

Newcastle Brain Tissue Resource

Information for Funeral Directors

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. Wherever possible informed consent is 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).

We usually register our donors during life although occasionally we do take tissue from those who have not been registered with us where there is a clear diagnosis and families are sure that this would have been the donor's wishes.

If someone who has already registered with us mentions this to you when arranging a pre-payment plan and you would like to know more or if at any time you would like to receive the most recent version of our leaflets please do not hesitate to call us.

When a potential donor dies

In order to be suitable for the full range of research uses, we need to collect the donated tissue within as short a period as possible. Ideally this is within 24 hours of death but for practical reasons this is not always achievable, particularly when the donation occurs over the weekend or holiday period and may be up to 72 hours. However it is very important to us that this interval is as short as possible. In the interim it is very important that the body is refrigerated to preserve the tissues. We appreciate that not all undertakers will have facilities for doing this and if necessary we can arrange for the body to be transferred to a hospital mortuary. As soon as the GP has agreed that they do not need to see the deceased again, we will be keen to arrange transfer of the body to a hospital mortuary as soon as possible in order for the consented tissues to be removed. If you are the family's chosen funeral directors we would usually ask you to do this for us (at our expense). If you have other commitments and are unable to do this transfer, we are happy to arrange another

means of transportation. Occasionally where the donor is resident some distance from Newcastle we may be able to arrange for the donation to take place in a local mortuary and for the tissue to be transported on to us. Alternatively, if you are coming from further afield, we may be able to arrange for the donation to take place on a 'wait and return' basis. This will need to be arranged in advance. 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.

We understand that there are lots of demands on your time too and really appreciate any help you can give us with this. It is really helpful if we can get an accurate estimate of time of arrival at the mortuary so that the team can be ready for the donation to take place as soon as possible. If it is being done on a 'wait and return' basis then it will reduce your waiting time considerably if we can be ready to do the donation immediately. The donation itself will usually take about an hour. Donations are almost always completed within 24 hours of arrival at the mortuary so even if it is not 'wait and return' it will usually be possible to return the body to your own premises the following day. It is a good idea however, to contact the mortuary before setting out to avoid delay. We reassure families that the donation process will not interfere with the funeral and that they can still view the body afterwards if they wish.

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. Collection of the whole brain is the priority in this situation.

On arrival at the hospital the body must be booked in in the normal way. At the RVI this is via the reception in the Leazes Wing. Bodies must have a wristband with three forms of ID – name, address and date of birth. This must match the information on the consent form which we will already have sent to the mortuary. We will usually send you a fax confirming the details we have and asking you to do the transfer for us.

Invoices should be sent to:

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