

# Brain and Organ Donation



Deciding to leave your brain to medical research after your death can help scientists learn more about neurological conditions and help other people after you are gone. In some cases post-mortem examination of the brain may also give valuable clues about the diagnosis for conditions which could not be determined during your lifetime thus giving important information to relatives.

There are brain banks around the country which accept and store brain tissue from people with neurological conditions and from healthy people with 'normal' brains for comparison. If you see a neurologist at a tertiary hospital, they can sometimes refer you to brain bank facilities linked to their hospital; for example if you are a patient at the London Ataxia Centre under Dr Paola Giunti, she can give you more information on leaving your brain to the brain bank at Queen Square. Dr Kevin Talbot at the John Radcliffe Hospital in Oxford will also discuss brain donation on an individual basis and can be reached through Ataxia UK.

If there is not a brain bank facility connected to your hospital you can register with the Medical Research Council's Brain Bank at the Institute of Psychiatry, King's College London, and they will liaise with services local to you where appropriate or arrange transferral to their premises. They accept people with cerebellar ataxia and other neurodegenerative conditions on to their register.

Contact the Brain Bank in order to receive an information pack or to discuss any queries.

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It is important to discuss your wishes with your family so they are aware of your intentions and can be prepared. It is best to arrange things well in advance so that your details are on record with the brain bank and your doctor, to ensure everyone is aware of the procedure and there is minimal delay. This will also reduce stress at a difficult time. The transport costs to remove the brain and return the body for the funeral are paid by the brain bank so there will be no additional costs to your family.

If you want to donate other body organs (including heart, kidneys, lungs, small bowel and pancreas) you can join the organ donor register. Pre-existing medical conditions such as cerebellar ataxia or Friedreich's ataxia do not mean that you cannot be an organ donor as the decision about the suitability of individual organs is made as needed by specialist healthcare professionals in the transplant team and they will take into account your past medical history. The only conditions which automatically exclude you from being an organ donor are HIV/AIDS or if you have or are at risk of having CJD.

You can sign up to the **NHS Organ Donor Register** on the website: [www.uktransplant.org.uk](http://www.uktransplant.org.uk) or by calling the NHS Organ Donor Line:

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Ataxia UK, Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE

[www.ataxia.org.uk](http://www.ataxia.org.uk)

Tel: 020 7582 1444

[helpline@ataxia.org.uk](mailto:helpline@ataxia.org.uk)

Helpline: 0845 644 0606

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