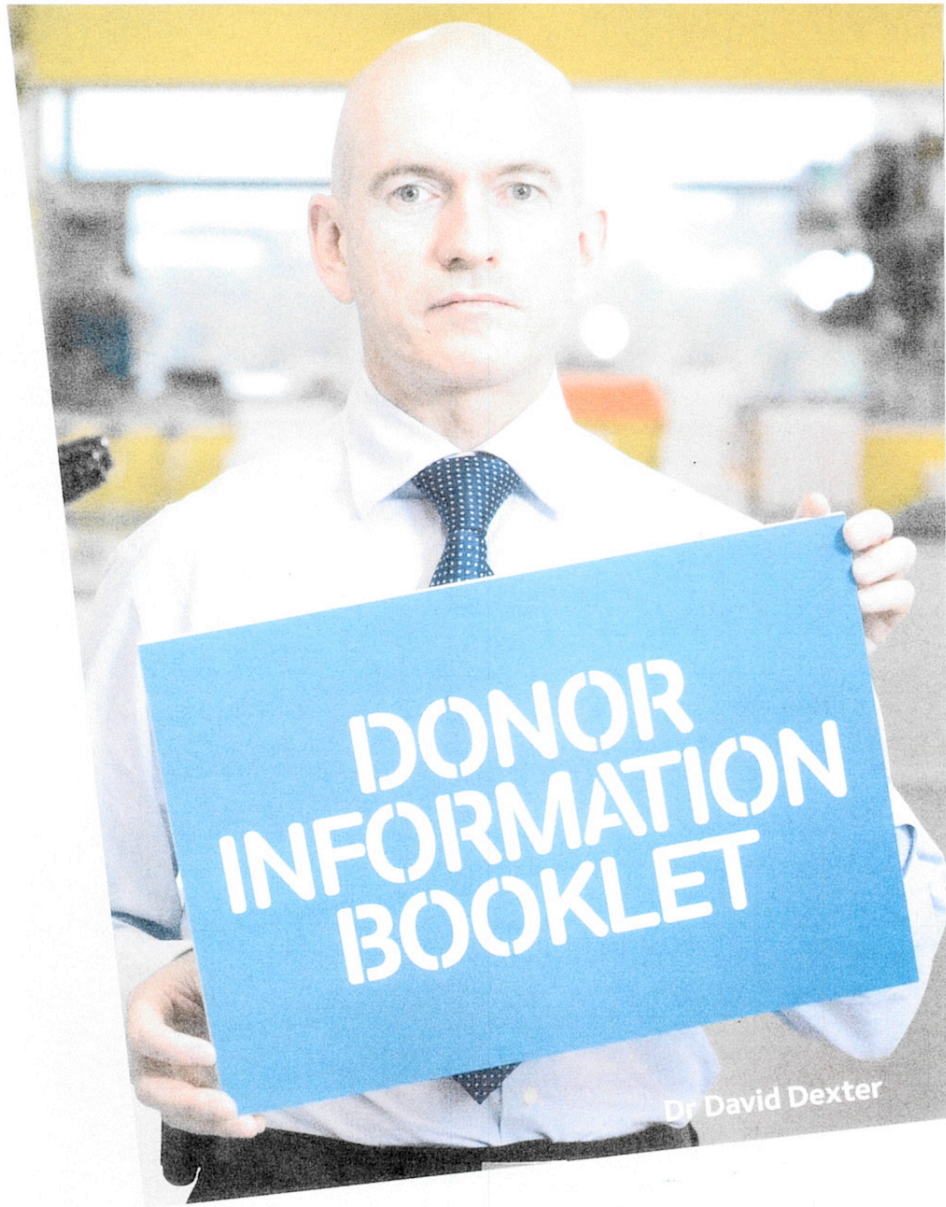


PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



Dr David Dexter

The Parkinson's UK Brain Bank

In association with
**Imperial College
London**

Version 1/2011

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Julia Steele, Research Technician

INTRODUCING THE BRAIN BANK

We're the UK's largest brain bank dedicated to Parkinson's. We collect the tissue from people with and without the condition.

We collect the brain, spinal cord and a sample of cerebrospinal fluid – the clear fluid that surrounds the brain and spinal cord.

Our donated tissue is currently supporting projects in the UK and around the world.

This research could lead to discoveries that help us to find a cure and improve life for everyone affected by Parkinson's.

The brain bank is wholly funded by Parkinson's UK and supplies tissue free of charge to researchers studying Parkinson's all over the world.

It is regularly reviewed by an independent panel including experts on Parkinson's, tissue banking, research and people affected by the condition. And all our processes have gained approval from the National Research Ethics Service.

We have a full brain bank information pack which you can read and then discuss the matter with those close to you.

If you do not have an information pack and want to request one, or for any other questions contact the brain bank directly:

020 7594 9732

brainbank@imperial.ac.uk

parkinsons.org.uk/brainbank

**ONE BRAIN CAN
BE USED IN UP
TO 50 RESEARCH
STUDIES**

USING MY TISSUE

What tissue is collected for research?

We collect the entire brain, the entire spinal cord and a sample of cerebrospinal fluid – the clear, colourless liquid that surrounds the brain and spinal cord. In the future, we may need to collect small samples of other tissues such as skin or gut for research.

Why is tissue needed for Parkinson's research?

People with Parkinson's don't have enough of a chemical called dopamine because certain nerve cells in their brain have died. By studying brain tissue from people with and without Parkinson's we are beginning to understand why these nerve cells die. This is vital to developing treatments that can slow, stop or even reverse Parkinson's. In addition to research your tissue may also be used for teaching purposes in the training of health care professionals.

I don't have Parkinson's. Could my brain still help researchers?

Yes, researchers urgently need brains without Parkinson's – also called 'control' brains. Control brains are essential for experiments. Scientists can only work out what is going wrong in Parkinson's by comparing control brains with the brains of people with Parkinson's.

What about similar conditions?

We also collect tissue from people with Parkinson's related disorders including multiple system atrophy and progressive supranuclear palsy.

Can I donate other parts of my body through other donor schemes as well?

Yes, we can work with other UK organ donor schemes for transplantation and research, including the NHS Organ Donor Register. Just let us know which other donor scheme you are registered with by phone, email or letter and we'll update your record. Unfortunately, we cannot work with whole body donation schemes – as these require the whole body including the brain.



Dr David Dexter

COLLECTING MY TISSUE

What is the tissue collection process?

The brain bank team are told of the death of a donor by someone phoning our 24 hour emergency number: **07659 104537** which is clearly given on your brain bank donor card.

The Parkinson's UK Brain Bank team then arrange:

- The body to be transported to the hospital nearest to place of death
- A pathologist or post mortem technician at the hospital to retrieve the tissue
- A member of the brain bank team travels to collect the tissue
- The body to be returned to undertakers for the funeral
- The tissue is then taken to the brain bank for processing and storage

**WE'RE ON
CALL 24 HOURS
A DAY**

6

What will my next-of-kin need to do?

- Register the death with the GP or if out of working hours with the on-call locum doctor so as to obtain a death certificate.
- Arrange a funeral director. The brain bank team will work with the funeral directors to arrange tissue collection if the donor died at home.

When will the tissue be retrieved?

Brain and spinal cord tissue deteriorate very rapidly. We aim to collect tissue within 24 hours of death. But we can accept brains up to 48 hours after death.

The Parkinson's UK Brain Bank team is on call 24 hours a day and we aim to organise and carry out the donation as quickly and smoothly as possible. Please make sure that your next of kin or legal representative, and the healthcare professionals looking after you know of your wish to donate.

Why is it sometimes NOT possible to go ahead with the tissue collection?

We try to avoid delays by working closely with families and professionals. But sometimes we are unable to collect and preserve tissue within 48 hours. On these rare occasions we cannot go ahead with collection because after 48 hours tissue are unfortunately no longer suitable for research. And, if donated tissue is not going to be used for the purpose specified in the given consent, The Human Tissue Act (2006) states that it must not be taken.

Possible reasons why we may be unable to collect tissue:

- Lack of a death certificate
- Death being referred to the coroner for cause of death to be confirmed
- Lack of suitable hospital mortuary facilities to remove the tissue
- Other conditions which affect the brain such as cancer, or infections like HIV

Will brain donation interfere with my funeral arrangements or having an open casket viewing?

No, brain donation will not delay or interfere with your plans for a funeral, cremation or burial. The brain and spinal cord are removed in a respectful and careful manner that will not affect the appearance of the body.



STORING MY TISSUE

How will my tissue be made available to researchers?

To help as many research projects as possible, your brain will be divided into hundreds of samples. These samples are stored safely and securely at the Parkinson's UK Brain Bank.

Scientists from the UK and around the world use our tissue in their research. Our panel of scientific experts and people affected by Parkinson's carefully review each application before approving the projects we supply tissue to.

We cannot predict what type of project your tissue will be used for or where the research will be carried out. Tissue may also be used for teaching purposes or in the training of healthcare professionals. However, all research we support is ethically and scientifically approved, and will help us better understand Parkinson's and ultimately find a cure.

WE COLLECT
MORE THAN
120 BRAINS
PER YEAR

How will my tissue be stored and how will it be disposed of?

We carefully preserve donated tissue by storing it either in formaldehyde (a liquid fixative) or freezing them at -85°C . This means the tissue can be used for research for up to ten years or more.

When tissue is no longer suitable for research we carefully dispose of it, after consultation with Parkinson's UK and other appropriate organisations. All tissue is disposed of in a respectful manner. We never forget the people that the tissue we receive represents.



USING MY PERSONAL INFORMATION

Do you need to know my medical history?

Yes. Having access to detailed information about each donor's medical history means that researchers can match up specific symptoms with the changes they see in the brain.

When you join the Brain Donor Register we request permission to access your medical records and ask you to fill in a detailed questionnaire every two years. This gives us vital information about your symptoms, lifestyle, and medications.

This information is kept strictly confidential and provided to researchers on an anonymous basis.

Will my personal details and medical records be kept confidential?

Yes. All registration forms and associated paperwork are stored securely and remain strictly confidential. When a brain is donated, each donor is given a unique identification code and all personal information is removed. Personal details are never shared with anyone outside of the Parkinson's UK Brain Bank – including researchers.

What if I sign up and then change my mind?

We understand that brain donation is not right for everyone. You are free to change your mind at any time – just contact the brain bank to let us know. We will then return your signed consent forms and remove your details from our database.

**WE'RE SUPPORTING
PROJECTS IN THE
UK AND AROUND
THE WORLD**



We're the Parkinson's support and research charity.

If you want an information pack or for any
other questions contact the brain bank direct:

Parkinson's UK Brain Bank
Centre for Neuroscience
Imperial College London
Hammersmith Hospital Campus
160 Du Cane Road
London W12 0NN

020 7594 9732
brainbank@imperial.ac.uk
parkinsons.org.uk/brainbank

Parkinson's UK

Free* confidential helpline **0808 800 0303**

parkinsons.org.uk

hello@parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

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