

# Occupational therapy for people with Parkinson's

Second edition

Ana Aragon and Jill Kings

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## Foreword (second edition)

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Since the first edition of the occupational therapy guideline for people with Parkinson's was published, the Parkinson's community has marked the 200<sup>th</sup> anniversary of the publication of James Parkinson's *Essay on the shaking palsy*. While a cure remains elusive, progress has been made. New evidence has emerged and therapy has evolved, so updated guidance for occupational therapists is welcome.

The conception of Parkinson's as a disease of dopamine neurons causing motor problems is an outdated oversimplification. Non-motor symptoms, many of them described in the original *Essay on the shaking palsy*, may have a greater effect on quality of life than the motor symptoms. Many Parkinson's symptoms (hallucinations, postural instability, dementia, postural hypotension, constipation) do not respond to dopamine replacement therapy and alternative treatment approaches are needed.

This new edition builds on the previous edition. It includes advice and guidance from the diagnostic phase to end-of-life palliation. Further evidence on the importance of exercise in Parkinson's is presented. Guidance on the role of the occupational therapist in assessment and management of sexual dysfunction in Parkinson's is also now included.

In the foreword to the first edition of the occupational therapy guideline for people with Parkinson's, the difficulties of designing clinical trials for occupational therapy interventions were acknowledged; namely the interventions are highly individualised and patient-centred in nature, so choosing a single appropriate outcome measure is difficult. Nonetheless, the results of the PD REHAB trial were anticipated with cautious optimism. For many, the results of the trial were disappointing because, at first glance, it appeared to show that 'occupational therapy and physiotherapy' do not work in mild to moderate Parkinson's. But the trial needs more careful interpretation. Only those in whom the benefit of therapy was uncertain were included; thus those with greatest therapy need, those most likely to benefit from therapy interventions, may have been excluded. The therapy intervention studied was four hours of therapy that was not Parkinson's-specific and did not include much aerobic exercise. In retrospect, it is not surprising that this intervention did not improve activities of daily living. Obviously there are better ways of delivering therapy and this guidance provides a blueprint.

The guidance here is clear and concise. It will be welcomed by occupational therapists trying to help people with Parkinson's achieve their goals. It will also be welcomed by geriatricians and neurologists, who understand the limitations of medication and value the pragmatic problem-solving skills of their occupational therapy colleagues.

**Dr Rob Skelly FRCP**  
*Consultant Physician*  
*Royal Derby Hospital*

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## Foreword (first edition)

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It has long been recognised that people with Parkinson's want access to therapies. They recognise the benefits that occupational therapy, physiotherapy, and speech and language therapy can bring to their functional status and quality of life, and appreciate the way in which interventions are tailored to their specific activity and participation needs.

This individual approach, while valued by people with Parkinson's, has also presented obstacles to widespread recognition of the benefits of occupational therapy. Each individual with Parkinson's is unique; the combination of a range of physical, mental and emotional symptoms impacting on a specific physical, social and vocational environment means that a 'one size fits all' intervention with a single outcome measure is of limited, if any, value. Not surprisingly, there has been little consensus, few randomised controlled trials, and therefore little evidence to synthesise. As stated in the Cochrane review (Dixon *et al* 2007), 'there is inadequate evidence to evaluate the effect of occupational therapy for people with Parkinson's disease' but lack of evidence does not mean lack of efficacy.

All this is now changing. First, there is an increasing recognition that other types of evidence should be considered as well as the gold standard randomised controlled trial. Second, there is a growing consensus about the role of an occupational therapist in treating people with Parkinson's. And third, there is a large, multicentre randomised controlled trial starting, PD REHAB, funded by the Health Technology Assessment programme, which will examine the impact of occupational therapy and physiotherapy in people with Parkinson's.

Thus, this best-practice guideline is timely. It synthesises the available evidence, drawing on information from a range of sources, including an understanding of the pathophysiology of Parkinson's, theories of motor control, clinical trials, expert opinion and consensus, as well as experience gained in the treatment of other progressive long-term conditions. With this excellent document occupational therapists will have a resource that identifies the considerable evidence base for their treatments and intervention strategies; clinicians, as well as people with Parkinson's, will be able to argue effectively for the role of occupational therapy in the management of Parkinson's; and interventions will be easier to define and evaluate. The authors are to be congratulated for producing such a practical, relevant and accessible document.

**Dr Diane Playford**  
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Consultant Neurologist, National Hospital for Neurology and Neurosurgery  
Queen Square, London*

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# The perspective of a person living with Parkinson's

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This comprehensive document contains many ideas to help people achieve the best possible life with Parkinson's. It gives detailed explanations of the symptoms and difficulties encountered with Parkinson's.

Maintaining my self-confidence has always been important. Increased confidence encourages me to try new activities and to enjoy an active social life. The advice in this document should encourage people with Parkinson's to do more for themselves for as long as possible.

I was particularly interested in the advice concerning the newly diagnosed. In the past, these people would not have been offered an appointment with an occupational therapist. This document demonstrates that occupational therapists could offer significant help to the newly diagnosed and those who remain fairly active. It offers occupational therapists the relevant advice and information concerning the benefits, over time, of increasing activity, and of the potential to slow the progression of Parkinson's.

I was diagnosed with Parkinson's 10 years ago. Five years ago, the changes in my mobility, balance, flexibility and strength were all impacting on my life. I was determined to do something about it. For the past five years, I have exercised regularly and, in part, intensively. I have gradually built up to five hours a week of moderate and intensive exercise, as well as daily walking the dogs.

My levodopa medication is little changed over the past five years. My balance, flexibility, stamina and strength are much improved compared with five years ago. I have more energy. Intensive exercise has completely changed my life with Parkinson's.

If only I had known what intensive exercise could do, I would have started immediately upon diagnosis. Contact with an occupational therapist soon after diagnosis could encourage others with Parkinson's to start exercising immediately.

This document reassures me that there are many things that can help me as my Parkinson's progresses. This document will be valuable for health professionals, and for people with Parkinson's and their families. Occupational therapists could reduce the frustration that people with Parkinson's and their families experience every day. This would improve everyone's physical and mental wellbeing.

***Jane Rideout***



# Section A

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## Guidance development and background

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# The process of developing the guidance

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## i) Introduction

Parkinson's evolves into a highly complex condition with most people experiencing a personal combination of physical, cognitive and/or emotional symptoms. Such changes often lead to restrictions affecting a range of activities and limit participation in everyday life. Therefore, occupational therapists require access to knowledge and skills concerning Parkinson's and need to be aware of ways to identify each individual's key concerns.

This second edition aims to support occupational therapists to deliver care that is effective and underpinned by evidence when working with people living with Parkinson's.

## ii) What is new?

During the development of the first edition of this guidance, 'best available' evidence from neighbouring disciplines was used because of the paucity of specific research evaluating the impact of occupational therapy for people with Parkinson's. This evidence, and the subsequent best practice guidance, was then ratified via an expert group to develop the 2010 guide (see Appendix 2).

The last eight years have seen a rapid growth in the evidence base across a broad range of treatments for Parkinson's, including evaluation of the impact of occupational therapy. This evidence has informed the National Institute for Health and Care Excellence (NICE) *Parkinson's disease in adults* guideline (NICE 2017), which updates their recommendations about diagnosis, medical and non-medical treatments for people living with Parkinson's. Access to occupational therapy from the time of diagnosis is also highlighted in a set of five Parkinson's-specific Quality Standards (QS164, NICE 2018) available via this link <https://www.nice.org.uk/guidance/qs164> to describe high-quality care and priority areas for service improvement.

The Scottish Intercollegiate Guidelines Network (SIGN) has also published evidence-based recommendations about the *Diagnosis and pharmacological management of Parkinson's disease*, to support best practice in Scotland (SIGN 2010).

NICE identified 1,263 publications concerning occupational therapy and Parkinson's in a systematic search to inform the update of its national guidelines on Parkinson's (NICE 2017). Items identified were then screened by their titles and abstracts, and reviewed against the inclusion and exclusion criteria in the review protocol. This refinement led to 18 full papers being obtained for further examination. Of these, 17 studies were then excluded after being assessed as having an 'inappropriate study design or as being focused on physical therapy – rather than occupational therapy' and other similar reasons, and, therefore, failing to meet the strict eligibility criteria specified in the NICE review protocol (NICE 2017). The one remaining study evaluated further by NICE was a rigorous, randomised controlled trial of a short course of individually tailored, community-based, occupational therapy sessions that included both a family caregiver and person living with Parkinson's (Sturkenboom *et al* 2014, Sturkenboom *et al* 2015).

This study showed that ‘real world’ occupational therapy, delivered by therapists who had been trained in using a Parkinson’s-specific approach, provides value for money and functional gains that have positive impacts on quality of life. Benefits for both carers and people with Parkinson’s were shown using the Canadian Occupational Performance Measure to capture person-centred outcomes as the primary end point, when compared to control pairs who received usual care alone. This robust evidence provided by Sturkenboom *et al* (2014 and 2015) was deemed of sufficient quality to inform the 2017 NICE guideline update about occupational therapy. The two recommendations made by NICE about occupational therapy for people with Parkinson’s are presented at the beginning of Section B of this guidance.

### iii) Rationale, aim and target audience of the guidance

This occupational therapy best-practice guidance aims to:

1. Place the person with Parkinson’s and their family at the centre of all occupational therapy interventions.
2. Support occupational therapists in the holistic assessment and treatment of people living with Parkinson’s.
3. Introduce novel and condition-specific occupational therapy interventions.
4. Summarise and interpret the best available evidence to support best-practice occupational therapy intervention in the UK.

### iv) Peer and user involvement

This second edition has been peer-reviewed by members of the Royal College of Occupational Therapists Specialist Section – Neurological Practice. Nine responses were received and their comments were incorporated where relevant (see [Appendix 1: A1.2](#)).

An Expert Advisory group of three occupational therapists and a Consultant Physician, all with a special interest in Parkinson’s and related movement disorders and all currently working in the NHS, has subsequently reviewed the second edition, and their comments have been incorporated (see [Appendix 1: A1.3](#)).

Parkinson’s UK supported this update by reviewing and making comments on the draft text. Parkinson’s UK also invited people with Parkinson’s to comment on the second edition when the final draft was almost complete. The content of this guidance was then refined and updated accordingly (see [Appendix 1: A1.4](#) and [A1.5](#)).

The first edition of this document was also reviewed by a person living with Parkinson’s and revised following comments made (see [Appendix 2: A2.6](#)).

#### **Note on terminology**

Family members often provide the majority of care required by a person with Parkinson’s – independent paid or unpaid carers may then further support this. In this guidance, ‘family or caregiver’ is used as a generic term to describe all who supply formal or informal, paid or unpaid care. The term ‘Parkinson’s’ is used in preference to ‘Parkinson’s Disease’ throughout the majority of this document.

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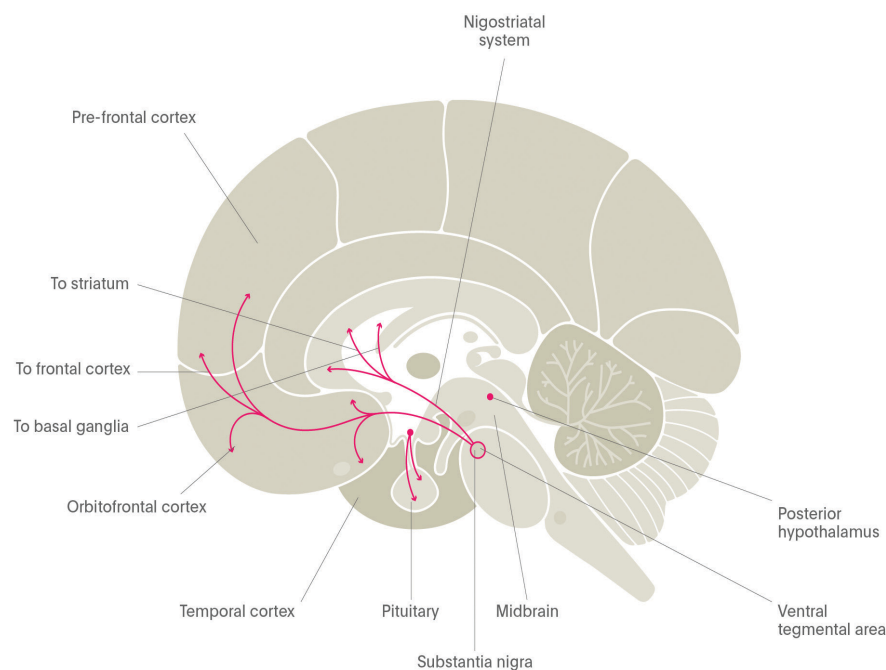
# Background

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## i) An overview of Parkinson's

Parkinson's is a chronic, insidiously progressing, neurological condition. The most common clinical features are believed to result from the progressive degeneration and death of dopamine-producing neurons in the substantia nigra, located within the basal ganglia (Schapira 1999). Additional changes in related brain regions and in other neurotransmitters, such as noradrenaline, serotonin, glutamate and GABA (gamma-aminobutyric acid) are also suspected of being involved in Parkinson's, but the exact roles and mechanisms of these structures and substances remain uncertain (Fox *et al* 2009).

Below, Figure 1 shows some of the main dopamine pathways in the healthy brain: projections arise from the substantia nigra to regions concerned with sensory stimuli and movement, cognitive function, reward and emotional behaviour and neuronal control of the hypothalamic-pituitary endocrine system.



**Figure 1:** Some of the main dopamine pathways in the healthy brain

Permission granted to download and use this image from The Lundbeck Institute Campus resource library online at: <https://institute.progress.im/en/image-bank>

### **The role of dopamine in the performance of skilled movement**

Dopamine is a major neurochemical messenger and acts as a 'fuel' that promotes the functions of a group of closely interacting structures collectively known as the basal ganglia (Obeso *et al* 2008). The basal ganglia are where dopamine is produced and are located deep in the lower regions of the primitive brain, just above and around the brain

stem. In Parkinson's, dopamine availability gradually reduces over time, and this lack of dopamine is believed to be one of the major factors in the development and progression of associated symptoms.

A major role of the basal ganglia is to orchestrate the performance of well-learned, voluntary and semi-automatic motor skills and movement sequences through the planning, preparation, initiation and sequencing of movements (Wichmann and DeLong 1996, Bradshaw *et al* 1998, O'Shea *et al* 2002). Dopamine also contributes to other cognitive processes, such as maintaining and switching locus of attention, drive and motivation, mood, problem-solving, decision-making and visual perception.

Functional abilities such as balance, walking, speech, handwriting, typing, fastening buttons, driving, and many other simple, or complex – though familiar – routine activities like playing a sport, or a musical instrument, are all skills which are usually controlled via the mechanisms of dopamine and the basal ganglia, once they have become well learnt.

Research using highly specialised brain-imaging techniques shows that initial learning of a novel motor task occurs in a range of locations in the cortex (higher brain) and elsewhere in the brain, with exact locations varying according to the mode of learning. Initially, motor skills are acquired mainly through activity in the cortex by application of conscious attention, with each new skill becoming well learnt, following repeated practice (Jeptner *et al* 1997a, Jeptner *et al* 1997b).

Basal ganglia involvement seems to become dominant after repeated practice has consolidated a specific motor skill, which can then be performed with minimal attentional resources and apparent ease. Eventually, well-learned motor skills can be performed with minimal use of conscious attention, allowing simultaneous performance of two or more well-known activities, while attention is focused elsewhere (Turner *et al* 2002).

The ability to perform several well-learned tasks simultaneously, which is often taken for granted, is made possible through the action of an efficiently functioning 'auto-pilot' facility, provided by the mechanisms of dopamine and the basal ganglia. A set of motor plans, relating to all motor skills that have been learnt by an individual, is stored in the higher motor cortex of the brain, with a lifelong potential for addition of new skills while the brain remains healthy and intact (Cools *et al* 1984, Robertson and Flowers 1990, Morris and Iansek 1997).

### **When do Parkinson's symptoms begin?**

Research suggests that when between 70 and 80 per cent of normal levels of dopamine supply have been lost, the typical motor symptoms of Parkinson's appear (Agid 1991, Schapira 1999). In retrospect, after diagnosis of Parkinson's is made, it may often be observed that Parkinson's-related signs and symptoms had been developing over the past five, 10 or even 20 years. The slow but continuing fall in dopamine production over the years accounts for the ongoing degenerative course of the condition.

### **Prevalence of Parkinson's**

Parkinson's is a common neurodegenerative disorder and the average age at diagnosis is older than 60 years. The incidence and prevalence of Parkinson's in the UK has recently been reviewed and as a result in late 2017 it was estimated that around 145,000 people in the UK have been diagnosed with the condition; that's about one in 350 adults in the UK. And, Parkinson's diagnoses are set to rise by nearly a fifth by 2025 (Parkinson's UK 2017).

The image below illustrates a healthy dopamine terminal, showing the stream of dopamine production and release. L-Tyrosine is converted into Tyrosine-derived dopamine, stored in synaptic vesicles and released from the axon terminals, which in turn derive from a nigrostriatal dopaminergic neuron. This process declines very slowly in people with Parkinson's.

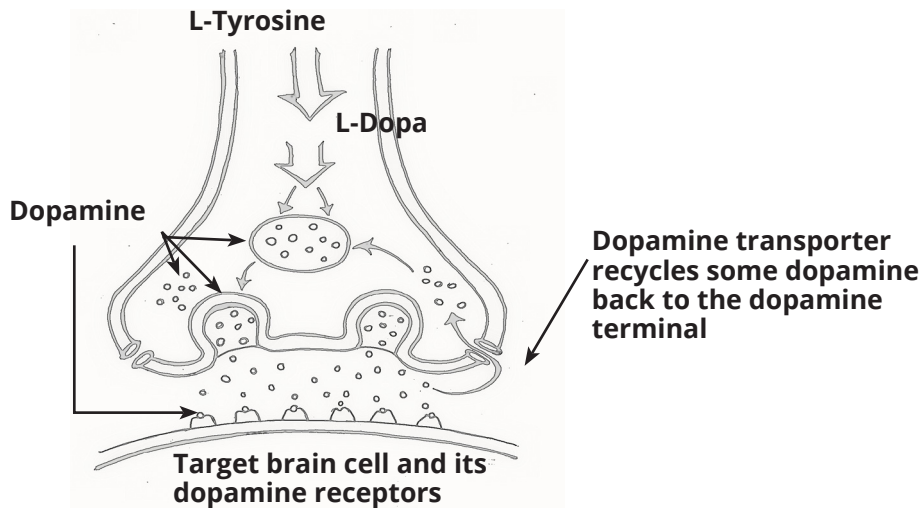


Figure 2: A healthy dopamine terminal Original image by Ana Aragon

### Diagnosing Parkinson's

Currently, no definitive scan or biochemical test is available to confirm the presence of Parkinson's. Therefore, diagnosis is made on the basis of clinical evaluation achieved through a combination of careful history taking and physical examination. The classic triad of motor symptoms seen in Parkinson's is also present in a range of related, but distinct, Parkinsonian disorders, some of which have quite different prognoses and require different medical management approaches to those used for Parkinson's. Use of the UK Parkinson's Disease Society Brain Bank criteria for its diagnosis is recommended to help with the differential diagnosis of Parkinson's (NICE 2017). These criteria are commonly used in many countries around the world.

Parkinson's is a highly complex, idiosyncratic, paradoxical and diverse condition. The main motor symptoms are:

- **Akinesia:** poverty of movement.
- **Bradykinesia:** slowness of movement.
- **Hypokinesia:** reduced scaling of movements, affecting many motor activities, including balance, co-ordination, speech, swallowing, handwriting, and facial expression.
- **Rigidity:** raised and sustained high muscle tone and stiffness, which may initially be asymmetrical, or limited to certain muscle groups.
- **Rest tremor:** involuntary fine movements, which usually begin in one hand or leg. This symptom only affects about 70 per cent of people with Parkinson's.

And eventually, also:

- **Postural instability:** balance and gait problems, which develop over time as Parkinson's progresses (Bilney *et al* 2003, Clarke 2007, Morris *et al* 2015).

Over recent years, however, the presence and impact of more than 45 non-motor symptoms, which may occur in combination with the more commonly recognised motor features of Parkinson's, have gained attention and growing recognition in the Parkinson's knowledge and evidence base. People with Parkinson's often report that their non-motor symptoms are causing greater distress and reductions in quality of life than the motor symptoms of their condition. It is, therefore, vitally important to consider the existence, impact and management of non-motor symptoms, as well as addressing the more obvious motor symptoms of Parkinson's. This great complexity of symptoms also suggests the need for a multidisciplinary approach for the management of people with Parkinson's, and for support for their carers (Chaudhuri *et al* 2006).

A pair of useful and simple screening tools has been developed to aid the identification of non-motor symptoms in people with Parkinson's. *The Non-motor Symptoms Questionnaire* (Parkinson's UK 2016a) is designed to be completed by a person with Parkinson's, a family member or caregiver, prior to a medical, nursing or therapy review. The companion *Non-motor Scale* covers similar non-motor symptoms, but is designed to be scored by a healthcare professional. Further information is available from the Parkinson's UK website (<https://www.parkinsons.org.uk/professionals/resources/non-motor-symptoms-questionnaire>).

### **Non-motor symptoms of Parkinson's**

Non-motor symptoms often develop in association with, and sometimes prior to, the main motor features of Parkinson's. Various combinations of non-motor features are often experienced individually as a separate and commonly fluctuating subset of symptoms. More than 40 non-motor symptoms are known to be associated with Parkinson's, yet each individual living with the condition will experience just a few or more, but not all of these.

The most frequently reported and problematic non-motor symptoms include:

- **Autonomic failure:** for example, postural hypotension (a sudden fall in blood pressure on rising from lying or sitting – consequently a risk factor for falls), excessive sweating or episodes of feeling very hot or very cold.
- **Continence problems** are also related to autonomic failure. Constipation; frequency and/or urgency of urine; delayed sphincter response when attempting to use the toilet; incomplete bladder emptying (which increases the risk of bladder infection); nocturia (frequency of urine at night) and reverse diurnal bladder rhythm (passing the majority of urine at night instead of during the day), are all commonly experienced.
- **Sexual health issues:** for example, erectile dysfunction or reduced libido. Hypersexuality may also develop as a side effect of some anti-Parkinson's medications. Satisfaction with sexual life is often a major determinant of self-rated quality of life, although this is seldom considered in health assessments.
- **Fatigue** of rapid onset following relatively short periods of activity or sustained use of a particular muscle group or limb/s. Some people with Parkinson's also report feelings of general fatigue and of mental fatigability. Reduced capacity for concentration

is often reported, even in the early stages of the condition.

- **Pain** that cannot be attributed to other causes may be related to Parkinson's in itself. Pain may be intense and prolonged, related to muscle rigidity, and may include dystonic muscle cramp (dystonia), affecting a part of the body such as a foot, the lower back, or one side of the neck (cervical dystonia). Parkinson's pain in any part of the body, especially during the later part of the night, may be closely associated with 'off phases' of the anti-Parkinson's medication cycle, and hence anti-Parkinson's medication adjustments may bring relief.
- **Sleep and night-time problems:** for example, insomnia; sleep fragmentation; vivid or disturbing dreams; and REM (rapid eye movement) sleep disorder, also known as REM sleep behaviour disorder (RBD), which causes dreams to be acted out physically, not uncommonly resulting in injuries to the person with Parkinson's or their bed-partner. RBD occurs as a result of brain stem changes that disrupt the normal sleep paralysis that occurs during dreaming episodes. Restless legs and nocturia are also common. Night-time immobility may lead to difficulties getting in and out of bed and a reduced ability to turn and move in bed.
- **Cognitive changes** may include dysexecutive-type problems, such as difficulties in planning, decision-making, problem-solving and organisation. Poor concentration, difficulty maintaining a train of thought and switching from one topic to another are common (Turner *et al* 2002). Additional problems can include difficulty recalling timeframes or sequences of events, or difficulties reading a clock face. Cognitive changes are seen in approximately 75 per cent of people with Parkinson's at the time of diagnosis, but are absent in some, possibly more so in those with a benign, tremor-predominant form of Parkinson's (Foltynie *et al* 2004). Visuo-spatial disturbances, including difficulties judging depth and width (e.g. at doorways), sometimes also occur (Lee *et al* 1998, Lee and Harris 1999 and 2001, Lee *et al* 2001). Changes in contrast sensitivity, colour vision and central processing of visual data may lead to problems with object recognition and the perception of motion. Visual dysfunction in Parkinson's may be important in the development of visual hallucinations and gait disorder (Weil *et al* 2016).
- **Emotional and neuropsychiatric problems:** for example, anxiety; depression; irritability; apathy and lack of motivation; and mood swings, with intense low or anxious feelings during 'off phases'. Visual hallucinations may be benign or distressing, and occur with or without psychotic delusional beliefs. Hallucinations, usually visual, may be associated with the condition itself, or be a side effect of anti-Parkinson's medications. Feeling that there is someone or something positioned behind oneself is also sometimes reported.
- **Dementia** affects around 30 per cent people with Parkinson's (Aarsland *et al* 2005). People with Parkinson's have a significantly increased risk of developing dementia. People develop Parkinson's at different ages, so some live with the condition longer than others, however, research suggests that at least 75 per cent of those living more than 10 years with Parkinson's will develop dementia (Aarsland and Kurz 2010).

In view of the highly complex nature of Parkinson's symptoms, a multidisciplinary approach is considered to be beneficial to both people with Parkinson's and carers in order to optimise quality of life and management of symptoms, and also to minimise the potentially draining effect of treating this very complex condition alone (Bhatia *et al* 2001, Chaudhuri *et al* 2006).



## Common terminology used

### • Parkinsonism

The main symptoms of Parkinson's can also be symptoms of other disorders. Conditions that produce these symptoms are known collectively as forms of Parkinsonism and include other related, but less common, conditions such as Lewy body dementia, multiple system atrophy (MSA) and progressive supranuclear palsy (PSP). (There are sometimes also called atypical Parkinsonisms, Parkinson's Plus syndromes/or disorders.)

### • Idiopathic Parkinson's disease

Parkinson's disease is the most common form of Parkinsonism and is sometimes referred to as 'idiopathic Parkinson's disease' (IPD), which means Parkinson's disease of unknown cause. Parkinson's disease is also referred to as Parkinson's, thus avoiding the false impressions of being contagious, or of being a terminal condition.

### • The 'on/off' syndrome

The terms 'on' and 'off' are used to describe the abrupt changes in mobility of some people with long-standing Parkinson's, who take levodopa medication. The 'on/off' syndrome can best be described as an unpredictable shift from relative wellness and mobility, being 'on', to a sudden inability to move, going 'off' – although 'off' to 'on' can occur just as suddenly. The speed of this shift can be so dramatic that some people have likened the effect to a light switch being turned on and off. Others use the term 'yo-yoing' to describe the same effect.

'On/off' effects do not just affect a person's mobility, however. They are often accompanied by changes in other symptoms, such as an increase in anxiety, visual disturbances, sweating or, sometimes, pain. Some people can find 'on/off' fluctuations very distressing, especially when they happen suddenly and unexpectedly. Others learn to judge in advance when an episode is likely to occur.

### • 'Start hesitation' and 'freezing'

'Start hesitation', also referred to as a motor block, occurs at the start of an action, for example, when beginning to speak, or start walking. 'Freezing' is a term used to describe the experience of stopping suddenly and without intending to do so, as may commonly occur while walking. Both lead to being unable to proceed for several seconds or minutes. Freezing of gait is reported as feeling as if the feet are 'frozen' or stuck to the ground, while often the top half of the body is still able to continue to move forward (leading to a risk of falling). While freezing episodes tend to last only a few seconds, 'on/off' fluctuations can continue for several minutes, or even hours. It is thought that different processes of the brain are involved for each phenomenon.

### • Dyskinesia

The exact cause of dyskinesia is unknown, but current thinking suggests this may be induced by pulsatile dopaminergic stimulation (pulse-like surges of dopamine availability at the neural synapses) brought about by long-term use of various anti-Parkinson's medications. Dyskinesia is a medical term for involuntary movements other than tremor, which are not intended or willed by the person concerned. These involuntary, sometimes fidgety, movements may include twitches, jerks, twisting or writhing movements, or a simple restlessness. Dyskinesias may appear in different forms, and their frequency and timing differ from person to person. Some people may have dyskinesias for most of the day, but for others they may only appear after taking an anti-Parkinson's tablet, or just before the next is due. Some people may barely notice their dyskinesias, while for others they may be a source of great concern. Often, involuntary

movements can be more upsetting to an observer than to the person experiencing them. 'Peak dose' dyskinesia, occurring about 30 minutes or so after the last medication dose, is the most common type of dyskinesia and may improve with medication adjustment.

## ii) Medical and surgical interventions

There is currently no cure for Parkinson's. At present a wide range of drugs can be used to try to control the symptoms experienced. This is done by:

- Increasing the level of dopamine that reaches the brain.
- Stimulating the parts of the brain where dopamine works.
- Blocking the action of other chemicals, such as enzymes that break down dopamine within the brain.

A well-tailored, regularly reviewed and adjusted medication regime can reduce the severity of symptoms dramatically but, as the years pass and the number of healthy dopamine nerves decline, medication may become increasingly ineffective. Once a dose of anti-Parkinson's medication has been absorbed, with the effect of raising levels of dopamine availability within the brain, the dose of medication is said to have 'kicked in', or the person is said to have 'switched on'. Section 1.3 of the 2017 NICE guidelines recommends treatment with levodopa (L-dopa) if the person with Parkinson's has functional impairment resulting from motor symptoms.

At first, most people treated with L-dopa three to four times a day have a good response. As time passes, the effect of the medication may seem to 'wear off' before the next dose is due. Later, dyskinesias may occur and response to doses may become unpredictable. Onset of action of medication may be delayed or a dose may not work at all. Gastroparesis (delayed emptying of the stomach) and protein-rich foods can interfere with L-dopa absorption.

Together wearing off, delayed 'on', dose failures and unpredictable 'on/off' episodes are sometimes termed motor fluctuations. Motor fluctuations or dyskinesias occur in 50 per cent of people with Parkinson's within five years of starting L-dopa treatment (Nutt 2001, LeWitt 2008). At this stage, effects of medication tend to become less smooth, with increasingly dramatic contrasts in abilities to move, speak and think. Regular reviews, at least every six to 12 months, are recommended to help fine-tune medication regimes for as smooth a control of symptoms as possible. The need for referral to other healthcare professions such as occupational therapy, physiotherapy, and speech and language therapy should also be considered at diagnosis and during regular reviews (NICE 2017).

### Commonly used medical treatments

- **Levodopa** has been the standard symptomatic therapy for Parkinson's for about 50 years. This is the precursor of dopamine, which is deficient in the brains of people with Parkinson's. However, levodopa (L-dopa) preparations eventually contribute to the development of motor complications in Parkinson's. These comprise abnormal involuntary movements, or dyskinesias, along with response fluctuations in which people experience a 'wearing off' of the drug's effects and/or unpredictable switching between the 'on' and the 'off' states. L-dopa remains the most efficacious drug

treatment for Parkinson's. It mainly works to improve motor function, but may also improve mood by stimulating dopaminergic nerves in the limbic system.

NICE currently recommends that levodopa be used as a symptomatic treatment for people with early Parkinson's, with the dose kept as low as possible to maintain good function and in order to reduce the development of motor complications (NICE 2017).

- **Dopamine** agonists directly stimulate the parts of the brain where dopamine works and mimic its function. To varying degrees, they have a longer duration of action than levodopa and may suit some people better in the early stages of the condition. The dopamine agonists tend to cause fewer dyskinesia and motor fluctuations but more impulse control disorder (e.g. hypersexuality, gambling) and more hallucinations. There may also be an anti-depressant effect for people with Parkinson's who take dopamine agonist medications. A new trans-dermal dopamine agonist (medicated skin patch) is now available, in addition to the traditional oral dopamine agonists.
- **Amantadine** promotes the release of dopamine from the nerve cells in the brain and enables it to stay longer at its site of action. It is also a weak NMDA-type glutamate receptor antagonist [NMDA = N-methyl-D-aspartate]. This action may explain its mild anti-dyskinesia action. Amantadine is mainly used for this anti-dyskinetic effect. This may also be useful to help manage fatigue. It is also used in the treatment of fatigue in multiple sclerosis. It has some anticholinergic activity but may cause confusion in the elderly. It was originally developed as an antiviral drug but is no longer recommended for the treatment or prevention of influenza.
- **Anticholinergics**, such as trihexyphenidyl, have some useful effect in reducing tremor, but minimal effect on rigidity and bradykinesia. They have fallen out of favour because of their predictable side effects: dry mouth, blurred vision, constipation and confusion.
- **COMT inhibitors** work by blocking an enzyme that breaks down levodopa, thus prolonging the action of levodopa doses.
- **MAO-B inhibitors** work by blocking the enzyme monoamine oxidase type B (MAO-B), which breaks down dopamine in the brain.
- **Acetylcholinesterase inhibitors for the treatment of Parkinson's Disease Dementia.** While motor problems are largely explained by a dopamine deficit, cognitive problems are largely explained by a cholinergic deficit. Cholinergic function is boosted by acetylcholinesterase inhibitors, which block the breakdown of acetylcholine. These drugs have been shown to be effective in Alzheimer's, Parkinson's disease dementia and Dementia with Lewy bodies (Rolinski *et al* 2012).

While these treatments have a definite benefit, the effect size is often small. Reductions in visual hallucinations can be impressive. Potential benefits have to be balanced against potential side effects, which include: tremor; urinary symptoms; nausea; vomiting; and dizziness.

### Surgical interventions

Over the past few years, there has been renewed interest in surgery to treat Parkinson's. Surgery is generally only used to treat people who have had Parkinson's for some time and whose symptoms are not controlled effectively by medication. It may also be used for people who are experiencing very troublesome dyskinesias.

### Examples of surgery for Parkinson's are:

- **Deep brain stimulation (DBS)**, which involves implanting a wire, with four electrodes at its tip, into one of three parts of the brain:
  - The thalamus (thalamic stimulation).
  - The globus pallidus (pallidal stimulation).
  - The subthalamic region (subthalamic stimulation).

A wire is then connected to a small Implantable Pulse Generator, which is planted under the skin, typically below the clavicle. When the stimulator is switched on using a magnet, electrical signals are sent to the brain to control or reduce Parkinson's symptoms. When the stimulator is switched off, the symptoms return. DBS controls or reduces specific symptoms. Most people who have DBS continue to need treatment with anti-Parkinson's medication. This is because DBS helps control motor symptoms, but does not stop the progression of the condition, or cure underlying Parkinson's-related pathology. DBS is a slight misnomer, in the sense that the stimulator blocks rather than stimulates at its site of action. It does the same thing as a destructive lesion (see more on lesioning below) but is reversible. DBS works best for L-dopa-responsive patients and for L-dopa-responsive symptoms. DBS allows L-dopa dose to be reduced so dyskinesia, motor fluctuations and other L-dopa side effects can be reduced. On average, DBS is used after 11–13 years of Parkinson's. Use of DBS has the potential to improve quality of life if used as soon as motor fluctuations occur (Schuepbach *et al* 2013). Current NICE guidelines (2017) recommend DBS be considered for people with advanced Parkinson's whose symptoms are not adequately controlled by best medical therapy.

- **Lesioning** techniques involve making selective damage to certain cells within specific areas of the brain. The target site is located with the aid of computer technology. An electrode is then inserted, with its tip at the optimum point. By passing an electric current through the tip, a small, destructive lesion is made. These lesions are known to have a beneficial effect on some of the symptoms of Parkinson's, but very little lesioning is now undertaken in the UK for Parkinson's, due to the permanent and irreversible nature of the technique, as compared to newer approaches such as DBS.

### New and future treatments and interventions for Parkinson's include:

- **Focused ultrasound:** this novel, non-invasive, therapeutic technology uses ultrasonic energy beams, focused precisely and accurately on targets deep in the brain. Focused ultrasound enables treatment without surgery and without damaging surrounding normal tissue. This treatment is not widely available as yet, but may become a more common therapeutic option in future if further research shows it can consistently produce a variety of therapeutic effects, improve quality of life and reduce costs of care for people living with Parkinson's (Magara *et al* 2014).
- **Gamma knife (GK) surgery** is a development in the application of lesioning, using one dose of gamma radiation through the skin and skull. The effects of GK surgery may take weeks or months to be seen, and the risks as compared to other surgical procedures are, as yet, unknown. The GK is not, strictly speaking, a knife, but several beams of gamma radiation focused on a target in the brain. GK surgery, also known as Stereotactic radiosurgery, is a treatment option for patients with tremor that does not respond to medications. While DBS has a proven track record, GK surgery

is non-invasive (no burr holes, no wires left inside) so has a low risk of infection and intracerebral bleeding. Patients reluctant to undergo standard surgical treatment or those unfit to do so might be suitable for surgery using gamma knife. There is good evidence for GK thalamotomy (80–100 per cent success rates for treatment of tremor) but results for GK pallidotomy for treatment of bradykinesia and dyskinesia are mixed, while side effects from damage to surrounding structures may take time to emerge (Elaimy *et al* 2010).

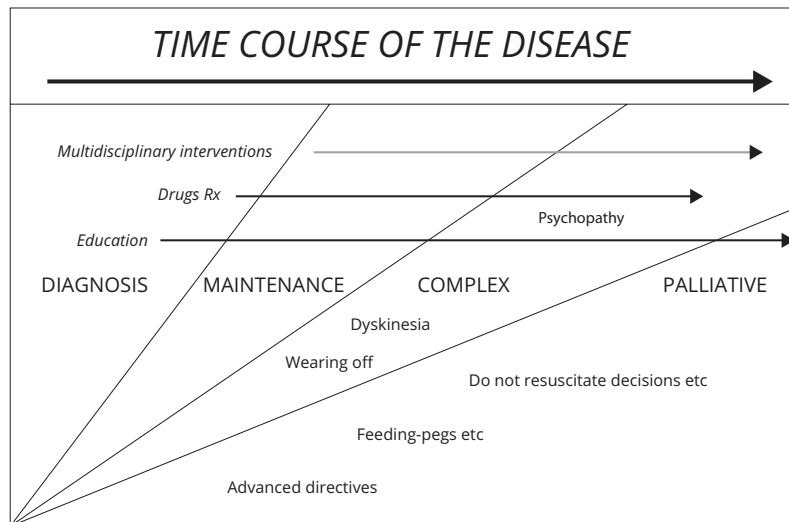
- **Stem cell and foetal brain tissue implants:** controversial research is under way to explore the use of stem cells or embryonic cells transplanted into the basal ganglia, because these cells have the capacity to develop into all cells found in the human body. Much more research is needed if scientists are to understand how stem cells work and how they can be used to produce a viable treatment for Parkinson's (Astradsson and Aziz 2016).
- **Gene therapy** is a new approach to treating medical conditions, in essence using genes as drugs. It works by introducing normal genes into the cells of people with certain disorders to overcome the effects of defective genes, which may cause, or have a part to play in the development of the condition. In the case of people with Parkinson's, gene therapy could be developed to re-programme cells to make more dopamine, for example (Stoessl 2014).
- **Improved methods for diagnosis** are also being explored – current efforts include testing of blood, saliva, skin secretions, the gut, eyes and even sense of smell. Meanwhile, hi-tech scans are becoming increasingly more sophisticated at imaging the brain, so as big data is collected this route may one day provide reliable diagnostic evidence.

### iii) Measuring disability and progression of the condition

The main motor symptoms of Parkinson's only appear after a 70–80 per cent reduction of dopamine has occurred. Dopamine production continues to fall over subsequent years, giving Parkinson's its progressive nature. Each person with Parkinson's has a different experience of the condition. The rate and character of the progression varies enormously from one person to another.

#### Categorisation

The original edition of *Parkinson's disease: diagnosis and management in primary and secondary care* (NICE 2006) and other publications (MacMahon and Thomas 1998) make use of four main categories to describe Parkinson's, as shown in [Figure 3](#) on the next page.



**Figure 3:** The four main categories to describe Parkinson's  
 Reproduced with kind permission (Thomas, MacMahon and Maguire 2006)

This framework guides mainly medical interventions over time, but can be misleading. Not all people with Parkinson's will progress through all four of the stages described, hence occupational therapy treatment interventions need to be based on individual problems with occupational performance, irrespective of the medical categorisation.

### Measurement tools

Various Parkinson's-specific standardised measures, mainly intended for use in a research context, have been developed in past years. Among other Parkinson's-specific items, functional mobility and activities of daily living (ADL) parameters are used within scales such as:

- **Unified Parkinson's Disease Rating Scale (UPDRS):** a comprehensive 50-question assessment of both motor and non-motor symptoms associated with Parkinson's. This measure has been designed and refined for completion by a person with Parkinson's or caregiver, with assistance by the 'investigator' to ensure completeness and clarity if needed (Goetz *et al* 2008).
- **PDQ39:** a 39-question Parkinson's quality-of-life measure (Peto *et al* 1995, Fitzpatrick *et al* 1997, Jenkinson *et al* 2008).
- **PDQ8:** an eight-question Parkinson's quality-of-life measure (Jenkinson *et al* 1998, Jenkinson and Fitzpatrick 2007, Jenkinson *et al* 2008).
- **Hoehn and Yahr:** a five-point disease severity scale, based on a mix of Parkinson's-related pathology, impairment and disability (Hoehn and Yahr 1967).

These measures provide quantitative data about the severity, stage, or impact of Parkinson's and are commonly used in research. They do not, however, take environmental, social, and contextual factors, or the personal relevance of the domains measured, into account.

There is currently no comprehensive, standardised, occupational therapy assessment or measurement tool specific to Parkinson's. In daily clinical practice, occupational therapists use a wide range of standardised and in-house assessment formats, with no

single uniform assessment currently being used by occupational therapists in the UK.

The following assessment/measurement tools are currently considered appropriate for occupational therapists to use with people living with Parkinson's:

- **Canadian Occupational Performance Measure** (COPM) (Law *et al* 2005).
- **Assessment of Motor and Process Skills** (AMPS) (Fisher and Bray Jones 2012).
- **Fatigue Impact Scale** (FIS) (Whitehead 2009).

#### iv) **The impact of Parkinson's on occupational performance**

The World Federation of Occupational Therapists (WFOT) statement on occupational therapy begins as follows:

*Occupational therapy is a client-centred health profession concerned with promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life.*

*Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement.*

(WFOT 2010)

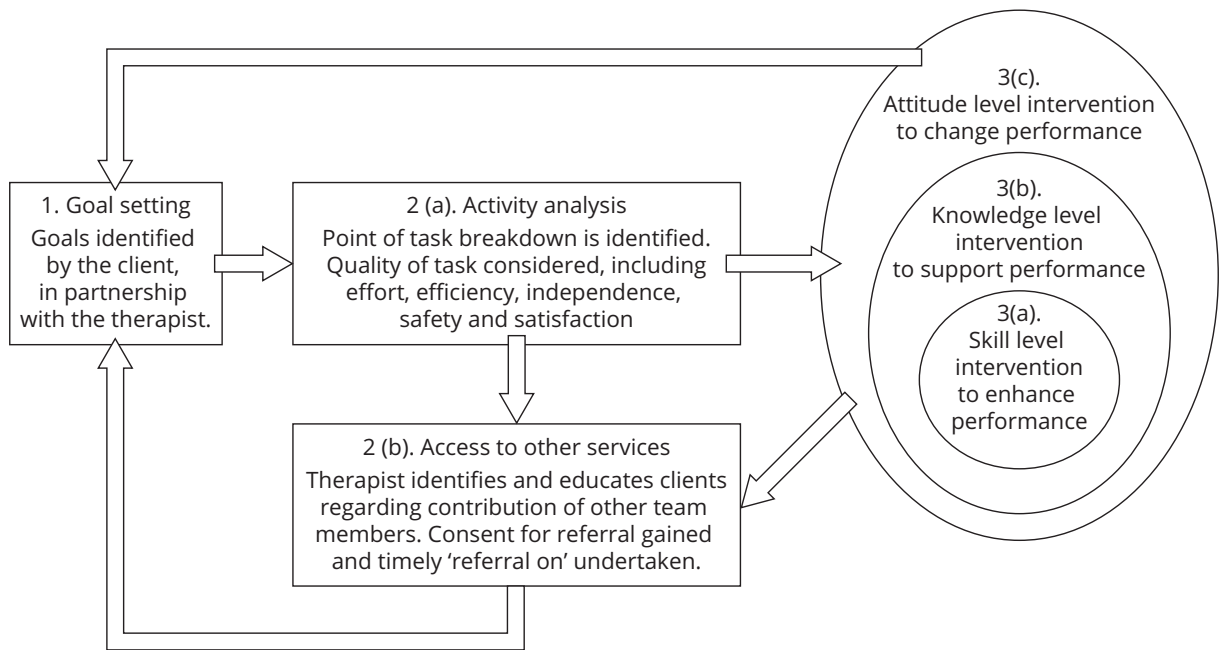
The *International classification of functioning* (WHO 2001) offers an internationally recognised language to describe the impact of disease on functioning.

There is limited published information about the processes and techniques used by occupational therapists when treating people with Parkinson's. Deane *et al* (2003a and 2003b) concluded from their surveys that current UK practice emphasises functional goals 'centred on independence, safety and confidence, including activities such as transfers, mobility and self-care' (Deane *et al* 2003b, p252).

#### **The principles of occupational therapy for people living with Parkinson's include:**

- Early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, develop appropriate coping strategies.
- Client-centred assessment and intervention.
- Development of goals in collaboration with the individual and carer, with regular review.
- Employment of a wide range of interventions to address physical and psychosocial problems to enhance participation in everyday activities such as self-care, mobility, domestic and family roles, work and leisure (NICE 2017).

The occupational therapy framework model developed by Jain, Kings and Playford (2005) can be used to scaffold interventions with people with Parkinson's and may be used dynamically as the condition progresses (see [Figure 4](#)).



**Figure 4:** The variety of occupational therapy interventions used to change skills, knowledge and attitude with people with Parkinson’s and support their carers. (See Sections 2, 3 and 4 of these good practice points and other guidance for further detail.) Reproduced with kind permission (Jain, Kings and Playford 2005)

Table 1, on the facing page, provides an overview of problems an individual with Parkinson’s may experience.



**Table 1: Common impairments of people with Parkinson's and their impacts on activities and participation**

Impairments	Problems with activity and participation
Increased stiffness and reduced trunk flexibility	Difficulty turning and moving impacting on bed mobility, all activities of daily living (ADLs), transfers, driving, social interactions, community living skills.
Gait/balance problems, e.g: <ul style="list-style-type: none"> <li>• Start hesitation</li> <li>• Shuffling gait</li> <li>• Slowness</li> <li>• Festination</li> <li>• Freezing episodes</li> <li>• Postural instability</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty taking the initial step to begin walking.</li> <li>• Shortened stride length and increased risk of tripping.</li> <li>• Reduced speed when walking.</li> <li>• Increased walking speed over time, may have difficulty stopping.</li> <li>• Feet appear to become rooted to the spot.</li> <li>• Problems with co-ordination when changing direction or turning.</li> <li>• Impaired balance, reduced saving reactions, increased risk of falls.</li> </ul>
<ul style="list-style-type: none"> <li>• Reduced manual dexterity, poor coordination and tremor</li> <li>• Micrographia</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty with manual and bi-manual tasks e.g. eating, fastening buttons, applying makeup, writing.</li> <li>• Handwriting may shrink and become illegible.</li> </ul>
<ul style="list-style-type: none"> <li>• Dysarthria</li> <li>• Poor breath support</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of voice clarity and decreased speech intelligibility.</li> <li>• Reduced volume of speech.</li> </ul>
Fatigue	Reduced endurance during all activities of daily living.
Cognitive changes, e.g: <ul style="list-style-type: none"> <li>• Bradyphrenia</li> <li>• Impaired executive function</li> <li>• Impaired attention</li> <li>• Reduced motivation</li> <li>• Depression</li> <li>• Anxiety</li> <li>• Hallucinations, perhaps with delusions and possibly dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Generalised slowing of thinking processes.</li> <li>• Reduced problem-solving and decision-making skills.</li> <li>• Reduced concentration and ability to maintain, or switch, attention.</li> <li>• Apathy, reduced interest and drive leading to social isolation.</li> <li>• Low mood, feelings of sadness or despair, leading to stress, fear and withdrawal, resulting in confusion and inability to maintain own safety.</li> <li>• Direct impact on ability to maintain role expectations particularly at home, work, leisure, and socially.</li> </ul>



# Section B

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## Guidance and good practice points

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# Quality improvement and drivers for change

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The 2017 NICE guidance (NG71) updates and replaces the original Parkinson's NICE guideline published in June 2006 and, while it does not explore specific occupational therapy interventions, it offers two new guidance statements regarding the nature and timing of occupational therapy as below. Recognition of the need for an occupational therapist with experience of Parkinson's and the value of occupational therapy for people in early stages of Parkinson's is a paradigm shift from common models of therapeutic intervention in the UK.

## **2017 NICE guidance (NG71) Occupational therapy recommendations**

1.7.5 Consider referring people who are in the early stages of Parkinson's disease to an occupational therapist with experience of Parkinson's disease for assessment, education and advice on motor and non-motor symptoms. [2017]

1.7.6 Offer Parkinson's disease-specific occupational therapy for people who are having difficulties with activities of daily living. [2017]

*<https://www.nice.org.uk/guidance/ng71/chapter/Recommendations#non-pharmacological-management-of-motor-and-non-motor-symptoms>*

Parkinson's UK has developed a range of tools for learning to assist occupational therapists working with people living with Parkinson's in any role or setting, to inform the implementation of recommendations about occupational therapy by NICE and to support use of this guidance.

Parkinson's UK is the support and research charity leading work to find a cure, and ensure no one has to face Parkinson's alone. The UK Parkinson's Excellence Network was established in 2015 by Parkinson's UK – to enable professionals involved in care to collaborate for service improvements and workforce development. A flexible Learning Pathway for occupational therapists, with resources to support clinical interventions and details of opportunities for self-guided or shared learning, is available within the Learning Hub area of the UK Parkinson's Excellence Network (<http://www.parkinsons.org.uk/professionals/learning-hub>).

## **The need for occupational therapists to have Parkinson's-specific experience**

To understand the many functional difficulties reported by people with Parkinson's, occupational therapists need a comprehensive understanding of the role and functions of dopamine and the basal ganglia. The diverse nature and range of motor and non-motor symptoms of Parkinson's manifest themselves to varying degrees and at varying times (Hariz 2011). Parkinson's is a fluid and fluctuating condition with anti-Parkinson's medications only lessening symptoms for temporary periods. Therefore occupational therapy intervention needs to advise and educate people about these facts and address task specific symptoms that emerge and persist in the presence of optimum pharmacological and/or neurosurgical treatments.

### The value of earlier occupational therapy intervention

Across the UK health and social care system there are typically three key points where Parkinson's-specific occupational therapy treatment may be accessed:

1. At diagnosis – where a definitive diagnosis is confirmed by a specialist.
2. Staying well – time after diagnosis where people need advice and education.
3. Increasing problems – the period where symptoms impact on activities and participation.

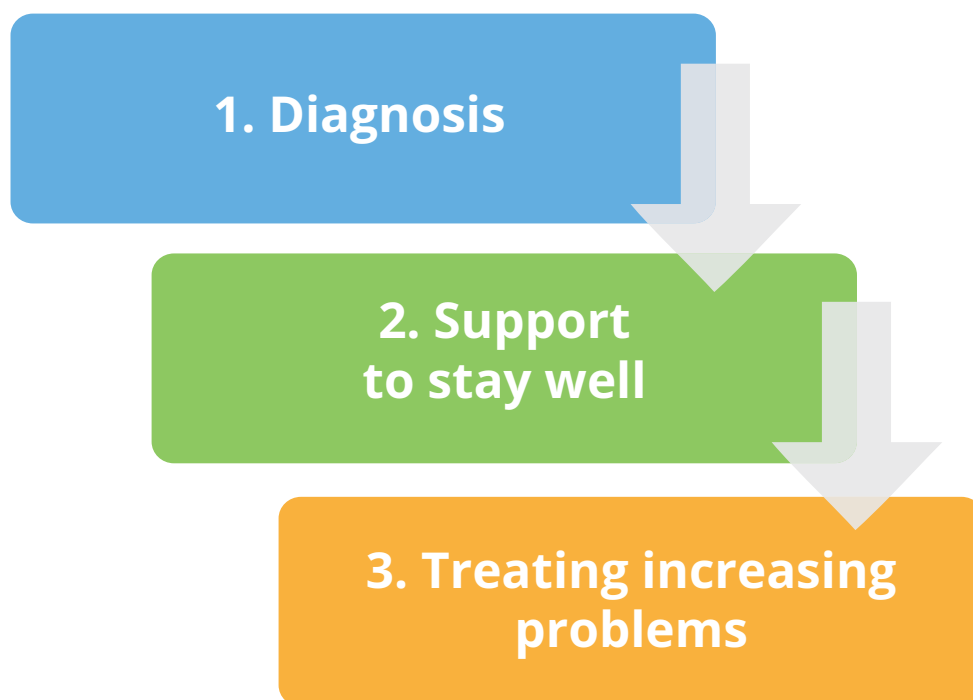


Figure 5: Earlier occupational therapy intervention: a paradigm shift  
Original image by Jill Kings

Standard models of occupational therapy see most referrals for occupational therapy treatment made at the third point, when the person has increasing occupational performance dysfunction that is apparent and problematic (PDS 1998, Foster *et al* 2014).

The 2017 NICE guidance for Parkinson's supports therapeutic input, delivered by an experienced occupational therapist from the earliest point in the patient journey, with an emphasis on 'staying well'. As per the findings by Jain, Kings and Playford (2005) knowledge, skill and attitude level occupational therapy interventions focused on education and advice, can be utilised to enable people to consider all their choices and to make decisions about how to stay well.

Therefore, this second edition has been restructured to reflect the significant change to the timing of when people with Parkinson's gain access to occupational therapy treatment. It is for individual clinicians, within their wider teams, to look at how they redesign their services to reflect the way contemporary treatment needs to be delivered now, and in the future.

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# 1

## Staying well

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The symptoms of Parkinson's typically develop subtly over many years, with progressive physical and cognitive decline having a cumulative impact on quality of life over time.

Parkinson's is usually diagnosed in people over the age of 60 and it is estimated that 18,400 new diagnoses of Parkinson's are made in the UK each year (Parkinson's UK 2017). It is less common for younger adults to develop Parkinson's in their early or mid-adult life. Younger adults can face particular challenges getting a diagnosis and coping with the condition at a time when the demands of life are often at their greatest. Getting a confirmed diagnosis of Parkinson's often takes months or years, and tends to take longer for people who develop the condition at a younger age. Particular challenges for younger adults with Parkinson's may include providing support for children and teenagers, needing help and information about work and money, and coping with the emotional effects of being diagnosed at a younger age.

Pre-motor symptoms of Parkinson's may develop slowly for several years or longer before the condition is diagnosed. Rapid Eye Movement (REM) sleep behaviour disorder, loss of the sense of smell (hyposmia), constipation, anxiety and depression have been suggested as features of the 'prodromal phase' of Parkinson's (Calnea *et al* 2008, Barber *et al* 2017, Reichmann 2017).

The updated guidelines for Parkinson's published by NICE (2017) recommend early occupational therapy assessment, education and advice, thus acknowledging the role of occupational therapy in supporting people with Parkinson's from the start of their condition (Jansa and Aragon 2015, AOTA 2014, Sturkenboom *et al* 2011).

Individuals affected by Parkinson's face not only the onset of physical impairments but also the psychosocial problems resulting from a body that may feel out of control. Initial problems may arise from subtle but notable early changes including:

- Reduced facial expression and gesticulation.
- Reduced clarity and/or volume of speech.
- Feelings of embarrassment, stress or frustration at being slow or clumsy.
- Stress resulting from coping with daily life or work.
- Being misunderstood by others who misinterpret changes in behaviour.
- Social withdrawal and reduced ability to participate socially.
- Isolation due to social difficulties and others' lack of understanding.

Wellbeing programmes to promote understanding of Parkinson's symptoms and encourage resilience and coping have an increasing evidence base and are offered nationally by various local Parkinson's UK groups. Models of support are based on

health education and are offered to people with Parkinson's and their family or carers, providing effective peer-to-peer contact and real-life self-help. Details of the Self-Management Programme, dates and locations, are available from the Parkinson's UK's website (<https://www.parkinsons.org.uk/information-and-support/self-management-programme>).

Following development with and for people with Parkinson's at the Oxford Parkinson's Disease Centre, in collaboration with the UK Parkinson's Excellence Network, the First Steps programme is also now being rolled out across the UK. From the point of being diagnosed, the programme aims to equip people with Parkinson's and their significant others to come to terms with the condition psychologically and to adapt positively to the changes it brings to their lives.

Ghahari and Packer (2012) evaluated the impact of a self-management programme including education and advice offered at the time of diagnosis for people with Parkinson's disease, multiple sclerosis, or post-polio syndrome. Participants reported improved wellbeing, reduced depression, lessened anxiety, lowered stress and improved social support. These findings consolidate earlier work by Mulligan *et al* (2011) who evaluated a self-management programme for people with Parkinson's. Participants expressed increased understanding of their condition and engaged in more exercise as a result of active involvement in the programme. Thus, Parkinson's-specific educational self-management programmes can provide a forum to learn about Parkinson's, meet others on a similar journey, and learn about living well with the condition (Mulligan *et al* 2011, Ghahari and Packer 2012).

## 1.1 Self-efficacy and resilience

In the early stages of adjusting to a diagnosis of Parkinson's, maintaining a sense of control and self-efficacy is key to staying well physically and emotionally (Turner *et al* 2002). People may try to avoid reliance on pharmacological intervention and spend time focusing on finding a cure rather than adapting to the impact the condition is having on their way of life.

Promoting self-efficacy is a key role for the occupational therapist, and supporting the person with Parkinson's and their family as early as feasible after diagnosis is fundamental. Offering education about Parkinson's, and why people experience a repertoire of difficulties with functional activities, is critical to supporting understanding and facilitating attitude level change over time.

Advice on key health promotion messages in the early stages of the condition includes:

- Maintaining social activities and networks, adapting rather than withdrawing from them.
- Maintaining physical fitness via cardio vascular exercise, e.g. walking, dancing, cycling.
- Maintaining a healthy weight.
- Stopping smoking and reducing alcohol intake.

Learning how to adapt rather than withdraw from activities can promote the development of positive coping methods, which the individual can draw on

throughout the condition. Maintaining work for as long as possible promotes financial independence, role retention and self-worth, as well as providing social contacts.

Good mental health and resilience are key for people living with long-term health conditions. Following diagnosis of any long-term neurological condition, it is common for people to report problems with sleeping, anxiety and low mood. These symptoms may be of greater concern to people with Parkinson's than early physical/motor symptoms of the condition. Furthermore, some people experience mental health issues as part of the condition and not just as a response to having a long-term condition. Recent work undertaken by The Neurological Alliance (2017) concerning the parity of esteem for people living with neurological conditions, suggests that people should be offered self-management resources to support their individual emotional, cognitive and mental health needs. These are available at: [neural.org.uk/store/assets/files/696/original/Parity-of-esteem-for-people-affected-by-neuro-conditions-2017.pdf](https://neural.org.uk/store/assets/files/696/original/Parity-of-esteem-for-people-affected-by-neuro-conditions-2017.pdf)

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote self-efficacy, resilience and positive coping methods with people with Parkinson's, it is recommended that they:

**G 1.1.1:** Assess participation restrictions affecting family, work, leisure and social roles as soon as is feasible after diagnosis.

**G 1.1.2:** Consider lifestyle planning and coping strategies to promote and maintain engagement in personally meaningful roles and activities, aid choice, dignity and continued participation in social life and recreational opportunities.

**G 1.1.3:** Offer client-centred education, advice and information to promote participation and self-management.

**G 1.1.4:** Signpost to local services, support and groups, including education and interventions to support health and wellbeing such as mindfulness training, meditation, cognitive behavioural therapy, relaxation classes and yoga groups.

## **1.2 Roles and relationships**

Changes in relationship dynamics are common when someone has Parkinson's and can occur at any stage of the condition. These, usually gradual, changes may affect both sexual and platonic relationships with partners, as well as relationships with siblings, children and friends.

Factors that may contribute to changes in roles and relationships include:

- Discrepancies in expectations between the person with Parkinson's and their partner following diagnosis.
- Role reversals where the partner feels overburdened and the person with Parkinson's feels that they have no role, leading to hostility, resentment, and feelings of loss and powerlessness.



- Loss of role as the main breadwinner, creating tension and financial worries in addition to loss of self-esteem and feelings of low self-worth for the person with Parkinson's.
- Withdrawal from normal family life due to communication difficulties, depression and mood swings.
- Fatigue, sleep disturbance and loss of interest in sexual relationships compounding the normal balance of a partnership, leading to stress and ongoing strain.

The impact of a loved one developing Parkinson's can be significant to close family and carers. Nevertheless, taking time to measure this impact can be overlooked. A recent study examining carer strain and the impact of being an informal carer for a partner with moderate to advanced Parkinson's found that support reduced carer strain and improved quality of life (Hand *et al* 2018).

For carers in England, *The Care Act 2014* (Great Britain. Parliament 2014) defines the duty local authorities now have in law to complete an assessment for carers and provide support for those that meet eligibility criteria. The Care Act Factsheet 8 supplies guidance on the law for carers (<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-8-the-law-for-carers>).

Although the whole healthcare team has a role to play in managing the maintenance of relationships, the occupational therapist often gains insight into these sensitive issues while spending time with the family in their own home. Clear and accessible information about the impact of Parkinson's on roles and relationships should be given as soon as is feasible after diagnosis, and issues around coping and adjustment dealt with sensitively and confidentially.

### **Guidance and Good Practice Points**

For occupational therapists aiming to support people with Parkinson's in coping with the impact on their roles and relationships, it is recommended that they:

**G 1.2.1:** Promote maintenance of normal roles, daily routines and social habits by suggesting and supporting task modification.

**G 1.2.2:** Review night-time routines to reduce avoidable sleep disturbance (see Section B).

**G 1.2.3:** Implement a fatigue management programme as required.

**G 1.2.4:** Act on concerns about the health and wellbeing of the family including sexual relationships, without delay, and with consent, for example by referring to a family support worker, counsellor, or specialist nurse.

**G 1.2.5:** Assess for carer strain and refer on for additional carer support as indicated.

## 1.3 Sexual wellbeing and intimacy

Sexual wellbeing is a fundamental goal for most adults, yet in professional settings the topic of sexuality is often ignored, or is a cause for embarrassment among staff. An illness such as Parkinson's, and resulting emotional and bodily changes, can cause people to feel unattractive and sexually undesirable. It is often an occupational therapist who is spending time getting to know each person's personal values and preferences. Therefore, an occupational therapist is well placed to offer a listening ear to concerns about sexual issues and intimacy, the effects the condition may be having on their partner and to offer useful advice and support.

### **Common effects of Parkinson's on sexual wellbeing**

Motor and non-motor symptoms of Parkinson's can contribute to sexual dysfunction. For example, some or all of the following may interfere with the expression of sexual and non-sexual intimacy: fatigue, depression, tremor, muscle rigidity, 'clumsiness', involuntary movements (dyskinesia), decreased sex drive (lowered libido), pain, bladder dysfunction, reduced facial expression, impaired speech, excess salivation and sweating.

A variety of sexual difficulties are recognised as non-motor symptoms faced by some people living with Parkinson's (Bronner 2011). Symptoms affecting sexual life may play a major role in the deterioration of quality of life of people with Parkinson's and their partners although, as these issues are rarely discussed, it remains uncertain how common they are.

Both women and men with Parkinson's may experience loss of desire, the negative effects of motor problems, and dissatisfaction with sexual life. Hypersexuality can also affect both men and women. Erectile dysfunction and problems with ejaculation are commonly experienced by men with Parkinson's. Meanwhile, women with Parkinson's may be troubled by loss of lubrication and involuntary urination during sex, while younger women may also have to contend with difficulties managing menstruation and complications affecting pregnancy and motherhood.

### **Supporting sexual wellbeing**

Given the high prevalence of symptoms that can adversely affect sexual wellbeing for people with Parkinson's, occupational therapists need to be able to pass on information and advice about useful approaches and strategies to assist people who wish to address their sexual concerns.

Simple screening questions, such as:

- *"Do you have any concerns about the way Parkinson's affects your sexual life?"* can be used to invite a person to reveal sexual concerns, if they wish.
- *"Have you recently felt less interested in sex, or more interested in sex than before?"* can be asked, to check for possible low libido or hyper-sexuality.
- *"Do you find it difficult to have sex when you try?"* is another way to start a discussion.

Some people who take dopamine agonists or other anti-Parkinson's medications experience a change in behaviour, such as hyper-sexuality, that can arise fairly rapidly, and if not checked can lead to serious personal and social consequences.

If specific problems are identified, appropriate management options can be considered (Preston and Edmans 2016). If a person with Parkinson's is troubled in this respect,

medication regimens should be reviewed for possible effects on sexual wellbeing in all cases.

### **Treating changes in an intimate relationship and difficulties related to sex and intimacy**

Education, counselling and specific suggestions about ways and methods to support sexual wellbeing should be provided by an appropriate healthcare professional such as a suitably informed and skilled occupational therapist, nurse, or social worker. Referral back to the doctor prescribing medication may also be required.

It is helpful for each person or couple to define their own goals regarding intimacy and sexual activity. If one partner no longer wants to, or cannot, have full sexual intercourse, hugging, holding hands, kissing, and touching are important ways of being intimate and showing affection to help keep a loving relationship alive.

If slowness of movement interferes with sexual relations, new positions that require less movement on the part of the person with Parkinson's can be explored. With imagination, creativity, and flexibility, some couples find new ways of relating intimately. A little planning can enhance the experience for both partners. For example, include candlelight, soft music, loving words and privacy to help set the stage for a satisfying experience.

Further advice and ideas can be gained by discussion with a trained sex therapist, who will have experience in addressing communication barriers and in helping a couple to find mutually satisfying ways of interacting together.

### **Compulsive, impulsive or hypersexual behaviours**

Hypersexuality is a type of impulsive and compulsive behaviour in which people find themselves increasingly preoccupied with sexual feelings and thoughts. Sexual impulses become more intense and might be felt at inappropriate times. Hypersexuality may also be accompanied by sexual delusions and hallucinations, such as imagining that a partner is having an affair.

For people with Parkinson's the risk of developing impulsive, hypersexual or compulsive behaviour is particularly high in younger adults with the condition. Long intervals between diagnosis and medical reviews, and failure by healthcare professionals to ask patients if they have concerns about their sexual wellbeing, can create the opportunity for considerable distress. It is estimated that about 13 per cent of people who take dopamine-based and/or dopamine agonist medications develop compulsive or impulsive behaviours. Relationship strain due to hypersexual behaviour may lead to a breakdown in communication.

Unfortunately, severe and unrecognised hypersexuality, or other impulsive or compulsive behaviours, can result in the eventual separation or divorce of a previously contented couple. Some couples may enjoy extra sex as a result of one partner's hypersexuality. But, for others it may become a difficult and distressing problem, particularly if the sexual desire feels 'out of control', or is out of character.

Hypersexual behaviour in people with Parkinson's is more commonly associated with men, earlier disease onset, dopamine-agonist therapy and depression. If impulsive, compulsive or hypersexual behaviour is identified, this unwanted reaction to medication should be treated by a suitably qualified clinician – primarily by diminishing the dose of the culprit medicine (NICE 2017, section 1.4).

### **Reproductive health of women with Parkinson's**

Of individuals diagnosed with Parkinson's under the age of 40, around half are women, who will be of child-bearing age. In a survey, a majority of menstruating women with Parkinson's reported that they experienced pre-menstrual worsening of their Parkinson's symptoms and changes in response to anti-Parkinson's medications (Tolson *et al* 2002). Other medications, such as oral contraceptives or hormone replacement therapy, as well as surgical treatments, can result in further hormonal changes. Thus, there might be benefit in adjusting medication regimens during the menstrual cycle in younger women with Parkinson's, who experience menstrual-related fluctuations of their symptoms.

There are few accounts of pregnancy in women with Parkinson's, so information in this area is somewhat scant. It is known that Parkinson's does not affect fertility in either women or men, and neither does it affect a woman's ability to carry a pregnancy to full term, or to produce a healthy baby.

Women with Parkinson's who plan to have a baby should be warned that the long-term impact on progression of the natural course of the disease is unclear and that their Parkinson's symptoms may increase during pregnancy. A careful review of medication for women planning to become or who are pregnant is important.

Although little data is available, it is suggested that some medications should not be used during pregnancy, and other drugs, although considered safe, should be used in the lowest effective dosage.

#### **Guidance and Good Practice Points**

For occupational therapists aiming to address sexual wellbeing and intimacy concerns of people with Parkinson's (Sandowski 1993, Bronner 2011, Parkinson's UK 2014, Preston and Edmans 2016), it is recommended that:

**G 1.3.1:** Several screening questions about sexual health and intimacy should be added into a holistic occupational therapy assessment process.

**G 1.3.2:** Time should be set aside to explore issues raised around sexual wellbeing and intimacy, with both the person with Parkinson's and their partner, towards identifying goals of treatment.

**G 1.3.3:** Occupational therapists should be aware of symptoms of dopamine-related hypersexuality, acting quickly to raise their concerns with the prescribing doctor.

**G 1.3.4:** Specific information to support the management of a variety of sexual dysfunctions in both men and woman with Parkinson's is accessed and shared in an understandable way.

**G 1.3.5:** Referral on to other healthcare colleagues such as specialist nurses, sexual health workers, counsellors and medical colleagues should be undertaken with consent, for advice regarding pregnancy and specific sexual dysfunction issues that require additional treatment.

## 1.4 Work

For people in full or part-time work, the diagnosis of Parkinson's will raise many questions. However, with appropriate management, some people may be able to work for some years, while others may leave the workplace early (Schrag and Banks 2006). Disclosing a diagnosis is a very personal thing and people differ in the timing of their disclosure for a variety of reasons. Telling an employer does not mean that a person's diagnosis has to be public knowledge, although giving some information to colleagues often leads to better support and assistance in the workplace. In most circumstances, disclosure of such personal information is the responsibility of the person concerned. However, if a situation warrants, then an occupational therapist could undertake the role of a 'work coach' with or on behalf of the person with Parkinson's. Consent and confidentiality issues should be discussed, agreed and recorded before such action is taken.

If having Parkinson's may have an impact on health and safety in the workplace, the employer needs to be informed so that a risk assessment can be jointly carried out and any reasonable adjustments put in place. This would need to be reviewed on a regular basis with the occupational therapist having a pivotal role in such reviews and recommendations.

Work retention is a growing area for occupational therapists and there is an increasing body of research indicating the positive benefit of vocational input for people with progressive neurological disorders (Sweetland *et al* 2007). The *Disability Discrimination Act 2005* was replaced in the UK (except Northern Ireland) by the *Equality Act 2010* (Great Britain, Parliament 2010). This Act places greater onus on employers to support disabled employees. Further information about work retention programmes and practical employment support is available from the Department of Work and Pensions (<http://www.dwp.gov.uk>).

As the condition progresses, a person with Parkinson's may need to give up work completely, earlier than they would have done if not diagnosed with Parkinson's. This may be because working with Parkinson's is becoming too difficult and the individual needs to concentrate their limited energy on other aspects of daily life.

If an employee is considering retiring due to poor health, they should be encouraged to talk to someone about the decision. This may be a family member, trusted friend, counsellor or others who have gone through retirement (Parkinson's UK 2018).

### Guidance and Good Practice Points

For occupational therapists aiming to address work-related issues with people with Parkinson's, it is recommended that:

**G 1.4.1:** Support and information about work retention initiatives should be offered to enable diagnosis disclosure at the right time for the individual.

**G 1.4.2:** A realistic assessment of whether an individual can safely and feasibly return to work should be offered. The occupational therapist should provide a link between the person with Parkinson's, their workplace and government services such as Disability Employment Advisors and the Access to Work scheme, as required.

**G 1.4.3:** Guidance about the employer's role and responsibility under the *Equality Act* (Great Britain. Parliament 2010) should be given to the employer by the occupational therapist with the consent of the person concerned.

**G 1.4.4:** If practical problems are being experienced at work, a work assessment visit should be undertaken without delay, to fully establish key physical and cognitive difficulties.

**G 1.4.5:** Recommendations should be made regarding reasonable workplace adjustments required to enable the person with Parkinson's physically and cognitively to undertake their job, for example changes to role content, hours of work and expectations.

**G 1.4.6:** If the person with Parkinson's decides to stop working, the emotional, practical and financial impact should be explored and discussions held with employers, human resources and/or trade unions, to establish the most favourable terms and timing.

## 1.5 Social, recreational and leisure activities

Both the physical and mental health benefits of social interaction and physical activity are well established (NICE 2008). Given the risks of social isolation reported by people with Parkinson's (Turner *et al* 2002), occupational therapists offer a unique contribution to facilitating a sense of satisfaction, achievement and enjoyment of daily life for those with whom they work.

Studies looking at the neuroprotective effects of exercise and activity-based interventions for people with Parkinson's are increasing (Stallibrass *et al* 2002, Crizzle and Newhouse 2006, Hackney *et al* 2007, Fisher *et al* 2008, Dibble *et al* 2009, Hackney and Earhart 2009, Hackney and Earhart 2010, Li *et al* 2012, Pohl *et al* 2013). Although many of these studies can be critiqued for their design, overall findings point towards significant benefits of participating in regular physical activity for people with Parkinson's.

Physical activity has recently been flagged by NICE in Recommendation 1.7.2 on Physiotherapy and Physical Activity (NICE 2017). For people recently diagnosed with Parkinson's who are seeking to slow the progression of the disease, truly challenging exercise regimes are required. The neuroprotective impact of intensive exercise (sometimes known as re-calibration training) is the premise of high-intensity exercise techniques such as PD Warrior (<https://pdwarrior.com/professionals/>).

Occupational therapists can explore exercise and physical activity routines in their assessment of people with Parkinson's and where indicated, can motivate adoption of regular high-intensity exercise. The Parkinson's UK Exercise Framework is a useful online resource to support the choice of exercise styles to suit the individual and their symptoms. This framework gives key messages for professionals and outlines a blend of styles, types and high intensity exercises that can be used to help people stay active over the course of the condition. Information is available from the Parkinson's UK website (<https://www.parkinsons.org.uk/professionals/exercise-framework-professionals>).

In addition, there is a rapidly expanding evidence base outlining the nature, intensity and dosage of exercise programmes evaluated in formal trials (see, for example, Frazzitta *et al* 2015, Allen 2015). Recent evidence demonstrates the benefits of both physical activity (Snider *et al* 2015) and mental exercise (Paris *et al* 2011) for people with Parkinson's. Similar benefits are also believed possible for people with other neuro-pathologies such as Alzheimer's disease.

Physical activity or exercise that is cognitively complex appears to be more beneficial than equivalent movement of a repetitive and unchallenging nature. The cognitive element of exercise appears to enhance memory by way of regular priming of decision-making during new learning. It has also been suggested that exercise appears to improve the speed of learning, by priming more efficient encoding (Gomez-Pinilla and Hillman 2013).

When considering the neuroprotective benefits of active lifestyle, people with Parkinson's should be encouraged to undertake daily exercise that is mentally, as well as physically, engaging, such as:

- a daily walk or pottering in a garden;
- dancing in a class or at home (if needed with support by holding onto a chair or an exercise rail);
- yoga or tai chi.

These and any other favoured recreations of a physical and mental nature, provide implicit opportunities for physical conditioning, pleasure, new experience and new learning.

Promotion of lifestyle changes involves: thinking, planning and finally taking action. Encouragement to start, maintain and restart physical and mental activity or exercise is a simple message, but its importance should not be overlooked by occupational therapists. Motivational interviewing techniques can be a useful tool to effect behaviour change (Clifford and Curtis 2015).

It is also encouraging to note that the more frail a person with Parkinson's is at the time of commencing a gentle exercise routine, the greater are the benefits gained. Therefore, it appears it is never too late to benefit from taking up a new form of enjoyable and engaging activity.

Parkinson's UK can offer advice and information to promote participation, signposting local services that provide appropriate activity and leisure opportunities for people with Parkinson's. Parkinson's UK also supplies peer support, education and other self-help programmes. Information about Parkinson's UK should be offered to the person with Parkinson's, with ongoing support provided to enable them to make choices about using such services in their own time.

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote social, recreational and leisure activities with people with Parkinson's, it is recommended that:

**G 1.5.1:** Social, recreational and leisure priorities should be explored as part of an early occupational therapy assessment. Goals can then be identified by using a

client-centred assessment tool such as COPM (Law *et al* 2005).

**G 1.5.2:** To promote mental and physical wellbeing, a person with Parkinson's should be encouraged to participate in pleasurable pastimes, and social and recreational aspects of daily life. To enable this, it may be necessary to initiate a comprehensive assessment of need for help with routine personal care or domestic tasks and access to community activities.

**G 1.5.3:** Promote participation (perhaps by signposting to local services) in appropriate physical activity, exercise and active leisure opportunities for people with Parkinson's. Aim for daily movement sessions lasting from 10 to 30 minutes. Moderate intensity activities that require engagement of balance, e.g walking or dancing, are useful. Include short periods of higher-intensity effort and aim to increase scope of the activity as progress is made.

**G 1.5.4:** A 'single task' approach should be adopted, which may enable greater success with tasks and hence aid satisfaction in achievements; for example, consider sitting on a stool to garden, rather than bending and reaching from standing.

**G 1.5.5:** Individualised cueing and fatigue management techniques should be incorporated into chosen leisure pursuits with supported practice in the environment in which the task will be undertaken.

**G 1.5.6:** Support should be offered to maintain or learn new computer skills, and help with training, adapting hardware and settings, sourced free of charge via the national charity AbilityNet ([www.abilitynet.org.uk](http://www.abilitynet.org.uk)).

**G 1.5.7:** Access to local facilities or services for people with Parkinson's should be signposted, with attendance at Parkinson's UK local groups and activities promoted ([www.parkinsons.org.uk](http://www.parkinsons.org.uk)).

## 1.6 Driving

All drivers with Parkinson's should be advised of their obligation to notify the Driver and Vehicle Licensing Agency (DVLA) and their car insurance company of their condition at the time of diagnosis (NICE 2017). As of March 2015, it is illegal in England and Wales to drive if you are unfit to do so because you are on legal drugs. Legal drugs are prescription or over-the-counter medicines. While the drugs listed under this law are not Parkinson's-specific drugs, people with the condition may be prescribed them to treat associated symptoms, such as anxiety, or for other health problems. More information is available from the Parkinson's UK website (<https://www.parkinsons.org.uk/information-and-support/driving>).

In January 2018, the DVLA issued updated guidance on the reporting of medical conditions including a diagnosis of Parkinson's. A driver can make their report online, by phone or by post using the appropriate form. Failure to do so can lead to a fine of up to £1,000 and may lead to prosecution in the case of an accident. Information is available from the DVLA website (<https://www.gov.uk/parkinsons-disease-and-driving>).



In Northern Ireland, the Driver and Vehicle Agency (DVA) regulates driving, and rules are similar to other parts of the UK. Information about declaring a medical condition to the DVA in Northern Ireland is available online (<https://www.nidirect.gov.uk/articles/how-tell-dva-about-medical-condition>).

There are a number of reasons why a person with Parkinson's may require an assessment of their fitness to drive over time, including reduced speed of response, rigidity inhibiting safe manoeuvres, daytime hypersomnolence, visual disturbances, undesirable impact and unpredictability of medication, etc (Parkinson's UK 2014). The responsibility for establishing an individual's fitness to drive lies with the DVLA. Once assessed, if permission to continue driving is granted, there will be ongoing planned reviews, generally every one to three years.

The RCOT Briefing on *Fitness to drive* provides occupational therapists with information on communicating concerns about a person's ability to drive safely. The Briefing is available for members to download from the RCOT website (<https://www.rcot.co.uk/practice-resources/occupational-therapy-topics/preventionpublic-health>).

## 1.7 Community living skills and outdoor mobility

It is now well recognised that Parkinson's often affects cognitive function even during the early stage of the condition (Williams-Gray *et al* 2009, Weintraub *et al* 2015) and that cognitive changes may restrict participation in social and community life.

Enabling people with Parkinson's to undertake activities outside the home has positive benefits on physical and mental wellbeing (DH 2005). However, a national members' survey by the Parkinson's Disease Society published in 2008 (PDS 2008) suggested that half of respondents wanted to undertake activities outside the home but could not. Reasons given included: feeling too unwell, tiredness, lack of public toilets, problems coping with busy streets, poor public transport, and difficulties with access to buildings.

Anxiety regarding loss of balance and falling, and concerns about freezing of gait in busy places such as supermarkets and town centres may discourage people with Parkinson's from participating in what were once regular pursuits (PDS 1998, APPG for PD 2009). If walking around shops proves difficult or effortful, most large shopping centres have a 'Shopmobility' service from which scooters may be rented. The social element of going out to do the shopping is lost when shopping online. Switching to online shopping for all needs, although practical if facilities exist, is not always a welcomed alternative.

A folding three-wheeled walking aid, perhaps with a built-in seat, bag or tray can offer stability and a place for occasional rests. A rubber ferrule-tipped walking pole, or pair of poles, a standard or an extra-long walking stick, can also provide some added support during outdoor activities. However, any walking aid should only be recommended following careful assessment in each case, preferably involving a physiotherapist with expertise regarding Parkinson's (Constantinescu *et al* 2007). It should be noted that some people with Parkinson's find walking easier without the use of any mechanical support, perhaps preferring the guidance of a companion's arm. Consideration should also be given to having a standby manual wheelchair for longer distances outdoors where this will enable continued social participation. Practising car transfers for those who travel as a car passenger can be used to promote confidence even when physical skills are still well preserved.

A selection of adaptive aids and equipment found to be of particular use by people with

Parkinson's is available from the Parkinson's UK online shop. (As many items are also more widely available, a search online may reveal a cheaper supplier for most products listed there).

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote opportunities to participate in community life and outdoor mobility for people with Parkinson's, it is recommended that they:

**G 1.7.1:** Suggest that people choose a time to leave the house when their medication is most effective to optimise outdoor mobility.

**G 1.7.2:** Ensure that external grab rails and path rails are in situ as required between the home and the public highway.

**G 1.7.3:** If it is important to the individual to maintain their ability to go out shopping, suggest avoiding busy times. Explore and address barriers and devise strategies for tasks such as: buying clothes, using supermarkets, managing at check-outs, purse and payment card management, coping with bagging goods, using 'scan and shop' (where available) to reduce unpacking and repacking of goods.

**G 1.7.4:** Encourage proactive planning of the exact route to be taken when walking outdoors. Once on foot, regular pauses should be used to reassess the immediate route ahead for obstacles, such as PAUSE-LOOK-PLAN-WALK, repeating as necessary.

**G 1.7.5:** Suggest walking along the side of the pavement near the shop fronts to avoid lamp posts and other street furniture, thus aiding the flow of walking.

**G 1.7.6:** Encourage proactive planning regarding the distance between toilets en route, and where required shops are in relation to the car park, bus stop, etc.

**G 1.7.7:** Provide information about the RADAR toilet key scheme.

**G 1.7.8:** Discuss using a manual wheelchair for outdoor use when walking outdoors becomes increasingly problematic.

**G 1.7.9:** Make a referral to the local wheelchair service if the person with Parkinson's is willing to accept an outdoor manual wheelchair.

**G 1.7.10:** Introduce Shopmobility schemes and undertake supervised practice as required.

**G 1.7.11:** Review outdoor mobility and car transfers at least every six months, and provide equipment as required, such as using 'power packs' for manual wheelchairs to assist the pusher, car transfer discs and/or a portable handle to aid transfers up and down from car seats.

**G 1.7.12:** Supply information about disabled parking schemes as required.

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# 2

## Specific strategies for initiating and maintaining movement

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Movement is the basis of human life and all the motor skills that have become well-learned by an individual are constantly held in suppression, until expression of a particular action or ability is required. The basal ganglia (fuelled by dopamine), in association with other regions of the brain, control the selection of a required motor skill and its activation by way of a process of dis-inhibition, to permit performance of a desired motor skill, movement sequence or task.

For example, think about travelling on a simple journey through a small house. This will involve activation of movements such as rising from sitting, walking straight ahead, turning corners, climbing and descending stairs. Each type of action is governed by a separate motor plan. The processes of activating and of changing smoothly from one motor plan or skill to another require the switchlike action of dopamine. The preparation, initiation, sequencing and timing of well-learned motor skills and movement sequences are all organised by the basal ganglia. This allows conscious attention to be focused on 'the task in hand' with well-known movements, e.g. walking or turning over in bed, being performed 'automatically' and with very little impact on conscious attention.

In the healthy individual, it is not uncommon for five or more tasks to be performed simultaneously and without the need for much conscious attention.

In the 'normal' brain, there is a brief pre-movement activity phase (lasting about 1/200th of a second) during which a specific well-learned motor skill or movement sequence to be performed is prepared for action, before it occurs. This activity happens mainly within a group of structures strongly linked to the basal ganglia region, including the pre-motor, motor sensory and supplementary motor areas located up in the brain cortex. Complex neural circuits form pathways with excitatory and inhibitory, or 'accelerator' and 'brakelike', feedback mechanisms, which act swiftly and at an unconscious level (Wichmann and DeLong 1996, Bradshaw *et al* 1998). Pre-movement activity ensures a smooth flowing performance, with appropriate finetuning of the calibration of an action or task, where that skill is already well learnt. Depending on the force required and circumstances of the action to be performed, a specific selection of the muscle spindles within particular muscle groups will be recruited to participate in the performance. This allows varying degrees of force to be expressed during performance of a semi-automatic (well-known) movement or motor skill.

As Parkinson's progresses, basal ganglia dysfunction linked to lack of availability of dopamine leads to organisational errors, with reduced ability to automatically select, plan, prepare for, sequence and 'run' desired well-learned motor skills or movement sequences. Neurochemical changes associated with Parkinson's appear to impair ability to learn, so grasp of new concepts or novel processes may also become difficult after the onset of symptoms in Parkinson's.

Impairment of the fundamental processes described above can be considered to be similar to 'autopilot failure'. This is expressed in Parkinson's as the typical slowing of thought and movement, errors of reduced scaling (amplitude) and disturbed regulation

of voluntary motor function, leading to the reduced flow of movements made by people with Parkinson's during task performance.

Cognitive and sensory attentional strategies seem to utilise alternative pathways for reaching a goal. Although the exact mechanisms being employed when using 'alternative pathways' are not yet fully understood, it is believed that messages are routed via non-pathological regions of the brain. This avoids the basal ganglia altogether, using short neural circuits within the higher regions of the brain, such as pathways used to respond to sensory input at a survival-response 'reflex-type' level.

Clinical experience and the wider knowledge base suggest that cognitive and sensory attentional strategies can be beneficial, inexpensive and simple to use. Therefore, they provide a valuable intervention resource for occupational therapists in the management of people with Parkinson's and may also sometimes be found to be of benefit to people with other related Parkinsonian syndromes.

### **Treatment principles for people with Parkinson's**

Current knowledge of the role of the basal ganglia and of its dysfunction as seen in Parkinson's provides a rationale for the use of disease-specific cognitive and sensory treatment strategies (Rubinstein *et al* 2002, Nieuwboer *et al* 2007, Parkinson's Disease Society 2007, Robertson *et al* 2008, Morris *et al* 2009). Increasing knowledge of the brain and the complex nature of Parkinson's supports these interventions and further work to produce applied and high-level evidence is under way.

For occupational therapy to be effective for people with Parkinson's, three key principles must be understood and incorporated wherever possible into all therapy interventions:

- 1. Conscious attention is required for the performance of well-learned motor skills and movement sequences** performed automatically prior to onset of Parkinson's. By employing a high level of attentional resources, as used for performance of a novel task, it appears that physical actions can be directed via voluntary control mechanisms, effectively bypassing lower brain involvement. The application of focused attention seems to reduce spontaneous reliance on dysfunctional systems, and enables people with Parkinson's to be in more direct control of their motor performance.
- 2. Consider the value of limiting multitasking and of practising instead only certain selected multitask activities.** Multitasking allows several well-learned motor plans to be performed simultaneously. This facility is in fact highly intricate and relies on the well-functioning basal ganglia acting as an 'autopilot system'. One of the paradoxical features of Parkinson's is that being stretched by multitask performance impacts most on the least attention-demanding or most automatic task. For example, standing balance is affected or gait deteriorates while talking. Therefore, sitting down when getting dressed, to write, or for other manual tasks, and to swallow tablets, eat or drink, may reduce the risk of falls and balance problems, or swallowing difficulties during performance (Yogev-Seligmann *et al* 2012, Brauer and Morris 2010, Canning *et al* 2008).
- 3. Encourage the use of cognitive and sensory cues and triggers to guide the flow of motor performance and ideas.** Cues work in real time and function as a compensatory mechanism that uses higher brain circuits, accessed without major disturbance, despite dopamine deficiency. Over a period of time (several years in many cases), a chosen method may become less effective. If this happens, another

phase of experimentation will be needed and usually involves switching to a different category of stimulus or 'cue'.

## 2.1 Intrinsic cueing techniques

For those in the early and middle stages of Parkinson's, several internally generated cueing methods can be taught to enhance functional ability (Morris 2000). Intrinsic methods may also sometimes be effective even in the later stages of the condition, although the teaching of their use will need to be simplified if introduced at this time. As with many areas of intervention described in this guidance, further evidence is keenly awaited to further support use of these techniques.

### **Positive attitude / emotional set**

Expectations of frustration and failure at the outset of engaging in a task can become common, where experience of poor performance reinforces such ideas. As the basal ganglia have strong links with the limbic system, which is associated with emotion, a constructive attitude and expectation of success ('I will...') may improve function if this idea is held in the mind at the commencement of performing an action. Emotional attitude can have a very strong influence on motor performance and it may be of great benefit to discuss this in some detail.

### **Mental rehearsal (Morris 2000)**

Imagining in detail the action(s) about to be performed before commencing the movement seems to compensate for the lack of pre-movement activity, which is seen in the normal brain immediately prior to commencement of movement, but which is less evident in Parkinson's. Remembering or imagining actions as a preparation for a challenging task can be done briefly, but must contain as much detail as possible. Imagining perfect performance is also necessary for this 'manual priming' to be beneficial prior to actual movement.

### **Internal dialogue (Farley and Koshland 2005, Maitra 2007)**

This form of intrinsic cueing entails talking through actions silently, using simple direct instructions, while actually doing the movements (as if showing the ropes to someone who has not done the task before). For example, when shuffling of gait is a problem silently chanting words, e.g. repeatedly saying 'big steps', can increase stride length dramatically. It is the nouns and verbs that seem to be the most effective. Alternatively, some people respond better to saying the commentary out loud to themselves, thus using an auditory-sensory pathway as well as internal cognitive mechanisms.

Building on this type of approach, a very structured rehabilitation technique where specific attention is paid to speaking LOUD and moving BIG has grown in popularity (Mahler *et al* 2015, Fox *et al* 2012).

### **Visualisation (Tamir *et al* 2007)**

Thinking of, remembering and imagining are other ways of describing this facility in a more accessible way. People vary in their modes of thought, some being very open to using their imagination, while others relate far more naturally to other methods. For example, where 'freezing' in doorways or other places occurs, visualising stepping over something like a log, or a transverse line (like at the end of a running track), can sometimes give sufficient stimulus to trigger restart of walking.

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote functional abilities with people with Parkinson's, it is recommended that:

**G 2.1.1:** the use of effective intrinsic cueing techniques should be trialled with the person with Parkinson's in a relevant environment and should be practised with all who provide assistance.

## **2.2 Extrinsic cueing techniques**

The use of external sensory stimuli may be an effective way to facilitate gait (Nieuwboer et al 2007, Morris *et al* 2009), enhance performance of other motor skills, and aid communication with people with Parkinson's. Application of conscious attention and concentration during performance is of paramount importance when using externally generated cues and triggers, just as with internally generated cues, as described above.

### **Visual environment**

The layout of the environment has a strong influence on the flow of mobility for people with Parkinson's. The repositioning of furniture to simplify the visual impact of its layout can enhance mobility around the home and other frequently used environments. Ideally, central (coffee) tables should be moved out to the side of the room, thus allowing direct access from armchair to door, and to TV or other frequently visited areas within the room. Patterned floors and carpets may present special challenges for people with Parkinson's, sometimes inhibiting walking in such an area altogether.

Avoidance of patterns and multiple colours in flooring is recommended where possible, to promote ease of walking around the home. If different coloured or textured flooring is required between two rooms to be used frequently by someone who freezes often at doorways, then the use of a staggered threshold, by continuing a floor covering through the doorway to end in the shape of a doormat inside the next room, may also be helpful. In cluttered, crowded and unfamiliar places, pausing to plan a route and negotiate obstacles safely, as far ahead as can be seen, may aid ease of walking. Further pauses to survey and plan again will be necessary as the next area comes into view.

### **Visual cues**

#### ***i) Floor markers***

Increased stride length can be facilitated by strips of coloured tape, e.g. bi-coloured hazard tape, or plain masking tape, applied to the floor in places where freezing or difficulty negotiating a turn in a corridor regularly occur. Strips of adhesive tape approximately 45 centimetres (18 inches) in length can be stuck to the floor in troublesome areas. Strips need to be of a colour contrasting with the surface below, and should be placed parallel at intervals to approximately match the individual's stride length (Martin 1967). Where a 90° corner or other turn is the problem, strips should be placed to 'fan' around the bend. It is not important whether the feet fall on or between the strips. They will only be effective, however, if they are seen and attended to during use. (Walking upstairs is rarely a serious problem for people with Parkinson's as the lines of the steps seem to act as cues to maintain the flow of gait.)

### **ii) Cue cards**

Brief written directions for a specific task can be used either as a prompt at the time of movement, or memorised and recited during movement to facilitate performance. Standard or individualised text may be used, depending on requirements, with well-sequenced keywords, appropriate for prompting the required movements. Below is an example of a simple dressing cue card (not to scale).



Cue cards are easily made and can be laminated for improved appearance and durability.

### **iii) Laser lights**

Laser lights on walking frames and canes are increasingly available and may be useful as visual cues particularly for those who experience freezing of gait (McCandless *et al* 2016).

### **Auditory cues**

Intrinsic cueing, using the sound of a person's own spoken voice can be used to initiate and maintain performance of a motor task or movement sequence. This form of cue is sometimes more effective than sub-vocal or silent self-talk in the later stages of the condition. Here, we seem to see voluntary, internally generated cues being relayed back into the brain via auditory pathways. Auditory cues may also be provided in a variety of other forms, as outlined below.

#### **i) Verbal commands (Behrman *et al* 1998)**

Concise instructions, spoken by a separate person (carer, therapist, etc.) may be used to cue (prepare for), trigger (initiate) and maintain the flow of motor skills and sequences. Speaking in a conversational tone, or too quietly, is much less effective and should therefore be avoided. Results can be instantaneous in those who are responsive to this form of auditory cue. Individual experimentation will reveal whether auditory cues are required to initiate a movement sequence alone, or if it is necessary to continue repeating the cues throughout the activity (especially as in the case of walking). Chanted commands such as 'One, two, one, two'; 'Left, right'; or 'Long steps...' can be repeated to increase stride length and so reduce shuffling of gait. Rising from sitting, once poised and ready, is often difficult to initiate in Parkinson's; in such cases a verbal command such as 'One, two, three, stand' can act as a preparatory cue, and then trigger getting up. Other verbal commands can be devised to suit individual needs. Always keep commands clear, brief, and well-sequenced. With a little training and practice, family and/or carers may be able to progress from giving physical assistance with transfers and walking, to giving assistance using verbal prompts alone.

### **ii) Metronomes**

Studies using metronomes have been conducted for overcoming start-hesitation, or ignition-failure, as this has been called, and freezing, or motor blocks, occurring during movement (Lim *et al* 2005a, Lim *et al* 2005b, Rochester *et al* 2005). These studies show encouraging responses to the sound of a metronome where the individual is sensitive to this form of stimulus. Compact, commercially available metronomes can be worn clipped to a belt or waistband. A small earpiece linked by a fine flex is sometimes used in conjunction with a metronome. A small inexpensive in-ear metronome is also now available. In some cases, the beat-rate was set at 110–120 beats per minute for women and at 105–115 beats for men, corresponding to the usual cadence rate for normal adults. To overcome start-hesitation, walking was triggered by turning on the metronome and concentrating on stepping in time to the beat. Once walking had been facilitated, the metronome was turned off (if left on it may have become a distraction that could have impeded progress). If considering purchase of a metronome for use as described, remember to consider design and dexterity requirements when making your choice. Metronomes may be purchased from suppliers of musical instruments and accessories.

### **iii) Music and rhythm**

Beneficial effects of music and rhythm for helping to trigger and maintain the flow of voluntary movements have been noted by some physiotherapists, who include dancing (e.g. waltz style) to music at the end of group exercise classes for people with Parkinson's. Use of this mode of auditory stimulus may become more popular in the future. Recent evidence supports the benefits of tango-dancing to improve the mobility and quality of life of people with Parkinson's (Hackney *et al* 2007). Conductive Education, originally developed as a system of training for children with motor disorders, aiming to reduce dependence on mobility aids, also employs rhythmical facilitation and is used by some people with Parkinson's for management of difficult movements and activities (see more online at <https://conductive-education.org.uk/adult-services/parkinsons/>).

#### **Guidance and Good Practice Points**

For occupational therapists aiming to promote functional abilities with people with Parkinson's, it is recommended that:

**G 2.2.1:** The use of effective, extrinsic cueing techniques should be trialled with the person with Parkinson's in a relevant environment and should be practised with all who provide assistance.

**G 2.2.2:** When teaching the cueing concepts and techniques outlined above, the occupational therapist should aim to:

- Engage conscious attention and focus on the task in hand.
- Increase understanding through education about the basis of functional difficulties.
- Give a small range of alternative techniques (with which the person with Parkinson's and family and/or carers may experiment) to address specific functional issues.
- Demonstrate movement strategies to offer a visual frame of reference.
- Involve as many senses as possible in the learning process.



- Supply feedback on performance in an honest and supportive manner in order to motivate and raise confidence.
- Provide plenty of opportunities for practice to reinforce learning.
- Supply recall aids (cue cards, prompt sheets and short written reminders), but avoid overloading with these.
- Breakdown complicated sequences into smaller parts. Use the method of: THINK-LOOK-PLAN-DO.
- Encourage focus of attention through the use of verbal and visual prompts.
- Encourage the person with Parkinson's to allow themselves sufficient time, and to use prompts when switching between tasks.

### **Emerging novel movement therapies and technologies**

Recent developments in the understanding of rehabilitative interventions specifically applied to people with Parkinson's, using Action Observation and Motor Imagery (Abbruzzese *et al* 2015), Cognitive Training (Paris *et al* 2011) and the potential for Motor Learning to support improved arm function (Felix *et al* 2012) have emerged to underpin some of the methods outlined in this guidance.

The potential for computer-aided assessment and even computer-guided treatment/activity, such as use of sensors to explore freezing of upper limbs for people with Parkinson's, has been described (Williams *et al* 2013). This is an area of rapid development so further digital measurement and evaluation tools are likely to emerge in the near future. Interventions using neurorobotics and gaming technology (exergaming) permit sensor-based measurements to be taken, allowing temporal and spatial domains of bodily movement to be assessed. The Parkinson's KinetiGraph™ was reported by Griffiths and colleagues (2012) as an emerging tool that can gather movement data, and so be used to help assess quality of movement during activities of daily living.

A single case report by Zettergren *et al* (2011) evaluated the impact of training using the Nintendo Wii Fit™ and reflected on the impact on gait speed, balance, functional mobility and depression in a person with Parkinson's. Esculier *et al* and Pompeu *et al* (2012) have also reported on a home-based balance training programme, using a Wii Fit™ balance board. And finally, Picelli *et al* (2014) have also explored robot-assisted arm training in patients with Parkinson's.

The reader is encouraged to keep abreast of such novel developments, and to be aware that the role of technology in assessment and future therapeutic intervention still needs considerably more evaluation.

## **2.3 Cognitive and mental health issues and their impact on day-to-day life**

Approximately 75 per cent of people with Parkinson's experience some degree of cognitive or emotional impairment at the time of diagnosis (Foltynie *et al* 2004). Depression and anxiety are common in Parkinson's: Parkinson's disease in adults (NICE

2017) suggests that depression affects 40–50 per cent of people with Parkinson's. Mood changes in Parkinson's may be the result of neurochemical imbalance, as well as being in part due to a reaction to the condition itself.

Metabolic differences in some of the substructures of the limbic system (the 'emotional brain' located in between the basal ganglia and the cortex) have also been reported by researchers. Using modern scanning techniques, brain images showing the physical basis of depression in people with Parkinson's have been recorded (Remy *et al* 2005).

### **Cognitive, emotional and neuropsychiatric impairments in people with Parkinson's**

#### ***i) Executive functioning***

On a cognitive level, difficulty shifting mental set (topic) leads to reduced flexibility of thought processes. The increased time required for mental processing, poor problem-solving skills, difficulties in lateral thinking, apathy, and reduced motivation and initiative also have impacts on many levels. Furthermore, a variety of visuospatial disturbances is known to add to these difficulties for some people with Parkinson's (Lee *et al* 1998, Lee and Harris 1999; 2001, Lee *et al* 2001, Lieb *et al* 1999). Although intelligence (IQ) has been shown to remain largely unaffected by Parkinson's, cognitive and emotional changes can lead to communication difficulties and result in a disorganised lifestyle. Even in the case of an individual who was once well-organised, an air of chaos may develop in his/her life when living with Parkinson's, unless time and attention are given to this problem, or support in managing finances and organisation of daily chores is available.

#### ***ii) Apathy***

Some people with Parkinson's appear to be more apathetic, as a direct or indirect result of their reduced dopamine levels. Anhedonia is a lack of pleasure-seeking behaviour, and in Parkinson's this may present as a reduction in participation in previously enjoyed social and recreational interests and activities. Apathy is more common in people with Parkinson's, although this in itself may or may not be a concern to the person experiencing it. Close friends, relatives and carers may, in fact, find the person's apathy more distressing than the apathetic person does him or herself.

On the surface, apathy may appear similar to depression, which is known to be more prevalent in people with Parkinson's than in people with similar neuro-degenerative conditions, such as multiple sclerosis. Differentiation between depression and apathy – without distress and in the absence of depression – can be a challenge. There are various tests and screening tools available for identifying depression; however, in practice, many of these are less robust when applied to a population with Parkinson's, as compared to a general population. The most reliable way of differentiating between apathy and depression is, not surprisingly, to ask the person with Parkinson's how they feel. Expressions about feeling sad, low, blue or unhappy, etc. are suggestive of depression.

#### ***iii) Depression***

In Parkinson's, depression may be another consequence of neurochemical changes; in particular, loss of dopamine and noradrenaline availability within the limbic system. Depression may also occur as a reaction to the diagnosis and impairment resulting from the progressive nature of the condition. Mood swings in people with Parkinson's between a negative, depressed outlook and a positive outlook may occur as part of an 'on/off' pattern linked to medication. Depression may be accompanied by anxiety or occur on its own.

Even if not formally diagnosed as 'depressed', 30–40 per cent or more of people with Parkinson's may experience significant feelings of depression at some point during the

course of the condition and this may have a negative impact on their quality of life. A study by Schrag, Jahanshahi and Quinn (2000) found that depression was the strongest indicator of reduced quality of life in people with Parkinson's. Depression can lead to increased social isolation and carer stress (Playfer and Hindle 2008). Often depression is associated with anxiety and sometimes with apathy as well (Wee *et al* 2016).

Dopamine, the main neurotransmitter in short supply in the brains of people with Parkinson's, is also one of three neurotransmitters involved in depression. The other two, serotonin and noradrenaline, are also affected by the brain changes in Parkinson's. These changes in brain chemicals may make people with Parkinson's more likely to become depressed, yet no two people are alike, and the causes of depression will vary. Having severe Parkinson's symptoms does not necessarily make someone more likely to get depressed. Younger people with Parkinson's do, however, seem to be more at risk of depression than older people with Parkinson's.

Depression in Parkinson's can be difficult to diagnose, as a number of other problems may overlap with the symptoms of depression:

- Some people with Parkinson's have sleep and night-time problems, which may make them feel tired and listless, without being depressed.
- Fatigue and lack of energy is very common in Parkinson's, even in people without sleep problems. Fatigue is a common complaint in depression; however, feeling fatigued is not the same as feeling depressed.
- Some people experience bradyphrenia (slowness of thinking), a cognitive impairment that is distinct from dementia, but which may give a false impression of depression.
- People with Parkinson's can sometimes look and sound depressed, even if they feel OK 'inside'. The stooped posture, quiet monotonous voice, lack of eye contact and difficulties with facial expression may make a person appear depressed when they are not actually feeling low.

Parkinson's can lead to a reduced willingness to try new things or to carry out activities that are difficult or demanding. These changes, however, do not necessarily lead to a reduced ability to enjoy things, even if the range of activities engaged in is more limited.

People with Parkinson's may be particularly vulnerable to depression at times when their symptoms suddenly worsen, a drug loses its benefit, or new symptoms emerge. The main clue to diagnosis of depression is loss of interest or enjoyment, particularly in activities that were enjoyed or that the person with Parkinson's found rewarding until recently, especially social activities. Social disengagement can reinforce feelings of loss, hopelessness and low self-worth. Opportunities to feel happy or good about things are also reduced by loss of social life. However, loss of motivation or initiative can also occur as symptoms of Parkinson's. As a result, reports by people with Parkinson's of a loss of pleasure are a better indicator for depression than reports of loss of interest.

Depression may improve with dopaminergic medication (L-dopa or a dopamine agonist). Nortripyline appears effective (Menza *et al* 2009) but concerns about side effects limits its use in the elderly. SSRI (selective serotonin reuptake inhibitor) antidepressants are used more frequently despite mixed results in clinical trials (Rocha *et al* 2013).

### **iv) Anxiety**

In Parkinson's, anxiety may be based on the very real fear of being unable to cope with a disability, as well as being a result of changes in brain chemicals, particularly in noradrenaline and serotonin levels. Anxiety may inhibit ability to engage in activity and cause distress, as in fear of falling, or of eating and drinking in public. For family, friends and carers, anxiety can be a very difficult problem to live with and may restrict normal daytoday activities, such as going out and socialising. Referral to a mental health specialist should be considered in such cases.

Some people with Parkinson's have anxiety related to the 'on/off' state of their motor symptoms. When 'off' and less able to move, people with Parkinson's may develop significant anxiety symptoms and, at times, may have panic attacks. Those with no clear 'on/off' phenomena may experience generalised anxiety if their motor symptoms are under-treated.

If anxiety is a problem it should be discussed with a Parkinson's specialist, as anti-Parkinson's medication changes may help. Simple anxiety management and relaxation techniques may also be beneficial. There is little good evidence to guide drug treatment of anxiety. If anxiety occurs in tandem with medication (dopamine) troughs, adjustment of the Parkinson's medication regime may help. Non-drug approaches are often helpful but, if medication is required, SSRIs and/or a benzodiazepine such as diazepam may help.

### **v) Memory impairment**

Evidence from research shows that new learning in people with Parkinson's is unusually dependent on the provision of external sensory cues, or provision of very explicit structuring. Very specific memory problems have been demonstrated in research involving Parkinson's subjects, indicating that an external recall aid is required to elicit recollection. Recognition, on the other hand, is usually normal (as when an external prompt or cue that elicits a memory is provided), but recall, in the absence of any form of external stimulus, is generally impaired (Buytenhuijs *et al* 1994).

Other memory problems and features commonly associated with dementia, especially short-term memory impairment and difficulty recalling names, tend to occur in a majority of people with Parkinson's in the later stages of the disease. In such circumstances, it may be reassuring to hear that most people with any form of dementia can continue to live in their community at all stages of the condition, often with formal and/or informal support to help maximise independence for as long as possible. NICE recommends that cholinesterase inhibitors be offered for individuals diagnosed with Parkinson's dementia. If cholinesterase inhibitors are ineffective or not well tolerated, memantine can be offered (NICE 2017).

### **vi) Hallucinations**

Hallucinations associated with Parkinson's, or as a result of over-stimulation by anti-Parkinson's medications, are usually visual and in the form of people or animals – sometimes of miniature size. Hallucinations are known to be a risk factor for the development of mild to moderate dementia in advanced Parkinson's. People with Parkinson's have reported that visual hallucinations tend to be less intrusive if recognised by themselves as such, when experiencing them. Anti-Parkinson's medications should be reviewed if hallucinations are reported to be causing distress. Education about this side effect of such medication may also help increase insight and reduce distress.

If hallucinations are troublesome, reduction of dopaminergic medication should be considered. Dopamine agonists may be more prone to cause hallucinations than L-dopa. If reduction of dopamine treatment is ineffective or not possible, rivastigmine or newer

antipsychotic medication may be considered. Rivastigmine is an acetylcholinesterase inhibitor licensed for the treatment of Parkinson's dementia. When hallucinations occur in the context of dementia, rivastigmine may be effective in reducing hallucinations with some clinicians prescribing rivastigmine for hallucinations even in the absence of dementia.

Older antipsychotic medications block dopamine receptors and therefore cause unwanted side effects in people with Parkinson's. Newer antipsychotics that do not cause much deterioration in Parkinson's motor symptoms include clozapine and quetiapine (NICE 2017). Clozapine is effective but patients must be registered and careful monitoring with blood tests is required.

### **vii) Psychosis**

Delusions in the form of bizarre or obsessive ideas, often in combination with hallucinations, may have a major impact on ability to cope with daily life. If distressing delusional ideas are reported, the need for medication review and adjustment should be discussed with the person's doctor or nurse specialist.

### **viii) Impulsivity disorders**

Occasional, but not so rare, side effects of some anti-Parkinson's medications (especially in younger males) may include changes in personality, in the form of compulsive shopping, gambling, collecting and sorting of items (punding), other repetitive behaviours, or hypersexuality. It is not uncommon for such behaviours to cause considerable problems and distress before they are recognised as being the result of over-stimulation by anti-Parkinson's medications. If such symptoms are identified, the need for review and adjustments to medication should be discussed with the person's doctor or nurse specialist.

#### **Guidance and Good Practice Points**

For occupational therapists aiming to assess and promote the mental wellbeing of people with Parkinson's, it is recommended that:

**G 2.3.1:** The person with Parkinson's should be screened for cognitive impairment by use of functional and/or standardised assessment.

**G 2.3.2:** The person with Parkinson's should be screened for emotional and neuropsychiatric impairment by use of communication, observation and liaison with family and/or carers.

**G 2.3.3:** Consideration is given to educational discussion focused on attitude and behaviour changes, supported by the use of anxiety management and relaxation techniques – either on an individual or group basis. Or, consider referral to the local Improving Access to Psychological Therapies (IAPT) NHS programme if appropriate.

**G 2.3.4:** Consideration is given to the use of strategies to compensate for specific cognitive impairments highlighted in the assessment.

**G 2.3.5:** Occupational therapists educate the person with Parkinson's and all family and/or carers regarding the cause and management of cognitive, emotional and neuropsychiatric impairments.

**G 2.3.6:** Occupational therapists refer family and/or carers to sources of support in relation to the management of cognitive, emotional and neuropsychiatric impairments.

### **New learning and carryover of skills from one environment to another**

By providing time and opportunities for discussion and education about the effects of insufficient and fluctuating levels of dopamine, in accessible language and to a degree appropriate to the individual, observable and often dramatic functional benefits may be achieved.

People with Parkinson's may already realise that using their attention more consciously, for example, enables them to perform tasks more easily and with better 'flow'. Once understood and reinforced, people with Parkinson's usually show greater inclination to adopt this approach. Others, while recognising that greater concentration is required for routine tasks, may persist in relying on 'autopilot' for fear that adapting their behaviour would be equivalent to 'giving in' – until, that is, they are able to gain a better general understanding of their condition. Although re-establishment of the 'autopilot' facility is not to be expected, habitual application of management strategies which people with Parkinson's have learned may be of ongoing value. Clinical experience shows that the use of metaphorical and allegorical language may greatly aid the understanding of people with Parkinson's of any unfamiliar ideas that need to be conveyed.

#### **Guidance and Good Practice Points**

**G 2.3.7:** To promote new learning with people with Parkinson's, the occupational therapist should:

- Assess the person with Parkinson's at various times of the day to generate an accurate representation of the range of their cognitive performance.
- Ensure new learning is undertaken while the person is 'on' or at their most alert.
- Educate and involve regular family and/or carers to promote carry-over into daily life.
- Engage the full attention of the person with Parkinson's by minimising distractions during assessment and interventions.
- Discuss the problem(s) and, if relevant, discuss ways that people with similar difficulties have resolved the same problem(s).
- Provide a visual frame of reference by demonstrating a movement strategy, ensuring that the person with Parkinson's watches your performance of the movements, using verbal prompts to look at the section of the body that is being moved if this is not done spontaneously.
- Supply a verbal frame of reference by using brief, clear descriptions of actions and instructions, emphasising key words.
- Use guided mental rehearsal (by asking the person with Parkinson's to imagine doing each element of a movement sequence while remaining still) if getting started is proving quite difficult.
- Offer a proprioceptive frame of reference by giving hands-on input and the physical facilitation of movements.

- Consider using a backward-chaining approach (Maskill and Tempest 2017) when a person with Parkinson's is struggling to learn a movement sequence.
- Encourage the person with Parkinson's to talk through key elements of their movements aloud, or internalise key words if preferred, while performing actions.
- Use a cue card positioned where it will be seen when doing a problem activity.

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# 3

## Optimising activities

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There was a paucity of useful and significant research underpinning occupational therapy interventions validated specifically for people with Parkinson's when the first edition of this guidance was published. An analysis of what was then considered to be current practice, and best practice in occupational therapy for people with Parkinson's (Deane *et al* 2003a; Deane *et al* 2003b) suggested that occupational therapists had four main roles, namely: problem-solver, educator, networker, and supporter. The survey (Deane *et al* 2003a) also demonstrated that occupational therapists lacked knowledge about condition-specific interventions and tended to focus on self-care.

In more recent years, a few well-conducted and controlled studies, along with further evidence (Rao 2010 and 2014) have emerged to show the value of occupational therapy and other rehabilitative interventions for people with Parkinson's. Most studies evaluated occupational therapy alone, or within the context of a course of multidisciplinary team rehabilitation sessions delivered to outpatients in groups or individually in community settings (Tickle-Degnen *et al* 2010, Ransmayr 2011, Gage *et al* 2014, Sturkenboom *et al* 2014, Sturkenboom *et al* 2015, Bloem *et al* 2015) or a course of rehabilitation during an inpatient stay (Monticone *et al* 2015).

While these recent studies describe interventions offered to people with Parkinson's, the work of Jain *et al* (2004 and 2005) illustrates the overarching process of identifying and treating occupational dysfunction in a group of clients with a progressive complex movement disorder. Jain *et al* (2004, 2005) proposed that three distinct but interconnected levels of interventions are used by occupational therapists including:

### 1. Skill-level intervention

This level of intervention enhanced the quality of performance by providing 'hands-on' treatment aimed at body-level problems. For example, the therapist would teach the client how to use weight transference techniques during transfers, or encourage the client to use a different pattern of movement when moving from lying to sitting.

### 2. Knowledge-level intervention

This level of intervention supported performance by increasing knowledge about how to modify the task. The client's skills would remain the same but the therapists might provide information about troublesome body-level symptoms or details about accessing equipment or resources, to enable the client to make an informed choice.

### 3. Attitude-level intervention

This level of intervention changed performance by modifying attitude and expectations to facilitate psychological adjustment. Therapists would work with the client to change the task completely, for example the need to walk outdoors was replaced by using a scooter; the need to go to the supermarket was removed by internet shopping.



## 3.1 Mobility

The main gait and balance problems experienced by people with Parkinson's are:

- Start hesitation, leading to difficulty taking the initial step to begin walking.
- Shuffling gait, giving a shortened stride length.
- Slowness, with a markedly reduced speed when walking.
- Festination, when walking speeds up over time, leading to difficulty stopping.
- Problems when changing direction or turning.
- Freezing episodes, when the feet appear to become rooted to the spot.
- Postural instability, impaired balance and reduced saving reactions increasing risk of falls.
- Dyskinesia, presenting as involuntary writhing due to unwanted drug side effects.
- Tremor, impairing the quality and smoothness of movement at rest and on initiation of movement, often involving arms more than legs.

The efficacy of physiotherapy for improving mobility, balance and gait difficulties experienced by people with Parkinson's is now well established (Keus *et al* 2014) A growing body of high quality evidence is emerging to support the use of a range of physical activity or exercise approaches (Morris *et al* 2010, Petzinger *et al* 2010, Smania *et al* 2010, Goodwin *et al* 2011, Mirelman *et al* 2011, Frazzitta 2013, Allen *et al* 2015, Snider *et al* 2015).

As noted earlier, the neuroprotective impact of intensive exercise is the premise of emerging exercise techniques such as PD Warrior ([www.pdwarrior.com](http://www.pdwarrior.com)). The intensity and dosage of such intensive exercise programme has a growing evidence base (Frazzitta *et al* 2015) and has been flagged by NICE as a research recommendation (NICE 2017).

In addition, long-term behaviours that tend towards 'being regularly active, even at a moderate intensity' have been shown to yield the greatest benefits (Snider *et al* 2015) when compared with a sedentary lifestyle or just one or two intense activity sessions a week. A local daily walk and keeping physically moving frequently every day at home, appear to optimise gait and balance more effectively compared with a generally sedentary lifestyle perhaps with one or two 'gym' sessions a week.

Occupational therapists are encouraged to work collaboratively with physiotherapy colleagues to address mobility problems and promote positive habits that aid the maintenance of mobility in the community, to support participation in work, leisure and in everyday home life.

### Guidance and Good Practice Points

For occupational therapists aiming to promote mobility with people with Parkinson's, it is recommended that:

**G 3.1.1:** A combination of intrinsic and extrinsic cueing techniques should be trialled within each person's home environment.

**G 3.1.2:** Once appropriate cueing techniques have been identified, these should be practised with family and/or carers within the environment the person with Parkinson's has to negotiate.

**Occupational therapists should encourage people with Parkinson's to:**

**G 3.1.3:** Practise 'concentrating' on walking, avoiding all non-essential talking while moving along.

**G 3.1.4:** Pause when speaking and to touch something solid, for example a wall or lamp post, in order to aid balance while talking and standing.

**G 3.1.5:** Focus on stepping their feet around when turning a corner, or turning to sit down.

**G 3.1.6:** Come to a stop prior to changing direction if this manoeuvre is problematic; for example turning from a corridor into a room.

**G 3.1.7:** Walk in an arc to change direction in a wide, spacious area; this is safer than an abrupt or pivoting turn.

**G 3.1.8:** Optimise their stability by standing with feet shoulder-width apart and one foot a pace in front of the other when looking or reaching up.

**Occupational therapists should also:**

**G 3.1.9:** Collaborate with physiotherapy colleagues to explore if a suitable exercise or physical activity routine is established. If not, some form of physical routine should be recommended and initiated according to personal interest and with supervision as required, e.g. consider creating an area at home for daily movement sessions, such as a securely-fixed horizontal 'exercise bar', to aid a safe regular exercise routine.

**G 3.1.10:** Review/monitor the use of walking aids to ensure their suitability and avoid a potential increased risk of falling.

**G 3.1.11:** Assess the need for extra banister rails, spiral Newell post rails for corners on stairs and grab rails, by steps or by the toilet, and arrange provision without delay if required.

**G 3.1.12:** Consider the use of rails down corridors and outdoor steps to act as a visual cue and to increase confidence even if instability is not a problem.

**G 3.1.13:** Assess the need for additional lighting, for example automatic night-lights, a 'touch light' by the bed, good lighting on stairs or mattress sensors that turn lights on when someone leaves their bed.

**G 3.1.14:** Improve the flow of walking by reducing the number of obstacles, including rugs and mats; by rearranging furniture; and if possible by minimising contrasting colours and textures on the floor.

**G 3.1.15:** Assess each person's specific circumstances for provision of a stair lift via a means-tested Disabled Facilities Grant, or the option of a through-floor vertical lift, should mobility and transfers deteriorate.

## 3.2 Addressing falls

Falls are commonplace for people with Parkinson's, more so in the later stages as the disease progresses (Wood *et al* 2002). The main impairments that contribute to falls are postural instability, impaired balance and reduced saving reactions. Visuospatial disturbances may also play a part in some cases. Interruptions or disturbance when walking can also lead to falls, as concentration on the task of walking safely is particularly important for people with Parkinson's. Carrying items while walking can also reduce the ability to maintain balance. For tasks usually done from a standing position, especially if one hand is used by the person with Parkinson's to aid balance when working, such as when washing at a basin, a perching stool may be useful and reduce the risk of falling during performance of the task.

Medication-induced dyskinesia can markedly impact on the safety of movement during 'on' phases and related falls may be predicted by using a falls diary to record and correlate dyskinesia and/or falls with the medication cycle. Such diaries can help optimise medication use, e.g. changing to a dispersible L-Dopa preparation or taking morning medication at a pre-set time prior to rising, to increase the efficacy of daily routines and better manage dyskinesic episodes and falls.

Dyskinesia may also be managed by identifying helpful positions, such as sitting or lying, or undertaking activities such as dancing or walking may be of benefit. Also, consider avoiding any recognised exacerbating movements where possible.

If falling is unavoidable, having a proactive falls action plan and means of calling for assistance following a fall can reduce distress and time spent on the floor. Use of an appropriate alerting device such as a whistle, 'fall alert' pager, mobile phone, or telecare alarm system should be encouraged, both during the day and overnight. Manual handling equipment, such as a mobile hoist or inflatable lifting cushion suitable to raise someone from the floor should also be provided. On-site instruction and practice with getting on and off the floor using cueing techniques or cue cards should be given as required.

There is increasing evidence to show that engaging in regular physical exercise can contribute to a reduced risk of falls (Allen *et al* 2010, Canning *et al* 2014, Canning *et al* 2015, Morris *et al* 2015) and, therefore, short Parkinson's-specific exercise courses are sometimes offered to those who have fallen, or are thought to be at risk of falls.

### Guidance and Good Practice Points

For occupational therapists aiming to reduce the risk of falls with people with Parkinson's, it is recommended that:

**G 3.2.1:** A multifactorial fall screening tool should be used to highlight all risks including osteoporosis and bone health risk factors. See Assessment and Management of fracture risk in patients with Parkinson's disease (Lyell *et al* 2015) for information about bone health assessment.

**G 3.2.2:** A falls diary is completed by the person with Parkinson's or their family carer, to help identify when, where and how falls are occurring.

**G 3.2.3:** Full attention and concentration on walking should be reinforced.

**G 3.2.4:** When carrying items, alternative strategies and/or equipment should be identified, such as using pockets, a diagonal shoulder bag, body belt, or net bags on walking frames.

**G 3.2.5:** Use of a perching stool should be considered as required to avoid standing during tasks.

**G 3.2.6:** Trolley use should be trialled carefully: low trolleys may exacerbate stooping; high platform style trolleys may be useful, but may exacerbate a tendency to increase the speed of walking due to festination of gait.

**G 3.2.7:** Timing of dyskinetic episodes in relation to the use of medication should be recorded, and movements, tasks or positions that help to relieve, or exacerbate, involuntary movement identified.

**G 3.2.8:** Advice should be given on adapting routines and activities undertaken during dyskinetic episodes.

**G 3.2.9:** Walking at a slightly increased speed and in time to a regular beat when dyskinetic may improve gait and reduce the likelihood of falling.

**G 3.2.10:** A suitable means of raising the alarm in the event of a fall should be identified and provided without delay.

**G 3.2.11:** An appropriate and safe way of getting off the floor should be identified and practised on-site, and any equipment required provided without delay.

**G 3.2.12:** A suitable and individually tailored exercise routine, with supervision as required should be initiated with the support of a physiotherapist if appropriate. Consider the need for a securely fixed horizontal exercise bar at home, to aid a regular exercise routine.

### 3.3 Transfers

Sit-to-stand transfers from chairs, toilets and the bedside commonly present difficulties, with people with Parkinson's often requiring physical assistance when getting up. Generally, appropriate elements of the movements needed to rise from sitting are performed, but in the wrong order, sometimes leading to a series of failed attempts before people with Parkinson's manage to get up fully.

Use of suitably worded verbal cues may be of benefit. Family/carers may feel frustrated at the speed at which the transfer is carried out and may want to try to assist physically. They should be advised against this and educated appropriately. Using this approach, the caregiver may be able to give verbal cues instead of physical assistance. Alternatively, or in addition, a cue card can be used to visually prompt application of a movement strategy if one is placed within view of regularly used seating (Mak and Hui-Chan 2008). See [Section 2](#) for further details on cueing techniques.

Below is an example of a cue card to be read silently or out loud by the person with Parkinson's, or out loud by a carer, to aid rising from sitting.

**Method for getting up from an armchair:**

1. Move bottom to front of seat.
2. Place feet flat on the floor, close to the chair and slightly apart.
3. Put hands in position ready to push down on armrests.
4. Lean forwards, nose over toes.
- and ... 5. Push down through legs and arms.

...1, 2, 3, and UP.

If starting an action is the problem, mentally rehearsing doing the action without difficulty, and involving as many senses as possible during the imagined practice, may help subsequent performance of the action. Recalling a detailed memory of getting up easily from a chair, for example, will prime neural circuits that are the same as those used for actual performance of the specific task.

Below is an example cue card with instructions for a caregiver to read aloud, to aid a person with Parkinson's to rise from sitting.

**How to get up from an armchair, when 'feeling stuck':**

- First, imagine moving to the front of the seat.
- Next, imagine placing feet close to the chair and slightly apart.
- Hands ready to push down on the armrests ...
- Then, imagine the feeling of pushing down through legs and arms, and rising up easily, into a standing position.
- After having briefly run through the actions in your mind ...
- Now prepare for real action with a '1, 2, 3, stand-up' (or use other phrases to suit).

The need for equipment to aid transfers should be individually assessed and, if required, trialled over time on-site. Removing the need to perform more challenging transfers, for example by provision of chair raisers or a riser-recliner armchair (see Section 3.5 on posture and seating), or by replacing a bath with a level-access shower, should be considered to optimise safety during these transfers and reduce the burden on carers.

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote transfers with people with Parkinson's, it is recommended that:

**G 3.3.1:** The need for an immediate turn on standing and starting walking is removed where possible.

**G 3.3.2:** Appropriate cueing strategies should be identified, practised and consistently used by all family and/or carers who provide assistance for transfers.

**G 3.3.3:** Different cueing strategies be used, as required, for different transfers in different environments.

**G 3.3.4:** Consideration be given to preparing for action by using mental rehearsal or motor imagery, which may benefit people who have problems initiating the action of standing from sitting.

**G 3.3.5:** Equipment be provided as necessary to ensure optimal transfer surface heights.

**G 3.3.6:** When rising from a chair without arms, a 90° turn towards the intended direction should be made to allow use of one arm on the back of the chair to give support and aid rising.

**G 3.3.7:** Freestanding toilet frames should be avoided because they can exacerbate problems with movement due to their tendency to move on use; frames that are fixed to the floor, drop down or wall-fixed grab rails, may be used as alternatives.

**G 3.3.8:** The need for fixed grab rails by the toilet and bath/shower should be assessed and equipment installed without delay as required.

**G 3.3.9:** If bathing and an over-bath shower is in situ, equipment to avoid getting into the bottom of the bath, such as a wide shower board or swivel bather, should be assessed for and provided without delay as required.

**G 3.3.10:** Mechanical bath lifts should be considered for those who prefer or need to bathe.

**G 3.3.11:** If a shower cubicle with a tray is being used, supervision while stepping over the shower lip should be considered, in addition to wall-affixed rails and a secured shower seat to optimise safety.

**G 3.3.12:** If a bath is being replaced by a shower, a level-access shower with secured seating at a suitable height (perhaps with armrest attached), and handrails, should be provided as required. Half-height shower doors will enable a carer to assist the person in the shower if necessary. This could be provided via a means-tested disabled facilities grant.

## 3.4 Bed mobility

Bed mobility is often impaired in people with Parkinson's and may be experienced for some time before the diagnosis of Parkinson's itself. Frequent urination at night (nocturia) or possible reversal of bladder rhythm, causing frequent need for bladder-emptying during the night, are commonly experienced by people with Parkinson's. For those living alone, severe bed mobility difficulties may necessitate admission to a residential placement, while for those with a frequent need for assistance at night this may cause 'intolerable' stress on their partner or caregiver.

People with Parkinson's tend to 'travel' across the mattress when turning in bed and so may need more space than usual as a result. Although a powered profiling bed or mattress elevator can sometimes be useful, bed mobility difficulties tend to arise from rigidity of the trunk and subsequent difficulties rolling, hence problems often persist despite the use of these items of equipment. People often find that, due to sliding down the bed, a mattress elevator raises only their head and does not help them when trying to sit up. Techniques for moving towards the head of the bed, such as bridging, should be considered. Selecting key pieces of equipment, and breaking down the task of mobilising in bed into stages, may promote night-time mobility.

### Guidance and Good Practice Points

For occupational therapists aiming to promote bed mobility and bed transfers with people with Parkinson's, it is recommended that they:

**G 3.4.1:** Teach movement methods for turning over, for adjusting position in bed, and for getting out of bed. For example, teach an ergonomic movement sequence as used by people who have low back pain.

The example cue card below starts with the person lying on their back.

<p style="text-align: center;">Bed Mobility Plan</p> <p style="text-align: center;">Bend knees</p> <p style="text-align: center;">Turn head</p> <p style="text-align: center;">Reach over</p> <p style="text-align: center;">... and roll ...</p> <p style="text-align: center;">and next, to get up out of bed ...</p> <p style="text-align: center;">Drop legs over edge</p> <p style="text-align: center;">and push ... to sit-up</p>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

- Teach bridging: when lying on the back, bend knees up and raise hips off the mattress, then move a small distance sideways, before lowering hips again.
- Teach the person with Parkinson's how to alternate the movement of the three main sections of the body. To move across the mattress, shift one section of the body at a time (head and shoulders being one section, hips and feet the others). This will enable easier re-positioning away from the edge of the bed or straightening up if lying at an angle across the mattress.
- Encourage getting into bed by sitting on the bedside as near to the pillows as possible, shuffling the bottom well back and lifting legs onto the bed, before lying down.

**G 3.4.2:** Assess with care for the use of profiling and adjustable bed aids, for example mattress elevators, as the movement of these items may cause freezing or prove difficult to use if the person is 'off'. Equipment should be individually assessed for and trialled over time on-site, and provision organised without delay if required.

**G 3.4.3:** Assess for the use of a bedside grab rail and, once provided, practise turning and rising from the bedside on-site. Ensure that the rail is fitted at the shoulder level of the bed occupant to provide a comfortable grip.

**G 3.4.4:** Assess the need for bedroom-based toileting facilities (commode, urinal) for use during the night and organise provision without delay as required.

**G 3.4.5:** Encourage the use of night-lighting when getting up during the night.

**G 3.4.6:** Consider the use of satin night-wear, or a satin half-length sheet avoiding the feet area, to aid movement in bed by reducing friction. Do not use both, as this may cause a risk of sliding out of bed, and ensure the bed height is such that safe flat-foot placement on the floor is guaranteed.

## 3.5 Posture and seating

People with Parkinson's commonly have a stooped posture and also a tendency to lean to one side, especially at 'off times' of the medication cycle. As a result, complaints of neck and back pain are common. Reduced awareness of the position of the body in space may in part account for falls in people with Parkinson's.

The Alexander Technique may be helpful for improving day-to-day movement (NICE 2017). There is evidence that lessons in the Alexander Technique are likely to lead to sustained benefit for people with Parkinson's (Stallibrass *et al* 2002). More information about the Alexander Technique for people with Parkinson's is available from the NHS choices website ([www.nhs.uk/Conditions/Parkinsons-disease/Pages/Introduction.aspx](http://www.nhs.uk/Conditions/Parkinsons-disease/Pages/Introduction.aspx)).

Other methods for addressing poor posture include:

- Encouraging improved awareness of poor posture with verbal prompts to 'straighten up' and for people with Parkinson's to check their own posture at regular intervals.
- Use of a high-backed chair to give a physical prompt to the head.
- Repositioning the TV so it is directly in front of the person, not to the side.
- To counter the effects of gravity, maintain the length of ligaments and avoid the development of contractures, build 'counter strategies' into daily routine (Lockley and Buchanan 2006). For example:
  - Time spent in a standing position with the back up against a wall for short periods, slowly building up to two minutes twice daily if well tolerated.
  - Time spent in supine and/or prone lying.
- Consider the use of a car safety-restraining strap if a passenger tends to lean towards the driver when travelling by car.

Well-proportioned seating is especially relevant for people with movement disorders, and the acquisition of a suitable armchair should be considered. Chair raisers and



powered riser–recliner type chairs may suit some people with Parkinson's. Users of powered seating tend to rise unaided when feeling able and use the powered lifting mode only when necessary (see [Section 3.3](#) for a management strategy to aid rising from an armchair).

If dyskinesias occur when sitting in an armchair, there may be a risk of sliding forwards and possibly falling out of the seat. For mild to moderate dyskinesias, a one-way glide sheet or latex netting placed on the seat cushion may be enough to give additional resistance to slipping forwards. For more significant dyskinesias, a deep pressure-relief foam cushion with a ramped (thicker) front edge, secured with non-slip material, may be useful to place on the chair cushion. When there are concerns regarding safety while sitting, use of an armchair with a tilt-in-space mechanism should be considered.

If a person is no longer able to maintain a balanced upright posture for any useful length of time in unsupported sitting, postural support, such as lateral supports in an armchair or wheelchair, should be considered (Pope 2007) and a full review of posture and pressure care over a 24-hour period undertaken and reviewed as required (see [Section 4](#) regarding end-of-life care).

### Guidance and Good Practice Points

For occupational therapists aiming to promote improvements in posture and in comfort when seated for people with Parkinson's, it is recommended that:

**G 3.5.1:** Increased awareness and self-correction of postural problems should be encouraged.

**G 3.5.2:** Counter strategies, such as standing against a wall and lying in supine and/or prone positions should be built in to daily routine of the person with Parkinson's.

**G 3.5.3:** Posture and positioning while travelling in a car should be reviewed and additional support straps provided without delay as required.

**G 3.5.4:** Positioning and comfort in an armchair should be reviewed over time.

**G 3.5.5:** Individual assessment of suitability for the following should be undertaken:

- Chair raisers, for raising the seat height.
- A chair with a riser mechanism.
- A chair with a recline and/or tilt-in-space mechanism.
- A chair with a vertical rise (rather than a standard rise) and tilt-in-space mechanism.

These should be fully assessed on-site over time. Use mechanical devices with caution because movement may cause freezing or the device may prove difficult to use when the person is 'off' or in the complex stage of the disease.

**G 3.5.6:** If dyskinesias are experienced, safety in the chair should be reviewed when the person is dyskinetic, and suitable solutions trialled. For example:

- Use of a secured, one-way glide sheet or latex netting over a normal seat cushion,

n.b: do not use over a pressure cushion as it may interfere with its pressure-relieving properties.

- Use of a secured, ramped, deep-pressure cushion with the thickest part at the front of the seat.
- Use of a tilt-in-space mechanism.

**G 3.5.7:** Postural support in both an armchair and a wheelchair should be provided for those who cannot sit unsupported for a useful length of time.

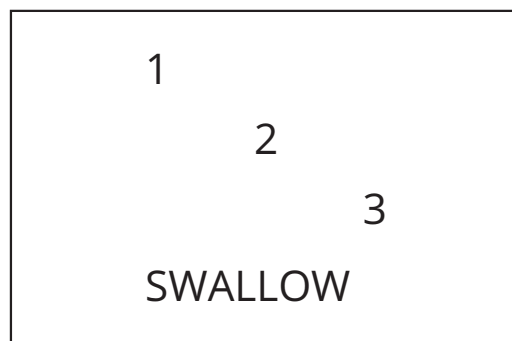
**G 3.5.8:** A review of wheelchair suitability, with a tilt-in-space option, should be undertaken, and modified armchair seating considered for those people who are unable to sit comfortably or safely.

## 3.6 Eating and drinking

People with Parkinson's often report that they are slow and messy in eating and drinking, which demands greater effort. This can lead to them losing interest in food and withdrawing from previously enjoyed family and social activities involving food or drink.

Referral to a speech and language therapist should be considered where difficulties with swallowing and coughing when taking tablets, food or drink are reported. Excess saliva building up in the mouth troubles some people with Parkinson's, often causing social embarrassment as a result. This situation is due to a reduction in the frequency with which people with Parkinson's automatically swallow saliva as it is produced, rather than excessive saliva production. Improving posture will help to some extent, as will developing the habit of swallowing a couple of times when the person with Parkinson's can feel saliva building up.

Good sitting posture, adequate lighting and as few distractions as possible are recommended if mealtime problems occur. Additionally, assess for whether modified eating and drinking equipment are required to reduce difficulties. Weighted cutlery sometimes helps to dampen a tremor that persists during movement, but should be considered carefully as it may exaggerate fatigue.



If getting swallowing started is a problem, use of a cue card as illustrated above may be beneficial. The person with Parkinson's should read the cue card silently and aim to commence swallowing on reading the word SWALLOW on the card.

**Guidance and Good Practice Points**

For occupational therapists aiming to promote eating and drinking abilities with people with Parkinson's, it is recommended that:

**G 3.6.1:** If coughing on food or drink is reported, a referral to a speech and language therapist should be made without delay.

**G 3.6.2:** If the build-up of saliva is a problem, the occupational therapist should encourage good upright sitting posture and frequent voluntary swallowing.

**G 3.6.3:** If swallowing is problematic, the occupational therapist should trial the use of self-cueing.

**G 3.6.4:** Good posture, good lighting and reducing distraction at mealtimes should be encouraged.

**G 3.6.5:** Modified eating and/or drinking equipment should be assessed for and provided without delay, as required. For example:

- Plate mats, raised-edge/lip-edge plates or pasta bowls help to prevent food from spilling.
- Bendable straws may be suitable, if weakness or tremor inhibits holding a cup.
- One-way valve straws may also be useful if normal straw use is difficult.
- Cut-away mugs may be useful for those with limited neck mobility.
- The use of a fork-knife can help if co-ordination between knife and fork is impaired.
- The use of a spoon-fork can help if food tends to be dropped between the plate and the mouth.
- Large-handled cutlery may be useful for those who have reduced grip strength.
- Weighted cutlery may help to dampen a tremor that persists during movement (but should be assessed on a case-by-case basis).
- Plate-warming devices are also useful.

**G 3.6.6:** For tremor-specific problems try one-touch boilers, café style sugar/coffee dispensers that dispense just one spoonful with one tip, sachets of coffee or sugar.

## 3.7 Self-care routines

Functional abilities will be improved once the first dose of anti-Parkinson's medication has been absorbed. Therefore, it helps to begin morning self-care routines after taking

the first dose of the day (see [Section 3.9](#) on fatigue). People with Parkinson's tend to report that their personal care routines are generally slow and tiring, cause poor balance and increase the risk of a fall if done in a standing position. Some people report that dressing can take from 30 minutes up to as long as two hours or more daily.

A client-centred approach should be taken when assessing personal care. Expending precious energy dressing independently may result in a person with Parkinson's being too fatigued to carry out any further meaningful tasks for the remainder of the day and thus, on balance, reduce their quality of life. However, some people with Parkinson's may wish to maintain their independence in this task in spite of the time that it takes them to perform. Others may prefer a package of care to assist them with washing and dressing so that they are not so exhausted that they are prevented from accessing work or leisure activities in the community, or simply in order to enable them to continue daily routines in their home.

The introduction of dressing aids may exacerbate frustration however, as people with Parkinson's often find that using novel processes and gadgets leads to confusion. Consideration should be given to clothing adaptations, such as replacing buttons with Velcro, as well as general advice about suitable clothing that is easy to put on and take off and has fastenings that are simple to use (Meara and Koller 2000). For those who wish to retain their independence but want to be able to dress themselves more easily, practising a dressing routine (as detailed in G 3.7.4 below), while avoiding distractions, may be of benefit.

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote self-care routines with people with Parkinson's, it is recommended that:

**G 3.7.1:** The timing of the first dose of anti-Parkinson's medication is established, because this has important bearing on function. If it is usually taken after washing and dressing, liaise with the medication prescriber to see if the first dose may be taken before the individual gets washed and dressed.

**G 3.7.2:** If self-care routines are lengthy or frustrating, or if the person with Parkinson's prefers, assistance should be provided in the morning and/or evening.

**G 3.7.3:** Use of a perching stool should be assessed for and provided without delay, as required.

**G 3.7.4:** If the person wishes to dress independently, the following useful dressing procedures should be practised:

- Collect all the clothes and lay them out in the correct order for dressing.
- Sit down on a chair or on the bed, close to the clothes.
- Concentrate on dressing, avoiding distracting thoughts, sounds or conversations.
- Before putting on each item, encourage the person with Parkinson's to rehearse the dressing task mentally.
- Encourage the description of each body movement while dressing, for example

'Put the right hand into this sleeve and pull up'.

- Stand to pull up pants and trousers, making sure the body is well balanced.
- Sit down to do all buttons and fastenings.
- Reinforce by emphasising the need for the person with Parkinson's to tackle one task at a time, to concentrate fully on the task and to describe each movement as it is performed. (Adapted from Morris *et al* 1996).

**G 3.7.5:** Dressing aids such as button hooks may lead to confusion and should only be used selectively after individual trial.

## 3.8 Domestic skills

During all stages of Parkinson's, performance of domestic tasks, such as meal preparation, housework and shopping, may be affected by poor dexterity, impaired balance, reduced ability to multitask and increasing levels of fatigue. Possible cognitive changes relating to planning, organisation and decision-making skills may also impact on abilities to manage homemaking and money management tasks.

For some people being able to continue as the primary home-maker may be central to their role within the family unit and key to their continued self-esteem. Although small items of equipment may help improve the ease and safety of working in the kitchen, consideration should be given to modifying the nature of the task, for example by buying pre-prepared vegetables or pre-prepared meals, and/or to removing the need for that person to undertake the task altogether, for example by shopping for food on the internet, or by employing a cleaner. If the person with Parkinson's wishes to continue with kitchen activities, reorganising cupboards so that the most commonly used items are placed within easy reach will improve access and may reduce fatigue.

### Guidance and Good Practice Points

For occupational therapists aiming to promote domestic skills and abilities with people with Parkinson's, it is recommended that:

**G 3.8.1:** Small items of equipment should be assessed for and provided without delay. For example:

- Non-slip latex netting or matting may ease jar opening.
- Wire mesh or chip baskets may help when draining pans of vegetables.
- A ring-puller gadget may reduce difficulty opening ring-pull cans of food.
- Lever taps or tap turners may reduce effort when using taps.

**G 3.8.2:** Use of a perching stool should be considered in order to avoid standing

during tasks such as meal preparation or ironing.

**G 3.8.3:** Trolley use should be trialled carefully: low trolleys may exacerbate stooping and though high platform-style trolleys may be useful, they may also increase a tendency to gather speed of walking due to festination of gait.

**G 3.8.4:** Pacing the preparation of meals should be explored as a way of alleviating fatigue, for example by doing some preparation earlier in the day, so that there is less to do when actually cooking the meal.

**G 3.8.5:** Consideration should be given to breaking down domestic tasks into component actions to allow successful participation in some aspects of the activity.

**G 3.8.6:** Introducing convenience foods and internet shopping should be considered where appropriate.

**G 3.8.7:** Occupational therapists should explore the need for assistance with, or delegation of, some or all of the housework, ironing, household maintenance tasks, and/or management of paperwork/finances.

## 3.9 Fatigue management

There is a developing body of evidence that suggests that fatigue management programmes may have a positive effect on quality of life for people with progressive neurological disorders (Ward and Winters 2003). People with Parkinson's often complain of finding that they tire quickly following relatively short periods of (limited) physical exertion. This may be due to the effort of staying upright against gravity and inefficient movement strategies. Anecdotally, they will often complain of 'mental fatigue' if they have been in a busy or social environment. The impact of fatigue may be formally measured using the Fatigue Impact Scale (Whitehead 2009) and re-measured once a programme has been instigated.

Optimising management of anti-Parkinson's medication will improve function and self-management in all areas of daily life, as well as helping to minimise fatigue. Consideration must be given to the usual medication regime and who is available to assist with medication management if memory, dexterity or physical skills are impaired. Reviewing a person's daily routine, prioritising tasks, restructuring activities according to energy levels, and introducing regular rest periods, including good sleep hygiene, will all contribute to fatigue management (Jahanshahi and Marsden 1998).

### Guidance and Good Practice Points

For occupational therapists aiming to promote self-management of fatigue with people with Parkinson's, it is recommended that:

**G 3.9.1:** The impact of fatigue on performance in all activities of daily living should be assessed and/or formally measured.

**G 3.9.2:** A structured fatigue-management programme should be introduced, using techniques such as:

- A diary to record specific tasks that increase fatigue and specific times of the day when fatigue is more of a problem.
- Identifying priorities and how to best use limited reserves of energy.
- Identifying labour-saving and energy-conservation opportunities, such as the use of a scooter outdoors, rather than struggling to walk.
- Delegating some tasks to optimise use of time and energy.
- Planning and pacing activity by balancing periods of activity, including gentle exercise, and proactive rest through the course of the day.
- Regular recuperation times, minimising episodes of intense exhaustion having delayed rest for too long.

**G 3.9.3:** Compliance with the prescribed anti-Parkinson's medication regime should be optimised, with appropriate use of medication boxes and/or electronic reminders and/or assistance of other people as required.

**G 3.9.4:** Good sleep hygiene routine should be promoted; for example falling asleep in a chair during the daytime and early evening napping should be avoided. A 40-minute nap in the afternoon can prevent early evening fatigue, but this nap should be in bed, for no longer than 40 minutes, and should be factored in to a regular routine.

## 3.10 Handwriting and communication technology

Micrographia, or diminishing handwriting, is commonly seen with people with Parkinson's (Oliveira *et al* 1997). In addition to writing diminishing in size, the script often slopes towards the far corners instead of going straight across the page, and a more 'spidery' or 'scrawled' style may also be evident. Recent evidence suggests individuals with greater freezing of gait associated with their Parkinson's also have the most difficulty with handwriting (Heremans *et al* 2016). These findings suggest that deficient movement sequencing and poor adaptation affecting activities of the hands and arms are another challenge for people living with freezing of gait.

With the advent of technology, there is an increasing need for people to master technology such as mobile phones and computers. Although larger-button devices can assist, expert advice and support can be accessed free of charge via AbilityNet, a national charity that aims to help people of all abilities access technology.

### **Guidance and Good Practice Points**

For occupational therapists aiming to promote handwriting abilities with people with Parkinson's (Oliveira *et al* 1997), it is recommended that:

**G 3.10.1:** When writing, people with Parkinson's should sit comfortably and in an upright position at a table, with good lighting.

**G 3.10.2:** To improve the size of writing, occupational therapists should suggest that people with Parkinson's:

- Trial a fibre-tip pen or a gel-ink pen, as these 'flow' most smoothly.
- Use a pen grip, a wide pen or a pen with a built-in grip to give a more comfortable and relaxed (less tight) hold on the pen.
- Use lined paper, or a heavy lined sheet below a plain page (as often found in a block of writing paper).
- Avoid distractions such as TV, radio, background music, etc.
- Concentrate and avoid rushing when writing.
- Think 'big' often while writing.
- Pay close attention to forming each letter while writing.
- Aim up to the line above on each upward pen stroke.
- Follow the line on the paper to guide writing straight along.

**G 3.10.3:** If writing style is rapid, the cue of thinking the words 'big and slow' may help focus attention on writing less automatically and hence more clearly.

**G 3.10.4:** If writing is spidery or scrawly, thinking the words 'smooth' or 'slow and smooth' may be helpful.

**G 3.10.5:** If writing has significantly changed or is illegible, provide advice on contacting banks regarding alternative electronic means of accessing funds.

**G 3.10.6:** Support should be offered to maintain or learn new computer skills, and help with training, adapting hardware and settings sourced free of charge via the national charity AbilityNet ([www.abilitynet.org.uk](http://www.abilitynet.org.uk)).



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## End-of-life care

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Although Parkinson's is progressive, in itself it is not a terminal condition and the palliative phase of Parkinson's may last for two years or much longer. With good multidisciplinary management and a proactive attitude, however, people with Parkinson's may live active lives for one, two or more decades before Parkinson's reaches its most advanced stage. The palliative phase of Parkinson's begins when anti-Parkinson's medications fail to sufficiently relieve symptoms, or cause intolerable side effects, and is, therefore, the stage at which the emphasis of care shifts from the provision of 'therapeutic medical interventions' to a focus on interventions that maximise comfort, dignity and quality of life. Reduction of anti-Parkinson's medications at this stage may be desirable to lower distressing side effects such as psychosis or extreme dyskinesias, at the cost of a correlated decrease in mobility.

The *End of life care strategy* (Department of Health 2008 and subsequently reviewed in the 2017 document *Choice in end of life care*) was published with the aim of improving the provision of services to all adults nearing the end of their lives. The strategy acknowledges that, in the past, the profile of end-of-life care within the NHS and social care services has been relatively low, and that the quality of care delivered has been very variable. It is hoped that implementation of the strategy will improve access to high-quality care for all people approaching the end of life. Furthermore, the strategy states that high-quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice, or elsewhere.

Although there is little evidence demonstrating the efficacy of occupational therapy at the palliative or end-of-life stage for people with Parkinson's, occupational therapists have valuable contributions to make in the context of end-of-life care. Occupational therapists are often involved in the forward planning needed to manage end-of-life care at home; advising on ground floor living, manual handling equipment and care package requirements.

Anecdotally, occupational therapy intervention at this stage focuses on improving quality of life by easing the burden and perceived suffering of both the person with Parkinson's and their family and/or carers. This can be achieved by promoting opportunities for enjoyment of free time (for example, through access to music, radio, time spent outdoors, etc.) and through anticipating and preventing the complications that immobility brings, such as ensuring appropriate positioning and that pressure care is provided. It is also aided by assessing and managing the risks associated with increased physical dependence, and by giving information, support and advice to reduce distress and offer realistic choices if end-of-life care can no longer be managed safely in the person's own home.

### 4.1 A 24-hour approach to posture, positioning and pressure care

Regular changes in position over a 24-hour period are essential for maintaining muscle length and preventing contracture formation in people with profound and progressive

neurological disorders (Pope 1997, Pope 1992, Goldsmith 2000). Pressure risk should be measured and pressure care should also be managed proactively over a 24-hour period (NICE 2014).

#### **Guidance and Good Practice Points**

For occupational therapists aiming to address palliative or end-of-life care with people with Parkinson's, it is recommended that:

**G 4.1.1:** A comprehensive review of posture and positioning over a 24-hour period should be undertaken.

**G 4.1.2:** A suitable 24-hour positioning regime should be implemented, including advice on managing positioning in bed, in an armchair, in a wheelchair or in a car.

**G 4.1.3:** Consideration should be given to time spent in standing to help maintain tissue length and prevent contracture formation (Lockley and Buchanan 2006).

**G 4.1.4:** Wheelchair suitability should be reviewed, with a tilt-in-space option and modified seating considered for those people who are unable to sit comfortably or safely (Pope 2007).

**G 4.1.5:** The suitability of the person's armchair should be reviewed, with consideration given to an adjustable chair that can be modified to meet the person's needs over many hours, for example with a tilt and recline mechanism, adjustable seat height, built-in lateral support and head rest, etc.

**G 4.1.6:** The use of t-rolls, wedges and sleep systems should be considered as an adjunct to positioning.

**G 4.1.7:** Joint assessment with splinting and orthotic colleagues should be considered to optimise the prevention and management of joint contractures.

**G 4.1.8:** The risk of developing pressure ulcers should be assessed using a valid and reliable pressure risk rating scale (NICE 2014) and recorded with a clear review date.

**G 4.1.9:** Pressure care products such as pressure cushions (which may be used in a wheelchair, armchair and/or car seat) should be considered and pressure mattresses provided without delay.

## **4.2 Manual handling and minimising risk**

The manual handling issues that people with Parkinson's experience in the palliative stage of the condition are considerable. This not only places them at risk, but also affects their carers, who may be frail or elderly. Assessment, education, training and reassessment/review should be considered a dynamic and ongoing process, with clear and concise safer-handling plans implemented at all times (RCOT 2018).

Working alongside family and care agencies, who may not have an understanding of the condition and the importance of medication timing on the individual's ability to move,

is an important element of good practice. Condition-specific training and education for family and/or carers may be useful in explaining why the person with Parkinson's may be relatively mobile during the day, but may require hoisting in the evening and overnight for bed transfers.

#### **Guidance and Good Practice Points**

For occupational therapists aiming to address manual handling and the minimisation of related risk in people with Parkinson's, it is recommended that:

**G 4.2.1:** A review of all transfers and manual handling scenarios throughout a 24-hour period should be undertaken.

**G 4.2.2:** The manual handling risks associated with each transfer technique or activity that includes a moving and handling element should be assessed and recorded, with a clear review date.

**G 4.2.3:** The level of carer input should be reviewed in line with manual handling recommendations.

**G 4.2.4:** The physical burden and competency of the person or people undertaking the manual handling should be taken into consideration and reviewed regularly.

**G 4.2.5:** Any manual handling equipment identified as suitable should be provided without delay and trialled on-site to establish its suitability.

**G 4.2.6:** A training programme should be provided and recorded to ensure the person who will be using the equipment has demonstrated they are safe to do so.

**G 4.2.7:** Clear written and/or pictorial reference information about the equipment should be provided and a point of contact given, in case any problems arise.

**G 4.2.8:** Major adaptations such as stair lifts, ceiling track hoists, etc., should be considered as required, with arrangements for servicing/review of equipment provided in place.

**G 4.2.9:** Refusal to consider and/or fund major adaptations on the grounds of prognosis alone should be challenged.

### **4.3 Alternative living arrangements**

Proactive end-of-life planning, in conjunction with palliative care services, may help maintain the comfort, dignity and quality of life of the person with Parkinson's and allow them to stay in their own home if that is where they wish to die. If living independently becomes too much of a struggle, or if a caregiver is no longer able to meet the needs of a person with Parkinson's with the available support at home, proactive care planning, additional family support and promoting choice about where a person is best cared for can avoid a breakdown of the home situation and avoid the need for an emergency hospital admission, or an emergency placement.

### **Guidance and Good Practice Points**

For occupational therapists aiming to address alternative living arrangements with people with Parkinson's, it is recommended that:

- G 4.3.1:** Manual handling risks and burden of care must be reviewed (at least) monthly.
- G 4.3.2:** The perceived burden of care should be measured using a valid and reliable measurement tool, e.g. Caregiver Strain Index (Robinson 1983).
- G 4.3.3:** Concerns about the health and wellbeing of the family (including children) should be acted upon without delay, and with consent, for example by referring to a family support worker or counsellor.
- G 4.3.4:** The team should meet the person with Parkinson's and their family and/or carers to discuss concerns about risk, health and wellbeing and to raise options for additional external support, respite care, alternative accommodation or placement.
- G 4.3.5:** Information should be presented in a sensitive and understandable way, with written information provided to allow decision-making at an appropriate pace.
- G 4.3.6:** Emotional and practical support should be offered to help family members to reach their own decisions concerning changes to living arrangements such as placement in sheltered accommodation, a care home or hospice.
- G 4.3.7:** Establishing mental capacity should be undertaken as required.
- G 4.3.8:** Reassessment of the 24-hour routine of the person with Parkinson's must be undertaken once they are living elsewhere and equipment required provided without delay. If the person moves to a residential care facility, ensure the facility is equipped to meet the needs of the person with Parkinson's.
- G 4.3.9:** All practical attempts should be made to enable the person with Parkinson's to die in their own home if that is what they wish.

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# Glossary

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*Abridged from Parkinson's disease: diagnosis and management in primary and secondary care (NICE 2006).*

<b>Akinesia</b>	Absence or reduced functionality of movements
<b>ADL</b>	Activities of daily living
<b>Bradykinesia</b>	Slowness of movement
<b>Carer (caregiver)</b>	Someone other than a health professional who is involved in caring for a person with a medical condition, such as a relative or spouse
<b>Cochrane Review</b>	A systematic review of the evidence from randomised controlled trials relating to a particular health problem or healthcare intervention
<b>DBS</b>	Deep brain stimulation
<b>Diagnostic study</b>	Any research study aimed at evaluating the utility of a diagnostic procedure
<b>Disease-modifying therapy</b>	Any treatment that beneficially affects the underlying pathophysiology of Parkinson's (also known as 'neuroprotection')
<b>Dysarthria</b>	Slurred or otherwise impaired speech
<b>Dysarthria profile</b>	A description of the dysarthric person's problems, to supply the speech therapist with indications of where to begin in treatment
<b>Dyskinesia</b>	The impairment of the power of voluntary movement, resulting in fragmentary or incomplete movements
<b>Dysphagia</b>	Difficulty in swallowing
<b>Dystonia</b>	Disordered tonicity of muscle
<b>Hypersomnolence</b>	Excessive sleepiness
<b>Hypokinesia</b>	Decreased muscular activity, bradykinesia, reduced or slowed movement
<b>LD</b>	Levodopa (L-dopa)
<b>MSA</b>	Multiple system atrophy

<b>NICE</b>	National Institute for Health and Care Excellence
<b>NSF</b>	National Service Framework
<b>'Off' time</b>	The duration of time when anti-Parkinson's medication is not controlling the person's symptoms or is 'wearing-off'
<b>'On' time</b>	The duration of time when anti-Parkinson's medication is controlling symptoms of Parkinson's
<b>PDNS</b>	Parkinson's disease nurse specialist
<b>PDS</b>	Parkinson's Disease Society (now Parkinson's UK)
<b>PSP</b>	Progressive supranuclear palsy
<b>Quality of life</b>	Refers to the patient's ability to enjoy normal life activities, sometimes used as an outcome measure in a clinical trial
<b>RCT</b>	Randomised controlled trials
<b>Rigidity</b>	Abnormal stiffness or inflexibility
<b>Sialorrhoea</b>	Increased saliva or drooling
<b>Somnolence</b>	Sleepiness or unnatural drowsiness
<b>Stereotactic surgery</b>	A precise method of locating deep brain structures by using three-dimensional coordinates. This surgical technique may either involve stimulation or lesioning of the located site
<b>Videofluoroscopy</b>	A test for assessing the integrity of the oral and pharyngeal stages of the swallowing process. Involves videotaping fluoroscopic images as the patient swallows a bolus of barium

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# Appendix 1:

## Development and ratification of the 2nd edition

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The 2nd edition of this guide has built on the content of the 1st edition and updated areas where there is more direct evidence available to inform effective occupational therapy intervention for people with Parkinson's.

This 2nd edition has subsequently been ratified by expert occupational therapists, colleagues at Parkinson's UK, occupational therapists with an interest in Parkinson's, medical colleagues and people with Parkinson's in a five-stage process:

1. The 1st edition guideline content was updated by the original authors, Ana Aragon and Jill Kings, two expert occupational therapists with a special interest in Parkinson's and progressive neurological disorders (see [A1.1](#)).
2. Early in the process of updating the guidance, new evidence for the 2nd edition and a copy of the 1st edition were reviewed by Dr Kevin Galbraith of Parkinson's UK. This check of sense and evidence allowed feedback to be incorporated as required.
1. All members of the Royal College of Occupational Therapists Specialist Section – Neurological Practice were invited by email to comment on a working draft of the revised 2nd edition – with nine practising occupational therapists contributing (see [A1.3](#)).
1. The final content was agreed by three recognised clinical experts in the field of occupational therapy and Parkinson's. Overall content was also reviewed and agreed by Consultant Physician Dr Robert Skelly (see [A1.2](#)).
2. Parkinson's UK's Public Involvement Manager invited its members to contribute their thoughts and views about the overall content of the guide and its value to occupational therapists working with people with Parkinson's (see [A1.4](#)).

This document was also peer reviewed by the Royal College of Occupational Therapists' Practice Publications Group in January 2018.

## A1.1 Authors' details

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## A1.2 Members of the 2017 Expert Advisory Group

Respondant	Position	Place of work
Fiona Dyer	Specialist Occupational Therapist	Neuro Rehabilitation Department Community Rehabilitation Team, County Durham and Darlington NHS Foundation Trust, Chester le Street Community Hospital
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Dr Robert Skelly	Consultant Physician	Derby Parkinson's Disease Services, Derbyshire Community Health Services NHS Trust, Royal Derby Hospital



### A1.3 Draft guidance consultation with members of the RCOT Specialist Section – Neurological Practice (April 2017)

Respondant	Position	Place of work
Nikki Adams	Specialist Occupational Therapist for Parkinson's	Virgin Healthcare, Clara Cross Centre, St Martin Hospital, Bath
Ereshini Bhoola	Senior Occupational Therapist	BUPA Cromwell Hospital, London
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Kate Hayward	Chair: RCOTSS-NP Long Term Conditions Forum	National Hospital for Neurology and Neurosurgery, London
Sandra Parker	Community Rehabilitation Occupational Therapist	Central Cheshire Integrated Care Partnership
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Alison Wiesner	Occupational Therapy Lead	Hertfordshire Neurological Service

### A1.4 Additional contributors to the 2nd edition

People invited to comment through forums hosted by Parkinson's UK	
Barbara Potter	Wife and carer of a person with Parkinson's, and Parkinson's Voice
Jane Rideout	Person diagnosed with Parkinson's
Advisers and supporters from Parkinson's UK	
Laura Cockram	Head of Policy and Campaigning
Kevin Galbraith	Critical Appraisal
Daiga Heisters	Head of UK Parkinson's Excellence Network
Jade Oorthuysen-Dunne	Involvement Manager
Tanith Muller	Parliamentary and Campaigns Manager, Scotland

## A1.5 Additional contributors' comments summary

Theme	Key points used to update draft text for 2nd edition
Carers	The term 'family or caregiver' used as a generic term to describe all who provide gratuitous or paid care – but this terminology would usually only include unpaid carers. Carer burden should be explored.
Daily activities	Tips suggested for shopping, handling money, clothes and cooking.
Dementia	Helpful to reassure that most people with dementia continue to live in their community, and that support is available to maximise independence.
Driving	New policy 2018.
Exercise	More specific advice to encourage/establish better habits (from early stage). New Parkinson's UK exercise Framework.
Sex and intimacy	Useful information and good attempt at removing the taboo and embarrassment about sexual problems.
Updated statistics about Parkinson's	New Incidence and Prevalence figures published December 2017.
Work	Need to realistically assess whether a person can safely and feasibly return to work, as well as refer to government services.

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# Appendix 2:

## Development and ratification of the 1st edition

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The guidelines were ratified by occupational therapists with an interest in Parkinson's in three stages:

1. The initial guideline content was written by two expert occupational therapists with a special interest in Parkinson's and progressive neurological disorders (see [A2.1](#)).
2. Draft guideline content was validated and revised by the advisory team, including four recognised clinical/academic experts in the field of occupational therapy and Parkinson's (see [A2.2](#)).
3. The final guideline content was agreed by consensus by a further 13 practising occupational therapists at a consensus event held at the College of Occupational Therapists (see [A2.4](#)).

General content was also reviewed and agreed by Dr Diane Playford, Senior Lecturer at the Institute of Neurology and Consultant Neurologist at the National Hospital for Neurology and Neurosurgery, London.

### A2.1 Authors' details

Name	Title
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<b>Jill Kings (née Dawson)</b> MSc Dip COT SROT	Consultant Practitioner in Neurological Occupational Therapy and Rehabilitation  Formerly: Clinical Specialist Occupational Therapist and Therapy and Rehabilitation Services Manager National Hospital for Neurology and Neurosurgery London

## A2.2 Expert advisory group

Theme	Title
Angela Birleson	Principal Clinician Integrated Occupational Therapy Service Middlesbrough, Redcar and Cleveland Unit, James Cook Hospital
Angela Carroll	Senior Practitioner Occupational Therapist Caerphilly Social Services
Vicky Kelly	Lead Clinician Occupational Therapist NHS Knowsley Seddon Suite Intermediate Care Unit, St Helens Hospital, Merseyside
Charmaine Meek	Research Assistant PD REHAB Trial College of Medical and Dental Sciences, University of Birmingham
Dr Diane Playford	Senior Lecturer, Institute of Neurology Consultant Neurologist, National Hospital for Neurology and Neurosurgery, London

## A2.3 1st edition: the process of achieving consensus

1. On 30 June 2009, an email invitation was sent to members of the College of Occupational Therapists Specialist Section – Neurological Practice inviting them to attend a consensus day at the College of Occupational Therapists (COT) on 28 July 2009 to ratify the guidelines.
2. The same email was sent to COT with a request to forward to the Chairs of the COT Specialist Section for Older People and Housing for circulation to their members.
3. Seventeen people responded to the email, with 13 attending the consensus day.
4. During the consensus day, participants were split equally into two working groups, with each group facilitated by one of the two co-authors and editors, and co-facilitated by an expert occupational therapist in Parkinson's.
5. Each of the working groups was given the Guideline Development and Background sections of the draft document and two of the four guidelines sections.
6. Each group was asked to reach agreement on the specific content of their section of the guideline by discussing and agreeing if the guideline was:
  - good practice;
  - contemporary practice; and
  - something, as occupational therapists, that they should be undertaking?
7. Agreement was by informal discussion and debate. Participants were invited to reword

the guideline or remove it if they felt it was not appropriate and did not represent good or contemporary practice, or was something that an occupational therapist should not consider undertaking.

8. If disagreement ensued, a majority agreement via a formal show of hands was requested. It was agreed in advance that 70 per cent would constitute a sufficient majority. If the working group failed to reach majority agreement, the guideline was brought to the full group for agreement during the summary session.
9. During the summary session, informal discussion was facilitated regarding the general 'usability' of the guideline, including consideration of the structure, layout, readability, level of information, illustrations, title and presentation of underpinning evidence.

## A2.4 Consensus day participants

Name	Title
Ereshini Bhoola	Lead Therapist, Integrated Neurological Services, Richmond
Fiona Dyer	Specialist Occupational Therapist, Chester-le-Street Community Hospital, County Durham
Amy Edwards	Professional Affairs Officer Long Term Conditions, College of Occupational Therapists, London
Rosalind Graba	Senior Community Occupational Therapist, Knutsford Community Hospital, Cheshire
Joanne Hurford	Band 7 Occupational Therapist, National Hospital for Neurology and Neurosurgery, London
Nicola Keelan	Band 6 Specialist Occupational Therapist, St George's Hospital, London
Pauline Miller	Specialist Occupational Therapist, King's College Hospital, London
Lauren Mosley	Occupational Therapist, Long Term Neurological Conditions Team, Pinderfields General Hospital, West Yorkshire
Moya Neale	Occupational Therapist, Bronglais Hospital, Ceredigion
Sally Ann Richardson	Occupational Therapy Team Leader, Neurosciences/Stroke, York Hospital
Hennie Sleeman	Band 7 Occupational Therapist, West Sussex PCT, Community Neuro Team, Worthing
Jacqui Wakefield	Consultant Therapist, King's College Hospital, London
Alison Wood	Band 7 Occupational Therapist, Havering PCT, Community Rehab Service, St George's Hospital

## A2.5 1st edition: involving occupational therapists and people with Parkinson's

The experiences and opinions of occupational therapy from the perspective of 230 people living with Parkinson's, in four European countries, have also informed the development of these Good Practice Points and other guidance, with a high level of consensus that people would recommend occupational therapy to others (Jansa *et al* 2011).

### Focus group questionnaire

During the development process, a focus group was held in Bristol by one of the authors (Ana Aragon) on 20 January 2009. A group of approximately 12 occupational therapists employed by Avon and Wiltshire Mental Health Partnership NHS Trust attended. The group was asked the following questions to ensure that the guidelines would be as relevant to mental health-based occupational therapists practising with people with Parkinson's and related conditions as it would be to other occupational therapists.

**Meeting purpose:** to explore the experiences and needs of occupational therapists working in mental health, with people who have Parkinson's and related disorders.

### Questions

1. What Parkinsonian conditions do you see:

- regularly;
- occasionally?

**A:** In roughly decreasing frequency: Idiopathic Parkinson's disease, Lewy body dementia, drug-induced Parkinsonism, e.g. from anti-psychotics, Vascular Parkinsonism.

2. What stage of Parkinsonism do you usually see?

**A:** From before diagnosis, as in cases of depression, anxiety and drug-induced Parkinsonism, and then mainly seen at complex stage and with psychosis at palliative stage.

3. In what settings do you see Parkinsonian patients?

**A:** Day hospital, care homes, intermediate care/rehabilitation (six-week assessment stay), own home, mental health in-patient wards.

4. What other healthcare professions do you work with regularly?

**A:** Community psychiatric nurses, social workers, physiotherapists, psychologists and doctors.

5. What level of physiotherapy input is available for your Parkinsonian patients?

**A:** Most teams have access to physiotherapy. But sometimes there is an unmet need for physiotherapy.

6. How do the roles of occupational therapy and psychology interact in your team?

**A:** Occupational therapists felt there was an overlap with: activity analysis and intervention, facilitation of group dynamics in activity groups, discussion groups – e.g. anxiety management, reminiscence, life review – as a group or one to one.

7. What functional issues do you address in your Parkinsonian patients?

**A:** Medication management, ADL-personal care, transfers, mobility; reintroduction to social, personal, family, leisure and domestic roles; raising motivation, teaching cognitive strategies; respite arrangements, equipment, grab rails, falls reduction, advice on simplifying home layout to improve mobility, floor strips application.

8. What palliative interventions do you provide to your Parkinsonian patients?

**A:** Assessments for assistive technologies, hoists, home environment, care needs and when placements from home are considered; referrals to pressure relief specialist occupational therapist.

9. What information and resources relating to Parkinsonism do you use?

**A:** One-day courses and presentations on Parkinson's rehabilitation; written information about Parkinson's rehabilitation methods; information from peers, Parkinson's Disease Society local branch and local Parkinson's service occupational therapist.

10. What information and resources about Parkinsonism do you need, or would you find useful?

**A:** Speech and language therapy service, Parkinson's skills training and subject updating, information about research on value of leisure and exercise.

## A2.6 Comments from a person with Parkinson's (1st edition)

I write as a person with Parkinson's and as a retired GP. There is no more effective way to learn the full effect of a condition on daily life than the opportunity to experience it first-hand. I am delighted to be asked to comment on these occupational therapy guidelines for Parkinson's from a patient's point of view, having seen this and an earlier version.

I have been privileged to attend a weekly course for people with Parkinson's organised by an occupational therapist at St Martin's Hospital, Bath. I found this helpful, particularly at an early stage of the condition. The course introduced me to cueing and other techniques for dealing with problems. I am sure others will be equally helped by these occupational therapy guidelines.

I particularly like the clear overview of Parkinson's suitable for all to read, patients, carers and professionals alike. I like the detail of how to cope with the loss of the automatic pilot. Overcoming this loss requires enormous effort. This must contribute to the fatigue, which can be a major problem in coping with the condition.

This well-constructed booklet will be invaluable for those of us living with Parkinson's.

I see it being used as a daily reference to find helpful advice for many aspects of Parkinson's and on any immediate problem. It is the sort of book to dip into when needed. This will promote self-help and independence. None of us wants to come to be dependent on others for coping with routine activities of daily life.

My husband has no comments. He does not regard himself as a carer although he helps me in several small ways. My condition does impinge on his life, too.

I wish the authors and Parkinson's UK every success in producing such a useful set of guidelines for occupational therapists.

***Dr Dileas Sweetenham,***  
*Chair, Bath branch Parkinson's UK*



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