What happens to tissue not used for research?
Any tissue not used for research will be respectfully disposed of lawfully following the Human Tissue Authority codes of practice.

Who can consent to brain, spinal cord and pituitary tissue donation?
1. The individual themselves
2. Nominated Individual (NI) on the individual's death
3. A Person in a Qualifying Relationship (PQR)

For definitions see below.

Nominated Individual (NI).
Someone appointed by the donor who has the responsibility (and legal authority) to consent to donation on death of the donor.

In the absence of an NI, Person(s) in a Qualifying Relationship (PQR) are listed in order of precedence:
- spouse or partner,
- parent or child
- brother or sister
- niece or nephew
- grandparent or grandchild
- stepfather or stepmother
- half brother or half sister
- friend of long standing.

Important information
If you change your mind in the future you can simply inform the CBB at any time. See contact details below.

Contact information
If you require any further information about brain tissue donation please contact the Cambridge Brain Bank.
Monday to Friday
09:00 to 17:00 hrs
Tel: 01223 217336
or by email:
brbank@addenbrookes.nhs.uk

Information on the National Research Ethics Service can be found at:
www.nres.npsa.nhs.uk

This leaflet has been developed by the Cambridge Brain Bank as part of their support for research into dementias and normal ageing.

We are a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0169.

Other formats
If you would like this information in another language or audio, please contact
Interpreting services on telephone: 01223 256998, or email:
interpreting@addenbrookes.nhs.uk
For Large Print information please contact the patient information team:
patient.info@addenbrookes.nhs.uk

Donor information
Cambridge Brain Bank (CBB)
Part of Cambridge University Hospitals Human Research Tissue Bank

The donation of brain, spinal cord, pituitary tissue and cerebrospinal fluid after death

You are probably familiar with organ donations of the heart, kidneys or eyes to sustain the health or even the life of people in need.

Similarly, the donation of brain, spinal cord, pituitary tissue and cerebrospinal fluid (CSF) for research is a precious and unique gift. Scientists can learn and understand more about disease processes when they are able to work on donated tissue. Ultimately, we hope that scientific work of this kind will lead to better and more effective treatments and that future generations will benefit from your help.

There are many diseases that affect the brain, spinal cord and pituitary; these include the various forms of dementia, motor neurone disease, multiple sclerosis, brain infections and tumours. Medical professionals involved in this type of research and working with patients affected by these forms of disease need to study the tissue in detail and this can only be done after death. We are therefore asking patients with such diseases to consider donating their brain, spinal cord (either partial or complete), pituitary tissue and CSF after their death. As researchers and scientists need to study both brains from people with and without a disease as part of their work we are also asking persons with no neurological disease to donate their brain, spinal cord, pituitary tissue and CSF after death.

The donation of brain, spinal cord, pituitary tissue and CSF after death is a big decision and needs to be discussed with family and friends. Advice is available from the Cambridge Brain Bank (CBB) research nurse who would be very happy to discuss any concerns or questions you or your family may have.

Why do we want pituitary tissue as well as brain and spinal cord donation?
The pituitary is a small gland attached to the base of the brain. It produces hormones which regulate other
hormone producing glands in the body controlling growth and many other processes. Pituitary tissue is needed within diagnostic clinical laboratories as well as for research. The pituitary gland is easily removed during brain donation.

Does the CBB need to know any medical or personal details Yes, if possible. Having access to information about each donor’s medical history means that researchers can match up specific symptoms with the changes they find in the tissues. When someone registers with the CBB we ask permission to access medical records and also that a questionnaire is completed about symptoms, lifestyle and medication every five years by the donor, the Nominated Individual* (NI) or Person in a Qualifying Relationship* (PQR).

*For explanation please see last page.

This information is kept strictly confidential and only provided to researchers in an anonymised form.

Creutzfeldt Jakob disease (‘CJD’)
We must take special measures if there is a possibility you have been at risk of CJD or variant CJD disease (sometimes incorrectly referred to as ‘mad cow disease’). We therefore ask all donors if they have been told that they are at increased risk of either of these forms of CJD.

Why is brain, spinal cord and pituitary tissue needed for medical research?
We are still unable to diagnose many of the diseases of the brain, spinal cord and pituitary with absolute certainty during life and in many cases no cures are available at present.

After death a detailed examination of brain, spinal cord and pituitary tissue enables scientists to study the changes which are related to the disease. The findings of this examination will be given to the donor’s clinician where appropriate. We hope this will lead to better understanding of the diseases and eventually to a cure.

What is cerebrospinal fluid (CSF)?
This is the colourless fluid that surrounds the brain and spinal cord. This is obtained during donation.

Why is brain tissue from people not suffering from a neurological disease necessary?
The researchers need to document all the changes that may occur in life in a normal brain so they can identify changes that are specific for a disease of the brain.

When should plans be made for donating brain, spinal cord and pituitary tissue?
It is important to make the necessary arrangements for brain, spinal cord and pituitary tissue donation well in advance. Family members need time to discuss this issue and to explore any possible disagreements. The death of a loved one is a time of enormous emotional stress and not the time for discussing such emotive issues as tissue donation. As time passes it may be necessary for you to alert new people or family members of your wish to donate and to remind others who may have forgotten.

Will the tissue donation cost the family anything?
No. All costs directly related to the donation are met by the CBB. Funeral costs are the responsibility of the family.

Will the donation affect funeral arrangements
There should be no disruption to funeral arrangements. The donation is carried out as soon as possible after death. This does not delay funeral arrangements. The donation is carried out under the supervision of a pathologist and does not leave any apparent marks.

Will the family find out what the brain, spinal cord and pituitary tissue showed in a clinical examination?
The CBB always writes to relatives thanking them for the donation and asking them to indicate whether they wish to receive a report on the final clinical diagnosis. It can take a number of months for the final clinical results to become available.

If requested, a summary of the findings can be provided to the NI* or PQR*, or a complete medical report may be sent to the donor’s general practitioner.

*For explanation please see last page.