

Newcastle Brain Tissue Resource

Information for GP's

Newcastle Brain Tissue Resource is a large tissue bank which supplies samples of human brain tissue for research, primarily into dementia and neurodegenerative disease. It currently receives funding from the MRC and the NIHR funded Biomedical Centre on Ageing. NBTR works in co-operation with other brain banks in the UK and is part of the Brains for Dementia Research network funded by the Alzheimer's Society and the Alzheimer Research UK. NBTR is licensed by the Human Tissue Authority as a research tissue bank. Many of those donating tissue are also part of the clinical research programme into dementia and neurodegenerative disease which is carried out on Newcastle University's Campus for Ageing and Vitality. Others are volunteers who have contacted us through the Brains for Dementia Research project or directly through our website or their clinical team. As well as those with a diagnosis of dementia, we also encourage donation of tissue by neurologically and cognitively normal controls. Some GPs surgeries display our leaflets in their waiting rooms. Wherever possible informed consent will be sought from the donor themselves during their lifetime, although this is not always possible as, due to the nature of the diseases, some may not have legal capacity. However our policy is to involve the potential donor to the limit of their understanding even when the documentation has to be signed by a consultee (usually a close family member). Wherever possible one of our trained liaison nurses carries out a minimal cognitive assessment annually to ensure that we have current information about the potential donor's cognitive state. This includes standard scales intended to detect problems with memory, orientation and depression.

During a potential donor's lifetime

When consent is given to donation it is our usual practice to ask permission from the potential donor/family to send a copy of the consent form to their GP as well as their consultant and/or nursing home if appropriate. We also include a leaflet about what to do when a potential donor dies for your information. Usually we rely family members or nursing home staff to inform us in the event of the donor's death via the dedicated phone line. It would be really useful to us if there could be an alert placed on the potential donors medical record so that practices are aware that we are involved in the event of the participant's death.

If a participant's health or cognitive state gives cause for concern at an annual assessment, (for instance if they score highly on a depression or parkinsonism scale) they will be asked for consent to contact the practice and pass on the relevant information. Sometimes it may just be more appropriate to suggest that they should contact their GP practice themselves.

Other than a general duty of care to participants, our nurses are not able to offer any help or treatment.

If a potential donor who has already registered with us joins your list or if at any time you would like to receive the most recent version of our leaflets please let us know.

When a potential donor dies

In order to be suitable for the full range of research uses, particularly neurochemistry, we need to collect the donated tissue within as short a period as possible. Ideally this should be within 24 hours but in practical terms this is not always achievable. In the interim we need to arrange for the body to be refrigerated. In order for the tissue to be removed we will usually arrange transfer of the body as soon as possible to a hospital mortuary using the family's chosen funeral directors (at our expense). Occasionally where the donor is resident some distance from Newcastle we may arrange for the donation to take place in a local mortuary and for the tissue to be transported to us. Once we have been informed of the death via the brain donation line (0191 208 1345) the nurse on call will be able to advise on all these issues.

GP's can help speed the donation process by completing whatever they need to do for the death certificate as quickly as possible. This is particularly the case where a death occurs over the weekend or holiday period. We do not need the death certificate itself, just an assurance from the GP that we can move the body without interfering with the certification process. We understand that there are lots of demands on your time too and appreciate any help you can give us with this. If you are unable to issue the death certificate (due to DOLS for instance) it still can be very helpful for us to know that too, so that we can liaise with the coroner. Donation is still often possible in these circumstances with the coroner's agreement.

Many donors have agreed to donate both brain and spinal cord and sometimes other small samples. However, depending on the circumstances, it is not always possible to collect all the samples, particularly if there are time pressures. Collection of the whole brain is in as short a time as possible is the priority in this situation.

We can reassure families that the donation process will not interfere with the funeral and that they can view the body afterwards if they wish.

After the donation

It generally takes about 6 months for the diagnostic process to be complete. We then hold a clinico-pathological meeting during which we examine all the clinical and pathological evidence and form a consensus diagnosis which will be used to categorise the tissue for research use. We may contact your practice for information to help us in this process. We will have sought the donor family's consent to do this.

We do not routinely feedback diagnostic results directly to GP's as in the past they have told us that they no longer keep records on patients after this time but if you have a particular interest please let us know. We usually give families brief information about the diagnosis in a letter. They can then ask for a copy of the neuropathology reports if they wish. As these can be quite complex, sometimes families ask us to send copies of the result to a GP of their choosing so that they can discuss the results with them. If one of your patients has asked you to do this and you would like help from a neuropathologist to interpret the results please get in touch - we would be very happy to help.