

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



Parkinson's UK Brain Bank: answering your questions about brain donation

In association with
**Imperial College
London**

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CONTENTS

About the tissue we collect	4
How brain tissue is used in Parkinson's research	6
Becoming a donor	8
Collecting brain tissue – information for next-of-kin	10
When a donation cannot be fulfilled	12
Using my personal information	14



INTRODUCING THE BRAIN BANK

The Parkinson's UK brain bank is the world's only brain bank dedicated to Parkinson's research.

The Brain Bank is funded by Parkinson's UK and based at Imperial College London.

We collect precious tissue from people with and without the condition who have decided to leave their brains to Parkinson's research.

The tissue is supplied to researchers all over the world who are studying Parkinson's. This research could lead to discoveries that help us to find a cure and improve life for everyone affected by Parkinson's.

The work of the Brain Bank is regularly reviewed by an independent panel of scientific experts and people affected by the condition and all our processes have gained approval from the National Research Ethics Service.

This information booklet is designed to answer any questions you may have about brain donation.

If, after reading the booklet, you are interested in joining the donor register, please discuss it with those close to you.

You can find the registration forms on our website or request them by contacting the Brain Bank directly. We are happy to answer any questions you may have.

Website
parkinsons.org.uk/brainbank

By phone
020 7594 9732

By email
brainbank@imperial.ac.uk

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

ABOUT THE TISSUE WE COLLECT

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.

If a full post mortem is being conducted by the hospital, or on the order of the coroner, we may also collect samples of colon, intestines, spleen, liver, cervical lymph nodes and adrenal gland.

As we learn more about Parkinson's and other parts of the body that can be affected, in future we may need to collect small samples of other tissues for research – such as from the gut, or samples of skin tissue.

If this happens, we will always ask your next-of-kin's permission before removing any material in addition to what is listed above.

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 and we'll update your record.

Unfortunately, we cannot work with whole body donation schemes – as these require the whole body including the brain.

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.



HOW BRAIN TISSUE IS USED IN PARKINSON'S 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.

Studying donated brain tissue has already led to major advances in our understanding of Parkinson's – including identifying changes in the brain cells affected in the condition, such as increased levels of iron.

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

As a result, new treatments are currently being developed and tested that may help to remove excess iron in the brain that could be helpful for people with Parkinson's.

Brain tissue is also helping us to understand the origins of the complex non-motor symptoms of Parkinson's – including hallucinations and sleep problems – which we hope will aid the development of new and better treatments to help those who experience these debilitating symptoms.

How is tissue made available to researchers?

To help as many research projects as possible, each brain is divided into around 250 samples. These samples are stored safely and securely at the Parkinson's UK Brain Bank.

Scientists from the UK and around the world apply to use the tissue in their research.

We have a panel of scientific experts and people affected by Parkinson's, who carefully review each application before approving the projects to which we supply tissue.

The researchers we support provide us with a written report so that we can track the outcomes of research carried out using donated tissue.

What type of research might my tissue be used in?

We cannot predict what type of project your tissue will be used for or where the research will be carried out as we support a wide variety of Parkinson's-related research projects that take place all over the world – and one brain may be used in many different projects.

However, every project we support is ethically and scientifically approved, and will help us better understand Parkinson's and ultimately find a cure.

In addition to research, your tissue may also be used for teaching purposes in the training of health care professionals, in the UK.

How and where will my tissue be stored?

We carefully preserve donated tissue by storing it at the Brain Bank in Hammersmith Hospital in London,

either in formaldehyde (a liquid fixative) or by freezing it at -85°C . This means the tissue can be used for research over several years.

What happens when tissue can no longer be used?

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 and families that the tissue we receive comes from, and their gift to everyone affected by Parkinson's.



BECOMING A DONOR

What do I do if I would like to donate my brain?

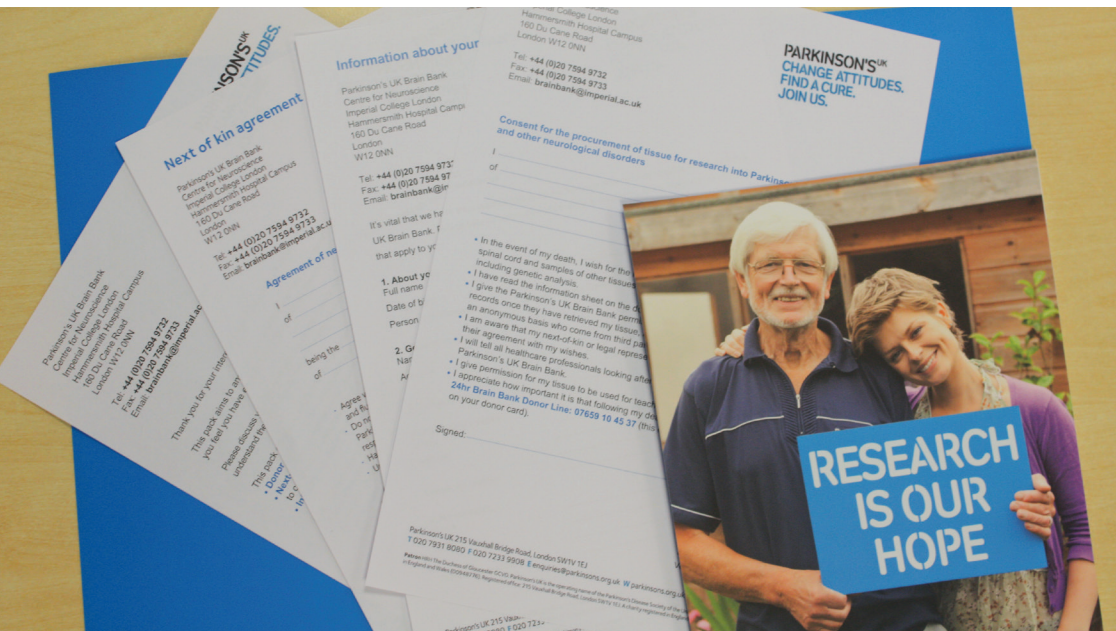
If you decide that you wish to donate your brain to Parkinson's, please discuss it with your next-of-kin and those close to you.

You can find the registration forms on our website or request them by contacting us directly. Your next-of-kin or a legal representative will also need to complete a form as they will be vital in making sure that we can carry out your wishes.

When we receive your completed forms we will record your details on our secure and confidential system and issue you with an information pack including your donor card.

What can I do to prepare for donation?

- Keep our 24 hour emergency contact number with you at all times – it will be on your donor card along with your personal donor number.





- Make sure that your next-of-kin is aware of your wishes and the process of collection. Make sure they know where to find the 24 hour emergency number and have a copy of 'What to do if a donor dies' information sheet.
- Discuss your wishes with key medical professionals, such as your GP, and ask them to update your medical records accordingly.

Will brain donation affect 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

**WE COLLECT
MORE THAN
120 BRAINS
PER YEAR**

removed in a respectful and careful manner that will not affect the appearance of the body.

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.

COLLECTING BRAIN TISSUE – INFORMATION FOR NEXT-OF-KIN

How quickly does tissue need to be collected?

We aim to collect tissue as quickly as possible. Brain and spinal cord tissues deteriorate very rapidly and 48 hours after death, tissue is no longer suitable for Parkinson's research.

What does my next-of-kin need to do when I die

If a donor has died or is not expected to live much longer, someone must call our emergency number as soon as possible, the number is **07659 104537**.

We respond within 30 minutes to calls to our emergency number between 9am and 5pm, Monday-Sunday. If we receive their message outside these hours we'll be in touch first thing the next day. Please do not call the emergency number unless a donor has died or is likely to die. For all other queries about the Parkinson's UK Brain Bank please call

our regular office number on **020 7594 9732**.

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

Tissue cannot be removed until we have a signed medical certificate of death, so the next-of-kin will need to request one from the donor's GP or a hospital doctor as soon as possible.

The body also needs to be kept cold to help to preserve the tissue. So the body should be transferred as quickly as possible to:

- a funeral director if the death occurred at home or in a care home
- a mortuary if the death occurred in hospital

What further help is available for next-of-kin?

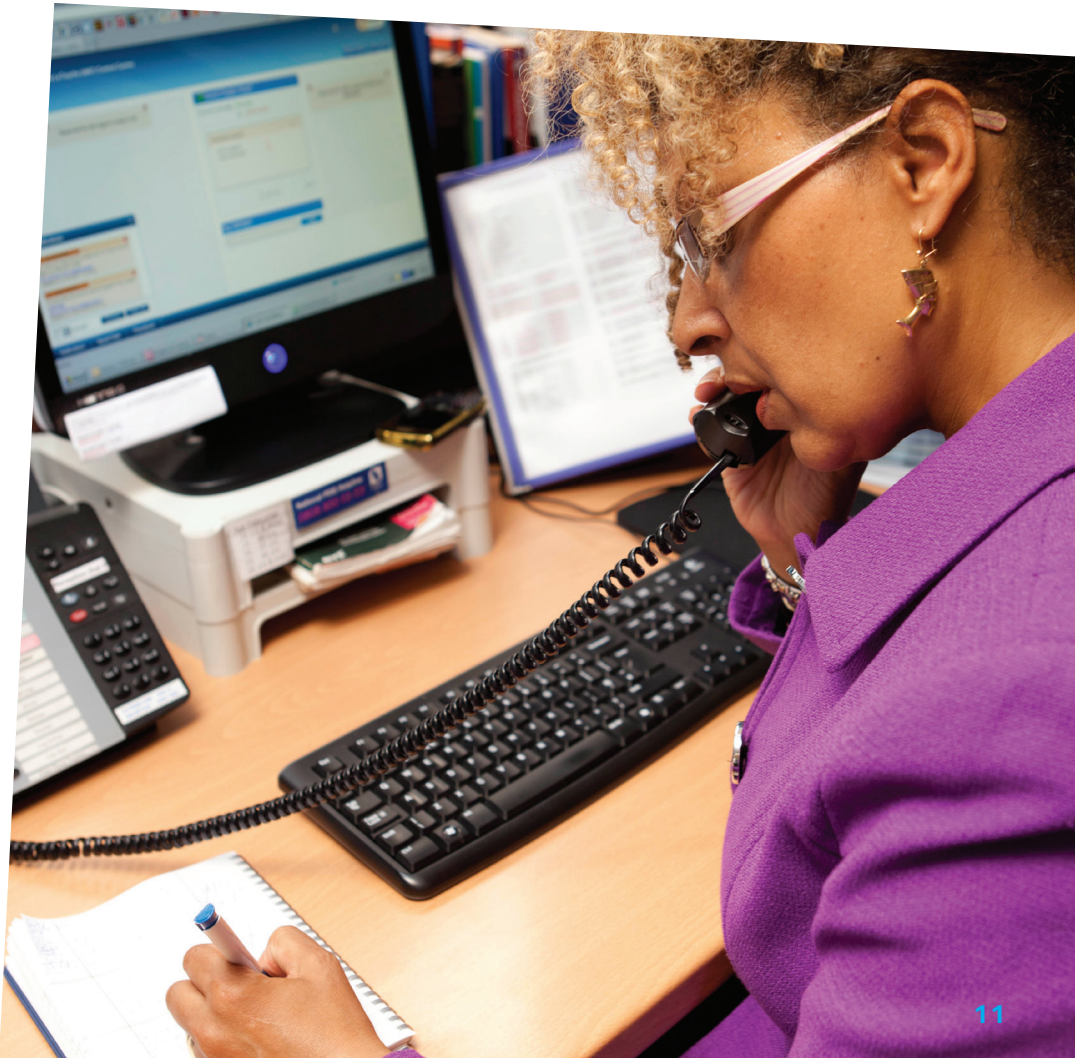
We really appreciate their help during this difficult time, and we're

committed to doing everything we can to support families through the process.

The Parkinson's UK Brain Bank team will talk the next-of-kin through what they need to do and will work closely with hospitals and undertakers to organise tissue collection as quickly and smoothly as possible.

We have produced an information sheet called 'What to do if a donor dies' to guide people through the process. This is available on the website at parkinsons.org.uk/brainbank and will be sent to you with your donor card if you register.

After a brain has been collected we carry out an in-depth examination of the tissue and we send a letter to the next-of-kin to explain our findings.



WHEN A DONATION CANNOT BE FULFILLED

How often is brain donation successful?

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 is unfortunately no longer suitable for research.

We are committed to doing absolutely everything we can to honour our donors' wishes.

But it's really important that our donors and their families are aware that there are occasions where we are unable to collect tissue within the crucial 48 hour window.

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

If a death needs to be referred to the coroner for further investigation, this takes priority and usually means we

cannot collect tissue within the 48 hour period.

Occasionally a donor may have an infection – such as HIV – which means that it's unsafe to remove the tissue. Conditions such as stroke and cancer also make tissue unsuitable for Parkinson's research due to the damage caused to the brain by these conditions.

We are completely reliant on support from health professionals and the NHS to carry out tissue collections, and sometimes it is difficult to get a death certificate signed in time, or to find local mortuary staff able to remove the tissue for us.

These two issues are more of a problem overnight and at weekends when NHS staff are more stretched. We are working closely with Parkinson's UK and other brain banks across the UK to solve these problems.

Having a register of people willing to donate their brain tissue supports the future of research into Parkinson's,



Professor David Dexter

even if it is ultimately not possible to collect the tissue.

The circumstances that may prevent collection do not reduce the value

of the intended donation, the spirit in which the gift was made, or the efforts made by the donor's next-of-kin to fulfil the donors wishes.

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. This gives us vital information about your symptoms, lifestyle, and medications.

This information is kept strictly confidential and is completely anonymized before it is shared with researchers.

In exceptional circumstances when we can't access the relevant



information from your medical records we may approach your next-of-kin to get this information.

Using your tissue in research studies, such as genetic analysis, may generate information relevant to your relatives. If it does we will contact your next-of-kin and can help arrange genetic counselling.

Please note that on some occasions GPs will not be able to forward the information we supply to relatives as they may not have the necessary contact details for your next-of-kin.

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.

We hope that this booklet will have helped you make your decision about brain donation.

If you would like to request a donor registration pack or have any questions about the Parkinson's UK Brain Bank, please contact them directly at:

Parkinson's UK Brain Bank
Division of Brain Sciences
Imperial College London
Hammersmith Hospital Campus
160 Du Cane Road
London W12 0NN

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



Imagine not being able to move, sleep, or smile.
Feeling anxious or depressed and struggling to think
or remember. Your body not feeling like your own.
This is what Parkinson's can feel like.

Every hour, someone in the UK is told they have
Parkinson's – a brain condition that turns lives
upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have
whatever they need to take back control – from
information to inspiration.

We want everyone to get the best health and social
care. So we bring professionals together to drive
improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why
we inspire and support the international research
community to develop life-changing treatments,
faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)

hello@parkinsons.org.uk
parkinsons.org.uk