



BRAIN DONATION FOR RESEARCH

Brain tissue donation is a sensitive and very personal issue. However, the chance to further medical research can be a rewarding prospect for many patients and families affected by severe brain illness.

The decision to donate your brain to PSP and CBD research creates a long-lasting legacy: one donated brain can support literally dozens of research projects over many years. Brain banks provide a unique resource for researchers, enabling them to develop their understanding of the diseases and ultimately informing the search for treatments. For example, studies using donated brain tissue enabled researchers to discover special subtypes of PSP with important differences in symptoms and outlook, and to understand how PSP spreads in the brain in a way that new drugs can try to stop.

In addition, post mortem examination of the brain confirms the diagnosis of PSP or CBD with absolute certainty. A lot of research done with patients earlier in their lifetime becomes much more valuable if it can be linked to this confirmation. If you decide to donate, your family can receive a report on the final diagnosis if they wish.

If you decide that you would like to donate your brain tissue for use in research, it's best to ensure that your wishes are known to your family and others involved in your care. You can make arrangements to register your wishes with one of the brain banks local to you as planning ahead can make things much easier when the time comes.

INFORMATION **STARTS**
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Who can donate?

Both individuals with a neurological condition and healthy donors can register. Donations from healthy people are extremely helpful as they enable researchers to better distinguish the changes caused by disease from those that are down to normal wear and tear.

Will the donation affect funeral arrangements?

There should be no disruption to funeral arrangements. The donation is carried out as soon as possible at a local hospital mortuary. The donation is performed discretely and does not change facial appearance. The body is returned to the funeral director without delay and the brain is transported to the brain bank.

Can I still be an organ donor?

You can register for both organ donation and brain donation. However, there are a number of situations where either organ donation or brain donation is not possible. For example, the NHS organ donation team may decline some types of donation for transplant from people affected by severe brain disease. If organ donation is important to you it is best to discuss this in more depth with the brain bank of your choice and ensure that those closest to you understand your wishes.

Does the brain bank need medical or personal details?

Having access to information about a donor's medical history means that researchers can match up specific symptoms with the changes they find in the tissue. When you register with a brain bank you will probably be asked to give permission for the bank to access your medical records. You may also be asked to complete questionnaires about your symptoms and lifestyle. The information is kept strictly confidential and is only provided to researchers in anonymised form.

Is completion of the donation always possible?

Brain donation needs to take place as soon as possible, and ideally within 72 hours of death. On occasion, brain banks may be unable to accept a donation. This is due to a number of reasons, for example there may be a delay to the donation due to the circumstances of the donor's death or the donor may have had other illnesses such as stroke that affect the brain. For legal reasons some deaths require a post-mortem examination to be performed by Her Majesty's Coroner and in these circumstances the possibility of transfer of tissue to the brain bank would need to be discussed by the Coroner, brain bank staff and next of kin.

How will the brain tissue be used?

After donation, half of the brain is preserved for a diagnosis to be confirmed and for initial research. The rest is frozen rapidly in smaller pieces; these frozen samples last for many years. Brain tissue will only be analysed by authorised researchers whose projects have been

ethically and scientifically approved by the brain bank's committee. Banks may receive requests for tissue from researchers around the world who are working to better understand how neurological disease develops and how it may be treated.

What do I need to do now?

If you wish to register for brain donation or would like more in-depth information you can get in touch with your local brain bank. The staff there will be happy to answer any further questions you may have and will take you through the registration process. You may wish to make a note of all of the brain bank contact details that your relatives might need after you have passed away. If you do not have details of your local brain bank please contact the PSPA helpline.

Can I change my mind?

Yes you can change your mind at any time without giving a reason. Simply get in touch with the brain bank you have registered with.

What will my family need to do?

Your next of kin will need to get in touch with the brain bank you have registered with as soon as possible after your death. They will need the bank's phone number to hand, including any particular instructions for out-of-hours contact. The brain bank will then make all the necessary arrangements.

What if my family member is now too ill to decide but I think they would have wanted to donate?

Later in the course of illness, PSP and CBD can prevent someone from completing consent documentation themselves. However, if you are the next of kin to somebody in this situation and you believe that they would want to donate their brain, you may be able to register on their behalf.

Useful contacts

PSPA Helpline and
Information Service
Tel: 0300 0110 122
helpline@pspassociation.org.uk
www.pspassociation.org.uk

Acknowledgements

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