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
Mobile: 07847 808704
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.

Donor information
Cambridge Brain Bank (CBB)

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 neuron 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.

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.*

**Is completion of the donation always possible?**
In exceptional cases it may not be practically possible to arrange to bank the donated brain, spinal cord, pituitary tissue and CSF within a reasonable time period. Banking should be completed as soon as possible after death. We make every effort to ensure this is the case.

**What about confidentiality?**
Details of those who wish to donate to the bank will be entered onto a database. Confidentiality and anonymity will be maintained by a unique code number and all records are held securely. Researchers are not given any information which could identify the donor.

Data and tissue provided by the bank will only be analysed by authorised members of a research group whose project has been approved. The results of the research findings on individual donors will not be released.

**What types of research will be carried out on tissue donated to the bank?**
Only ethically and scientifically approved projects may use tissue obtained from the bank. Such research may involve many types of study, including genetic studies, and could lead to the discovery of genes that pre-dispose to or modify disease as well as the development of new drugs by the pharmacological industry.