Newcastle Brain Tissue Resource
Edwardson Building
Newcastle University
NE4 5PL

0191 208 1231
nbtr@ncl.ac.uk

Information sheet

Version 9.2 18 January 2024

Newcastle Brain Tissue Resource

Information for those interested in donating brain and nervous tissue for research

In order to develop better treatments and target them to those who may benefit, scientists still need to understand much more about the changes which occur in the brain and nervous system as different diseases progress and develop. As the proportion of older people in our population grows, disorders associated with ageing, such as dementia, Parkinson's disease and stroke will be even more of a challenge. Over 800,000 people in the UK have a diagnosis of dementia right now and this is likely to double in the next 40 years. Mental health, neurological and genetic problems affect people of all ages.   Although there have been major advances in medical techniques such as imaging, there is still no real substitute for examining samples of human brain tissue. For some diseases (cancer for instance), tissue removed during surgery, or blood samples, can be studied but this is not possible with the brain. Examining brain tissue after someone's death is still the only accurate way to diagnose the different types of dementia and can give us valuable information in other diseases too.. When looked at together with information about symptoms someone experienced, donated tissue can allow us to see what changes underlie particular problems. In order to do this, scientists also need to study tissue from people without disease ('normal controls').

We realise that not everyone will wish to consider the idea of donating tissue after death. If you feel it is not for you then we will fully understand if you do not wish to read further.

Newcastle Brain Tissue Resource

The Newcastle Brain Tissue Resource (NBTR) is a licensed tissue bank based at Newcastle University. It operates to standards set by the Human Tissue Authority and complies with all current legislation and guidance for working with human tissue. Tissue samples are provided to applicants whose projects are approved by the NBTR committee (this has both scientific and lay members and an independent chair who is not involved in the research). Over the last 40 years research using tissue from the resource has made significant contributions to understanding both normal brain ageing and brain disorders such as: Alzheimer's disease, Lewy Body disease, vascular dementia, Parkinson's disease, motor neurone disease and depression. Hundreds of scientific papers have been published based on our unique collection of brain tissue. This has contributed to important medical advances such as some of the current drug treatments for Alzheimer's disease and the identification and treatment of a common type of dementia in older people called Dementia with Lewy Bodies.

What does participation involve?

If you decide that you wish to donate your brain for research after your death you would be asked to sign a consent form to join our register.

Donations are especially valuable where we have detailed clinical information about the individual and the presence or absence of particular symptoms, so we also ask potential donors to allow us to collect this information. This may involve informal assessment interviews with a research nurse, every year for those with a diagnosis of memory impairment, every other year for those without impairment. The assessments are standardised sets of questions and include some questions for a person who knows you well. We also ask whether we may look at your medical records after tissue has been donated. The assessment interviews usually take about two hours and can take place in your own home. Some interviews may take place by telephone if this is possible. If any areas of concern are identified the research nurse would ask your permission to let your GP know about them.

You might be asked to give a small blood sample that could be linked later with the donated brain tissue. This is to see whether there may be changes present in the blood during life which might help predict who may later go on to develop diseases. If you agreed this, it would usually involve coming to one of our clinics where trained staff would take a sample of less than 20ml of blood (four teaspoons). As with any blood sampling there is a possible risk of mild discomfort when the sample is taken and that there may be some tenderness or bruising afterwards.

You might also be asked if you are willing to donate a small sample of Cerebrospinal Fluid (CSF) which would done in a clinic by a specially trained health professional who would perform a lumbar puncture (or spinal tap) to collect the sample. If you come to a clinic we will reimburse you for any travelling expenses. There is a separate consent form and information sheet for this which you would be given if you were interested in this aspect of the study. Samples are purely for research purposes and would not be able to tell us whether as an individual you are at risk of developing problems. Blood and CSF sampling is completely optional and your decision would not affect your participation as a tissue donor.

When the time came for tissue donation, it would take place in a suitable facility as soon as possible after death. This involves removing and examining the brain and, if possible, the spinal cord and a small blood sample and transporting it to us. The human brain is very complicated and so we usually keep the whole brain (and spinal cord) for diagnosis and research because the location, as well as the nature, of changes may be very important. In some cases we may also ask to examine samples from the heart, blood vessels and nervous system. We would only keep small samples (usually less than 2 cm) of these and specific consent would be sought for this. Although ideally we collect brain and spinal cord, depending on circumstances at the time of donation, it is sometimes only possible to collect the brain.

If you feel that donating tissue to NBTR is something you would like to do, you will be given as much information as you require, and opportunities to discuss taking part with the research team and to ask as many questions as you like. You may take as much time as you feel you need to consider your decision. If you decide to take part, we will ask you to complete a consent form. If, on the other hand, you decide brain donation is not for you, your decision will be respected, and your care will not be influenced in any way.

What if I do not have capacity?

We are interested in your wishes and feelings about tissue donation even if you do not have legal capacity to consent. If you cannot, or do not wish to, take part in the discussion a consultee (usually a family member or close friend) or nominated representative if you have one, can be asked about your wishes and previously expressed opinions and whether they feel you would have wished to take part in the project. If necessary, they can fill in the forms on your behalf.

Why am I asked to nominate a representative on the consent form?

If in the future you should lose your ability to decide for yourself, it is helpful to have a family member or friend who you trust to uphold your decision to take part. If this should happen without a representative being identified the consent could become invalid. There is a separate information sheet to explain what they need to do.

What would my family have to do when I die?

Normally a family member or representative (person nominated by you to represent you and carry out wishes regarding tissue donation) notifies NBTR when a potential brain donor dies. Your family/representative should contact us as soon as they can to let us know that death has occurred and that they are willing for the brain donation to be carried out. We will keep your family informed of the progress (in accordance with their wishes) and make all the arrangements necessary for the donation to take place. Brain and spinal cord donation does not interfere with, or delay normal funeral arrangements, and does not involve the family in additional expenses. We would provide you and your family or representative with detailed information so they would know exactly what to do when the time comes.

What happens after that?

A very detailed examination of the brain is performed which takes a few months. The research usually begins by examining the tissue using a microscope to find out about any disease processes that have affected the brain. We then use specialist techniques to investigate possible abnormalities in important brain and nerve-cell proteins, and in blood vessels in the brain.

When the examination is complete, we usually send a simple letter to your representative/family giving the final diagnosis but the full report is also available if they wish. This report is not written in lay language so it may be more appropriate to send to a G.P. of their choosing, for them to discuss with him/her. If the results have implications for family members, this can be addressed at that time.

We also analyse the DNA (genetic material) to look for abnormalities that are specific to some diseases. We will ask for specific consent for this, which you will be at liberty to refuse. Results are not generally in a form that is useful for feedback to individual families.
Once diagnosed, tissue would be stored long term in the Newcastle Brain Tissue Resource and be available for use in research into brain disorders.

What kinds of research would my donation be used for?

Many hundreds of scientific papers have already been published using donated tissue from NBTR, in areas such as Alzheimer’s disease, vascular dementia, Lewy Body dementia, frontotemporal dementia, Parkinson’s disease, motor neuron disease and depression. In the past these have contributed to new treatments for Alzheimer’s disease, and recognition of other types of dementia and development of treatments. The samples may be used for research using many kinds of methods and techniques. As knowledge grows, new techniques are being developed all the time.

Many samples are supplied to academic institutions elsewhere within the UK or worldwide.

Where samples are sent outside the UK we ask for confirmation that the work will be carried out to the same research and ethical standards.

As it is now possible to grow certain types of cells in the laboratory (stem cells), some researchers want to try to grow these cells using donated tissue. These cells can be extremely useful in that they can be converted into virtually any cell in the body and allow us to understand how different disorders affect cells, tissues, and organs to cause disease. As these cells are potentially capable of growing for very long periods, they will be stored indefinitely. Similar to the access to tissue, access to any cells will be carefully looked at, and the use of any cells produced from donated tissue will be closely regulated.

Sometimes samples are requested by commercial companies such as pharmaceutical companies - often working in partnership with NHS and academic institutions. This is in line with our policy of encouraging work which may lead to future treatments. Neither scientists nor relatives receive any extra financial benefit from this work.

Because human tissue is usually a better alternative, samples are not often used directly in research projects using animals. However, sometimes medical research does involve animals, particularly in the early stages.

You are at liberty to refuse permission for samples to be used for any of these purposes if you wish.

If you or your family would like more information about research supported by NBTR we produce a newsletter, which includes reports on recent studies conducted with donated brain tissue. We will send copies of this on request. If you would like us to do this we will ask permission to store your details for this purpose.

How is tissue stored?

We store the tissue in secure, purpose built facilities at Newcastle University to which only authorised staff have access. We freeze some tissue and keep it at a very low temperature so that we can use it for research over a long period (typically 10 years or more). The freezers have alarms and emergency systems so that we can deal quickly with any unexpected rise in temperature and ensure the tissue is always safe. We preserve other tissues in fixative for studies using a microscope.

Do researchers have to pay for the samples?

Brain banks are run as ‘not for profit’ organisations but because of the high running costs involved, those requesting tissue are asked to make a contribution if possible, using standard tariffs as agreed by the UK Brain Banks Network. However we are flexible and appreciate that sometimes a valuable project may not have sufficient funding for this and would not refuse an application entirely on financial grounds.

What about confidentiality?

To make sure we keep all our information confidential, the samples are issued to researchers labelled only with unique code numbers. We hold records securely on computer and in locked files. The donor's name is not known to the researchers and you would not be identified in any publications. Once you have signed a consent form your name is placed on a computerised register held at Newcastle University. Only the nurses who need to keep in touch with you in order to complete the regular assessments and the NBTR manager will have access to this.

How is the tissue disposed of at the end of the research?

Each individual donor may provide samples for many research projects over a period of many years. When we believe we have carried out all possible research on tissue from an individual donor, any remaining material is respectfully disposed of by us, unless other wishes have been stated. Families can withdraw their agreement to use of the tissue at any time, in which case any tissue still held would be disposed of respectfully according to their wishes. Samples already issued cannot be recalled.

How will we use information about you?

We will need to use information from you, and from your medical and study records for this research project.

This information will include your NHS number, name, contact details and details of your medical history. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to nbtr@ncl.ac.uk
- by ringing us on 0191 2081231

What can I do if I have a complaint?

- Complaints or concerns can be raised with the NBTR manager on 0191 2081231 or nbtr@ncl.ac.uk or with any member of the research team
- If you prefer you can talk to the Patient Liaison Service 0800 032 0202 or NorthofTynePALS@northumbria-healthcare.nhs.uk
- If your concerns are about donated tissue the Newcastle University Quality Assurance team can be contacted via **humantissueresearch@ncl.ac.uk**

What happens next?

We know that discussing tissue donation is a sensitive issue and one about which people have strong feelings. We will totally understand if you do not feel that it is right for you and do not want to proceed. If you do consent, you can still withdraw your agreement at any time without having to give a reason. We would recommend that you discuss your decision with your family so that they are aware of your wishes. We are happy to answer any questions or concerns you may have. Our research nurses are also very happy to come and talk things through with family members as well if you would like them to.