

# Organ Donation FAQ's

Organ or tissue donation, for many people, can be a difficult decision to make. Since donation happens after death, the decision-making process requires confronting one's own mortality and asking many questions relating personal and family hopes and values, as well as religious beliefs and commitments.

## Making the Decision to Donate

The primary reason most people decide to become organ donors is to help save or improve the lives of others. For the Huntington's community, this is especially important as donating brain tissue for research on Huntington's disease (HD) can potentially lead to new treatments and ultimately a cure for future generations.

The following FAQs can help you understand what is involved in brain and organ donation and may help you decide whether or not to donate

### Why is brain tissue needed for scientific research?

The brain is a very complex structure and it is necessary to examine it in its entirety in order to understand how different conditions affect different parts of the brain. Brains from people affected by neurological conditions are, therefore, essential for researchers devoted to finding treatment and cure for these conditions.

### Can I be an organ donor and a brain donor?

Yes. However, you have to make a separate registration or give separate permission to become a brain donor as well an organ donor. Please note, in Victoria as of September 2021 the Victorian Brain Bank is no longer accepting registrations for brain donation. Please refer to the Victorian Brain Bank for further information.

### What does brain donation involve?

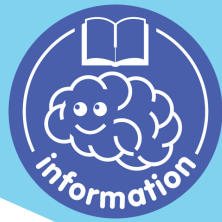
The post mortem examination is an orderly procedure supervised by a pathologist, which ideally take place within 24 hours after death but can take place up to 72 hours after.

### What happens to the brain tissue?

The brain is processed in ways to allow maximum information to be obtained and to ensure the tissue is usable in research for many years to come. Tissue that is no longer suitable for research will be disposed of in an ethical and respectful manner in accordance with the prevailing institution's procedure.

### Will brain and organ donation affect funeral arrangements?

The post mortem procedure does not affect or interfere with the normal course of events associated with a funeral. It does not affect the ability to have a viewing or open casket funeral as the tissue and organ are removed in such a way as to minimise visible marks.



# Organ Donation FAQ's

## Who will have access to the information about my brain and the post-mortem examination?

The personal and health information of all registered donors will be stored securely in a password-protected computer and locked files. The tissue will also be stored securely in a separate location and will be coded with a unique identification number. Only researchers will have access to the tissue and clinical information through the unique identifier. No donor is ever identified by name in any publications or presentations that result from the research.

## Is there any cost involved in brain donation?

There are no costs involved in brain donation.

## When should plans be made for this procedure?

You should make the necessary arrangements well in advance as this is a very important decision and family members need time to discuss it. Discussion with your senior next of kin and family members will help ensure your wishes are considered. It is also preferable to state your wishes in writing by using the brain donation consent forms which are available at Victorian Brain Bank Network (VBBN) offices.

## Can I withdraw after giving consent to donate?

You are free to withdraw your consent anytime and your decision will be fully respected and no questions will be asked.

If you would like to become a donor, you to have register and give your consent to donate by doing any of the following:

- Visit the Australian Organ Donor Register website:

<https://www.servicesaustralia.gov.au/individuals/services/medicare/australian-organ-donor-register>

- Contact the Victorian Brain Bank Network (VBBN) Coordinator, Fairlie Hinton:

<https://www.melbournebraincentre.edu.au/content/victorian-brain-bank-network-vbbn>