Brain Donation



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

When is the right time to 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 doctor your wishes.

It is important to enroll with an organization in advance. Some brain banks will not accept a donation unless they already know the person's wishes and have medical records, and this can take time. 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 delay funeral arrangements and an open casket viewing is still possible.

Do I have to pay to donate?

Most organizations assume financial

responsibility for transporting the brain tissue to a pathologist. Funeral expenses still need to be covered by the family.

Can anyone donate?

There are two reasons a brain may not be accepted: if the person passed away from a certain infectious disease or if the person was on a respirator prior to death.

As an organ donor, isn't my brain included?

Brain donation is not included if you are an organ donor. You need to sign up for brain donation separately.

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.

Which organizations accept brain tissue?

Call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) for a list of organizations that accept brain tissue. The Brain Support Network can also help walk you through the process and arrange donation:

www.brainsupportnetwork.org.

The National Institutes of Health NeuroBioBank (www.neurobiobank.nih.gov) collaborates with six brain banks who collect tissue and then allow scientists to request samples to support their research. Donate to the NeuroBioBank by signing up with the Brain Donor Project:

www.braindonorproject.org.

