

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**

# **PARKINSON'S PROFESSIONALS TOOLKIT**

**Resources and links for people  
affected by Parkinson's and  
healthcare professionals**

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# Parkinson's UK helpline & forum

The Parkinson's UK helpline number is a free helpful number for people affected by Parkinson's to seek, support, information and signposting to other services. There are local advisers who have a wealth of experience in Parkinson's related matters and a Parkinson's Nurse who can respond to general health enquiries.

**.Call on 0808 800 0303**

- **Email: [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**
- **Send your question: [general enquiry form](#)**
- **NGT Relay: 18001 0808 800 0303 (for use with smartphones, tablets, PCs and other devices. For more information see [www.ngts.org.uk](http://www.ngts.org.uk))**
- **Write to us: Helpline, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**

**Opening times:**

- Monday to Friday: 9am to 6pm
- Saturday: 10am to 2pm

Our helpline is closed on Sunday and bank holidays

Parkinson's UK website has a wealth of information and support <https://www.parkinsons.org.uk/>

Parkinson's UK online community forum <https://forum.parkinsons.org.uk/>

# Team Parkinson's

The team has already achieved so much, including:

- convincing the NHS to fund crucial Parkinson's medication
- creating specialist Parkinson's nurses
- funding research breakthroughs

But there's still more to do. And the more people who join in, the stronger we'll be.

We don't want cost to stop anyone from being able to join, so just chip in whatever you can – even if that's nothing right now. You'll also get:

- Team Parkinson's Toolkit
- The Parkinson and Progress magazines – either in the post or by email
- the opportunity to come to the Parkinson's UK Annual General Meeting (AGM)
- the chance to shape the charity's future by voting for trustees

Any questions?

Our friendly Supporter Care team is on hand to answer any questions about Team Parkinson's and how to join in. Please call 0800 138 6593 or email [team@parkinsons.org.uk](mailto:team@parkinsons.org.uk)

Or joining via this link -

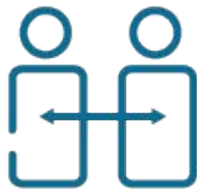
<https://www.parkinsons.org.uk/about-us/team-parkinsons>

# Parkinson's search postcode tool

Are you wanting to find out what support is available to people affected by Parkinson's locally? then please use our online postcode look up tool, or phone our helpline if you're not able to access online.

Signposting to mutual support, health and wellbeing and social activities within a local area

<https://www.parkinsons.org.uk/information-and-support>



## First Steps online free for recently diagnosed course

First Steps has been developed with people with Parkinson's, and is delivered by volunteer hosts who also live with the condition. The programme will help you take the first steps in processing your diagnosis, find out what information and support is available, and start living well with Parkinson's. A diagnosis of Parkinson's has an impact on family and friends, as well as the person with Parkinson's, so we welcome a family member or friend to take part with you.

If you have any questions, please contact the First Steps team on 020 7963 9381 or email [firststeps@parkinsons.org.uk](mailto:firststeps@parkinsons.org.uk).

<https://www.parkinsons.org.uk/professionals/first-steps-people-newly-diagnosed-parkinsons>

## Take part in Research

People affected by Parkinson's - including partners, family members and friends - can help shape research in lots of ways, including:

- helping us choose the right projects to fund
- planning and prioritising what areas to focus on
- communicating research in simple terms
- highlighting practical issues that could stop people taking part in research
- sharing the bigger picture of what it's like to live with Parkinson's
- bringing fresh ideas and insights <https://www.parkinsons.org.uk/research/get-involved-research>

**The Take Part Hub - Find research for you.** Research ranges from questionnaires you can fill in at home to trialling new treatments. Whatever you're ready for, you can make a difference by taking part. <https://www.parkinsons.org.uk/research/take-part-research>

# Parkinson's UK Call Companions Service

We're working with Re-engage to offer older people with Parkinson's, and the people who care for them, a telephone befriending service.

Living with Parkinson's, or caring for someone who does, can feel isolating. But you're not alone.

## A regular chat with someone who really listens

This service is completely free, and you can refer yourself or someone you care for. Once signed up, you'll be matched with a friendly volunteer who has similar interests to you. They'll call you every 1 or 2 weeks, depending on your preference, for a casual chat about anything you like.

All volunteers are fully trained and will be familiar with Parkinson's, but you don't have to talk about the condition during your calls.

### To use the service, you must be:

- a person with Parkinson's, or a carer of someone with the condition
  - over the age of 60
  - confident using a telephone.
- [Sign up for the Call Companions service](#)



# Parkinsons UK Grants

People with Parkinson's or other forms of progressive parkinsonism, and unpaid carers, can apply for a Parkinson's UK Grant up to £1,500.

<https://www.parkinsons.org.uk/about-us/parkinsons-uk-grants>

What we fund

- **Activities:** you can receive a maximum grant of £250 if your household savings are less than £6,000.
- **Electrical items:** you can receive a maximum grant of £500 if your household savings are less than £6,000. Grants for electrical items are limited to 1 application per household.
- **Respite care:** you can receive a maximum grant of £1,000 if your household savings are less than £16,000. Grants for respite care are limited to 1 application per household.
- **Specialist equipment or home adaptation:** you can receive a maximum grant of £1,600 if your household savings are less than £16,000. Grants for specialist equipment or home adaptation are limited to 1 application per household.

We don't fund holidays, long-term financial commitments or daily living costs. We won't consider applications to fund items that you've already paid for, or committed to paying for. We don't fund items or respite where funding should be available from the government or from your local authority.

If you have any questions about the grants programme, your eligibility, or your application, please email [grants@parkinsons.org.uk](mailto:grants@parkinsons.org.uk) or call us on **020 7963 3785**.

**PARKINSON'S<sup>UK</sup>**

# Exercise videos and advice

We offer a range of exercise videos, information and a toolkit to help you. Whether you have Parkinson's or live with someone who does, there is no one-size-fits-all approach. With Parkinson's, the best exercise to do depends on the way it affects you.

- Doing 2.5 hours of exercise a week can slow the progression of symptoms.
- Exercise can help manage physical symptoms and other symptoms such as sleep problems, fatigue, mood and mental health.
- Exercise can be as important as medication to help you take control and manage symptoms.



<https://www.parkinsons.org.uk/information-and-support/exercising-home-parkinsons-your-toolkit>

# Partnership with Everyone Active

**Everyone Active offers free membership for people with Parkinson's and their carers**

Membership includes:

- use of gym equipment
- swim facilities (where applicable)
- group exercise classes
- EXi digital, a prescribed physical activity programme
- Synergy Dance online classes.

There's a huge range of activities to help you get and stay active. No matter what stage of Parkinson's you're at, or what your physical ability is, there's something for everyone.

## Supporting people living with Parkinsons

As well as offering free membership to people with Parkinson's and their carers, Everyone Active is training staff in all of its leisure centres to be Parkinson's aware. And activity providers will complete Parkinson's UK training, to make sure they can support you in the right way.

Everyone Active is also running a buddy scheme so that an existing member with Parkinson's is there to welcome and support new members with the condition on their first visit.

[Everyone Active sign up](#)

## Information in accessible / other language formats

**We produce a range of resources in other languages, as well as accessible formats, such as large print, audio, CDs and easy-read.**

<https://www.parkinsons.org.uk/information-and-support/accessible-formats-and-other-languages>

# Printed / online information resources and Parkinson's Magazine

**Patient order information resources** - We produce information covering a wide range of topics related to Parkinson's.

You can find it all within the information section and download it to read in your own time. Or, if you prefer, you can order printed copies, which are completely free of charge if you live in the UK.

<https://www.parkinsons.org.uk/information-and-support/ordering-our-resources>

**Online Parkinson's Magazine** - *The Parkinson* magazine is packed with features to help you live well and manage your condition. Inside you'll find:

- real life stories and experiences from people living with or caring for someone with Parkinson's
- Q&As with experts
- tips from people affected by Parkinson's

**Also available in audio and printed copies 3x a year**

<https://www.parkinsons.org.uk/information-and-support/your-magazine>

# Become a Parkinson's UK volunteer

Our volunteers do amazing things. From helping at our events to supporting our research, they're improving the lives of everyone affected by Parkinson's.



[https://volunteer.parkinsons.org.uk/opportunities#display=grid&s=date\\_advertised&o=desc](https://volunteer.parkinsons.org.uk/opportunities#display=grid&s=date_advertised&o=desc)

# Resources for Professionals

Resources for Professionals

<https://www.parkinsons.org.uk/professionals/resources>

Learning Hub

<https://www.parkinsons.org.uk/professionals/events-and-learning>

Clinical Tools and Assessments

<https://www.parkinsons.org.uk/professionals/clinical-tools-and-assessments>

Guidelines

<https://www.parkinsons.org.uk/professionals/guidelines>

Learning and Events

<https://www.parkinsons.org.uk/professionals/events-and-learning>

Competency Framework for Parkinsons Nurses

<https://bit.ly/3z7OIhO>

# Supporting the family unit and care partners

A free online learning resource which examines how to support the families and care partners for people with Parkinson's for health and social care professionals

The course focuses on the following areas:

- What is a care partner?
- The impact of Parkinson's on care partners, and the family unit
- How to identify care partners that are struggling
- The importance of including care partners and the family unit in conversations
- Types of communication with care partners
- Data protection and legal issues surrounding working with care partners
- Advice on how to support care partners and families of people living with Parkinson's
- Advice on how to support care partners and family members of different ages, for different stages of Parkinson's



# Learning Pathways

**Parkinson's Learning Pathway for Health and Social Care Professionals**

<https://bit.ly/2XkxO2a>

**Register for the Parkinson's Nurse Learning Pathway**

<https://bit.ly/39bFlxl>

**Register for a Therapist Learning Pathway ( Physio, OT, SALT, Dietician)**

<https://bit.ly/3AdHV7B>

## Newly diagnosed patient pathway: Plymouth Hospitals NHS Trust

This newly diagnosed patient pathway is aimed at improving the experience of being diagnosed with Parkinson's.

<https://www.parkinsons.org.uk/professionals/resources/newly-diagnosed-patient-pathway-plymouth-hospitals-nhs-trust>

# Assessment Tools

**The Epworth Sleepiness Scale (ESS)** is a sleep issue rating scale that can be used to assess the 'daytime sleepiness' of people with Parkinson's.

<https://www.parkinsons.org.uk/professionals/resources/epworth-sleepiness-scale-ess>

**Hospital anxiety and depression scale (HADS)** This scale can be used by health and social care providers to assess levels of depression and anxiety in people affected by Parkinson's.

<https://www.parkinsons.org.uk/professionals/resources/hospital-anxiety-and-depression-scale-hads>

**Impulsive and compulsive behaviour in Parkinson's - monitoring and information tool.** This tool is for use during discussions between a healthcare professional and a person with Parkinson's. It helps to raise awareness of and monitor impulsive and compulsive behaviour.

<https://www.parkinsons.org.uk/professionals/resources/impulsive-and-compulsive-behaviour-parkinsons-monitoring-and-information>

**The Modified Bradykinesia Rating Scale (MBRS)** assesses speed, amplitude and rhythm of movements.

<https://www.parkinsons.org.uk/professionals/resources/modified-bradykinesia-rating-scale-mbrs>

# Continued....

**The non-motor symptoms questionnaire (NMSQ)** can be given to people affected by Parkinson's in order to aid health and social care professionals to assess their non-motor symptoms.

<https://www.parkinsons.org.uk/professionals/resources/non-motor-symptoms-questionnaire-nmsq>

**Nil by Mouth' Medication Dose Calculators and Guidelines**

<https://www.parkinsons.org.uk/professionals/resources/nil-mouth-medication-dose-calculators-and-guidelines>

**The Parkinson's Disease Fatigue Scale (PFS-16)** is a patient-rated scale that measures fatigue: one of the non-motor symptoms associated with Parkinson's.

<https://www.parkinsons.org.uk/professionals/resources/parkinsons-disease-fatigue-scale>

**This questionnaire assesses how often people affected by Parkinson's experience difficulties across 8 dimensions of daily living.**

<https://www.parkinsons.org.uk/professionals/resources/parkinsons-disease-questionnaire-pdq-39>

# Signposting at Diagnosis

Parkinson's UK provides information and support for anyone newly diagnosed with Parkinson's.

We've developed these resources to help you signpost people to this information at the point of their diagnosis.

<https://www.parkinsons.org.uk/professionals/resources/signposting-diagnosis>



# Exercise framework for professionals

We worked with people with Parkinson's, expert physiotherapists and exercise professionals to produce a Parkinson's exercise framework.

<https://www.parkinsons.org.uk/professionals/exercise-framework-professionals>

Moving medicine helps inform healthcare professionals to start up conversations about exercise

<https://movingmedicine.ac.uk/consultation-guides/condition/adult/parkinsons/>

Parkinson's UK Exercise Hub

<https://www.parkinsons.org.uk/professionals/exercise-hub>

# UK Parkinson's Audit - Transforming Care

**The UK Parkinson's Audit is the recognised quality improvement tool for Parkinson's services. It allows measurement of practice against evidence-based standards and patient feedback in a continuous cycle of improvement.**

<https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit-transforming-care>

# Get It On Time

The impact of not getting medication on time in hospital can be extremely debilitating causing stress, anxiety, immobility, severe tremors; and can be fatal in the worst cases.

The information and resources from the Get It on Time campaign can support people with Parkinson's with medicine management in preparation for a hospital stay. They can also support hospital and care home staff to make sure that patients and residents get their medication on time - every time.

Free of charge resources include:

- Get It on Time stickers
- Get It on Time laminated clock posters
- Get It on Time campaign posters

<https://www.parkinsons.org.uk/professionals/resources/get-it-time-resources-and-campaign>

<https://www.parkinsons.org.uk/get-involved/get-it-time>

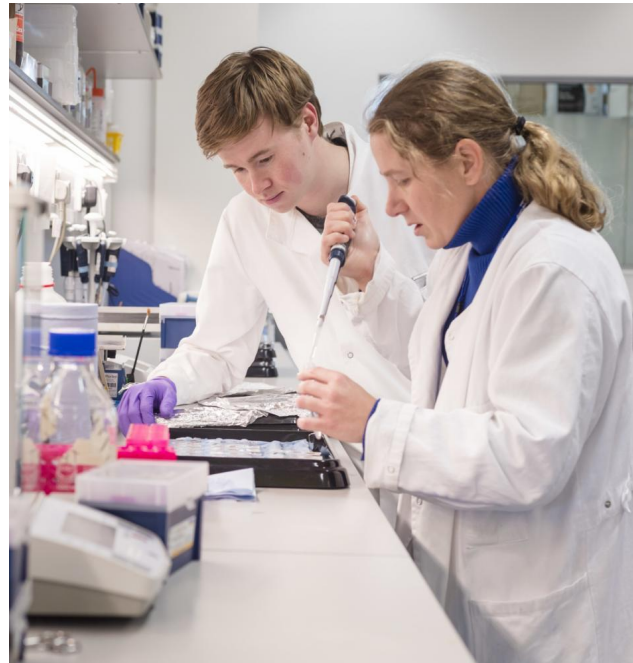
# Professional News

## News for Professionals

<https://www.parkinsons.org.uk/professionals/news>

## Excellence Network Working Groups

<https://www.parkinsons.org.uk/professionals/excellence-network-working-groups>





# Research

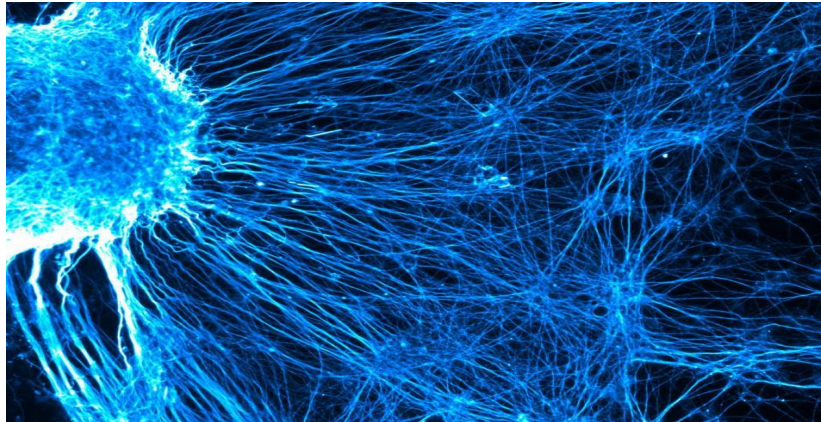
For over 50 years, Parkinson's UK has been driving forward research and we're close to major breakthroughs. By funding the right research into the most promising treatments, we get closer to a cure every day.

<https://www.parkinsons.org.uk/research/our-research-projects>

**Our research blog** <https://medium.com/parkinsons-uk/research/home>

**Research resources**

<https://www.parkinsons.org.uk/professionals/research-resources-professionals>



# Funding opportunities

**A list of organisations that provide funding for health and social care professionals for education, training and research.**

<https://www.parkinsons.org.uk/professionals/funding-opportunities>

Parkinson's UK bursary for health and social care professionals. This bursary has been offered to Parkinson's UK for application by health or social care professionals who want to attend a conference or undertake training and need some financial assistance. The bursary can be used to cover conference or course fees, travel or accommodation. You can apply for this bursary towards the cost of a ticket for the Excellence Network Conference.

# Excellence Network

**As a health or social care professional, you could work with someone affected by Parkinson's. The Excellence Network is here to help you provide better support, every day.**

**Join us to access resources, increase your knowledge of Parkinson's and collaborate with people affected by Parkinson's to transform health and care services.**

<https://www.parkinsons.org.uk/professionals/uk-parkinsons-excellence-net-work>

# THANK YOU

**Contact: Julie Wilson**  
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**07500 097222**

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