

Occupational therapy and Parkinson's

This information sheet explains what occupational therapy is, how it may help people with Parkinson's and how to get referred to an occupational therapist.

What is occupational therapy?

Occupational therapy can help people of all ages continue everyday activities when they become difficult to do.

An occupational therapist can help you carry on with a wide range of day-to-day tasks, so you can maintain your health and independence by:

- providing help and training on new ways to carry out daily activities such as bathing, dressing, eating, working and learning
- offering advice on adapting your home or workplace to meet your needs
- assessing and recommending equipment, such as mobility aids or wheelchairs, and advising on special devices to help around the home or workplace
- promoting your sense of wellbeing by helping you find ways to continue with hobbies and interests, such as gardening or sports

Occupational therapists are usually part of a local multidisciplinary team of healthcare professionals who work with people with various health conditions.

What will happen during my appointment?

During your first meeting, an occupational therapist will ask you about your home and work life, family and other roles and responsibilities, and the types of activities that you need and want to do. They will find out what is causing you difficulties and consider the effect of any other health issues on your day-to-day life.

You will be asked what your main priorities are, your usual lifestyle and what may be stopping you from carrying out daily routines. The occupational therapist will work with you to create an action plan including goals to be achieved over a course of sessions.

In some areas of the UK, occupational therapy services are provided to people in their own homes. In other areas, you may need an appointment to see an occupational therapist at a local hospital or healthcare clinic.

For people with long-term conditions such as Parkinson's, your occupational therapy service could include a course of rehabilitation sessions. What happens in these sessions will depend on what your individual goals and needs are and can involve your carer, if you have one. Sessions may take place in your home, where you can practice a specific technique for getting on and off your bed, for example. Appointments can also take place outside or at your workplace. If needed, the sessions can be used to help you choose and organise equipment or adaptations for your home or place of work.

How can an occupational therapist help me?

If you have Parkinson's, you may find it more difficult to do some of the everyday tasks and activities that you used to do easily. Occupational therapists understand that being able to perform these daily activities can be crucial to your health and sense of wellbeing.

Your occupational therapist may show you different ways to do a difficult task more easily, or give you advice about using strategies, techniques, gadgets, or equipment and new technologies where you need them. They may suggest practical changes, such as rearranging your furniture at home to make it easier to move around an awkward area. They can also advise you about using other services or forms of support for you and your family or friends.

Specialist occupational therapists can suggest 'cues' that may help you perform activities and complete tasks more easily. A cue is a way to help someone complete a task by offering them a prompt.

Occupational therapists can also help you develop strategies to cope with tasks that may become a problem in the future.

Find out more: see our information sheets *Falls and Parkinson's* and *Communication and Parkinson's*.

Help with Parkinson's symptoms

You may experience fatigue with Parkinson's, and get physically and mentally tired more quickly. Your occupational therapist can review your daily routine with you to help you manage this symptom. They will look at planning and pacing yourself and include gentle exercise and relaxation techniques.

People with Parkinson's can also experience problems with communication, including changes in handwriting and difficulties with facial expression. Occupational therapists can advise on coping strategies to help with these symptoms.

If you have Parkinson's, you may experience anxiety. This may be due to changes in chemicals in the brain, which control and regulate your mood, or because of any concerns you may have about living with a long-term condition. An occupational therapist may be able to help you find strategies to deal with this symptom. They can also refer you to a mental health specialist if necessary.

“ I worked with a tradesman who needed to improve the use of his forearm and hand, so he could continue to operate tools effectively at work. We used some software that has different hand grips and settings to operate a range of games, which helped him increase his muscle strength and range of movement. ”

Fiona, Specialist Occupational Therapist

Find out more: see our information sheets *Fatigue and Parkinson's*, *Communication and Parkinson's* and *Anxiety and Parkinson's*.

Providing information and support

Occupational therapists can help you make choices by providing information and explaining the various resources, services and benefits that are available to help you maintain family life, work and leisure interests.

An occupational therapist can also make referrals to other services and organisations that offer treatment, support or help. Or, if you prefer, contact details and information can be provided so that you and your family or friends can make contact when you want to.

Transport

An occupational therapist can give you advice about issues such as driving and accessing other forms of transport, or how to get practical help to allow you to keep meeting work or family commitments. They can also tell you more about how to get help when using trains and airports and how to apply for a Blue Badge parking permit.

Find out more: see our booklet *Driving and Parkinson's*.

Choosing equipment

You should not buy any equipment, such as reclining chairs or mobility scooters for example, without speaking to your occupational therapist first, even if the person selling the equipment claims to understand the needs of people with Parkinson's.

If an occupational therapist thinks you could benefit from using a piece of equipment, they may be able to provide basic items on loan, free of charge. Independent information and advice on choosing equipment is also available from the Disabled Living Foundation. See page 4 for their contact details.

Wheelchairs are available for hire through the NHS or health and social care service. Your occupational therapist can refer you to the relevant service in your area.

Find out more: see our information sheet *Equipment and disability aids*.

Help with funding for adaptations

Occupational therapists can advise and help arrange funding for minor home adaptations if you need them, such as fitting grab rails and hand rails by steps and stairs.

Usually occupational therapists based in the social services, social work section, or health and social care services of the local authority, can give advice about more expensive home adaptations, such as stair lifts, or accessible bathing facilities. They may advise you on any funding available. However, major home adaptations, such as the installation of a level-floor shower (wet room) are often subject to means testing.

“As mum needed help, I requested a home assessment with an occupational therapist. She was a tremendous help to us. We were able to look at many aids and pieces of larger equipment. She helped us find a company that routinely installed bathrooms for people with disabilities that was local and very experienced in this field.”

Julie, whose mum has Parkinson's

Means testing is a way of measuring how much money you have, including your savings, to decide whether you should receive money from the government or local authority to help pay for something you need, for example a level-floor shower.

For more information about possible grant funding for major adaptations, see www.gov.uk/disabled-facilities-grants

Find out more: see our information sheet *Equipment and disability aids*.

How do I find an occupational therapist?

Occupational therapists are employed in a variety of places including local health services, health and social care trusts, social services departments, rehabilitation units, day centres, residential homes, private practice and, in some areas, specialist multidisciplinary Parkinson's teams.

You can usually contact an occupational therapist through your GP, your social services or social work department, or health and social care trust, to see if it is possible to arrange for an occupational therapist to visit you at home. You can also ask your GP, specialist or Parkinson's nurse to try to refer you to a rehabilitation unit if you need to see other professionals too.

Referral should ideally be to an occupational therapist with specialist knowledge of Parkinson's. This may not always be possible, but ask your GP, specialist or Parkinson's nurse about being referred.

You can also pay for private occupational therapy. If you're interested in finding a private occupational therapist in your area, you can contact The British Association of Occupational Therapists and College of Occupational Therapists. See below for their contact details.

More information and support

Disabled Living Foundation

0300 999 0004

helpline@dlf.org.uk

www.dlf.org.uk

British Association of Occupational Therapists and College of Occupational Therapists

020 7357 6480

reception@cot.co.uk

www.cot.co.uk

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services. You can find out more at parkinsons.org.uk/nurses

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

Visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.

Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

Angela Birleson, Principal Clinician, James Cook University Hospital, Middlesbrough
Fiona Dyer, Specialist Occupational Therapist, Chester-le-street Community Hospital, County Durham
Clare Johnson, Specialist Occupational Therapist, London Road Community Hospital, Derby

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**
If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

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Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to **Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**, or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in I care for someone with Parkinson's
 I have a friend or family member with Parkinson's I'm a professional working with people with Parkinson's
 Other (please specify)
-

2. Where did you get this information from?

- GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser
 Ordered directly from us Call to the helpline
 Other (please specify)
-

3. Has it answered all your questions?

- Yes, completely Yes, mostly Not sure Partly Not at all

4. How easy was it to understand?

- Very easy Easy Not sure Quite difficult Very difficult

5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot It helped a little No change It didn't help It made things worse

6. What is your ethnic background?*

- Asian or Asian British Black or Black British Chinese Mixed White British White other
 Other (please specify)
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you? Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions

Every hour, two people in the UK are 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

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk

parkinsons.org.uk



Last updated March 2015. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
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