Occupational therapy for people with Parkinson's

Best practice guidelines

Ana Aragon and Jill Kings

In partnership with

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Foreword

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 reviews, '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.

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PART 1

Guideline development and background

The process of developing the guidelines

i) Introduction

The *National Service Framework for long-term conditions* (Department of Health 2005) and the National Institute for Health and Clinical Excellence (NICE) clinical guidance *Parkinson's disease: diagnosis and management in primary and secondary care* (NICE 2006) provide clear expectations and set out explicit clinical standards to improve service provision for people with progressive neurological conditions such as Parkinson's. Reflecting on and building on these key documents, an All Party Parliamentary Group (APPG) report on Parkinson's was published in 2009, entitled *Please mind the gap: Parkinson's disease services today* (APPG 2009). This report sets out the findings of an inquiry regarding 'access to health and social care services for people with Parkinson's disease and their carers'. Key recommendations of the report are to improve leadership; ensure drivers are in place to support implementation of national guidance; strengthen service monitoring; and support better commissioning and planning of services, through the provision of evidence and guidance, and in particular strengthening workforce planning so that sufficient skilled professionals are available to deliver high quality Parkinson's care. The above documents are set against the background of a large and rapidly growing neurological sciences evidence base and an increasing number of medical and surgical interventions for people with Parkinson's, some of which are very expensive and only available to a limited number of people with the condition.

Some progress has been made since the Parkinson's Disease Society (PDS) *Members' survey* was undertaken in 1997, as evidenced in their new members' survey conducted in 2007. This survey was responded to by over 13,000 people and is entitled *Life with Parkinson's today: room for improvement* (2008). This new PDS survey did find, however, that the majority of people with Parkinson's are still *not* being assessed for, or receiving, therapies to help them manage their condition, while access to therapies is called for when and as needed (Parkinson's Disease Society 2008). This contrasts starkly with the most recent Cochrane review which concludes that 'there is inadequate evidence to evaluate the effect of occupational therapy for people with Parkinson's disease' (Dixon et al 2009). Nevertheless, emergent evidence and anecdotal clinical experience suggest that many functional and psychosocial issues that persist despite good medical management of Parkinson's appear to be responsive to a condition-specific rehabilitative approach, such as the client-centred form of occupational therapy detailed in these Best Practice Guidelines.

Research into the efficacy and cost-effectiveness of combined occupational therapy and physiotherapy for people with Parkinson's commenced across the UK in 2009. This project, known as PD REHAB, is being co-ordinated from the University of Birmingham. The study is a phase III randomised controlled trial and aims to recruit 800 people with Parkinson's who report limitations in their activities of daily living. Results are expected to be available after five years.

In respect of the limited evidence available regarding occupational therapy efficacy, it appears that occupational therapists in the UK lack condition-specific knowledge and skills to treat people with Parkinson's. This was illustrated by Deane et al (2003a and 2003b) who undertook surveys of approximately 150 UK-based occupational therapists to gain data on current practice and to develop a consensus as to best practice in occupational therapy when treating people with Parkinson's. These two surveys showed that, despite a clear consensus that 'Parkinson's disease requires lifelong provision of occupational therapy within multidisciplinary teams', occupational therapy was usually provided over a relatively short period of time, after which the person with Parkinson's was usually discharged (Deane et al 2003a, 2003b). Occupational therapists who responded to these surveys also reported a lack of knowledge about condition-specific interventions and a tendency to focus on self-care goals. However, Deane et al have summarised four main roles that occupational therapists assumed when treating people with Parkinson's. These were: problem-solver, educator, networker, and supporter.

Currently, there is little higher-level, post-graduate Parkinson's-specific skills training available for health and social care professionals, including occupational therapists, in the UK. It is suggested here that this contributes to occupational therapists' apparent lack of Parkinson's-specific treatment skills and compounds the shortage of evidence to support their interventions. In an attempt to address the knowledge gap affecting a range of health and social care professionals, including occupational therapists, Parkinson's UK has supported Leeds Metropolitan University in the development of a part-time, distance learning (internet-based) Masters degree in Parkinson's Disease Practice, which commenced accepting students in autumn 2009.

ii) The aim of the guidelines and target audience

The purpose of these guidelines is to draw upon the widest relevant knowledge and evidence available, including evidence from neighbouring disciplines and clinical areas, to describe and inform contemporary best-practice occupational therapy for people with Parkinson's. In an attempt to update current occupational therapy practice regarding treatment techniques and approaches awaiting further evaluation, these guidelines incorporate numerous years of expert occupational therapy practice, with all approaches described here having been endorsed by occupational therapy practitioners across the UK (see Section iii: Ratification process).

The NICE *Parkinson's disease* guidelines (NICE 2006) and the UK Parkinson's Disease Society report (PDS 2008) recognise occupational therapy interventions as of key importance for people with Parkinson's. However, the detail of *how* to conduct occupational therapy for people with Parkinson's is omitted from the NICE *Parkinson's disease* guidelines. Parkinson's UK have therefore driven and supported the development of the guidelines in this document as a part of their Therapy Strategy to best support therapy provision for people with Parkinson's (PDS 2007a). A formal meta-analysis of available evidence about occupational therapy for Parkinson's was conducted in the drafting of the NICE guidelines for Parkinson's (NICE 2006) and has not been repeated here, in keeping with this project's emphasis on best-practice interventions. It is therefore suggested that readers familiarise themselves with the literature cited in this document and maintain an awareness of new evidence as it is published. These guidelines should be used as an adjunct to current occupational therapy practice and guidance to support clinical reasoning and judgement, pending more definitive evidence.

These occupational therapy best-practice guidelines aim 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 with Parkinson's.
3. Introduce novel and condition-specific occupational therapy interventions.
4. Provide a comprehensive overview of the nature and detail of currently agreed best-practice occupational therapy intervention in the UK.

The guidelines have been written as an easy reference guide and are built on recommendation no. 80 of the NICE 2006 guidelines (see Appendix 5 for full details). Practical examples of interventions have been included to allow occupational therapists from a variety of health and social care settings and specialties to readily apply new and contemporary treatments in their day-to-day practice.

These guidelines will be reviewed and updated by the College of Occupational Therapists Specialist Section – Neurological Practice in the future as required, and at least every five years.

iii) Ratification process

The guidelines were commissioned by the Parkinson's Disease Society (now Parkinson's UK) in conjunction with the College of Occupational Therapists Specialist Section – Neurological Practice.

In the preliminary stages of the guideline development process a group of 12 mental health occupational therapists were gathered for a focus group review (see Appendix 3). This was to ensure that the guidelines would be as relevant to mental health-based occupational therapists as they would be to other occupational therapists working with people with Parkinson's.

The guidelines have subsequently been 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 Appendix 1).
2. Draft guideline content was then validated and revised by the advisory team, including four recognised clinical/academic experts in the field of occupational therapy and Parkinson's (see Appendix 1).
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 Appendix 2).

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 (see Appendix 1).

iv) User involvement

The experiences and opinions of occupational therapy from the perspective of 230 people living with Parkinson's, in four European countries, has informed the development of these guidelines. (Results are currently being prepared for submission to a peer reviewed journal.)

In summary, this survey reports that just over half of the respondents (53.9 per cent) had seen an occupational therapist concerning their coping with Parkinson's. For these people, occupational therapy was frequently in relation to using arms and hands, carrying out daily activities, advice about assistive aids and equipment, and about environmental adaptations. Receiving information about further support and services, and education about Parkinson's, was also reported by a minority. In all four countries there was a high level of consensus among people who had received occupational therapy that they would recommend it to others with Parkinson's.

The document was also reviewed by a person living with Parkinson's and revised following comments made (see Appendix 4).

Note on terminology

The term 'family or care giver' will be used as a generic term to describe all who provide gratuitous or paid care.

Note that the Parkinson's Disease Society became Parkinson's UK in 2010. Past projects and publications of the Society are referenced under the old name. The Society's ongoing and future projects are referenced under its new name.

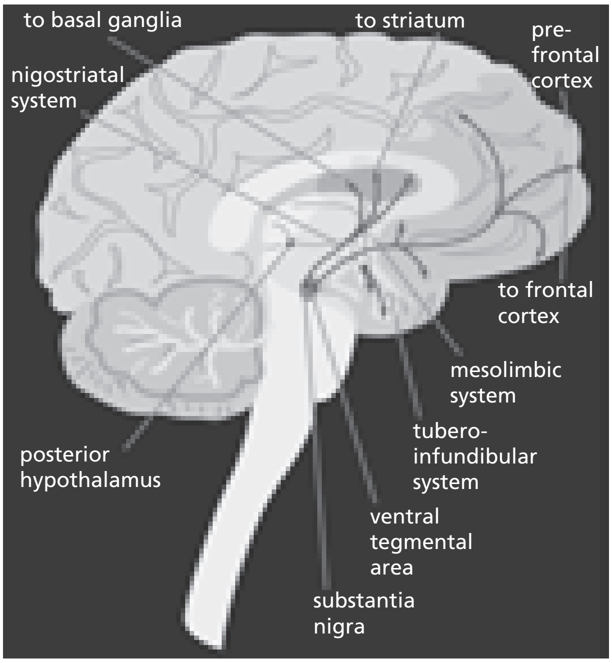
The term 'Parkinson's' is used in preference to 'Parkinson's Disease' throughout the majority of this document.

Background

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 neurones in the substantia nigra, located within the basal ganglia (Schapira 1999). Additional changes in related brain regions and in other neurotransmitters, such as noradrenaline, seratonin, glutamate and GABA, 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).

The diagram below shows some of the main dopamine pathways in the brain: projecting from the substantia nigra to the caudate nucleus-putamen (neostriatum – concerned with sensory stimuli and movement); the ventral tegmentum to the mesolimbic forebrain (believed to be associated with cognitive function, reward and emotional behaviour); and to the tubero-infundibular system (concerned with neuronal control of the hypothalmic-pituatory endocrine system).



Permission granted to download this image from *http://www.cnsforum.com*
(Kruk and Pycock 1993)

Accessed on 13.02.10.

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-learnt, 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 (Jueptner et al 1997a, 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-learnt 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-learnt 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 which 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).

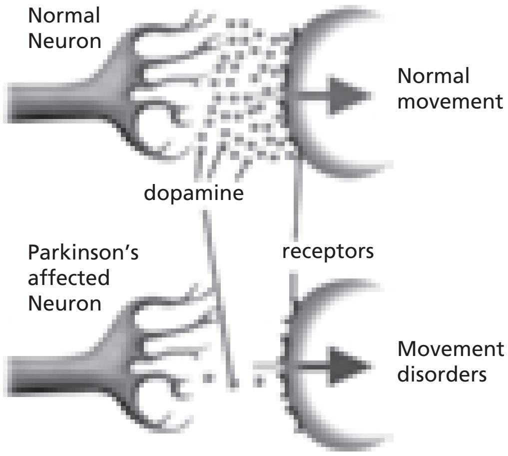
When do Parkinson's symptoms begin?

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, ten or even twenty 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 with an estimated 100–180 per 100,000 of the UK population being affected, roughly equivalent to 6–11 people per 6,000. There is a rising prevalence with age and a higher prevalence and incidence of Parkinson's in men (NICE 2006). The average age at diagnosis of Parkinson's is around 60

Dopamine levels in a normal and a Parkinson's affected neuron.



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Accessed on 13.02.10.

years. However, one in twenty people with Parkinson's are under 40 years old at the time of diagnosis (PDS 2008).

Diagnosing Parkinson's

Currently no definitive scan or biochemical test is available to confirm the presence of Parkinson's. Diagnosis is therefore 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 are 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 Parkinson's. Use of the UK Parkinson's Disease Society Brain Bank criteria for the diagnosis of Parkinson's is recommended to help with the differential diagnosis of Parkinson's (NICE 2006). 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; and **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).

Over the past ten years or so, the presence and impact of more than 40 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. Distress and reductions in quality of life for people with Parkinson's are often reported as being greater in relation to the experience of non-motor symptoms than to problems related to the motor symptoms of the 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 care givers (Chaudhuri et al 2006).

A pair of useful and simple screening tools have been developed to aid the identification of non-motor symptoms in people with Parkinson's. The Non-motor Symptoms Questionnaire is designed to be completed by a person with Parkinson's, or a family member or care giver, prior to a medical, nursing or therapy review. (The Questionnaire may be located using the search facility and downloaded from *http://www.parkinsons.org.uk*. Accessed on 13.02.10.) The companion Non-motor Scale covers similar non-motor symptoms, but is designed to be scored by a healthcare professional.

Non-motor symptoms of Parkinson's

Non-motor symptoms often develop in association with and sometimes preceding the main motor features of Parkinson's. These non-motor features are often experienced as a separate and commonly fluctuating, subset of symptoms which may include:

- **Autonomic failure:** for example, episodes of feeling very hot or very cold, or postural hypotension (a sudden fall in blood pressure on rising from lying or sitting and consequently a risk factor for falls).
- **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. Hyper-sexuality may also develop as a side effect of some anti-Parkinson's medications.
- **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 and mental fatigability.
- **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, 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 which 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 with problem-solving, planning, organisation and decision-making. 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 time frames or sequences of events, or difficulties reading a clock face. Feeling that there is someone or something positioned behind oneself is also sometimes reported. 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), also sometimes occur (Lee et al 1998, Lee and Harris 1999, 2001, Lee et al 2001).
- **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.
- **Dementia:** another neuropsychiatric problem, which may be seen as short-term memory failure and difficulty recalling names. Generally, dementia is mild to moderate and only occurs in the later stages of Parkinson's.

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 care givers 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). (These are also called Parkinson's Plus syndromes or disorders in some publications.)

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 if this happens). 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, that is, movements that 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 actually experiencing them.

ii) Medical and surgical interventions

There is currently no cure for Parkinson's. At present a wide range of drugs is 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, medication may become increasingly ineffective. Once a dose of anti-Parkinson's medication has been absorbed, which has 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'.

Time taken for an oral dose to 'kick in' tends to increase in relation to the number of years during which it is taken. Eventually, each dose may take up to an hour or more to take effect, possibly wearing off an hour or more before the next dose is due. 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 twelve 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 during these regular reviews (NICE 2006).

Commonly used medical treatments

Levodopa has been the standard symptomatic therapy for Parkinson's for more than 40 years. This is the precursor of dopamine, which is deficient in Parkinson's. However, levodopa 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.

NICE (2006) currently recommend 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.

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. 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 enable it to stay longer at its site of action. This may also be useful to help manage fatigue.

Anticholinergics are older drugs, less commonly prescribed now, that can have a mild effect on the symptoms of Parkinson's by blocking the action of the chemical messenger acetylcholine (involved in messages to muscles).

COMT inhibitors work by blocking an enzyme that breaks down levodopa, thus prolonging the action of levodopa doses.

MAO-Binhibit ors work by blocking the enzyme monoaomine oxidase type B (MAO-B), which breaks down dopamine in the brain.

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 (the procedure is known as thalamic stimulation).
- The globus pallidus (the procedure is known as pallidal stimulation).
- The subthalamic region (the procedure is known as subthalamic stimulation).

A wire is then connected to a small Implantable Pulse Generator (IPG), 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.

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:

Gamma knife surgery, which is a development in the application of lesioning, using one dose of gamma radiation through the skin and skull. The effects of gamma knife surgery may take weeks or months to be seen, and the risks of this type of surgery, as compared to other surgical procedures, are not yet known.

Stem cell and foetal brain tissue implants. Controversial research is underway 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.

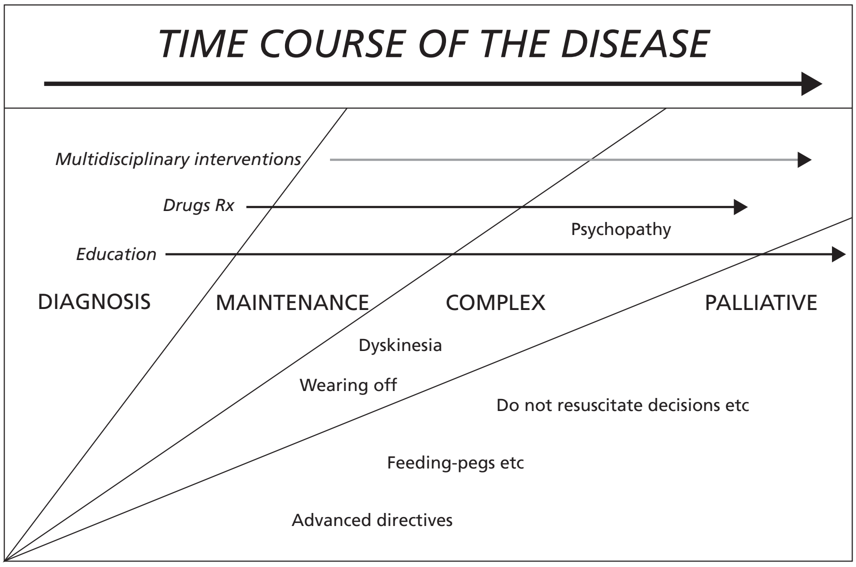
Gene therapy is a new approach to treating medical conditions, in essence using genes as drugs. It works by introducing normal genes into the cells of people with certain disorders to overcome the effects of defective genes, which may cause or have a part to play in the development of the condition. Although in most cases Parkinson's is not thought to be genetically inherited, it is hoped that gene therapy could still be used to prevent the death of nerve cells and promote the regeneration of cells in the early stages of the condition.

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

NICE (2006) *Parkinson's disease: diagnosis and management in primary and secondary care* and other publications (MacMahon and Thomas 1998) make use of four main categories to describe Parkinson's:



Reproduced with kind permission (Thomas et al 2006)

- Diagnosis
- Complex
- Maintenance
- Palliative

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, and 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):** Part II ADL score (Fahn and Elton 1987). A new UDPRS sponsored by the Movement Disorder Society (MDS), the MDS-UPDRS (2008), has an updated Part II – Motor Aspects of Experiences of Daily Living (M-EDL). This is designed for completion by a person with Parkinson's or caregiver, but can be reviewed by the 'investigator' to ensure completeness and clarity. For more details see *http://www.movementdisorders.org/publications/rating_scales/mds_updrs.pdf* Accessed on 20.04.2010.
- **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** staging of Parkinson's scale (Hoehn and Yahr 1967).

These measures provide quantitative data about the severity, stage, or impact of Parkinson's. They do not, however, take environmental, social, and contextual factors, or the personal relevance of the domains measured, into account (see Appendix 6 for additional assessment details).

There is currently no comprehensive, standardised, occupational therapy assessment/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 by occupational therapists to use with people with Parkinson's:

- **Assessment of Motor and Process Skills** (AMPS) (Fisher 2003).
- **Canadian Occupational Performance Measure** (COPM) (Law et al 2005).
- **Nottingham Extended Activities of Daily Living Assessment** (NEADL) (Nouri and Lincoln 1987).
- **Fatigue Impact Scale** (FIS) (Whitehead 2009).

iv) The impact of Parkinson's on occupational performance

The World Federation of Occupational Therapists (WFOT) describes occupational therapy as:

> *a 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 enabling people to do things that will enhance their ability to participate or by modifying their environment to better support participation.*
>
> (WFOT 2004)

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

Table 1 provides an overview of problems an individual with Parkinson's may experience.

Occupational therapy process frameworks

There is limited published information about the processes and techniques used by occupational therapists when treating people with Parkinson's. Deane et al (2003a, 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, p. 252).

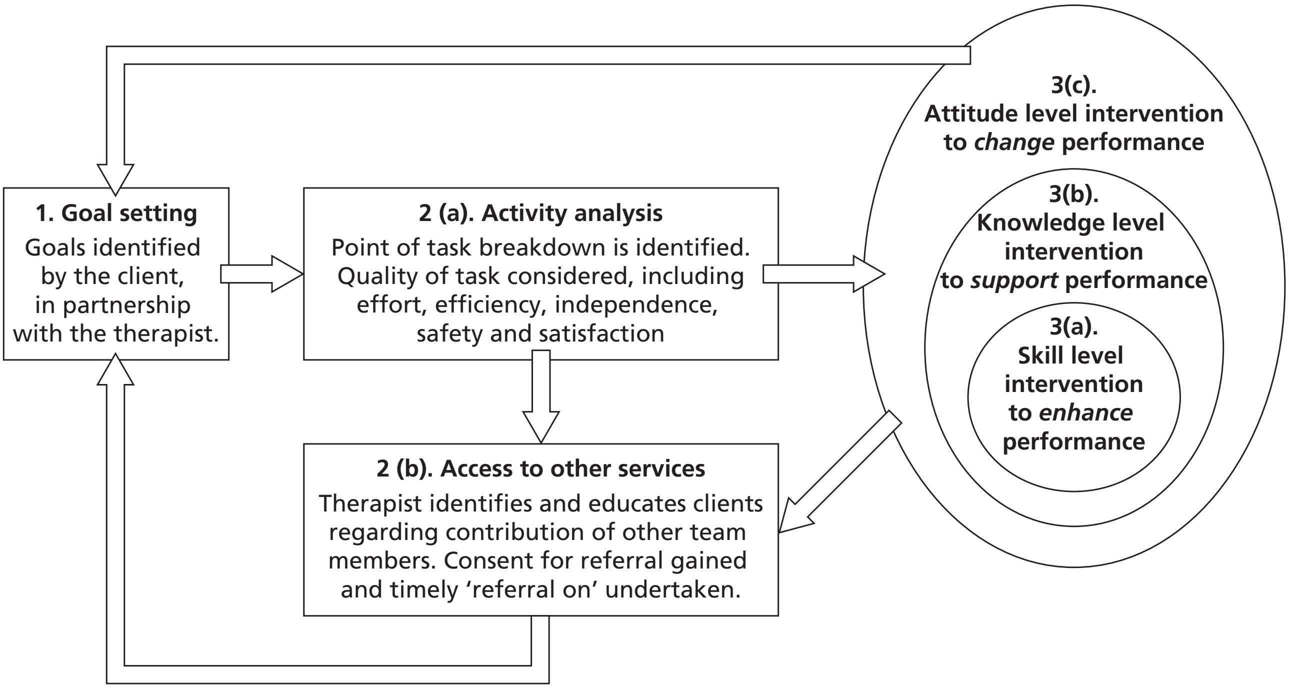
The principles of occupational therapy for Parkinson's include:

- Early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, to 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 2006).

An 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 1).

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 ADLs, transfers, driving, etc.
Gait/balance problems, e.g.:	
Start hesitation	Difficulty taking the initial step to begin walking.
Shuffling gait	Shortened stride length and increased risk of tripping.
Slowness	Reduced speed when walking.
Festination	Walking speeds up over time, may have difficulty stopping.
Freezing episodes	Feet appear to become rooted to the spot.
Postural instability	Problems with co-ordination when changing direction or turning. Impaired balance and reduced saving reactions, increasing risk of falls.
Reduced manual dexterity, poor co-ordination and tremor	Difficulty with manual and bi-manual tasks, e.g. eating, fastening buttons, applying makeup, writing.
Micrographia	Handwriting may shrink and become illegible.
Dysarthria	Loss of voice clarity and decreased speech intelligibility.
Poor breath support	Reduced volume of speech.
Fatigue	Reduced endurance during all activities of daily living.
Cognitive changes, e.g.:	
Bradyphrenia	Generalised slowing of thinking processes.
Impaired executive function	Reduced problem-solving and decision-making skills.
Impaired attention	Reduced concentration and ability to maintain, or switch, attention.
Reduced motivation	Apathy, reduced interest and drive leading to social isolation.
Depression	Low mood, feelings of sadness or despair.
Anxiety	Leading to stress, fear and withdrawal.
Hallucinations, perhaps with delusions and possibly dementia	Resulting in confusion and inability to maintain own safety.



Reproduced with kind permission (Jain et al 2005)

Figure 1 The variety of occupational therapy interventions used to change skills, knowledge and attitude with people with Parkinson's and support their care givers. (See Sections 2, 3 and 4 of these guidelines for further detail.)

PART 2

The guidelines

To understand the many functional difficulties reported by people with Parkinson's, occupational therapists will need to take into account the pivotal roles and functions of dopamine and the basal ganglia as set out earlier in this document. The diverse nature and range of motor and non-motor symptoms of Parkinson's manifest themselves to varying degrees and at varying times. Parkinson's is a fluid and fluctuating condition; anti-Parkinson's medications also lessen symptoms for temporary periods: therefore occupational therapy interventions need to address tasks and times when symptoms re-emerge or persist in the presence of optimum pharmacological and/or neurosurgical treatments.

1 Specific strategies for initiating and maintaining movement

All the motor skills that have become well-learnt by an individual are constantly held in suppression, until expression of a particular 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 disinhibition, 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 switch-like action of dopamine. The preparation, initiation, sequencing and timing of well-learnt 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-learnt 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 'brake-like', 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 fine-tuning 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.

In Parkinson's, 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-learnt, 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 development of Parkinson's.

Impairment of the fundamental processes described above can be considered to be similar to 'auto-pilot 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.

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, PDS 2007b, 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 underway.

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-learnt 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-learnt motor plans to be performed simultaneously. This facility is in fact highly intricate and relies on well-functioning basal ganglia acting as an 'auto-pilot 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.

   A small pilot study by Canning et al (2008) suggests that multitask training is feasible and may have sustained, worthwhile effects in individuals with mild to moderate Parkinson's.
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 which 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'.

Cognitive and sensory attentional strategies seem to utilise alternative pathways for reaching a goal. 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 avoiding 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. They therefore 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.

1.1 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 these guidelines, 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, silently chanting words when shuffling of gait is a problem, e.g. repeatedly saying 'Big Steps' can increase stride length dramatically. It is the nouns and verbs which 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.

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.

Guidelines

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

G 1.1.1: 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.

1.2 Extrinsic cueing techniques

The use of external sensory stimuli may be an effective way to facilitate gait (Nieuwboer et al 2007), 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. Mobility around the home and other frequently used environments can be enhanced by the repositioning of furniture to simplify the visual impact of its layout. Central (coffee) tables should ideally 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 cm (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 up stairs 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).

To fasten buttons:

Sit Down, and say to yourself…

‘Grip Button….

Find Hole…

Push Button into Hole…

and… Pull’

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

Auditory cues

As mentioned in Section 1.1 on intrinsic cueing, the sound of a person with Parkinson’s own 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 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 ‘1, 2, 3 . . . 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 care givers 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, 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 which 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 also employs rhythmical facilitation and is used by some people with Parkinson's for management of difficult movements and activities.

Guidelines

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

G 1.2.1: 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 1.2.2: 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.
- Provide a small range of alternative techniques (with which the person with Parkinson's and family and/or care givers may experiment) to address specific functional issues.
- Demonstrate movement strategies to provide a visual frame of reference.
- Involve as many senses as possible in the learning process.
- Provide 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.
- 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.

1.3 Factors impacting on engagement, motivation, learning and carryover

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: NICE (2006) *Parkinson's disease: diagnosis and management in primary and secondary care* suggests that depression affects 40–50% 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, who have recently been able to record brain images which show the physical basis of depression in people with Parkinson's (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 (I.Q.) in itself 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 care givers 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 neurodegenerative 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).

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 okay '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.

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 day-to-day 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.

v) Memory

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 of dementia, especially short-term memory impairment and difficulty with recalling names, tend to occur in late disease, but only in some people with Parkinson's.

vi) Hallucinations

Hallucinations associated with Parkinson's itself, 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. However, dementia in Parkinson's is milder than the severe dementia seen in Alzheimer's disease and people with Parkinson's are often relieved if this fact is brought to their attention at an early stage. 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 anti-Parkinson's medication may also help increase insight and reduce distress.

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 recognized 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.

Guidelines

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

G 1.3.1: the person with Parkinson's should be screened for cognitive impairment by use of functional and/or standardised assessment.

G 1.3.2: the person with Parkinson's should be screened for emotional and neuropsychiatric impairment by use of communication, observation and liaison with family and/or care givers.

G 1.3.3: consideration is given to the use of anxiety management and relaxation techniques either on an individual or group basis.

G 1.3.4: consideration is given to the use of strategies to compensate for specific cognitive impairments highlighted in the assessment.

G 1.3.5: occupational therapists educate the person with Parkinson's and all family and or care givers regarding the cause and management of cognitive, emotional and neuropsychiatric impairments.

G 1.3.6: occupational therapists refer family and/or care givers to sources of support in relation to the management of cognitive, emotional and neuropsychiatric impairments.

Impact on new learning and carryover

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 'auto-pilot' 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 'auto-pilot' facility is not to be expected, habitual application of management strategies which people with Parkinson's have learnt may be of ongoing value. Clinical experience shows that the use of metaphorical and allegorical language may greatly aid people with Parkinson's understanding of any unfamiliar ideas that need to be conveyed.

Guidelines

G 1.3.7: To promote new learning with people with Parkinson's, the occupational therapist should:

- Educate and involve regular family and/or care givers to promote carryover into daily life.
- Engage the person with Parkinson's full attention 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.
- Provide 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.
- Provide a proprioceptive frame of reference through the physical facilitation of movements.
- Consider using a backward-chaining approach 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 in a place where it will be seen when doing a problem activity.

2 Optimising activities

There is a paucity of useful and significant research underpinning occupational therapy interventions with people with Parkinson's. After extended analysis of current practice, and a Delphi study looking at best practice in occupational therapy for Parkinson's (Deane et al 2003a, Deane et al 2003b) it was suggested that occupational therapists have four main roles: problem-solver, educator, networker, and supporter. Deane et al (2003a) also demonstrated that occupational therapists lacked knowledge about condition-specific interventions and tended to focus on self-care.

Although specific occupational therapy research is lacking, it is possible to extrapolate potentially beneficial interventions from a small randomised controlled trial of occupational therapy with clients with Multiple System Atrophy, a complex movement disorder which has many parallels to Parkinson's due to its extra pyramidal symptoms and degenerative course (Jain et al 2004, 2005).

In the 2005 paper, Jain et al describe three distinct but interconnected steps (see Figure 1, p. 18) to improve occupational performance by:

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 practising weight transference techniques during transfers, or changing patterns 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 remain the same, but information about managing body-level symptoms, and access to equipment and resources, enabled clients to make informed choices.

3. **Attitude level intervention**

   This level of intervention changed performance by modifying attitude and expectations to facilitate psychological adjustment. The nature of the task was often changed 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.

Jain et al (2005) also list 'top ten goals of intervention' as identified by the clients:

1st	Maximise safety and reduce the risk of falls when mobilising indoors.
1st	Reduce effort and increase safety with bath transfers.
1st	Reduce effort and improve efficiency during kitchen/domestic/meal preparation tasks.
4th	Reduce impact of fatigue on all activities of daily living.
4th	Reduce effort during bed transfers.
4th	Reduce effort and increase safety during chair transfers.
7th	Decrease effort with toilet transfers.
7th	Improve efficiency and satisfaction when eating and drinking.
7th	Increase satisfaction with leisure activities.
10th	Reduce effort and increase safety when dressing.

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2.1 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.

There has been extensive research undertaken supporting the efficacy of physiotherapy on improving mobility and gait difficulties with people with Parkinson's; see the Dutch physiotherapy guidelines (KNGF 2006) for a comprehensive review. Occupational therapists need to work closely with physiotherapy colleagues when managing mobility problems at home.

Guidelines

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

G 2.1.1: a combination of intrinsic and extrinsic cueing techniques should be trialled within the person with Parkinson's environment.

G 2.1.2: once appropriate cueing techniques have been identified, these should be practised with family and/or care givers within the environment the person with Parkinson's has to negotiate.

Occupational therapists should encourage people with Parkinson's to:

G 2.1.3: practise 'concentrating' on walking, avoiding all non-essential talking while moving along.

G 2.1.4: 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 2.1.5: focus on stepping their feet around when turning a corner, or turning to sit down.

G 2.1.6: come to a stop prior to changing direction if this manoeuvre is problematic; for example turning from a corridor into a room.

G 2.1.7: walk in an arc to change direction in a wide, spacious area; this is safer than an abrupt or pivoting turn.

G 2.1.8: 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 2.1.9: review/monitor the use of walking aids to ensure their suitability and avoid a potential increased risk of falling.

G 2.1.10: assess for 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 2.1.11: consider the use of rails down corridors to act as a visual cue and to increase confidence (even if instability is not a problem).

G 2.1.12: assess for the need for additional lighting, for example automatic night-lights, a 'touch light' by the bed, and/or good lighting on stairs.

G 2.1.13: 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 2.1.14: assess the need 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.

2.2 Falls prevention

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. Dyskinetic episodes may be predicted by charting time, duration and times of anti-Parkinson's medication doses for a few days, to establish any regular peak dose, or biphasic patterns that emerge. Pacing routines and planning for coping with dyskinetic episodes, for example in considering 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 lift suitable to raise someone from the floor, may 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.

Guidelines

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

G 2.2.1: full attention and concentration on walking should be reinforced.

G 2.2.2: 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 2.2.3: use of a perching stool should be considered as required to avoid standing during tasks.

G 2.2.4: 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 2.2.5: 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 2.2.6: advice should be provided on adapting routines and activities undertaken during dyskinetic episodes.

G 2.2.7: 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 2.2.8: a suitable means of raising the alarm in the event of a fall should be identified and provided without delay.

G 2.2.9: an appropriate and safe way of getting off the floor should be identified and practised on-site, and any equipment required provided without delay.

2.3 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/care givers 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 care giver 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 1 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 which are the same as those used for actual performance of that specific task.

Below is an example of a cue card with instructions for a care giver 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 2.5 on posture and seating), or by replacing a bath with a level access shower, should be considered in order to ensure the safety of transfers and reduce the burden on care giver(s).

Guidelines

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

G 2.3.1: appropriate cueing strategies should be identified, practised and consistently used by all family and/or care givers who provide assistance for transfers.

G 2.3.2: different cueing strategies be used, as required, for different transfers in different environments.

G 2.3.3: 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 2.3.4: equipment be provided as necessary to ensure optimal transfer surface heights.

G 2.3.5: 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 2.3.6: free-standing 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 2.3.7: the need for fixed grab rails by the toilet and bath/shower should be assessed and equipment installed without delay as required.

G 2.3.8: 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 2.3.9: mechanical bath lifts should be considered for those who prefer or need to bathe.

G 2.3.10: 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 2.3.11: 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.

2.4 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. Frequency of 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 care giver.

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.

Guidelines

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

G 2.4.1: 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.

Bed Mobility Plan
Bend knees
Turn head
Reach over
… and *roll* …
and next, to get up out of bed …
Drop legs over edge
and *push* … to sit-up

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

- 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 2.4.2: 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 2.4.3: 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 2.4.4: assess the need for bedroom-based toileting facilities (commode, urinal) for use during the night and organise provision without delay as required.

G 2.4.5: encourage the use of night-lighting when getting up during the night.

G 2.4.6: consider the use of satin night-wear, or a satin half-length sheet, to aid movement in bed by reducing friction. Do not use both, as this is may cause a risk of sliding out of bed.

2.5 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 2006, R79). 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). For more details about the Alexander Technique for people with Parkinson's, see *http://www.parkinsons.org.uk*. Accessed on 13.02.10.

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 2.3 for 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).

Guidelines

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

G 2.5.1: increased awareness and self-correction of postural problems should be encouraged.

G 2.5.2: counter strategies, such as standing against a wall and lying in supine and/or prone should be built-in to the person with Parkinson’s daily routine.

G 2.5.3: posture and positioning while travelling in a car should be reviewed and additional support straps provided without delay as required.

G 2.5.4: positioning and comfort in an armchair should be reviewed over time.

G 2.5.5: 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.

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’.

G 2.5.6: 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 the seat cushion.
- 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 2.5.7: 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 2.5.8: 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.

2.6 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 people with Parkinson’s 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.

If mealtime problems occur, good sitting posture, adequate lighting and as few distractions as possible are recommended. 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.

1

2

3

SWALLOW

If getting swallowing started is a problem, use of a cue card as illustrated here 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.

Guidelines

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

G 2.6.1: if coughing on food or drink is reported, a referral to a speech and language therapist should be made without delay.

G 2.6.2: if the build-up of saliva is a problem, the occupational therapist should encourage good upright sitting posture and frequent voluntary swallowing.

G 2.6.3: if swallowing is problematic, the occupational therapist should trial the use ofs elf-cueing.

G 2.6.4: good posture, good lighting and reducing distraction at mealtimes should be encouraged.

G 2.6.5: modified eating and/or drinking equipment should be assessed for and provided without delay, as required. For example:

- Plate mats, raised-edge or lip-edge plates 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.

2.7 Self-care routines

Functional abilities will be improved once the first dose of anti-Parkinson's medication has been absorbed. It therefore helps to begin morning self-care routines after taking the first dose of the day (see Section 2.9 on fatigue). People with Parkinson's tend to report that their personal care routines are generally slow and tiring and 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, as 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. Some people with Parkinson's, however, 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 that will 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 in order simply 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 which 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 2.7.4 below), while avoiding distractions, may be of benefit.

Guidelines

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

G 2.7.1: 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 2.7.2: 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 2.7.3: use of a perching stool should be assessed for and provided without delay as required.

G 2.7.4: if the person wishes to dress themself independently, the following useful procedures should be practised:

- Collect all the clothes and lay them 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 (e.g. '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 to themself as it is performed.

(Adapted from Morris et al 1996)

G 2.7.5: dressing aids such as button hooks may lead to confusion and should only be used selectively after individual trial.

2.8 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 home-making 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.

Guidelines

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

G 2.8.1: 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 2.8.2: use of a perching stool should be considered in order to avoid standing during tasks such as meal preparation or ironing.

G 2.8.3: 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 2.8.4: 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 2.8.5: consideration be given to breaking down domestic tasks into component actions to allow successful participation in some aspects of the activity.

G 2.8.6: consideration be given to introducing convenience foods and internet shopping where appropriate.

G 2.8.7: 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.

2.9 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, people with Parkinson’s 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).

Guidelines

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

G 2.9.1: the impact of fatigue on performance in all activities of daily living should be assessed and/or formally measured.

G 2.9.2: 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 2.9.3: 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 2.9.4: 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.

2.10 Handwriting

Micrographia, or diminishing handwriting, is commonly seen with people with Parkinson's. 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 of script may also be evident.

Oliveira et al (1997) demonstrated the benefits of using visual or auditory cues with people with Parkinson's and micrographia. By encouraging subjects to write less automatically, there were improvements in the size and clarity of their handwriting.

Guidelines

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

G 2.10.1: when writing, people with Parkinson's should sit comfortably and in an upright position at a table, with good lighting.

G 2.10.2: 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 provide 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 2.10.3: if writing style is rapid, the cue of thinking ‘big and slow’ may help focus attention on writing less automatically and hence more clearly.

G 2.10.4: if writing is scrawly or spidery, thinking the words ‘smooth’ or ‘slow and smooth’ may be helpful.

G 2.10.5: if writing has significantly changed or is illegible, provide advice regarding contacting banks, getting a signature stamp made, and using alternative means of written communication such as computer technology.

3 Supporting participation

The symptoms of Parkinson's typically develop subtly over many years, with progressive physical and cognitive deterioration having a marked impact on quality of life. Although Parkinson's is more common in older people, in the UK it is estimated that of the 10,000 people diagnosed each year, one in twenty is under 40. Younger people with Parkinson's can face particular challenges coping with having the condition at a time when the demands of life are often at their greatest. Particular challenges 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.

Individuals affected by movement disorders such as Parkinson's face not only the physical impairments and limitations imposed by the condition itself, but also the psychosocial problems and stigma 'caused' by a body that may feel out of control. Such problems may arise as a result of many factors, including:

- Reduced facial expression and non-verbal communication behaviours.
- Reduced clarity and/or volume of speech.
- Feelings of embarrassment, stress or frustration at being slow.
- Stress resulting from coping with daily life or work.
- Being misunderstood by others, who wrongly attribute unusual movements, lack of expression, delayed speech, or poor balance, to lack of interest, low mood, dementia, or to being drunk.

Social withdrawal, a reduced ability to participate socially, and consequent isolation may occur as a response to social difficulties and others' lack of understanding.

A new healthcare education programme for people with Parkinson's is currently being developed by Parkinson's UK and Healthy Interactions – an organisation with experience and skills in this area. This project aims to develop an educational conversation-based, peer-to-peer, self-help programme for people with Parkinson's and their carers. Short courses are to be made available around the UK starting in 2010. It is hoped that it will become standard practice for people to be advised about the programme at the time of their diagnosis to help support them at this stressful and often lonely time. The programme will provide a forum to learn about Parkinson's, meet others on a similar journey, and learn about living well with the condition.

3.1 Self-efficacy

In the early stages of adjusting to a diagnosis of Parkinson's, maintaining a sense of control and self-efficacy is very important (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.

Education of people with Parkinson's and their family and/or care givers as to why they are experiencing difficulties with functional activities may be illuminating. Explaining what can be done in the early stages of the condition in terms of health promotion may pay dividends in the long term in terms of maintaining physical fitness – for example through activities such as dancing, walking, tai chi, etc. – and maintaining social activities and networks.

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 social contacts.

Guidelines

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

G 3.1.1: assess participation restrictions affecting family, work, leisure and social roles.

G 3.1.2: consider lifestyle planning and coping strategies to promote engagement in personally meaningful roles and activities.

G 3.1.3: offer client-centred education, advice and information to promote participation and self-management.

G 3.1.4: signpost to local services and peer support, including education, health promotion and self-help programmes.

3.2 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 or 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 between expectations following diagnosis between the person with Parkinson's and their partner. Role reversals may occur with partners feeling overburdened and the person with Parkinson's may feel that they have no role. This can lead to hostility, resentment, and feelings of loss and powerlessness. A loss of role as the main breadwinner may also create tension and financial worries in addition to loss of self-esteem and feelings of self-worth for the person with Parkinson's.

Communication difficulties, depression and mood swings can all lead to withdrawal from normal family life. Fatigue, sleep disturbance and loss of interest in sexual relationships may also compound the normal balance of a partnership, leading to stress and ongoing strain. Understandable information about the condition and its progression should be given with sensitivity to the person with Parkinson's, their partner and family members as required.

Although the whole 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.

Guidelines

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

G 3.2.1: promote maintenance of normal roles, daily routines and social habits by suggesting and practising task modification.

G 3.2.2: review night-time routines to reduce avoidable sleep disturbance (see Section 2).

G 3.2.3: implement a fatigue management programme as required.

G 3.2.4: 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.

3.3 Work

For people in full- or part-time work, the diagnosis of Parkinson's will raise many questions. However, with appropriate management, some people can continue to work for many years.

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.

If having Parkinson's may have an impact on health and safety in the workplace, the employer needs to be informed so they can undertake a risk assessment. Employers also need to know about any disability affecting an employee in order to make any reasonable adjustments.

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). Up-to-date information about work retention programmes and practical employment support can be found at *http://www.dwp.gov.uk*. Accessed on 13.02.10.

Guidelines

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

G 3.3.1: support and information about work retention initiatives should be offered to enable diagnosis disclosure at the right time for the individual.

G 3.3.2: the occupational therapist should adopt the role of pro-work advocate, providing a link between the person with Parkinson's, their workplace and government services such as Disability Employment Advisors and Access to Work, as required.

G 3.3.3: guidance about the employer's role and responsibility under the Disability Discrimination Act 2005 (Office of Public Sector Information 2005) should be given.

G 3.3.4: 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 3.3.5: 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, etc.

G 3.3.6: 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.

3.4 Social, recreational and leisure activities

Both the physical and mental health benefits of social interaction and physical activity are well established (NICE 2008). Occupational therapy for people with Parkinson's should aim to facilitate the greatest possible sense of satisfaction, sense of achievement and enjoyment of daily life, as those with Parkinson's can become socially isolated (Turner et al 2002).

Recently established evidence demonstrates the benefits of physical and mental exercise for people with Parkinson's. Similar benefits are also believed possible for people with other neuropathologies such as Alzheimer's disease. Furthermore, it seems that some forms of exercise are more or less effective than others and at the time of writing the best type and dose remains an area of debate.

For example, Stallibrass et al (2002) established measurable and sustained benefits in a randomised controlled trial of the Alexander Technique for people with idiopathic Parkinson's.

Numerous studies inform us about the 'quality of life' enhancing neuroprotective effects of exercise and activity-based interventions for people with Parkinson's (Crizzle and Newhouse 2006, Dibble et al 2009, Fisher et al 2008, Hackney et al 2007, Hackney and Earhart 2009). Exercise and bodily plus mental activity appear to increase blood flow and drive production of cerebral growth factors, such as BDNF, a neurotrophic factor which is found in locations such as the hippocampus. BDNF plays an important role in long-term memory, learning and higher thinking. Neurotrophins help to stimulate and control neurogenesis or the creation of new neurons during adult life. Such cerebral growth factors have also been shown to slow cognitive decline with age.

Exercise that is cognitively complex has been demonstrated 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.

When considering the neuroprotective benefits of active lifestyle maintenance and adjustments, people with Parkinson's should be encouraged to undertake daily exercise that is mentally as well as physically engaging. Activity such as a daily walk, or any enjoyed recreation of a physical and mental nature, provides 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. It is also encouraging to note that the more frail a person with Parkinson's is at commencing a gentle exercise routine, the greater are the benefits gained. It therefore appears that it is never too late to benefit from taking up a new form of enjoyable and engaging activity.

Parkinson's UK (which is a registered charity) can provide advice and information to promote participation, signposting local services that provide appropriate activity and leisure opportunities for people with Parkinson's. Parkinson's UK can also offer 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.

Guidelines

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

G 3.4.1: social, recreational and leisure priorities should be explored as part of a comprehensive occupational therapy assessment. Goals can then be identified by using a client-centred assessment tool such as COPM (Law et al 2005).

G 3.4.2: to promote mental and physical wellbeing, a person with Parkinson's should be encouraged to use some of their limited energy 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.

G 3.4.3: a 'single task' approach 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 3.4.4: 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; for example, practising walking up the stairs of the theatre; practising getting in and out of the church pews or cinema seats; or practising proactive rests during shopping trips, etc.

G 3.4.5: consideration should be given to the use of computers and other assistive technologies as an alternative or supplementary form of recreation, leisure and communication.

G 3.4.6: access to local facilities or services for people with Parkinson's should be signposted, with attendance at Parkinson's UK local groups or activities promoted.

3.5 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 2006).

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 hyper-somnolence, visual disturbances, undesirable impact and unpredictability of medication, etc. 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.

Occupational therapists do not themselves have a legal responsibility to notify the DVLA of any concerns about the ability of the person with Parkinson's to drive. Instead they should raise any concerns directly with the person with Parkinson's, reiterate to them that it is their obligation under law to inform the DVLA of their condition, not the occupational therapists, and advise the referring/responsible medic (e.g. the GP or hospital consultant) of any such concerns.

Guidelines

For occupational therapists who identify that a person with Parkinson's is a motor vehicle driver, it is recommended that:

G 3.5.1: in advance of any driving difficulties, information about the law and driving with Parkinson's should be provided. (Information is available from: *http://www.parkinsons.org.uk/pdf/b064_drivingandparkinsons.pdf*. Accessed on 13.02.10.)

G 3.5.2: if the person's fitness to drive is questionable, this must be raised with the person and/or their family without delay. All discussions should be documented and the relevant medic advised.

G 3.5.3: a referral to a driving assessment centre for a comprehensive assessment of driving ability should be considered, with information provided as required.

G 3.5.4: occupational therapists should provide information about disabled parking schemes as required.

3.6 Community living skills and outdoor mobility

Enabling people with Parkinson's to undertake activities outside the home has positive benefits on physical and mental wellbeing. 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.

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. If walking around shops proves difficult or effortful, most large shopping centres have a 'Shopmobility' service from which scooters may be rented. Consideration should be given to having a standby manual wheelchair for longer distances outdoors, and also to practising car transfers for those who travel as a passenger in a car.

Guidelines

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 3.6.1: suggest that people choose a time to leave the house when their medication is most effective.

G 3.6.2: seek to optimise outdoor mobility, and suggest avoiding shopping at busy times.

G 3.6.3: ensure that external grab rails and path rails are in situ as required between the home and the public highway.

G 3.6.4: 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 (i.e. PAUSE–LOOK–PLAN–WALK, repeating as necessary).

G 3.6.5: suggest walking along the side of the pavement near the shopfronts to avoid lamp-posts and other street furniture, thus aiding the flow of walking.

G 3.6.6: encourage proactive planning regarding the distance between toilets en route, where required shops are in relation to the car park, bus stop, etc.

G3.6.7: provide information about the RADAR toilet key scheme.

G 3.6.8: discuss using a manual wheelchair for outdoor use when walking outdoors becomes increasingly problematic.

G 3.6.9: make a referral to the local wheelchair service once the person with Parkinson's is willing to accept an outdoor manual wheelchair.

G 3.6.10: introduce Shopmobility schemes and undertake supervised practice as required.

G 3.6.11: review car transfers (at least) six monthly and provide equipment as required, such as a car transfer disc and/or a portable handle to aid transfers up and down from car seats.

G 3.6.12: provide information about disabled parking schemes as required.

4 End-of-life care

Although Parkinson's is progressive, it is not in itself 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 reduce distressing side effects such as psychosis or extreme dyskinesias, at the cost of a correlated reduction in mobility.

The *End of life care strategy* (Department of Health 2008) 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.

Anecdotally, occupational therapy intervention at this stage needs to focus on improving the quality of life by easing the burden and perceived suffering of both the person with Parkinson's and their family and/or care givers. 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 providing 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

Research suggests that 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 1992, 1997, Goldsmith 2000). Pressure risk should be measured and pressure care should also be managed proactively over a 24-hour period (NICE 2005).

Guidelines

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 (as relevant)
- When sitting 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: a review of wheelchair suitability should be undertaken, 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 and wedges should be considered as an adjunct to positioning.

G 4.1.7: the risk of developing pressure ulcers should be assessed using a valid and reliable pressure risk rating scale (NICE 2005) and recorded with a clear review date.

G 4.1.8: 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 care givers, who may themselves 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. Working alongside family and care agencies, who may not have an understanding of the condition and the importance of medication timing etc., is an important element of good practice. Condition-specific training and education for family and/or care givers 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.

Guidelines

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 that 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 care giver 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.

Guidelines

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.

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 with the person with Parkinson's and their family and/or care givers 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 person with Parkinson's 24-hour routine must be undertaken once they are living elsewhere and equipment required provided without delay.

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.

Glossary

Abridged from National Institute for Health and Clinical Excellence (2006) *Parkinson's disease: diagnosis and management in primary and secondary care*. London, NICE. Available at: *http://www.nice.org.uk/CG035* Accessed on 13.02.10.

Akinesia	Absence or reduced functionality of movements
Bradykinesia	Slowness of movement
Carer (care giver)	Someone other than a health professional who is involved in caring for a person with a medical condition, such as a relative or spouse
Cochrane Review	A systematic review of the evidence from randomised controlled trials relating to a particular health problem or healthcare intervention
DBS	Deep brain stimulation
Diagnostic study	Any research study aimed at evaluating the utility of a diagnostic procedure
Disease-modifying therapy	Any treatment that beneficially affects the underlying pathophysiology of Parkinson's disease (also known as 'neuroprotection')
Dysarthria	Slurred or otherwise impaired speech
Dysarthria profile	A description of the dysarthric person's problems, to supply the speech therapist with indications of where to begin in treatment
Dyskinesia	The impairment of the power of voluntary movement, resulting in fragmentary or incomplete movements
Dysphagia	Difficulty in swallowing
Dystonia	Disordered tonicity of muscle
Hypersomnolence	Excessive sleepiness
Hypokinesia	Decreased muscular activity, bradykinesia, reduced or slowed movement
LD	Levodopa
MSA	Multiple system atrophy
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
'Off' time	The duration of time when anti-Parkinsonian medication is not controlling the person's symptoms or is 'wearing-off'

'On' time	The duration of time when anti-Parkinsonian medication is controlling Parkinson's symptoms
PDNS	Parkinson's disease nurse specialist
PDS	Parkinson's Disease Society (now Parkinson's UK)
PSP	Progressive supranuclear palsy
Quality of life	Refers to the patient's ability to enjoy normal life activities, sometimes used as an outcome measure in a clinical trial
RCT	Randomised controlled trials
Rigidity	Abnormal stiffness or inflexibility
Sialorrhoea	Increased saliva or drooling
Somnolence	Sleepiness or unnatural drowsiness
Stereotactic surgery	A precise method of locating deep brain structures by using three-dimensional co-ordinates. The surgical technique may either involve stimulation or lesioning of the located site.
Videofluoroscopy	Videofluoroscopy is 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.

Appendixes

Appendix 1: the initial Guideline Development Team

Name	Title
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Consensus day participants

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Appendix 2: 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 on 28 July 2009 to ratify the guidelines.
2. The same email was sent to the COT Specialist Section lead Louise Cusack with a request that she circulate this to the Chairs of the COT Specialist Section for Older People and Housing for circulation to their members.
3. 17 people responded to the email invitation, 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 (see Appendix 1).
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 then asked to reach agreement on the specific content of each guideline in their sections by discussing and agreeing if the guideline was:
    - good practice?
    - contemporary practice?
    - something, as occupational therapists, that we 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 guidelines, including consideration of the structure, layout, readability, level of information, illustrations, title and presentation of underpinning evidence.

Appendix 3: Focus group questionnaire

During the development process a focus group was held in Bristol by one of the initial Guideline Development Team (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 were 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 (6-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, 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.

Appendix 4: Comments from a person with Parkinson's

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 firsthand. 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
Chairman, Bath Branch
Parkinson's UK

Appendix 5: NICE 2006 Guidelines

Reproduced for educational purposes, from the National Institute for Health and Clinical Excellence (2006) *Parkinson's disease: diagnosis and management in primary and secondary care*. London, NICE.

A full copy of this document is available at *http://www.nice.org.uk/CG035*. Accessed on 13.02.10.

10.4 Occupational therapy

Occupational therapy (OT) is a profession concerned with promoting health and wellbeing through occupation. The primary goal of OT is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying their environment to better support participation.[375]

Occupational therapists have expertise in assisting people who have disabilities to manage the practical aspects of everyday life. Referral to an occupational therapist can enable people with Parkinson's disease to maximise their current abilities, retain independence for as long as possible and develop their own coping strategies to deal with future problems.[376]

The principles of OT are:

- 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.

Current UK practice emphasises functional goals centred around independence, safety and confidence, including activities such as transfers, mobility and self-care.[377]

A wide variety of interventions are used in Parkinson's disease. Owing to the individualised nature of the therapeutic process, these may include practising skills, cognitive and sensory cueing strategies, problem solving, advice, education, provision of equipment and environmental adaptations.[378]

What is the effectiveness of occupational therapy versus standard medical therapy in the management of Parkinson's disease?

10.4.1 Methodology

A Cochrane review[379] was found on the effectiveness of OT versus placebo (or no interventions) in people with Parkinson's disease. The review included two randomised, parallel group trials, with a total of 84 people (N=64380 and N=20381). There were significant differences between the methodologies of the two studies. One trial[380] conducted 20 hours of treatment over 5 weeks with one-year follow-up while the other trial[381]conducted 12 hours of treatment over 1 month with no follow-up. The methodological limitations of these studies are covered in Section 10.3. Due to the lack of RCT evidence, papers with lower-level study designs (e.g. non-randomised and/or uncontrolled trials) were also included in the search, but no further papers were found which addressed the effectiveness of OT in the treatment of people with Parkinson's disease.

10.4.2 Evidence statements

With respect to clinical outcome measures[380]

- Barthel Index score, an assessment of ADL, was maintained over 1 year in those treated with occupational therapy.
- The group without the OT intervention lost an average of 4.6 points (out of a total score of 100) (p values not available).
- The other study[381] reported small differences in mean changes between groups on all outcome measures (motor impairment, activities of daily living, and quality-of-life measures) (p values not available).

10.4.3 From evidence to recommendation

In view of the methodological flaws in the trials and the small numbers of randomised participants, and only one outcome measure reported from one trial, there is insufficient evidence to support the efficacy of OT interventions in Parkinson's disease. However, the Guidelines Development Group supports the value of many of the aspects of this therapy, particularly with respect to the provision of aids and adaptations to maintain functional independence in people with Parkinson's disease. There is evidence to support this from one trial where there was maintenance of ADL scores in the treated group but a decline in those not treated. Further trials are required to evaluate the role of different aspects of OT.

Despite this lack of evidence, the experience of the GDG members supports the use of OT interventions in people with Parkinson's disease. It is recognised that, in practice, some of these interventions may be carried out by health professionals other than occupational therapists.

Recommendation

R80 Occupational therapy should be available for people with Parkinson's disease. Particular consideration should be given to: **D (GPP)**[*]

- Maintenance of work and family roles, home care and leisure activities.
- Improvement and maintenance of transfers and mobility.
- Improvement of personal self-care activities such as eating, drinking, washing and dressing.
- Environmental issues to improve safety and motor function.
- Cognitive assessment and appropriate intervention.

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[*] **D** = Expert opinion, formal consensus; **GPP** = Good Practice Point

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Appendix 6: Parkinson's specific measures

Unified Parkinson's Disease Rating Scale (UPDRS) (Fahn and Elton 1987)

This scale has recently been updated to encompass some key non-motor symptoms of Parkinson's by members of the Movement Disorders Society (MDS), USA. For online details of the MDS-UPDRS, see *http://www.movementdisorders.org*. From the homepage look under the publications tab for Rating scales. Accessed on 13.02.10.

The MDS-UPDRS is a rating tool used to follow the longitudinal course of Parkinson's. It is made up of four parts. 1) Non-motor experiences of daily living, split into two parts: 1a, behaviours assessed by the investigator, with information from the patient and caregivers; 1b, for completion by the patient with the help of caregivers if desired, but independently of the investigator. 2) Motor experiences of daily living, for completion by the patient and/or caregivers as part 1b. 3) Motor examination. 4) Motor complications.

PDQ39 and PDQ8

Licensed to the Health Services Research Unit, University of Oxford *http://www.publichealth.ox.ac.uk/units/hsru/PDQ*. Accessed on 13.02.10.

Jenkinson C, Fitzpatrick R, Peto V, Harris R and Saunders P (2008) *New user manual for the PDQ-39, PDQ-8 and PDQ index*. 2nd Edition. Publisher: Health Services Research Unit, University of Oxford. ISBN 1 874551 70 7 (Pbk), 114 pages.

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Hoehn and Yahr Staging of Parkinson's Disease Scale (Hoehn M and Yahr M 1967)

1. Stage One

1. Signs and symptoms on one side only.
2. Symptoms mild.
3. Symptoms inconvenient but not disabling.
4. Usually presents with tremor of one limb.
5. Friends have noticed changes in posture, locomotion and facial expression.

2. Stage Two

1. Symptoms are bilateral.
2. Minimal disability.
3. Posture and gait affected.

3. Stage Three

1. Significant slowing of body movements.
2. Early impairment of equilibrium on walking or standing.
3. Generalised dysfunction that is moderately severe.

4. Stage Four

1. Severe symptoms.
2. Can still walk to a limited extent.
3. Rigidity and bradykinesia.
4. No longer able to live alone.
5. Tremor may be less than earlier stages.

5. Stage Five

1. Cachectic stage.
2. Invalidism complete.
3. Cannot stand or walk.
4. Requires constant nursing care.

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Occupational Therapy for People with Parkinson's

Best practice guidelines

These practice guidelines draw upon the widest relevant knowledge and evidence available to describe and inform contemporary best practice occupational therapy for people with Parkinson's. They have been written as a pragmatic 'pick-up-and-use' guide, which includes practical examples of interventions to allow occupational therapists from a diverse variety of health and social care settings to readily apply new and existing treatments in their day-to-day practice.

These occupational therapy best practice guidelines aim to:

- Place the person with Parkinson's and their family at the centre of all occupational therapy interventions.
- Support occupational therapists in the holistic assessment and treatment of people with Parkinson's.
- Introduce novel and disease-specific occupational therapy interventions.
- Provide a comprehensive overview of the nature and detail of currently agreed best practice occupational therapy intervention in the UK.

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Ana Aragon worked in a specialist service for people with Parkinson's and related movement disorders from 1996 to 2007 and was a member of the occupational therapy working group for the 2006 NICE Parkinson's disease National Clinical Guidelines.

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