



Parkinson's
Disease Society

Occupational Therapy and Parkinson's

What is occupational therapy?

Each day, people take part in a wide variety of tasks, activities, and family, work and leisure roles. Occupational therapy (OT) seeks to reduce the impact of health problems on day-to-day life by helping people to remain independent, maintain their interests and to adapt to changes in their abilities.

What can OT offer to someone with Parkinson's?

For people with Parkinson's, simple tasks and daily activities that could be done automatically before can become slower and more difficult to carry out. OT (also short for 'occupational therapist') can help improve the effectiveness of carrying out everyday tasks that are generally taken for granted, but may have become more awkward because of having Parkinson's.

OT aims to help you to overcome the effects of your symptoms in your day-to-day life. It can help you continue to carry out tasks such as fastening buttons and dealing with clothing, as well as eating and drinking. It can also help people cope better with work and leisure activities, including handwriting, managing paperwork and organising familiar routines.

In addition, OT can help if problems occur with walking, especially in busy places, or with getting in and out of bed, moving in bed, using steps and stairs and maintaining balance.

The National Institute for Health and Clinical Excellence (NICE) Guideline for Parkinson's Disease (2006) covers NHS services for people living in England and Wales and recommends that the need for referral to an OT is considered from the time at which Parkinson's is first diagnosed and at each regular medical review,

every 6–12 months, thereafter. For those living in Scotland and Northern Ireland, similar levels of service constitute good practice. For more details, visit www.nice.org.uk

What happens when someone is referred to an OT?

During the first meeting, an OT will collect details of the person's home circumstances, and family roles and responsibilities, and the types of day-to-day activities that they need and want to do. This is usually done by talking to the person with Parkinson's and, if agreed by them, with family or friends. The OT may ask to observe performance of actions causing difficulties and will also consider the impact of other health issues if Parkinson's is not the only problem.

The OT will be aiming to assess and identify the person's main priorities for improvements and find out what is preventing them from carrying out their daily routines and usual lifestyle. Then, in collaboration with the person who is being assessed, an individually-tailored action plan will be devised, including goals to be addressed over a course of one or more sessions.

Sometimes, OT services are delivered to people in their own homes. In other areas of the UK, appointments to see an OT may be available at a local hospital or healthcare clinic. For people with long-term conditions such as Parkinson's, a comprehensive OT service could include a course of rehabilitation sessions and, if needed, assistance in selecting and organising home adaptations.

The main ways an OT can help

Solving problems – working together to find easier ways of doing particular tasks.

Sometimes, an OT may teach how a different



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method can be used to help someone do a difficult task more easily. Advice about using gadgets, equipment and new technologies may be given where suitable. Suggestions may sometimes be made about practical changes, such as re-organising the furniture at home to allow easier movement around an awkward area. In other situations, an OT may advise about using a suitable service or other form of support.

Equipment, such as reclining chairs, should not be purchased without the advice of an OT, even if the person selling the equipment claims to have knowledge of the needs of people with Parkinson's. The PDS has heard from many people who have spent a lot of money on unsuitable equipment/furniture.

Independent information and advice is also available from the Disabled Living Foundation. To find out more, visit www.dlf.org.uk or call 0845 130 9177.

Providing information and support – OTs can help people to make choices, by providing information and explanations about the various resources, services and benefits that are available to help maintain family life, work and leisure interests. Advice can be given about issues such as driving and accessing other forms of transport, or how to get practical assistance to allow someone to continue to meet work or family commitments.

Other information provided may include details of how to get help when using trains and airports, or how to apply for a Blue Badge Parking permit. OTs can also advise on coping strategies to help with Parkinson's symptoms such as fatigue, handwriting changes, and communication difficulties.

In some areas of the UK, an OT may be identified as a 'key worker' or 'care co-ordinator' for a person with Parkinson's, to act as their first point of contact for future requests for help and information as their condition changes. (This type of support will be more widely available in the future, as new services to promote health and wellbeing are developed and become more widespread.)

Contacting other useful services – with a person's consent, an OT can make referrals to other services and organisations that offer treatment, support or help. Or, if preferred, contact details and information can be provided so that people with Parkinson's, their families or friends can make contact themselves when they want to.

Help with funding adaptations

OTs can advise about minor home adaptations where needed, such as the installation of grab rails and hand rails by steps and stairs. An OT may also be able to organise the supply of some basic items of assistive equipment on free loan. Some OTs (usually those based in the social services section of the local council) can advise about more expensive home adaptations, such as stair lifts, or accessible bathroom facilities, like the installation of a level floor shower.

Means-tested grants may be available to help with the cost of such major adaptations and an OT can help with getting in touch with the relevant people about this. For example, the Disabled Facilities Grant has a means test similar to the test for Housing Benefit, which is used to decide how much financial assistance can be made available. The assistance offered can vary up to 100% of the total cost, to a maximum of



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£25,000. For more information about possible grant funding for major adaptations, contact your local council's occupational therapy service. See *below* for how to contact an OT.

Specialist OT for Parkinson's

In some areas, specialist Parkinson's services exist, generally in the form of an out patient clinic, based within a hospital. These multidisciplinary Parkinson's teams have developed around the UK in recent years, usually under the leadership of a consultant geriatrician or neurologist with a particular interest in Parkinson's. Such teams are able to provide a holistic approach to managing the concerns of people who have Parkinson's. An OT working in this type of service is likely to have a greater awareness and understanding of Parkinson's issues and of effective management methods. Such specialist OTs are also able to act as a source of advice and education for colleagues about Parkinson's, and issues relating to daily living activities.

How do I find an OT?

To request an OT service, you may contact your local social services directly, who will then arrange for an OT to visit you at home. Alternatively, you can ask your Parkinson's specialist or GP to refer you.

Referral should be to an OT with knowledge of Parkinson's, if one is available. Where referral is made to a general, non-specialist OT, it is helpful to ensure that they are aware of the less evident Parkinson's symptoms, such as tiring quickly with activity, balance problems, and the tendency for symptoms and abilities to fluctuate during the course of the day.

OT services vary across the UK and may be provided by local council social services departments, NHS Community or Primary Care Trusts, Acute NHS Trusts, and in a few areas, as mentioned above, specialist multidisciplinary Parkinson's teams, including an OT, are available.

Advice and intervention provided by NHS health and social services OTs in the UK is free of charge, as is a range of basic items of equipment and some minor home adaptations to aid independence and safety. However, major home adaptations like the installation of a level floor shower etc, are subject to means testing.

How does OT help improve services for people with Parkinson's?

The College of Occupational Therapists, based in London, is responsible for the overall leadership and ongoing development of the OT profession in the UK. The College of OT is always keen to contribute to the development of national policies and guidelines when opportunities occur. Representatives from the OT profession took part in writing the NICE Guideline for Parkinson's, which describe best practice for the care and treatment of people with Parkinson's.

How are OTs trained?

It takes a minimum of three years to obtain a degree in OT. Training includes the study of anatomy, physiology, and a wide range of physical and mental health conditions. OT students learn about a broad range of treatment methods, and must complete a minimum of 1,000 hours of supervised 'work experience' during their course. OTs often train alongside other healthcare professionals, such



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as speech and language therapists, podiatrists and physiotherapists.

What information is available for OTs working with people who have Parkinson's?

There is a section for OTs about Parkinson's in the PDS publication *The Professional's Guide to Parkinson's Disease* (code B126), available free of charge (up to 49 items). Contact Sharward Services (contact details at the end of this sheet) for more information.

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Parkinson's Disease Society

215 Vauxhall Bridge Road, London SW1V 1EJ, UK

Tel: 020 7931 8080 **Fax:** 020 7233 9908

Helpline: 0808 800 0303 **Text Relay:** 18001 0808 800 0303 (for textphone users only)

(The Helpline is a confidential service. Calls are free from UK landlines and some mobile networks)

Email: enquiries@parkinsons.org.uk **Website:** www.parkinsons.org.uk

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To obtain any PDS resource, please go online to www.parkinsons.org.uk or contact Sharward Services Ltd, the appointed PDS Distribution House, at Westerfield Business Centre, Main Road, Westerfield, Ipswich, Suffolk IP6 9AB

Tel: 01473 212115 **Fax:** 01473 212114 **Email:** parkinsons@sharward.co.uk