

## 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 by the autopsy. The brain and spinal cord autopsy requires only a few hours and will be conducted as soon as possible after the time of death.*

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

- Brain and spinal cord
- and other organ donation
- provides valuable tissue to
- researchers for anatomic,
- pathologic, genetic and
- neurochemical research.
- Major contributions to
- our understanding of these
- tragic and sometimes rare
- diseases may come from
- single case studies.

## YOU CAN HELP US

We are asking for your help in the struggle against ALS (amyotrophic lateral sclerosis or Lou Gehrig's Disease) and other motor neuron diseases such as PLS (primary lateral sclerosis) or HSP (hereditary spastic paraparesis). These disorders 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 the causes can be understood and effective treatments discovered to prevent or retard the disease. Brain and spinal cord donation at the time of death is one of the most important and generous gifts a patient with ALS or another neuromuscular disease can make.



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## BRAIN AND SPINAL CORD DONATION



TISSUE DONATION:  
THE DECISION  
AND THE PROCESS

INFORMATION FOR YOU  
AND YOUR FAMILY

## MAKING THE DECISION

Donation of tissue from the brain and spinal cord and possibly other organs such as the liver and kidney after the time of death 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 Neuromuscular Disorders Program 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 tissue donation 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.

By giving researchers the opportunity to examine the motor neurons and other cells of the human brain and spinal cord where these disorders begin, a better picture of the factors involved could lead to further discoveries, which may in turn lead to treatments and cures.

Tissue 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.

Religious or cultural factors may influence attitudes toward autopsy, and potential donors and their families may feel the need to obtain religious counseling.

## FOR RESEARCH PARTICIPANTS

**THE INTENT FORM.** Arrangements for the autopsy have to be made well in advance, which requires that tissue donors and their families know who to contact, and sign necessary forms in advance so that they are available at the time of death. Your signature on the form indicates your intention for an autopsy of the brain, spinal cord, and possibly other organs such as liver or kidney. However when death occurs, your family will also have to provide legal permission for the procedure. In Illinois, the family may sign this consent ahead of time.

**THE AUTOPSY.** The brain and spinal cord autopsy is done by experienced staff under the supervision of a neuropathologist and conducted at Northwestern Memorial Hospital.

**STEPS FOR ARRANGING AUTOPSY.** Notify the staff at the Neuromuscular Disorders Program 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 during office hours at **312-503-0160** or **312-503-2712**.

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 pager at **312-695-5005** and enter your phone number followed by the pound (#) sign. The Neuromuscular Program autopsy coordinator will call you back within thirty minutes.

## AND FOR FAMILIES

**LEGAL AUTOPSY PERMISSION.** The autopsy coordinator will ask the donor's next of kin for a legal written or telephone consent for the autopsy.

**DEATH CERTIFICATE.** The Illinois Medical Examiner requires us to have a death certificate signed by your family doctor. The funeral home will work with you to obtain the death certificate.

**TRANSPORTATION.** The autopsy coordinator will work with your funeral home to arrange transport to and from the hospital. Because it is important that this process be done in a timely fashion, we suggest that you choose a funeral home well in advance.

**COST.** Costs for transportation within the Chicago area and for the autopsy are covered by a grant from the Les Turner ALS Foundation and **YOU WILL NOT** be responsible for these charges.

### A CLOSING NOTE

Because tissue 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 Neuromuscular Disorders Program are available to answer questions. Thank you for your consideration.

