

Tips for Discussing Brain Donation with Loved Ones

Discussing death and brain donation can be sensitive topics. Here are some ways to approach it with your loved ones:

- Begin conversations early, as this decision can be tough. Allow time for multiple discussions.
- Reflect on prior discussions of tough topics. Past experiences can guide new ones. Share the reasons why you want to donate your brain. Share any fears you may have.
- Decide who contacts the Center at the time of death. Final permission comes from a healthcare power of attorney or next-of-kin.
- Invite loved ones to call our brain donation coordinators at 312.908.9339 to ask questions and ensure that all parties know what to do when the time comes.
- You can change your choice anytime. Our research team will check your decision at each annual visit.
- A surprising benefit of brain donation: a sense of comfort for loved ones. Despite their loss, some take solace knowing this action can positively impact public health, a “gift that keeps giving.”



“Brain donation is a rewarding thing in that it gives you power back over the disease. Power to fight back.”

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

The Brain Donation Program

Mon-Fri, 9am – 4pm CST: 312.908.9339
Email: adc@northwestern.edu

Northwestern University Alzheimer's Disease Research Center (NU ADRC)

300 E Superior Street, Tarry 8th Floor
Chicago, IL 60611

Project Manager:

Kate LaFroscia, 312.503.5103 (Office)

To report a death, call our 24-hour number: 773.495.2982

For more information about brain donation and research, visit:
brain.northwestern.edu/braindonation

Northwestern Medicine
Feinberg School of Medicine

Brain Donation

The gift of knowledge for future generations



Mesulam Center
for Cognitive Neurology & Alzheimer's Disease

The Importance of Brain Donation

Brain donation from our research participants increases our understanding of age-related cognitive change and dementia. Researchers compare brains from healthy individuals to those with cognitive deficits and link disease-related brain changes with cognitive symptoms observed during life. This allows researchers to grow their understanding of Alzheimer's disease (AD) dementia, primary progressive aphasia (PPA), and behavioral variant frontotemporal dementia (bvFTD).

Brain donation at Northwestern has led to incredible discoveries, including:

- A single brain disease, like AD, can cause different early symptoms in different people (e.g., memory loss in some, language loss/aphasia in others) depending on where the disease starts in the brain.
- Pick's disease is caused by an abnormal tau protein; this protein is unique from the tau protein found in AD and occupies different regions of the brain .
- TDP-43 is a novel protein abnormality that was originally found in the brains of those with ALS. However, we now know it can also lead to bvFTD and that a specific type of TDP-43 is found in many brains of individuals with AD.
- The brains of Northwestern SuperAgers, whose memory is much better than average for 80+ year olds, have healthier, bigger brain cells (neurons) than those with typical age-related memory loss.

Understanding the Process

If you choose to donate your brain at death, the following steps will be taken:

- 1** A family member, loved one, or nurse calls our **24-hour coordinator at 773.495.2982** as soon as possible to report the death.
- 2** Your healthcare power of attorney or next-of-kin will give consent for the brain-only autopsy.
- 3** A brain donation coordinator arranges transport to the autopsy location, and we cover the costs.
- 4** The brain autopsy will be at Northwestern Memorial Hospital (local) or another center identified by a coordinator (non-local). We cover the autopsy expenses.
- 5** Once the donation is complete, final arrangements can follow your loved ones' plans.
- 6** Next-of-kin or designated individuals will receive a Neuropathology Report 3-4 months after donor's passing and have an opportunity to discuss results with a clinical neurologist about the results, providing a sense of closure.



“Every patient that donates their brain is contributing to the knowledge of these diseases which will help researchers develop better diagnostics and treatments for future patients.”

What to Know About Our Brain Donation Program

Why should I consider brain donation?

Brain donation is a lasting gift, fueling ongoing research dedicated to identifying factors that are likely to lead to brain health and disease over the lifespan. Donor brains undergo a thorough investigation (i.e., a brain-only autopsy) that reveals a definitive neuropathologic diagnosis, which can provide clarity for loved ones. Sometimes the neuropathologic diagnosis is different from what was expected during life, which is why the autopsy is so important.

What happens to my brain once it has been donated?

Following brain-only autopsy, the brain is stored in the Northwestern Mesulam Center brain bank and can be requested by approved scientists for their studies of these diseases.

Will my loved ones receive feedback?

Yes, they will receive a neuropathology report detailing brain diseases and a definitive diagnosis. They can call our Center to discuss the report with a clinician and ask questions.

What is the cost?

There is NO cost to you or your loved ones for donating your brain to the Mesulam Center Brain Donation Program. Our research study covers all costs.

Will brain donation affect my final arrangements?

We arrange a brain-only autopsy as soon as we are notified of the donor's passing. This should not delay arrangements and will not alter physical appearance.