



Lewy Line
800.539.9767

The Ultimate Gift

Frequently Asked Questions (FAQ) about Brain Donation

At a Glance:

- The gift of a brain donation can help advance LBD research.
- By making a brain donation, families can receive a definitive diagnosis of the cause of dementia.
- The brain of a person with LBD who participated in a research study is especially valuable. Brain donations are also needed from people who do not have dementia.
- Donating a brain can be done at no cost to the family.
- Help is available to make the arrangements.

Why are Brain Donations Needed?

There is currently no cure for Lewy body dementia (LBD) and there are no treatments to slow down the disease progression. Further, LBD is the one of the most misdiagnosed forms of dementia.

Currently, the only way to diagnose LBD with 100% certainty is by a brain autopsy. Brain donations provide researchers with essential materials needed to learn what causes LBD, to improve our ability to diagnose the disorder and to pursue treatments and a cure. A single brain donation provides enough samples to support diverse studies, extending the impact one person can make on advancing research.

If You Are an Organ Donor, Does That Include Brain Donation?

Being an organ donor can directly benefit one or more living people. In comparison a brain donation is intended to establish a definitive diagnosis and to help advance research. As such, they are separate processes, both in decision-making and the advanced planning required.

- Signing up to become an **organ donor** does **not** mean your brain is included. Separate arrangements, such as those discussed in this Care Brief, need to be made in advance for brain donation.
- Similarly, donating your **body** for anatomical study does **not** mean your brain will be used for neurological research. Again, separate arrangements are needed.

Is Brain Donation Right for You?

One of the benefits of making a brain donation is learning the precise cause of a person's dementia. Many families find this gives them closure; the report from the neuropathologist helps resolve any

uncertainty about the clinical diagnosis provided during life. For others, a brain donation allows them to make a contribution to promote a better understanding of LBD; individuals may feel a sense of comfort and even pride for playing a role in research.

Brain donations are also needed from individuals who do not have a brain disorder; this offers another way that family members of someone with LBD can contribute to research.

The gift of a brain donation is voluntary; permission can be withdrawn at any time. Family members may need your help to understand why you are donating a brain. (Some will also need reassurance that brain donation does not prevent an open casket viewing.)

Is There a Cost to Be a Brain Donor?

Depending on brain bank chosen to receive the brain, there may or may not be a cost to the family.

- Some research studies include a brain autopsy in the study protocol. There would be no cost to the participants' families for the brain donation as part of the study; funding is provided by the study sponsor.
- Brain donations to the National Institutes of Health (NIH) NeuroBioBank do not have a direct cost to the donor or family; funding is provided by NIH.
- Brain donations to other brain banks at academic medical centers may have a cost involved, but this is not always the case. NOTE: In many cases, brain banks require the donor be a patient in their medical system to accept the donated brain.

How Much Time is Needed to Arrange a Brain Donation?

Just as when donating organs, it's helpful for families to discuss personal decisions about brain donation well in advance. It is also highly encouraged to register in advance to make brain donation. There are some consent/release forms that must be signed during registration. (Consent can be provided by a family member on behalf of someone who's unable to make their own arrangements. If necessary, a person can be registered quickly if death is imminent.)

RESOURCES

LBDA:

Overview: Brain Autopsies and Brain Donations - <https://www.lbda.org/brain-autopsies-and-brain-donations/>

The National Institutes of Health:

The NeuroBioBank (<https://neurobiobank.nih.gov>)

The Urgent Need for Brain Donation (<https://www.ninds.nih.gov/News-Events/Directors-Messages/All-Directors-Messages/NIH-NeuroBioBank-Addressing-Urgent-Need-Brain>)

Why a Brain Donation – A Legacy of Hope

(https://neurobiobank.nih.gov/static/NIMH%20Donate_accessible_REVISED.pdf?link_time=2019-07-19_13:20:24.623741)

Brain Registry Organizations

The Brain Donor Project (<https://braindonorproject.org>)

The Brain Support Network (<https://www.brainsupportnetwork.org>)



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