



# Brain Donation Program Frequently Asked Questions

## The Importance of Brain Donation

### What is the Brain Donation Program at the Northwestern Mesulam Center for?

The Brain Donation Program at the Mesulam Center:

- › Helps doctors figure out exactly what caused a person's dementia
- › Stores brain samples for scientists to study.

This helps us learn more about cognition and brain aging. Donating your brain is a generous way to help future generations.

### Why is brain donation important for research?

One donated brain can help with many research studies and ultimately benefit millions of people. Scientists study the brain to learn more about dementia, find better treatments, and understand normal brain aging.

### Why is brain donation important for families?

The only sure way to diagnose a brain disease is by examining the brain after death. Since dementia occasionally runs in families, knowing the disease in a relative's brain can help families prepare for the future.

### Who can be a donor?

At the Northwestern Mesulam Center, **we only accept brain donations from people who have been part of the ADRC Clinical Core study.** This is because studying brains from people we have followed for a long time helps us understand how brain functions, like memory, change over the time of follow up.

### Is brain donation useful if I don't have memory problems?

Yes! It's important to study the brains of people who don't have memory issues. This helps researchers understand what changes in the brain are normal with age and what changes are due to diseases.

### Why is it important for different types of people to be involved in brain donation research?

Having diverse participants helps researchers understand how dementia affects different groups of people. For example, research shows that African Americans and Latinos may have higher rates of dementia than Caucasians. More information is needed to understand why and how this affects these communities.

### What discoveries have come from brain donation?

Brain donations have led to many discoveries, such as:

- › Alzheimer's Disease (AD) can show different early symptoms in different people, like memory loss or trouble with communicating, depending on where the disease starts in the brain.
- › Pick's disease is caused by a different kind of tau protein than what's found in AD.
- › TDP-43 is a protein abnormality found in brains of people with ALS and also linked to other diseases like AD.
- › SuperAgers, who have better memory than most people over 80, have healthier, bigger brain cells than those with typical age-related memory loss.

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### Logistics

#### **What happens to my brain when I donate it?**

Specialists carefully remove the brain and prepare it for research. The brain is checked for any diseases that cause cognitive decline, and then stored properly for future studies. Your identity remains confidential. The brain tissue and findings are then used by Mesulam Center researchers and collaborators around the world to make discoveries about brain aging.

#### **Are there any costs for me or my family?**

No, there are no costs for you or your family for the brain donation. The Mesulam Center covers the costs of transportation, brain-only autopsy, and examination. However, the costs of your final arrangements are not covered.

#### **How does transportation work?**

We work with the Cremation Society of Illinois to handle transportation. They will take you to Northwestern Memorial Hospital for the brain donation and then to your final arrangements. If you live outside of Illinois, we'll coordinate with your chosen funeral home.

#### **What about religious beliefs?**

Most religions don't have rules against brain donation. However, you should discuss your decision with your religious leader or spiritual advisor to make sure it fits with your beliefs.

#### **Can I still have an open casket viewing?**

Yes. Brain donation does not change your appearance, so if you're having an open casket funeral or viewing, it will look the same.

#### **Will brain donation interfere with my funeral arrangements?**

No, brain donation won't affect your final arrangements. We will work closely with your family and funeral home to coordinate the donation so that it does not impact other plans.

#### **Can I donate other parts of my body too?**

Yes, but not with the Mesulam Center. Our Brain Bank only accepts brain donations. To donate other parts of your body, you should contact another organization (for example, the Anatomical Gift Association of Illinois) and arrange this separately. Our brain donation coordinators can't set that up for you. If you want to donate both your brain and body, we'll coordinate with the other organization to make sure the brain donation happens first.

#### **Can I still participate if I don't live in Illinois?**

Yes, you can! We can make arrangements to have the brain donation done at a hospital or other medical center near you. We'll work with local professionals to make sure everything goes smoothly.

#### **What if I change my mind about donating my brain?**

You can change your mind anytime. If you decide not to donate, just let us know by calling **312.503.5103** (Monday - Friday from 9:00 AM - 5:00 PM) and we'll update your record.

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### Involving Your Next-of-Kin

#### **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.

#### **Who should I tell about my decision to donate my brain?**

Talk to your family, friends, or anyone else who might help with your healthcare decisions about your wish to donate your brain. Your Healthcare Power of Attorney (HPoA) or next-of-kin must agree to the donation after you pass away. It's important for them to know your wishes. We can provide you with materials to share with your loved ones and help you explain your decision.

#### **What if I don't have a Healthcare Power of Attorney (HPoA)? Who is my next-of-kin?**

If you don't have an HPoA, your next-of-kin would be (in the following order):

- › Your surviving spouse (if you are married, not if you are divorced)
- › Your adult children
- › Your parents
- › Your adult siblings
- › Other adult relatives
- › The executor of your Will, but only if your Will allows them to handle your body.

#### **What will my HPoA or next-of-kin need to do?**

Before you pass away, your HPoA or next-of-kin should be aware of your wish to do brain donation. After you pass away, your HPoA or next-of-kin should contact us immediately at **773.495.2982**. We'll need them to give verbal consent for the brain donation.

#### **Will my family get the results of the brain examination?**

Yes, your HPoA, next-of-kin, or another appointed representative (chosen by you) will get a final report about the brain examination (autopsy report), usually three to four months after donation. They are welcome to also schedule a time to talk with our specialists if they have any questions.

### To Report a Death

When the donor has passed, please call our 24-hour number at **773.495.2982**.

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### More Information

Learn about brain donation and our research, at [brain.northwestern.edu/braindonation](https://brain.northwestern.edu/braindonation).

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**Our brain donation coordinators are available to assist you and your loved ones during the decision-making process.**

Contact Kate LaFroschia at **312.503.5103** or [kathryn.lafroschia@northwestern.edu](mailto:kathryn.lafroschia@northwestern.edu).