understood and effective treatments discovered to prevent or retard the disease. Brain donation at the time of death is one of the most generous gifts a patient with PD or another movement disorder can make.

Because brain donation is a personal and private decision, this brochure is meant to provide information for you to consider. Participation is voluntary and may be withdrawn at any time. Clinicians at the Movement Disorders Center are available to answer questions. Thank you for your consideration.



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**Northwestern Parkinson's
Disease and Movement
Disorders Center**

BRAIN DONATION



**Information for you and
your family**



WHY BRAIN DONATION?

The primary goals of neurology research are to find the cause of a disease and to develop new treatments. To achieve these goals, it is essential that medical investigators examine the brain tissue of patients who die with neurological diseases and compare findings to people without these conditions. Brain donation, therefore, becomes one of the most important contributions to research.

We are asking patients and their families to consider brain donation at the time of death. We understand what a personal and difficult decision this is, especially since it concerns the brain. However, scientists cannot resolve mysteries of diseases alone. We need patients' help.

Being a brain donor provides an immense contribution to science. In addition, brain donation provides a valuable service to families. The donor's family receives a full report detailing the neuropathologist's findings. Such information is useful if other family members develop a movement disorder or if there is a known family history.

Brain donation often helps patients and family members feel that they are providing a gift of hope to future generations, thereby diminishing the sense of hopelessness and despair.

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 donation. 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 time of death.*
- *Complete the "Autopsy Intent" form available in the Movement Disorders Clinic. This form is not a legally binding document, but it helps to keep our staff aware of your plans.*
- *Inquire about brain donation at your regular clinic visit and/or call our Center for more information. You may call (312)503-4397 to obtain information about the brain donation program.*

UNDERSTANDING THE APPROACH

Once you and your family choose to donate your brain to Northwestern's Parkinson's Disease and Movement Disorders Center, it is important to understand what will happen.

- You will need to notify your physician when death occurs. During week-day work hours, call Department of Neurology at 312-695-7950 and ask that the treating physician be notified. During weekends/nights, call the same number 312-695-7950; you will be connected to Neurology answering service. Once connected, ask that the treating physician be paged. Be prepared to provide your funeral home information to the treating physician.
- As soon as we are notified, we will arrange for transportation to Northwestern Memorial Hospital for brain removal.
- 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.
- The experienced pathology staff of the Northwestern University Feinberg School of Medicine will perform the brain autopsy. The autopsy provides a detailed examination of the brain to diagnose the abnormalities that caused the movement disorder. The tissue is stored for distribution for research projects.
- Northwestern Memorial Hospital will cover the autopsy cost. The cost of transportation of the body to Northwestern Memorial hospital will be the family's responsibility. Limited grant funding will be available in cases of financial need.