



MASSACHUSETTS
GENERAL HOSPITAL

*Gerontology Research Unit
MGH East
Bldg 149, Suite 2691
149 13th Street
Charlestown, MA 02129
(617) 726-5571 phone
(617) 726-5760 fax*



MASSACHUSETTS
Alzheimer's Disease
Research Center
www.madrc.org



HARVARD
MEDICAL SCHOOL

*Memory & Movement Disorders Units
WACC, Suite 830
Massachusetts General Hospital
Fruit Street
Boston, MA 02144
(617) 726-1728 phone
(617) 726-4101 fax*

Brain Donations

The Brain Tissue Center was established in 1984 to collect postmortem human brain specimens from normal individuals and from those who have been afflicted with a degenerative brain disease. Our mission is two-fold:

- 1) to supply families with a detailed neuropathological diagnosis;
- 2) to establish a centralized resource for brain research.

A centralized tissue resource is extremely valuable to researchers. Standardizing the way in which laboratory studies are performed eliminates discrepancies among individual researchers, and enables them to compare their work with that of physicians, neuroscientists, biochemists, and geneticists around the world who are working on these disorders. Families in turn often find comfort in the definitive diagnosis neuropathology can provide. Working together, the family, physician and pathologist can start to understand the connections between the physical state of the brain and the clinical or behavioral manifestations of the patient's illness.

The Center collects and distributes to research investigators tissue from both normal donors and from those with neurological disorders such as Alzheimer's and Parkinson's disease, Frontotemporal dementia, etc. All types of tissue are very much in demand. Diseased tissue is essential because of its potential use in research studies examining the causes of neurodegenerative disorders. Normal, undiseased tissue is equally important to obtain: one must establish normal ranges of values in order to determine what is abnormal. In all donations, the identity of the donor remains strictly confidential.



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Questions & Answers Regarding Brain Donation

- 1) **Why should I donate?** Brain donation is a valuable gift that provides tissue for numerous research studies throughout the United States and internationally. New clinical research methods and analogous "animal models" for degenerative diseases are now available; however, these methods do not replace the scientific need for direct examination of brain tissue. ***Our understanding of the biochemistry and tissue changes caused by these devastating disorders will only be achieved through the use of postmortem tissue.***

Therefore, brain donation at the time of death is one of the most important and generous gifts the patient and family can give. It provides us with the irreplaceable resources needed to perform the research that will enhance our ability to treat and perhaps someday cure these horrible illnesses.
- 2) **Who can donate?** Any legally competent adult can donate his or her brain, just as he or she can donate any other organ. We welcome the donation of normal or diseased brains from individuals who participate in our clinical trials or other specific research studies and from patients in the Memory and Movement Disorders Units. For more information on the types of research studies that we offer, please call 617-643-5200.
- 3) **What about my religious beliefs?** All the major religions support organ and tissue donation. However, since brain donation is an unique gift, if you have any specific questions or concerns about your religion's position on this issue, you may want to talk with a religious leader of your faith
- 4) **Can I still donate my body to science or make other organ donations when I donate my brain?** It is usually necessary to choose between donating one's organ(s) and donating one's entire body to a medical school. Most medical schools do not accept body donations from persons who have already donated any organ, including the brain. However, when the brain is donated to the Brain Tissue Center, there are no restrictions. In fact, we encourage the donation of other organs in addition to the brain, and are happy to facilitate them as part of the autopsy. However, we cannot arrange for these donations directly. It is best for potential donors to refer to the specific organ donation organizations, as the methods and requirements of such other donations differ and are constantly changing.
- 5) **What happens when the donor dies?** When a brain donor dies, the health care proxy or next of kin should call 617-726-1728 (24/7). If after office hours, press "0" (urgent matter/brain donation). A person from the urgent answering service will come on the line. This phone call will allow us to obtain the official permission for brain donation. The family may also be asked to donate their loved one's retina (only if closed casket) and/or fibroblasts



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from a skin sample. Fibroblasts are cells in connective tissues that produce collagen and other fibers.

- 6) **What special procedures must be followed at the time of death?** A protocol is available describing the exact procedure. The procedure may vary from case to case; however, the most important aspect is that ***the tissue must be removed as soon as possible after death.*** The brain must be removed before embalming or other funeral preparations.
- 7) **Must the brain autopsy be performed at Massachusetts General Hospital?** We request autopsies to be performed at the Massachusetts General Hospital (MGH) (if at all possible). For those who have participated in research studies such as clinical trials, neuroimaging studies, or other specific research studies, we will cover the cost of transportation with research funds. For all others, the family will need to be responsible for transportation costs.
- 8) **Who will remove the brain after death?** When the autopsy is performed at MGH, one of the Center's neuropathologists will remove the brain. If another hospital is to carry out the autopsy, the donor's physician should make the arrangements prior to death (at the time of the decision to donate). Documentation of the donor arrangements should be kept with personal papers (e.g., will, health care proxy, medical records). If the autopsy is to take place at a local hospital, please notify the Center of these plans, so that we can contact that hospital's pathology department when it is time to receive the donation.
- 9) **How will the autopsy be performed and what happens to the body?** The first step of the autopsy is to make a simple incision of the scalp. Then using surgical procedures, the skull is opened and the brain is removed. After the brain is removed, the skull is closed and the incision is stitched as in a surgical operation. The body is then released to the funeral director or to the designated person according to family wishes. An open casket service or other traditional arrangement will still be appropriate after the brain autopsy. The exact funeral arrangements remain the responsibility of the donor's family or estate.
- 10) **What happens after the brain is donated?** The Brain Tissue Center will acknowledge the receipt of the donation to the family. The Center will then review the donor's medical history and prepare a detailed neuropathological report including laboratory test results. This report will be sent to the family, and our staff are also available to answer any questions the family might have about the report.
- 11) **Is there any cost for the brain autopsy procedure?** Generally not as long as the donor has been a patient or research participant at MGH. However, if the individual is not a participant in our clinical trials or other specific research studies, the family may need to pay for transportation of the body, and for brain removal and transportation if the autopsy is performed elsewhere.



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Becoming a Brain Donor

Thank you for considering to participate in this important part of our research. Here is a summary of the steps potential donors must take to ensure donation of brain tissue:

- ❑ Discuss with your family and physician about your intent to donate and your arrangements.
- ❑ Fill out the Authorization for Autopsy/Brain Donation form and give it to your research study coordinator or to your Memory/Movement Disorders nurse or physician.
- ❑ Fill out the brain donor card and keep it in a convenient place. It has on it the phone number to call at the time of death. (We can laminate the card for you, if you like.)
- ❑ At the time of death, your health care proxy or next of kin should call 617-726-1728. If after hours, press "0" (urgent matter/brain donation). A person from the urgent answering service will come on the line.



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Authorization for Autopsy/Brain Donation

Provisional Consent of Living Donor

In the hope that this authorization will further the medical understanding of neurodegenerative diseases, I, _____ DOB: _____, an adult, do hereby authorize the postmortem examination of my body upon death, including the removal, examination, retention, and use of my brain for diagnostic and/or research purposes in the interest of determining the cause of my death and of advancing medical knowledge. My family may also be asked to donate my retina and fibroblasts from a skin sample. Fibroblasts are cells in connective tissues that produce collagen and other fibers.

Signature of Donor

Date

PRINT Donor's Name & Address

Witness

Provisional Consent of Next of Kin

I (we), being the legally authorized representative(s) of _____ DOB: _____, and being the (spouse/ child / parent / sibling / friend) of the aforementioned person and entitled by law to control his/her remains, do hereby authorize the postmortem examination of his/her body, including the removal, examination, retention, and use of his/her brain for diagnostic and/or research purposes in the interest of determining the cause of death and of advancing medical knowledge. I may also be asked to donate my loved one's retina and fibroblasts from a skin sample.

Signature(s) of Next of Kin

Date

PRINT Next of Kin's Name(s) & Address(es)

Witness



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Next of Kin Contact Information:

Name: _____

Address: _____

Telephone: _____

Funeral Home Contact Information:

Name: _____

Address: _____

Telephone: _____