

## Your legacy is only the beginning...



Theresa Dauncey Chief Executive, The National Brain Appeal

Legacies are vital to The National Brain Appeal. This pack provides information about the charity and how we support the ground-breaking work carried out by The National Hospital for Neurology and Neurosurgery and the UCL Queen Square Institute of Neurology.

By leaving a gift in your Will to The National Brain Appeal, you can make a real difference to the lives of the one in six of us affected by and/or living with a neurological condition.

That's 14.7 million mums, dads, sons, daughters, friends and colleagues who are affected. It's the challenge of our times.

If, like us, you want to invest in the future to fund innovation leading to new treatments and cures for neurological conditions, please consider leaving a legacy to The National Brain Appeal.

Charitable legacies are crucial to the success of the projects that The National Brain Appeal funds. We rely on legacy gifts to get projects up and running quickly and legacies have helped us to initiate many crucial programmes over the years.

We are extremely grateful for every legacy left to us, whether big or small, enabling us to offer more support to advance the field of neurology and neurosurgery.

Thank you for supporting the work of The National Brain Appeal and for considering leaving a legacy.

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Registered Charity No: 290173

# Why it is important to make a Will

A Will is a legally binding document that ensures that your wishes regarding your estate are carried out after your death. It provides peace of mind for you and your loved ones and ensures your wishes will be carried out exactly as you want.

If you own your own home, your Will enables you to choose who should receive the proceeds of its sale. You can decide who you would like to give any savings, shares or 'goods and chattels' (personal possessions) to. You can also use your Will to state your wishes for your funeral, for example requesting donations to charity instead of flowers.

If you do not have a Will, your estate may be distributed according to intestacy rules in which everything does not automatically pass to your partner or spouse and your possessions may not be distributed as you would have wished. And planning your Will can also reduce Inheritance Tax (gifts to charities are exempt).

It is advisable to seek legal advice in order to draw up your Will. A Will need not be absolute and final, as it can be revised and changed.

# Leaving a gift to The National Brain Appeal

We understand that family and loved ones will always take priority and we are extremely grateful for every legacy left to us. Whether large or small, a gift in your Will can make a real difference to the work that we are able to fund.

Charitable legacies account for around a quarter of our annual income and are crucial to the fundraising work we do.

By leaving a gift to The National Brain Appeal, you will be helping to fund pioneering research, provide access to the best technology for expert diagnosis and treatment, and train tomorrow's clinicians. This will be your lasting legacy and provide hope for the future for those affected by a neurological condition.



#### What we fund

Queen Square is an international centre of neurological excellence – our ambition is to fund new projects with the best promise of improving the outcome and quality of life for people with a neurological condition.

Our funding is grouped into six distinct areas as outlined here. You can read about some of the areas we have supported and also find out more about our latest appeals on our website: nationalbrainappeal.org

For your gift to have the biggest impact, we will put it towards a project in greatest need when your gift takes effect. If you are passionate about a particular area of funding you can also express a wish in your Will or make a gift subject to binding obligations\* as to its use. If you would like to express a wish or make a gift subject to a binding obligation, please get in touch so that we can ensure that we can comply with the terms of your gift.

\*If you state a binding obligation The National Brain Appeal may no longer be able to fulfil the purpose of the legacy at the time that the legacy takes effect.

### 1 Queen Square

New facilities and staff-led projects at The National Hospital and Institute of Neurology

Together, The National Hospital and the UCL Queen Square Institute of Neurology form one of the world's foremost neuroscience centres – leading the way in diagnosis, treatment and research of neurological and neuromuscular diseases including stroke, multiple sclerosis, brain cancer, epilepsy, Parkinson's disease, and dementias.



#### So far, we've raised £323k for... The Small Acorns Fund

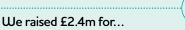
This fund is open to all front-line staff at Queen Square, giving them the opportunity to apply for funding to fast-track smaller scale projects that will have a big impact and benefit to patients. Since this fund was launched in 2014, we have been able to support almost 100 projects including: the introduction of a neurosurgical biocompatible 3D printing facility for the neurosurgery team; a project to sequence muscle-wasting and changes in patients with McArdle Disease; and a website supporting patients with Functional Neurological Disorder.



### <sup>2</sup> Neurodegeneration

# Supporting projects which help people with conditions where there is progressive degeneration

Neurodegenerative conditions are often incurable, usually debilitating and result in the death of nerve cells. They include Alzheimer's disease and other dementias, Parkinson's disease, prion disease and motor neurone disease.



# The Dementia Research Centre in Queen Square

The charity also has an ongoing commitment to provide funding in excess of £300,000 each year towards Rare Dementia Support.



#### We raised £1.4m for...

#### The Centre for Neuromuscular Diseases

The centre accommodates a large team of experts, research facilities and specialist systems to support the development of new treatments for conditions such as epilepsy, spinal muscular atrophy, motor neurone disease, myasthenia gravis and muscular dystrophy.

### **3 Neurosurgery**

#### Providing state-of-the-art equipment and facilities for the UK's largest neurosurgery unit

The National Hospital is renowned as a centre of neurosurgical excellence. The unit provides a local, national and international service for specialised neurosurgical problems such as epilepsy, brain cancer, movement disorders and complex spinal procedures.

# We raised £3.5m for...

# The first Brain Tumour Unit in the United Kingdom

We established and fully funded the Brain Tumour Unit, increasing the ability to run clinical trials and creating the first dedicated ward – The Molly Lane Fox Unit. This was recently doubled in size to cope with increased demand. The unit is a beacon for specialist care aimed at increasing survival rates and improving quality of life for adults with brain tumours, providing a hub for patients to take part in the latest clinical trials to find treatments for brain cancer.





## 4 Neurology

#### Funding initiatives to improve diagnosis, treatment and provide facilities for those with ongoing neurological conditions

People can be affected by neurological disorders from birth or as a result of injury or illness. Many are life threatening, most of them severely affect people's quality of life and cause life-long disability. The conditions that fall under this category and which are treated at The National Hospital include multiple sclerosis, epilepsy, and mitochondrial diseases, among many others.

Recently, we fully-funded a pioneering intensive therapy programme for people with aphasia (difficulty understanding and using language or speech as a result of brain injury).

#### We raised £1m for...

The UK's largest dedicated medical and surgical Neurocritical Care Unit

The Unit provides state-of-the-art facilities for critically ill patients.

#### We raised £1.5m for...

A new Interventional Neuroradiology Service for stroke at Queen Square



### 5 Technology & innovation

# Supporting projects which translate ground-breaking ideas into better results for patients

To maintain Queen Square's reputation as a pioneering centre of neurology, it's essential to invest in cutting-edge technology and innovation. We fund large-scale projects such as the BrainSuite, which is a combined system of Operating Room tools providing surgeons with instant real-time scanning, reducing re-operation and recurrence rates.

#### We raised £1.3m for...

#### The Neuroimaging Analysis Centre

The Centre supports the review of imaging of over 40,000 patients per year.



Smaller technological projects are important too, and we have helped to fund iPads that can be used to inform patients visually about procedures, including lumbar punctures, and for clinicians to assist with patient flow and discharge, along with apps to support speech therapy.

#### We raised £250k for...

# The running costs of the IPI-GLIO Immunotherapy trial

There is an urgent need for new treatments to improve clinical outcomes and survival for patients with glioblastoma. Glioblastoma is the most common type of primary, malignant and very aggressive brain tumour with around 2,200 cases diagnosed each year in England.

Dr Paul Mulholland is a consultant medical oncologist at The National Hospital for Neurology and Neurosurgery. He is very optimistic about new treatments including immunotherapy for treating glioblastoma. An immunotherapy drug, ipilimumab has been approved in Europe for use in patients with advanced melanoma and brain metastases (secondary tumours). The immunotherapy drug in a clinical trial showed a 10% improved survival rate.



Through our Innovation Fund, we are supporting the development of 'smart' instruments for keyhole brain surgery and a feasibility study in to reducing the risk of facial nerve paralysis for patients undergoing skull-base tumour surgery.

# 6 Education & staff development

#### Helping Queen Square to maintain its reputation as an international centre of neurological excellence.

We fund research fellow posts, award prizes to outstanding students at the Institute of Neurology, and encourage staff excellence at The National Hospital. Legacies have enabled the redevelopment of the Queen Square Medical Library, which marked a real turning point by providing on-site training facilities, a purpose-built archive and a museum. The library now gets more than 40,000 visits from students, researchers and clinicians each year.

#### We raised £105k for...

### New Physician Associate (PA) roles

We gave funding to pilot new roles within the neurology and neurosurgery teams. PAs are trained healthcare professionals working closely alongside doctors and medical teams. Increasingly, they are being appointed to provide continuity of care for inpatients. These roles proved so successful at The National Hospital that they have now been extended to the Daycare and Stroke Units. We also awarded £50,000 to fund two new Nursing Fellowships.





# How you can leave a gift in your Will to The National Brain Appeal

After taking care of your loved ones, if you would like to leave a gift to The National Brain Appeal, there are different ways that you can do so. All gifts will make a difference to the projects that we can fund and will support the one in six of us with a neurological condition.

It's a good idea to speak to a specialist who can make sure that your wishes are met and to get professional advice on areas such as Inheritance Tax.

#### **Pecuniary Bequest**

This is a fixed sum of money. When leaving a pecuniary gift it is worth remembering that inflation can decrease the value of the gift over time. It is therefore worth revising your Will from time to time or asking your legal adviser to make it index-linked (ensures your pledge will keep its value in line with inflation).

#### Residuary Bequest

This is a gift made once all of your loved ones have been taken care of and any debts have been paid off. You could choose to leave a percentage of the residue or the total of the residue

#### Specific Bequest

You could choose to leave a specific item such as shares, a house, jewellery or a painting.

#### Inheritance Tax

Inheritance Tax is tax payable on the value of your estate when you die. A gift in your Will is tax free and can help you reduce the Inheritance Tax on your estate from 40% to 36%, if you leave at least 10% of your 'net estate' to charity.

Please speak to a legal adviser who will be able to provide advice on the most tax efficient way to write a Will depending on your circumstances.

Here is some useful wording which you can provide to your legal adviser.

I hereby bequeath to The National Brain Appeal (Registered Charity No.290173) of Ormond House, London, WC1N 3JZ the following:

[Insert the preferred phrase]

The sum of £ .....

[or]

The residue of my estate.

[or]

A ..... share of the residue of my estate.

I declare that the receipt of the Charity's CEO or other proper officer shall be sufficient discharge for my executors".

If you wish to support research include the wording:

Such a bequest to be used specifically for research at The National Hospital for Neurology and Neurosurgery.

If you have a specific interest then that can simply be inserted, after the word research "into stroke" or any other specific condition but please do contact us first so that we can confirm we would be able to honour your wishes.

# Meta's story



Meta had successful surgery for a benign brain tumour at The National Hospital in 1988.

Since then both her husband and sister were diagnosed with neurological conditions.

"My husband had Parkinson's and has sadly passed away. My sister has multiple sclerosis – she's been living with it for more than 30 years now," says Meta. "These are cruel diseases for which there is no cure and little hope."

With this in mind Meta has made The National Brain Appeal a major beneficiary in her Will.

"The lack of a cure for so many debilitating neurological conditions is a strong motivator for me to want to help, and by leaving a legacy I can be part of something that will provide hope for others."

"I would love my legacy to be used for research — it would feel as if I am making a positive move against something that has had a huge impact on the people close to me," she explains.

# Penny's story



In 2004, Penny noticed that the fingers in her left hand had started to drop and that she had no energy.

She was referred to The National Hospital for Neurology and Neurosurgery (NHNN) and was diagnosed with Multifocal Motor Neuropathy (MMN), which she discovered was due to an earlier accident. Penny started treatment of IVIG infusions.

In 2006 a Day Care clinic was established at NHNN with a team of specialist nurses. Penny says "While sitting having our treatments, people began to communicate with each other. MMN is still a relatively unknown condition so to be able to share experiences was such a huge step forward."

"My own personal journey with MMN makes me want to give back in whatever way I can to the fantastic team of consultants and nurses who go above the call of a duty on a daily basis and who provide us all with such a comforting support system. That is why I have left a gift in my Will to The National Brain Appeal," she says.

"I want to help fund crucial research into all neurological conditions going forward."



# Will writing services

We've teamed up with Bequeathed (a free online Will writing service) and The Goodwill Partnership (a home-visit solicitor-provided service) to make it simpler for you to write or update your Will. Both services are available in England and Wales only.



free wills, valuable advice

Having an up-to-date Will is the only way to be sure the people and causes you care about are looked after.

With Bequeathed you can make a start on your Will immediately. Simply follow the steps to create a Will online. It's a free service.

Detailed guidance will help you to consider everything you need to think about when making a Will, and to identify any issues where expert legal advice could be valuable.

If you want legal advice at any stage, just ask. Bequeathed will connect you to a solicitor who'll give you a price to help you complete your Will face-to-face or over the phone.

Visit bequeathed.org/tnba



The Goodwill Partnership is the largest distributor of home-visit solicitor provided Wills in England and Wales.

They guarantee the lowest price for a home-visit Will which is checked and provided direct to you by a panel firm of solicitors who can also provide legal advice and storage of your signed Will.

The process of making your Will is made extremely simple. There are no visits to the solicitor; a trained counsellor comes to your home to take your Will instructions at a time convenient to you.

The Goodwill Partnership charge a low fixed price of £108 + VAT, however detailed your Will, wherever you live, with no hidden costs or upsell of any other products. Their home-visit service is free of charge and they also provide a small discount on a second Will for your spouse or partner.

Visit thegoodwillpartnership.co.uk/thenational-brain-appeal

# A glossary of legal terms

When it comes to Will writing, you might come across some terms that you haven't heard before. Here is a glossary of the most common terms used in Will writing.

#### Administrator

Someone appointed to deal with the administration of your estate if you do not leave a Will or there is no executor.

#### **Bequest**

A term for a gift that you leave to a person or organisation in your Will. There are several different types of bequest, but the main ones are:

#### Residuary bequest

A gift made of what is left of your estate after all other gifts have been handed out and debts paid off. To do this you may leave either the total of the residue or a percentage.

#### Pecuniary bequest

A gift made of a fixed sum of money. Unfortunately, the effect of inflation means that the value of a pecuniary gift will decrease over time.

#### Specific bequest

A particular named item that is a tangible asset e.g. a piece of jewellery, furniture or a painting.

#### Beneficiary

A person, or an organisation, to whom you leave a legacy or bequest in your Will.

#### Codicil

A document used to change or add to your existing Will. It must follow the same legal formalities as your Will.

#### **Estate**

The total sum of your personal possessions, property and money (minus any liabilities)

#### Executor

The person or people appointed by you in your Will to ensure your final wishes are carried out. These can be professionals, friends, family members or institutions such as banks and some charities.

#### Guardian

Someone who is responsible for children until they become 18.

#### Inheritance Tax

This tax is paid on the portion of your estate that is above the nil-rate threshold.

#### Intestate

The word used to describe someone who has died without a Will.

#### Legacy

Another word for a gift or bequest left in your Will.

#### Life Interest

The right of a beneficiary to benefit from part or all of an estate for their lifetime, which then passes to a second named beneficiary on their death.

#### **Probate**

When somebody dies leaving a Will, their executors will usually need to apply for a grant of probate. Once this is obtained, the executors can deal with the wishes expressed in the Will and distribute the gifts that have been left.

#### Testator/Testatrix

The name given to a person who has made a Will.

#### Trustee(s)

One or more people who manage a trust.

#### Witness

A person who signs your Will. They cannot be a beneficiary.

## Your legacy pledge

Whether big or small, if you are considering or have left a gift in your Will to The National Brain Appeal – we would be grateful to hear from you.

Filling in this form is not legally binding and any information that you provide us with will be kept confidential. Please tick the boxes where appropriate.

Title
Forename
Surname
Address
Postcode
Phone
Email
Please let us know if there is any other information that you would like to share regarding your planned gift:

- I am considering leaving a gift in my Will to The National Brain Appeal
- I have included a gift in my Will but wish for the value to remain confidential
- I am leaving a pecuniary gift (a fixed sum of money)
- I am leaving a residuary gift
  (a percentage of your estate after all
  other gifts have been handed out)
- I am leaving a specific gift (a particular named item that is a tangible asset)

We would like to be able to thank you and update you with the latest news about projects and research funded by The National Brain Appeal.

I would like to receive email updates about The National Brain Appeal's fundraising activities, events and the latest clinical breakthroughs

I would like to receive 'The National newspaper' – the Charity's bi-annual publication and The National Brain Appeal's Annual Review

Е	By email	By pos

#### Please send this form to:

The National Brain Appeal 3rd Floor Ormond House 26/27 Boswell St London WC1N 3JZ

or email it to info@nationalbrainappeal.org

#### Contact us

Please do contact us if you have any queries regarding leaving us a legacy in your Will.

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The National Brain Appeal Funding advances in neurology and neurosurgery





