

POSTMORTEM BRAIN DONATION – FREQUENTLY ASKED QUESTIONS

What is postmortem brain donation?

Postmortem brain donation is different from other organ donation. As an organ donor, you agree to give your organs to other people to help keep them alive. As a brain donor, your brain will be used for research purposes only—it will not be given to another person. Our scientists use brain tissue donated after death to better understand if and how some Long Life Family Study participants escape Alzheimer's disease and other related diseases.

What is a brain autopsy?

Brain autopsy is the process of analyzing a person's brain after death. Examination of the brain allows scientists to learn important information about brain aging, and also to determine whether or not the donor had Alzheimer's disease and/or another form of dementia.

How will researchers learn about Alzheimer's disease and/or other dementias from my brain donation?

Researchers study donated brains to determine the amounts and locations of abnormal proteins including amyloid plaques and tau tangles—the hallmarks of Alzheimer's. They also look for signs of other types of dementia. They also perform biochemical analyses to determine the amounts of specific pathology. This analysis—possible only when brain tissue is studied under a microscope—answers important questions asked by both researchers and the family of the donor.

Families will receive a full report on the type and levels of pathology which may be present in their loved one's brain. Researchers will gain a better understanding of the relationship between clinical test results, fluid and imaging biomarkers, and the brain changes detected in the donated tissue. These insights enable scientists to constantly test new ideas and advance discovery that may one day result in effective therapies.

Why is brain donation important?

Brain donation helps researchers better understand the secrets to healthy brain aging, as well as causes of and treatment options for Alzheimer's disease and related dementias. One donated brain can provide tissue for hundreds of research studies. In this way, it provides a gift of hope to future generations at risk of developing dementia.

Who is eligible for brain donation?

Every Long Life Family Study Participant can donate their brain. This includes participants who don't have cognitive impairment, as well as those who do. In fact, both are needed for this important research.

People without memory or other cognitive problems play a vital role in research on Alzheimer's disease and related dementias. They help us to identify the age-related processes and changes that occur in a cognitively healthy brain. This knowledge helps researchers determine which changes in the brain are specifically related to Alzheimer's disease and/or related dementias and which are normal parts of aging.

Why should I consider donating my brain?

Your donation will increase the chances that better diagnostic tools and treatment options are developed for Alzheimer's disease and related dementias.

Also, the results of the diagnostic evaluation of your brain will be provided to your family so that they will know whether or not you had any evidence of Alzheimer's disease or related disorder.

Who performs the Brain Autopsy?

Our pathology team at Columbia University Irving Medical Center handles all of the logistics and performs the autopsy and tissue analyses. They also will store your brain tissue for future studies by researchers.

Are there any fees to me or my family for brain donation?

The Long Life Family Study will pay for all expenses involved with the brain donation and autopsy.

Is brain donation compatible with my religion?

Most religious and ethical traditions view organ donation as valuable to society and believe that donating an organ is a personal decision. We encourage you to seek guidance from your spiritual leader if you have questions specific to your faith. We will do our best to accommodate any procedures that are in line with your faith.

Does brain donation interfere with funeral arrangements?

Brain donation does not affect or delay funeral arrangements. The brain removal is performed carefully and respectfully at the funeral home, and without delay, by an experienced professional and does not interfere with plans for open casket viewing or cremation.

When should I start thinking about brain donation?

It's never too early to start the conversation about brain donation. If you are considering brain donation, talk with your loved ones about it early in your decision-making process. This may reduce their stress at the time of donation.

Whom should I inform about my decision to donate?

It is important to inform those involved with your end-of-life planning and care about your decision to donate your brain. You may want to include relatives, friends, doctors, and other health professionals to help ensure that everyone involved is clear about your wishes. Remember to include brain donation wishes in your end-of-life arrangements, such as in medical advance directives and information for your funeral home.

When can my loved ones expect the results of the brain autopsy?

Your family or other designated recipient will receive an autopsy report. This can take up to six months. Clinicians from Columbia University Irving Medical Center are available to discuss the results by phone.

What happens to my brain once it's been donated?

An experienced professional will respectfully perform a brain autopsy. They will share the results with your family or other designated recipient. Brain tissue will be stored in a carefully controlled Brain Bank at Columbia University Irving Medical Center for future investigations by scientists.

Will my identity or other personal information be shared?

The identity of each donor is strictly confidential. Your name will not be included in any information sent to outside investigators. All distributed samples are coded in order to protect your and your family's anonymity and privacy.

What if I change my mind and no longer wish to donate my brain?

You can cancel your donation at any time. Please contact the Brain Donation Program Coordinator (Donovan Laing; 201-951-6661) as soon as possible should you want to change your decision.

From start to finish, what is involved in the brain donation process?

- Step 1: Inform your Long Life Family Study Research staff that you would like to be in the donation program.
- Step 2: The Research staff will refer you to research coordinator from the Taub Institute at Columbia University Irving Medical Center who will call you to go over the

statement of intent with regard to autopsy with you and your family. They will also complete the referral form, to designate a family member or other representative to contact your Long Life Family Study Research staff near (within days) or at the time of death.

- Step 3: The Long Life Family Study Research staff will assist your loved ones in making arrangements for the autopsy.
- Step 4: Typically, once your body is at the funeral home, a professional trained in removing the brain is sent to the funeral home where they remove the brain and arrange for it to be delivered to the pathology team at Columbia University Irving Medical Center either that day or the next.
- Step 5: The brain autopsy is performed and the brain tissue is then stored in what is called the New York Brain Bank, at Columbia University Irving Medical Center. Brain tissue is available to qualified scientists across the country for aging-related research.
- Step 6: Your family or other designated recipient is notified with the results of the brain autopsy. This may take up to six months. LLFS will also receive a copy of the brain autopsy report.