ALZHEIMER'S & DEMENTIA RESOURCE CENTER

Your Brain: A Priceless Gift
Questions and Answers About Brain Donation

Q. Why are brain autopsies so important and brain donations so needed?
A. The word "autopsy" stems from the Greek word *autopsia* meaning "to see with one's own eyes." The autopsy is essential both for research and diagnosis. Researchers need to study the brains of people who have been closely followed by a physician. The medical records contain vital clues as to how the disease began and progressed. Comparison of the clinical course of the disease, along with the changes found in the brain tissue help researchers to better understand dementia. Until a reliable clinical test is found, the only definitive way to obtain the diagnosis for Alzheimer's disease or one of the related dementias is by having the brain examined after death. The pathologist examines the brain tissue under the microscope, looking for the characteristic hallmarks of these diseases.

Q. Who can legally authorize an autopsy?
A. The person's next of kin gives consent for the autopsy, according to the order in this list: spouse, children of legal age, parents, siblings, grandparents, uncles/aunts/first cousins, legal guardian. That is, if there is a spouse, the spouse gives consent. If not, the decision moves to any children, then to parents, and so on. The person giving permission will be asked to sign a consent form for the procedure.

Q. Will I receive a report of the finding?
A. The person giving permission for the autopsy will receive a neuropathological report approximately 4-8 months later. Learning the precise cause often gives families a sense of closure. In the event that more than one family member has a similar disease, the neuropathological report provides vital information to the family and to their physicians about possible genetic implications.

Q. What effect will the donation have on funeral arrangements?
A. None. We will work with any funeral home chosen by the family. The removal of brain tissue does not leave any visible marks, therefore one may choose an open casket viewing. Since the autopsy is done within hours of the death, it will not interfere with the timing of funeral arrangements.

Q. When should arrangements for a brain donation be made?
A. Although people with dementia may live many years, it is important to make the necessary arrangements in advance. Family members need time to discuss this decision and explore any possible concerns. As this is a research program, consents will need to be signed and the research coordinators will need time to obtain the medical records.

A caregiver' s quote:

"Thank you for giving my mother her last hoorah, a gift to science and a gift to our future."

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