

Brain Donation



There is a great shortage of brain tissue for the study of many neurodegenerative disorders, including Parkinson's disease. Donations give researchers an opportunity to better understand these neurodegenerative disorders and provide insights on improving treatments and medications.

When should I (or a family member) volunteer to donate?

Deciding to be a brain donor can be difficult. It often helps to seek guidance from loved ones. Talk with your family about your intent to donate, make a living will, and tell your physician your wishes. You may enroll with an organization in advance to make the process easier. Forms will need to be filled out by you or the attending physician.

What is the process after end of life?

A family member or primary care physician will need to call the chosen organization's 24-hour telephone number to notify them of the passing. This must take place immediately. Some organizations require brain donations to take place within 12 hours of time of death, while some allow donations within 24 hours. Make sure you know the policy of your chosen organization in advance to avoid any delays.

Frequently Asked Questions

- » **Does donating brain tissue delay funeral arrangements?** Brain donation will not interfere with funeral arrangements, and the person may have an open casket viewing.
- » **Do I have to pay to donate?** While most organizations assume financial responsibility for transporting the brain tissue to a pathologist, others may require a small fee. Funeral expenses still need to be arranged by the family.
- » **Can anyone donate?** There are two reasons a brain may not be accepted:
 - 1) If the person passed away from a certain infectious disease
 - 2) If the person was on a respirator prior to death
- » **Can I change my mind?** Brain donation is a personal choice. You may opt out at any time by notifying the organization you signed up with.
- » **What organizations accept brain tissue?** Call the National Parkinson Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit the Brain and Biospecimen Repositories page on the website of the National Institute of Neurological Disorders and Stroke to find a list of organizations that accept brain tissue and their program information: www.ninds.nih.gov/research/parkinsonsweb/brain_banks/brain_biospecimen_repositories.htm