

The *Gift to Life* and *Gift to Life Plus* Programs are a clinical service that helps families to arrange an autopsy for a loved one at the time of death. Performance of an autopsy is a gift of knowledge to the succeeding generations of a person's family, eliminating uncertainty about the cause of illness, providing information about disease risk, improving public health records, and aiding medical research.

Brain Autopsy: Why is it Important?

Autopsy, examining the body after death, has many benefits. For families, learning the precise cause of the patient's illness may be a tremendous relief and help to ease uncertainty and doubt. It gives relatives accurate information about the cause of symptoms and confirms or modifies the diagnosis made during life. Autopsy provides relatives with accurate information about their family's medical history needed for their care and for future generations.

Results of an autopsy, also known as a postmortem examination, is becoming increasingly important as we learn more about Alzheimer's disease, memory loss, and other dementias. It is likely in the future to affect treatment recommendations for family members. Additionally, when an autopsy is done, brain tissue is stored and may be available for additional studies even many years later. For example, this tissue could be used for genetic studies that are important for research and provide useful information to relatives.

Autopsies are also an extremely important source of information about how the disease affects the anatomy of the brain. This information is used to direct future research into the causes of memory loss, their progression over time, and clues about effective treatment approaches. For example, researchers recently have found that a previously unrecognized abnormality in brains of patients with dementia called Lewy bodies may be present in 40% of persons with Alzheimer's disease and may account for some symptoms. We would never have learned this unless we conducted autopsies in addition to our clinical care. What we know about dementia has only been possible because of the commitment of patients and families like you. Even if individual family members do not benefit directly from a brain autopsy, it can lead to a better understanding of Alzheimer's disease and other dementias for future generations and an important measure to assess public health and quality of care.

For most people, the time immediately following the death of a family member is very difficult. It is therefore not a good time for making important decisions such as this. It is best to make the decision about whether or not to request a brain autopsy well in advance, with less stress and with consideration for the wishes of the patient and family. It is also necessary to pre-arrange an autopsy in advance, so that it can be performed appropriately to study brain disease.

Facts About Autopsy

Can there still be an open casket?

Yes. The removal of brain tissue does not cause any noticeable disfigurement.

Will the funeral arrangements be delayed?

With preplanning and careful coordination, there should be no delays for typical funeral arrangements. If the body is transported to the hospital rapidly after death, the procedure should be performed within 24 hours after death.

Do I have to tell my relatives, or will they know the brain has been removed?

You do not have to tell anyone if you do not wish to. Only on close inspection would anyone know that an autopsy has been performed.

Does an autopsy or donating brain tissue for research purposes interfere with religious beliefs?

Performance of an autopsy and brain donation does not conflict with most religious beliefs. If you have any questions concerning this issue, please contact your priest, minister, imam, or rabbi.

Who can legally grant permission for an autopsy to be performed?

Prior to death, an individual or family member can indicate their intent by signing a ***provisional*** consent. This permits arrangements to be planned. However, after death, the person's legal next-of-kin must authorize the autopsy before it can be performed. The following persons, in order of priority, may provide such consent:

- 1) Spouse
- 2) An adult son or daughter
- 3) Either parent
- 4) An adult brother or sister
- 5) A guardian of the decedent at the time of death.
- 6) Any other person authorized or under obligation to dispose of the body.

If there are several individuals in a category they must all agree. For example, in priority level 2, all adult children have equal authority and must be in agreement. Signing a provisional consent can help others by documenting a patient's wishes.

Which organs are examined at autopsy?

When consent for an autopsy is obtained from the next-of-kin after death of the patient, you will be given the option of either a brain only, or complete autopsy. In a complete autopsy, all major organs are examined. If the autopsy is done at an outside institution, generally we would recommend that a brain only autopsy is performed with the brain sent to the University of Utah Hospital. Outside institutions may not perform a detailed microscopic examination of the brain, even as part of a complete autopsy. The University of Utah has the only board-certified neuropathologist in the Intermountain West.

Will an autopsy report be sent to the family?

Yes. Typically, the report is sent to the family **one to two** months after completion of the autopsy procedure. Once you've received the autopsy report, contact your local physician and he/she will be able to discuss the autopsy results and its implications with you. This also can be arranged with the physicians of the Center for Alzheimer's Care, Imaging and Research at the University of Utah.

What should we do with the report?

We recommend that you keep the report in a safe place for future reference. The numbers on the report are important because they help family members obtain further information in the future if it is needed.

Who else will see the autopsy report?

The autopsy report is a medical document to be seen only by persons who have specific permission. This includes the next-of-kin, the local physician, and investigators in the Center for Alzheimer's Care, Imaging and Research.

What research will be done on the brain tissue?

Tissue samples and results of the autopsy may be shared with scientists after their research proposals are reviewed and approved. These studies may lead to improved understanding and advances in the diagnosis and treatment of Alzheimer's disease and related memory disorders. Samples are provided for biochemical and genetic studies labeled with numbers rather than names, to keep information anonymous. The results of these studies also may result in commercial products or patents. Families will not be responsible for any development costs nor share in the profits of any commercial application. If you want to learn about the results of any research studies that have included the patient's brain tissue you may contact the Center for Alzheimer's Care, Imaging and Research for further information.

Will genetic analysis be performed routinely?

No, genetic testing is not appropriate or possible for the majority of brain tissue we receive. Genetic test results presently do not alter treatment for Alzheimer's disease or other memory disorders. We store frozen brain tissue in every case possible, since it is most appropriate for genetic analysis. Genetic studies are most likely to be performed when there is a clear family history of dementia. These studies may be done at the University of Utah or at other collaborating laboratories.

If genetic analysis is performed, will family be informed?

Family members are not automatically informed when genetic testing of tissue is done. To inquire about the availability of genetic test results, contact the Center for Alzheimer's Care, Imaging and Research. All genetically related individuals may request the results of genetic testing. Results will be released only to a physician, who will assist with counseling and interpretation of results. There is a possibility that genetic test results will be unavailable or impossible to interpret with certainty.

Relatives have the right not to know the results of any genetic test(s). Relatives may not want to know about test results or may want to keep this information out of their medical records because it has the potential to affect insurability, employability, and social esteem.

Who else will see the results of genetic tests, if they are performed?

Results of genetic tests are kept confidential to the full extent of the law and may or may not be included in the electronic medical record. Genetic test results are shared with other investigators when appropriate for their research. In these cases, results are shared without identifying personal information to maintain confidentiality.

What is the difference between the Gift to Life and Gift to Life Plus Programs? How do I qualify for the Gift to Life Plus Program?

Individuals who have been patients at the University of Utah Health System or have participated in research studies at the Center for Alzheimer's Care, Imaging and Research automatically qualify for the *Gift to Life Plus* Program. Individuals in this Program have several advantages (Pluses):

1. There is no cost for autopsy if it is performed at the University of Utah
2. More accurate diagnosis is possible because of the availability of detailed clinical records and results of research studies
3. Because of the high quality clinical and research data, and stored DNA, the autopsy results and tissue are more valuable to researchers

Postmortem diagnostic services also are available to people who have not been evaluated at the University of Utah through the *Gift to Life* Program.

The *Gift to Life* and *Gift to Life Plus* Programs require arrangements to be completed before death. So that procedures can occur smoothly and without disruption, enrollment after death is not allowed.

Are there any costs or fees involved?

The costs depend upon whether the person is enrolled in the *Gift to Life Plus* Program or the *Gift to Life* Program.

Gift to Life Plus Program: The University of Utah Health System or the Center for Alzheimer's Care, Imaging and Research pays for the performance of the autopsy, if it is performed at the University of Utah. It also pays for the autopsy report. Family members must pay for the costs of transporting the body to and from the hospital where the autopsy is performed. If the autopsy is performed at an outside institution, the local hospital may or may not charge a fee for brain removal. Family members also are responsible for costs for sending brain to the University of Utah for examination. Potential costs will be estimated through the pre-arrangement process. Funds from gifts or research may be available to offset these costs in some cases.

Gift to Life Program: Family members are responsible for all costs of this service. This includes paying for 1) transportation of the body to and from the hospital where the autopsy is performed, 2) brain removal at an autopsy, 3) cost of shipping the brain to the University of Utah, if the autopsy is performed elsewhere, 4) microscopic examination of the brain and pathological diagnosis, and 5) the autopsy report. Potential costs will be estimated through the pre-arrangement process. The University of Utah currently charges \$550 for brain removal, microscopic examination of the brain, pathological diagnosis, and the autopsy report. Funds from gifts or research may be available to offset these costs in some cases.

There are no costs for pre-arrangement of an autopsy. This is a service provided by the Center for Alzheimer's Care, Imaging and Research. There are no charges for research testing. These costs are provided by gifts to the Center for Alzheimer's Care, Imaging and Research or through externally funded research grants.

Where is the autopsy done?

Pathologists at the University of Utah will perform the autopsy for patients living in the surrounding area. Because of the costs and difficulty in transporting the body long distances, we may recommend that an autopsy is performed at an outside institution and the brain sent to the University of Utah for microscopic examination. This will be determined as part of the pre-arrangement process.

When should pre-arrangements for an autopsy be made?

Planning should begin as soon as your decision is reached. **Autopsy preparations must be made before the time of death.** To indicate your "intent" for a brain autopsy, you should complete and sign the appropriate form for Provisional Consent for Brain Autopsy Pre-Arrangements.

Your decision about brain autopsy pre-arrangements should be shared with immediate family members, medical caregivers, and your funeral director, to avoid last minute confusion.

How can I help support the Gift to Life and Gift to Life Plus Programs?

The *Gift to Life* and *Gift to Life Plus* Programs are a service to the community provided by the Center for Alzheimer's Care, Imaging and Research. We realize that postmortem diagnostic services are important to patients and their families, yet often are unavailable. It is particularly difficult to confirm the diagnosis of serious brain diseases in the Intermountain West, because the University of Utah is the only institution in this entire region to have a board-certified neuropathologist. We are particularly fortunate to have a neuropathologist with a research interest in neurodegenerative diseases, including Alzheimer's disease and related disorders. The goal of the *Gift to Life* and *Gift to Life Plus* Programs is to make these critical services as widely available and affordable as possible.

The development of these Programs was made achievable through private donations to the Center and with the support of the University of Utah Health System and the University of Utah Department of Pathology. The most valuable donation you can make is through your participation in these Programs. We deeply appreciate the contribution this represents. You also can help support these Programs by telling others who may be interested. We gratefully welcome donations to help support and continue these Programs. We have established a fund to help pay for cost of the *Gift to Life* and *Gift to Life Plus* Programs and to provide funds to families to help offset their costs. Neurological diseases are very expensive and without the availability of such funds, often families otherwise would be unable to pay for expenses related to autopsy. Donations are tax-deductible and can be sent to directly to the Center at:

Gift to Life Program
Center for Alzheimer's Care, Imaging and Research
650 Komas Drive, #106-A
Salt Lake City, UT 84108

How can I get more information?

Information about the importance of autopsy and postmortem diagnosis can be obtained through the Utah Chapter of the Alzheimer's Association at (800) 371-6694, or www.alzutah.org. If you have any questions about the *Gift to Life Plus* or *Gift to Life* Programs or need a copy of the Enrollment Form, please call our Health Educator, Kathy Moran, at (801) 581-4771, or visit our website at www.utahmemory.org.