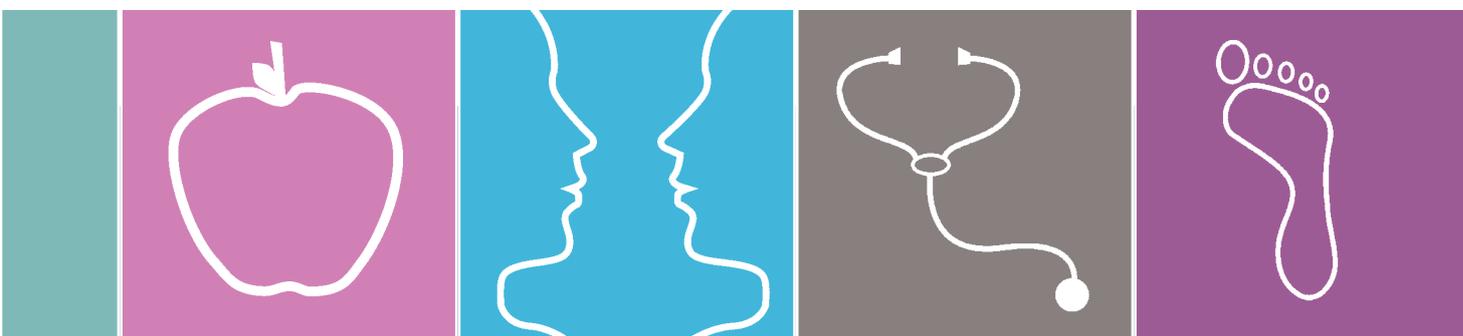


The Professional's Guide

to Parkinson's Disease



- dietitian
- GP
- nurse
- occupational therapist
- pharmacist
- physiotherapist
- social worker
- speech and language therapist



Parkinson's
Disease Society

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The Professional's Guide

to Parkinson's Disease



Foreword

There are 120,000 people in the UK with Parkinson's disease. This means it is likely that as a health or social care professional you regularly encounter people whose lives are affected by the condition.

Expert professional care can make a huge difference to the quality of life of those affected. The Parkinson's Disease Society (PDS) is committed to supporting professionals to deliver care of the highest quality and have therefore produced this guide for some of the key groups of professionals working in the field.

When we started this project we consulted many professionals to get their views on whether we should continue to produce information in separate packs aimed at different disciplines. The response was unanimous: all were in favour of bringing information together in one publication so it would be possible to cross-reference between sections to get a holistic view of the condition. This reflects the growing recognition of the importance of the multidisciplinary approach in the management of Parkinson's.

The guide is written by experts from different professionals groups and is divided into eight sections, each tailored to the relevant discipline:

- dietitian
- GP
- nurse
- occupational therapist
- pharmacist
- physiotherapist
- social worker
- speech and language therapist

Of course there are many more professionals involved with people with Parkinson's and we hope this guide will be a useful source of information for all of you.

The significance of the multidisciplinary team was highlighted in the 2006 NICE Guideline for Parkinson's, which signals the importance of access to specialist diagnosis, regular reviews, Parkinson's Disease Nurse Specialists, therapists and palliative care. It is important that commissioners build services in accordance with the Guideline and the PDS is working with commissioners and health and social care professionals to support this process.

One particular area in which PDS and health and social care professionals are collaborating effectively to improve care is in relation to medicines management in hospitals and care homes. The Society's 'Get it on time' campaign aims to ensure that people with Parkinson's get their medication on time, every time, as the timing of medication is crucial to their wellbeing. Hospital stays can be extended if medication is not managed properly and the person concerned is likely to require a higher level of care, at a significant cost in both time and resources to health services. Please contact us if you would like a 'Get it on time' campaign pack to help you make improvements in your area of practice.

The PDS will continue working to develop close links with professionals, who also play a key role in putting people in touch with the Society for further support and advice. Together we must reach every single person in the UK living with Parkinson's, to ensure they do not feel alone with their condition and have access to the highest quality services and support.

Further resources for professionals are available online at www.parkinsons.org.uk/for_professionals.aspx

About the Parkinson's Disease Society

The Parkinson's Disease Society (PDS) was established in 1969 and now has nearly 30,000 members, over 40,000 supporters and more than 330 branches and support groups throughout the UK.

We provide support and advice to people with Parkinson's, their carers, families and friends, and to health and social services professionals involved in management and care. Our free Helpline service, staffed by registered nurses and expert advisers, deals with more than 20,000 enquiries a year by telephone, email and letter.

We also produce a wealth of information for everyone affected by Parkinson's. Full details of all the resources available can be found on the PDS website.

Research is also a major focus of the PDS's work. Around a quarter of our total budget is spent on supporting projects that aim to identify and improve treatments, gain a greater understanding of the causes of the condition and, ultimately, develop a cure, which will allow people with Parkinson's to live a life that is free from the symptoms of the condition.

We also campaign for high-quality health and social care for all people with Parkinson's and their carers at a national and local level. We believe that all people with Parkinson's should have easy access to high-quality healthcare and the help and support they need.

Contact us

You can write to us at the following email addresses:

professionals@parkinsons.org.uk

campaigns@parkinsons.org.uk

enquiries@parkinsons.org.uk

events@parkinsons.org.uk

membership@parkinsons.org.uk

publications@parkinsons.org.uk

research@parkinsons.org.uk

Or you can call our freephone Helpline on **0808 800 0303**, Monday–Friday 9am–9.30pm, Saturday 9.30am–5.30pm. (The Helpline is a confidential service. Calls are free from UK landlines and some mobile networks.)

www.parkinsons.org.uk

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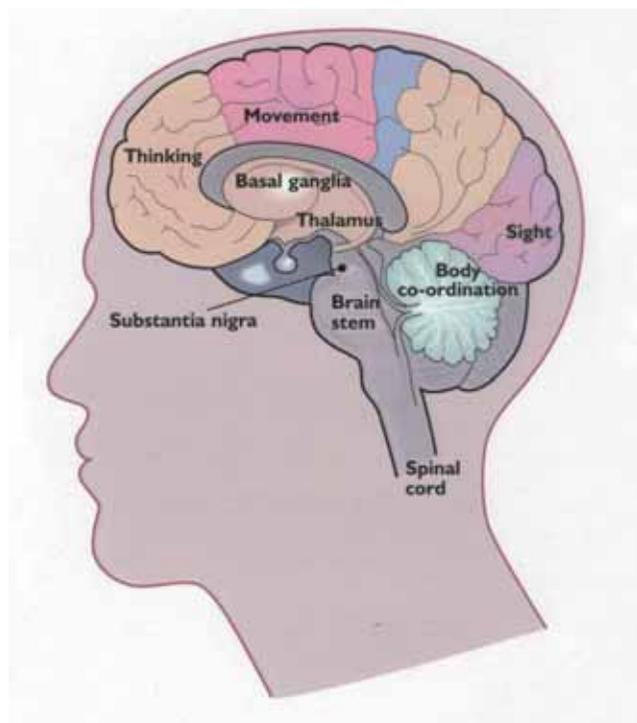
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About Parkinson's disease

What is Parkinson's

Parkinson's disease is a progressive neurological condition, resulting from the degeneration of dopamine-producing neurones in the substantia nigra, which is located within the basal ganglia, deep in the lower region of the brain, on either side of the brain stem. Microscopic deposits known as Lewy bodies are formed within dopamine-producing neurons and are characteristic of the pathology of the condition. Clinical signs of Parkinson's are evident when about 80% of the dopamine-producing neurons are lost.



Dopamine is a major neurochemical messenger that promotes the functions of the basal ganglia, which is also where the dopamine is produced. The basal ganglia's role is to orchestrate the performance of well-learned, voluntary and semi-automatic motor skills and movement sequences. Dopamine also contributes to other cognitive processes, such as maintaining and switching focus of attention, motivation, mood, problem-solving, decision-making and visual perception.

Parkinson's affects functional activities such as balance, walking, speech, handwriting, typing, fastening buttons, driving, and many other simple, or complex but familiar and routine activities, as they are usually controlled by the mechanisms of dopamine and the basal ganglia.

Motor symptoms

The main motor symptoms of Parkinson's are:

Bradykinesia – slowness of movement

Rigidity – raised tone, which may be asymmetrical, or limited to certain muscle groups

Tremor – involuntary shaking, trembling or quivering movements of the muscles. It is caused by the muscles alternately contracting and relaxing at a rapid pace

Postural instability – balance problems, usually presenting as a later feature of 'classic' (idiopathic) Parkinson's

These symptoms are explored in more detail throughout this Guide.

Non-motor symptoms (NMS)

Parkinson's is predominantly a movement disorder, but there is a growing awareness that it is also associated with many other problems that do not directly affect motor function. These non-motor features are of crucial importance since they have a major impact on quality of life.

NMS dominate the clinical picture of advanced Parkinson's but are often poorly recognised and insufficiently treated. Early recognition is essential and use of the multidisciplinary approach is paramount.

Neuropsychiatric

Anxiety disorders Anxiety disorders are common in Parkinson's. Anxiety can present as panic attacks or generalised anxiety, and can often be related to drug-induced motor fluctuations. They may also be present in

advance of the onset of the motor symptoms of the condition.

Apathy Apathy is now known to be a particular symptom of Parkinson's, independent of depression and fatigue.

Depression Depression in Parkinson's appears to be related to the degeneration of dopaminergic neurones in limbic and pre-frontal systems. Depression may present with feelings of guilt, helplessness, remorse or sadness.

Psychosis and visual hallucinations Hallucinations and other forms of psychotic behaviours occur in around 40% of individuals with Parkinson's who are on dopaminergic therapy. Psychotic symptoms can take the form of vivid visual hallucinations. Auditory and olfactory hallucinations are less common and may be associated with visual hallucinations or present independently. Delusional thinking can also occur.

Dementia A significant number of people with Parkinson's will develop cognitive changes severe enough to warrant a diagnosis of dementia. Dementia in Parkinson's is progressive and characterised by a severe dysexecutive syndrome, with impairment of visuospatial abilities and marked cognitive slowing.

Sleep disturbances

Most people with Parkinson's will have problems with sleep. The causes are multifactorial but degeneration of the sleep regulation centres in the brainstem and thalamocortical pathway is implicated.

Nocturnal non-motor symptoms These include restless legs syndrome (RLS) and rapid eye movement (REM) sleep behaviour disorder (RBD). RBD is characterised by loss of the normal skeletal muscle atonia during REM sleep, resulting in people physically acting out their dream, and can precede the development of the motor symptoms of Parkinson's in up to 40% of patients.

Excessive daytime sleepiness Excessive daytime sleepiness and dozing affects up to 50% of people with Parkinson's. It can occur early in the disease, sometimes predating the clinical diagnosis of Parkinson's. Causes include the disease itself – particularly in cases of dementia with Lewy bodies and Parkinson's disease dementia – poor sleep and anti-Parkinson's drugs.

Autonomic disturbance (dysautonomia)

Urinary dysfunction Bladder dysfunction in Parkinson's can affect up to 40% of individuals. The earliest and most commonly reported complaint is nocturia (waking at night one or more times to void) followed by urgency, frequency and urge incontinence.

Constipation Constipation occurs frequently in Parkinson's, affecting over 50% of individuals. It is one of the most common non-motor symptoms and can precede development of the condition.

Sexual dysfunction The most commonly reported sexual problem for men with Parkinson's is erectile dysfunction; for women it is difficulty with arousal (genital sensitivity or lubrication), orgasmic difficulty, dyspareunia or vaginismus.

Orthostatic (postural) hypotension Orthostatic hypotension can occur in up to 48% of people with Parkinson's. It is defined as a fall in systolic blood pressure of over 20mmHg on standing. Patients who are experiencing orthostatic hypotension may complain of dizziness, visual disturbances, falling or fainting. It can be due to central or peripheral autonomic dysfunction but it can also occur as a result of Parkinson's medications, antihypertensives or co-morbidities, such as anaemia.

Weight loss Unintended weight loss is common in Parkinson's, occurring in over 50% of individuals. Moderate or severe dyskinesia can be the cause but if significant loss occurs, other medical causes (eg malignancy, endocrine causes), dysphagia or poor diet should be considered and referral to the appropriate discipline instigated.

Dysphagia Swallowing difficulties in Parkinson's usually relate to disease severity and may affect all phases of the swallow process. There is a risk of aspiration pneumonia, malnutrition and dehydration. Dysphagia poses a major problem to the taking of medications that are critical in the successful management of Parkinson's.

Hyperhidrosis Excessive sweating may occur as an end-of-dose 'off' phenomenon or while in the 'on' motor state. It is usually associated with dyskinesias.

Sialorrhoea Excess saliva or drooling occurs in 70–80% of people with Parkinson's. Apart from social embarrassment and soiling of clothing, sialorrhoea may also be associated with perioral infection.

Sensory disturbance

Pain Pain is common in Parkinson's and can occur in up to 50% of patients. Patients may complain of sensory-type pains, that include paraesthesias, burning dyesthesias, coldness, numbness and deep aching within a nerve (neuropathic pain). Pain may be related to motor fluctuations or early morning dystonia and can also be a result of musculoskeletal pain secondary to parkinsonian rigidity and hypokinesia.

Olfaction Olfactory dysfunction eventually affects up to 90% of patients with Parkinson's and is a potential pre-clinical marker of the disease.

The PDS has produced the *Non-Motor Symptoms Questionnaire*, which can be completed by patients prior to consultation with their GP or nurse. This helps to highlight any non-motor symptoms that require treatment.

Who gets Parkinson's?

One in 500 people in the UK have Parkinson's. Statistically, men are slightly more likely to develop the condition than women.

The risk of developing Parkinson's increases with age, and symptoms often appear after the age of 50. Some people may not be diagnosed until they are in their seventies or eighties.

However, in some cases, Parkinson's is diagnosed before the age of 40, and this is known as young-onset Parkinson's disease. If Parkinson's is diagnosed before the age of 18, it is known as juvenile Parkinson's, although this is extremely rare. More information is available in the PDS's *Juvenile Parkinson's* information sheet.

What causes Parkinson's?

The cause(s) of Parkinson's is unknown. Most researchers believe that multiple factors play a contributory role in causing Parkinson's and that it is likely to be caused a combination of both genetic and environmental factors. Mitochondrial dysfunction and oxidative stress have also been implicated in neurodegeneration.

Genetic factors

Only a small number of genes have been directly linked to the development of Parkinson's. So far, mutations in at least nine genes have been identified as causing Parkinson's or affecting risk: alpha-synuclein (PARK1),

parkin (PARK2), ubiquitin carboxy-terminal hydroxylase L1 (PARK5), PINK1 (PARK6), DJ1 protein (PARK7), LRRK2 protein (PARK8), the nuclear receptor NURR1, HTRA2 and tau.

In a majority of cases, however, Parkinson's is not hereditary. At present, it is estimated that up to 5% of cases may have a genetic cause. The remaining 95% are considered 'idiopathic'. Scientists believe that while some people may have a genetic susceptibility to developing Parkinson's, the condition is only triggered following exposure to other factors.

Environmental factors

There is some evidence that environmental factors (such as toxins) may cause dopamine-producing nerve cells to die, leading to the development of Parkinson's. Several toxins, including the chemical MPTP, have been shown to cause Parkinson-like symptoms. There may also be a link between the use of herbicides and pesticides and the development of Parkinson's.

Diagnosis

It is important that there is an early diagnosis. If the condition is suspected, a patient should be quickly referred – untreated – to a neurologist or a geriatrician with a special interest in Parkinson's. The NICE Guideline on the diagnosis and management of Parkinson's says referral time should be no more than six weeks and should not exceed two weeks in cases where the condition is severe or complex.

The condition is diagnosed following a detailed clinical examination. There are no laboratory tests or easily available imaging tests to help make the diagnosis. While Single Proton Emission CT (SPECT) scanning may assist in making the diagnosis, this is only available in some centres. It is more likely to be used to exclude other conditions that may have similar symptoms.

There are some conditions that have symptoms similar to Parkinson's and are referred to as 'parkinsonism'.

These include essential (familial) tremor, post-encephalic parkinsonism, cerebrovascular parkinsonism, progressive supranuclear palsy (PSP), multiple system atrophy (MSA), corticobasal degeneration and Wilson's disease.

You can find out more about some of these conditions through the following organisations:

The National Tremor Foundation

Harold Wood Hospital (DSC)
Gubbins Lane
Romford
Essex
RM3 OAR
Tel: 01708 386399
Freephone: 0800 3288046
Email: tremorfoundation@aol.com
www.tremor.org.uk

Sarah Matheson Trust (for Multiple System Atrophy)

Box 200
St Mary's Hospital
Praed Street
London W2 1NY
Telephone: 020 7886 1520
www.msaweb.co.uk

PSP (Europe) Association

PSP House
167 Watling Street West
Towcester
Northants, NN12 6BXQ
Tel: 01327 322410
Email: psp@pspeur.org
www.pspeur.org

Treatments

Because of the highly complex, multifactoral spectrum of Parkinson's symptoms, a multidisciplinary team approach is considered to be beneficial to patients and their families and carers, in order to optimise quality of life and management of symptoms.

Modern advances in the use of drug therapies, neuro-surgical treatments, specialist nursing, Parkinson's-specific rehabilitation and other interventions can all contribute towards optimising the quality of life of people living with Parkinson's.

Drug regimens

The main aims of drug treatments for Parkinson's aim to:

- increase the level of dopamine that reaches the brain
- stimulate the parts of the brain where dopamine works

- block the action of other chemicals that affect dopamine, such as acetylcholine as well as several enzymes that reduce dopamine's effect

Detailed information about the different drugs available and their potential side effects can be found in the GP, nurse and pharmacist's sections of this Guide.

Traditional and alternative non-drug therapies

A multidisciplinary approach to Parkinson's should involve all the traditional therapists. This includes the dietitian, the occupational therapist, the physiotherapist and the speech and language therapist, whose roles are explored throughout this Guide.

Alternative or complementary therapies are treatments that may be used in addition to or alongside conventional medicine. Alternative therapies that may benefit people with Parkinson's include acupuncture, the Alexander technique, art therapy, conductive education, homeopathy, hydrotherapy, music therapy, pilates, reflexology and tai chi. The PDS booklet *Complementary Therapies and Parkinson's Disease* looks at these and many others in more detail.

Surgery

Surgery is available for some people with Parkinson's, depending on their symptoms. Procedures include deep brain stimulation, involving the implantation of a wire with four electrodes at its tip into the thalamus, the globus pallidus or the subthalamic nucleus. This wire is connected to an implantable pulse generator (IPG), which is implanted under the skin, often in the chest, rather like a pacemaker. When switched on, the IPG produces electrical signals, which are sent to the brain to stop or reduce Parkinson's symptoms.

More information on this and other surgical options can be found in the PDS booklet *Surgery and Parkinson's Disease*.

Policy and guidelines

NICE

Clinical Guideline on the diagnosis and management of Parkinson's disease in primary and secondary care in England and Wales. The Guideline has also been endorsed in Northern Ireland. Available at:

www.nice.org.uk/guidance/CG35

National Service Framework for Long-term (Neurological) Conditions

Establishes quality requirements for the delivery of health and social care for people with long-term neurological conditions in England.

Available at: www.dh.gov.uk/longtermconditions

Our Health, Our Care, Our Say

Government White Paper published in 2006, which indicates a new direction for health and social care in England. Available at: www.dh.gov.uk

Designed for Life

Welsh Assembly Government's vision and framework for creating world-class health and social care in Wales by 2015. Available at: new.wales.gov.uk

Caring for People Beyond Tomorrow

Northern Ireland Department of Health Social Services and Public Safety Strategy for Primary Care.

Available at: www.dhsspsni.gov.uk

Delivering for Health

Scottish Executive's plans to implement the recommendations of the National Service Framework for Service Change.

Available at: www.scotland.gov.uk

Medicines management

Reports into medicines management in hospitals and care homes.

Direct links to all the policies and guidelines outlined are available in the pages for professionals on the PDS website at www.parkinsons.org.uk

notes



The dietitian's guide to Parkinson's disease

Introduction

Everyone living with Parkinson's disease is unique and must be treated as an individual; the condition may not affect one person in the same way as the next. The ability to perform movements may also differ from one day to the next.

Nutrition has an important role to play in the management of Parkinson's. Attention to dietary elements of treatment can lessen the symptoms of the condition by improving nutritional status and the efficiency of drug therapy.

As the condition affects muscular movement, Parkinson's has widespread effects on eating: inability to swallow affects the nutritional status and there are also oral health issues to consider.

Weight loss appears to be common in people with Parkinson's, who seem to have a greater risk of developing malnutrition than a matched population, ie they have a lower body mass index (BMI), lower triceps skinfold thickness and lower percentage body weight.

The weight loss may be a result of reduced energy intake, increased energy expenditure or a combination of both. This will be explained in more detail in the section 'People in the advanced stages of Parkinson's'.

Factors that can affect energy intake and cause weight loss

- Poor appetite (often associated with medication)
- Sensory change (loss of smell and taste)
- Nausea/vomiting/dry mouth (a side effect of some anti-Parkinson's drugs)

- Swallowing difficulties (dysphagia)
- Early satiety
- Ill-fitting dentures
- Dementia
- Cognitive decline
- Appetite impairment due to mood changes, such as anxiety, depression, irritability and restlessness
- Chronic constipation
- Dietary manipulation while taking levodopa (L-dopa), ie elimination or reduction of protein intake as it interferes with the absorption of L-dopa
- Other side effects of medication, eg confusion and hallucinations

Physical and social factors

- Difficulty accessing food due to poor mobility
- Difficulties with cooking
- Difficulty using utensils to cook and eat due to tremor, rigidity or poor manual dexterity
- Lengthy meal times due to akinesia (slowness of movement), resulting in meals becoming less appetising, ie hot food becoming cold quickly
- Increased anxiety around eating and drinking due to tremor and poor manual dexterity (ie inability to manipulate food from plate to mouth) and loss of lip control (resulting in excess drooling, salivation and inability to retain fluids and semi-solids in the mouth)

Motor fluctuations, such as unpredictable 'off' periods around meal times and for extended periods during the day, can also affect ability to eat and drink enough.

Diet and nutrition in Parkinson's

The dietary management of people living with Parkinson's aims to:

- detect nutritional inadequacies at an early stage, through in-depth, thorough diet history
- instigate measures to correct deficiencies or nutrition-related problems
- identify ways to minimise any practical difficulties associated with eating or swallowing

- prevent undesirable weight gain or loss
- preserve lean muscle mass
- reduce the impact of the side effects of drug treatment on dietary intake
- provide tailored, individual guidance on ways to provide optimal nutrition and energy balance
- maintain good general and oral health
- regularly monitor nutritional status as the condition progresses
- encourage a diet that is high in fibre and fluid to prevent or manage constipation

The dietitian needs to work in collaboration with the other members of a multidisciplinary team to ensure that these aims are achieved.

Problems with muscular movement can also cause some people with Parkinson's to experience difficulties with eating, swallowing and bowel function, which, again, affects the nutritional status and oral health of the individual. Social isolation, loss of self-esteem and

depression increase the risk of developing malnutrition and dental disease, especially when high-sugar snacks and drinks replace well-balanced meals.

It is important to assist patients with Parkinson's and their carers in understanding and treating the diet-related problems associated with the condition.

The former Dietitians in Neurological Therapy (DINT), the Nutrition Advisory Group for Elderly People (NAGE) and various groups of the British Dietetic Association have collaborated to improve Parkinson's treatment, constantly reviewing patients' needs to improve quality of life and delay the need for institutional care. Simple screening and assessment tools, for example the Malnutrition Universal Screening Tool (MUST), can be used to detect and quantify nutritional status and identify persons at risk of malnutrition, particularly undernutrition.

The box below contains a detailed consultation checklist for extracting relevant information about a patient's current nutritional and physical status.

Consultation checklist for baseline assessment

- ✓ Current weight, height, BMI and weight history, to determine trends in weight, ie loss/gain, usually over the preceding 3–12 months
- ✓ Detailed dietary intake via seven-day food diary or 24-hour recall, to establish eating patterns and habits
- ✓ Swallowing (dysphagia) and chewing difficulties
- ✓ Dental and oral health
- ✓ Medications, including vitamin and mineral preparations
- ✓ Investigate any self-imposed dietary restrictions or unconventional diets
- ✓ Identify who does the shopping and cooking
- ✓ Determine level of mobility and physical activity
- ✓ Establish level of disabilities, if any, that may have an impact on dietary intake
- ✓ Activity (dyskinesia/akinesia) and rest patterns
- ✓ Medical and physical condition
- ✓ Other risk factors/socio-economic circumstances

This assessment is becoming routine during hospitalisation and can be part of any screening strategy used by healthcare professionals working in outpatient departments, day hospitals and community or care/residential home settings. It will identify people who require nutrition support, thus facilitating appropriate referrals to the nearest multidisciplinary team.

The multidisciplinary team (MDT)

There is no doubt that effective multidisciplinary working can improve the nutritional status of people with Parkinson's. The optimal multidisciplinary team includes neurologist, GP, doctor, nurse(s), assistants, physiotherapist, occupational therapist, speech and language therapist, dietitian, psychologist, dentist and pharmacist, with the support of carers (who are the providers of food and nourishment, as are catering services, when someone is hospitalised).

An appropriate service for people with Parkinson's should meet the physical, functional, psychological and social needs of patients and their carers. The service should provide a multidisciplinary ethos of assessment and treatment tailored to the individual needs of the patient.

The Parkinson's disease MDT should facilitate:

- the provision of a comprehensive service to patients and their carers, from diagnosis to the palliative stage, tailored to the individual's needs
- the provision of in-depth specialist assessment and treatment from a co-ordinated, specialist multidisciplinary team
- holistic care
- continuity of care through members of the team, especially the Parkinson's Disease Nurse Specialist (PDNS)
- a 'one-stop shop' approach, reducing the need for patients to deal with several appointments with various professionals at different venues
- the provision of information, education, life skills training, support and advice to patients, their carers and other healthcare professionals
- peer support through opportunities to interact with other patients with Parkinson's during the day or within group activities
- carer support through group activities and carer groups

Who is likely to be referred to you?

Newly diagnosed people with Parkinson's

There is no particular diet recommended for people diagnosed with Parkinson's. It is, however, important for all people newly diagnosed with Parkinson's to maintain an ideal weight for height. Being overweight or, more commonly in Parkinson's, underweight can have adverse effects on general health and wellbeing.

Typical advice would be:

- adopt a well-balanced diet in line with the Balance of Good Health guidelines, as set out in the Parkinson's Disease Society's (PDS) *Parkinson's and Diet* booklet

- establish and agree Ideal Body Weight (IBW) with client
- advise five portions of fruit and vegetables a day
- stress the importance of choosing high fibre foods and drinking at least two litres (eight glasses/cups) of fluid per day to prevent constipation
- advise regular daily exercise, taking into consideration level of mobility and disability if necessary – may need to refer to local physiotherapist for more tailored advice

People in the advanced stages of Parkinson's

Following the onset of the condition, as many as 50% of those living with Parkinson's will experience unintentional weight loss, and about 75% will experience eating difficulties of some sort (Palhagen et al, 2005; Krenkel JA, 2002; Abbott et al, 1992). Beyer et al (1995) found in their study that people living with Parkinson's are at least four times more likely to lose 10lbs more than age-matched controls. This has been attributed to subtle rather than acute bouts of

decreased energy intake (Toth, 1999). In this case, individualised guidance may be needed to help overcome the following problems.

Inadequate food intake

Written and verbal advice should be provided to help improve the nutrient intake through the use of energy-dense foods. Measures to fortify foods and imaginative use of nutritional supplements may be appropriate.

Dysphagia

This is one area that urgently needs addressing by the MDT, in particular the speech and language therapist (SLT), to prevent continued weight loss and malnutrition.

It has been found by Logemann et al (1997) that at least 95% of people with Parkinson's experience some type of swallowing difficulty. Specific advice may be given by the dietitian and SLT on texture-modified diets where appropriate. Purée diets are usually nutritionally inadequate and may not be energy-dense enough to prevent weight loss. The patient and/or carers should be advised on strategies to prevent this from happening. Imaginative use of oral sip feeds may be necessary too.

Spillages and physical difficulties eating

The following approaches, advised in close liaison with the occupational therapist (OT), may help:

- Use of a non-slip mat or damp cloth under the plate or bowl
- Large, adapted cutlery
- Two-handed cups, to prevent spillage
- A 'stay-warm' plate, to keep food hot if meal times are lengthy
- Use of energy-dense 'finger foods'

Side effects of medication

A dry mouth can be a side effect of anticholinergic treatments, so these drugs should be taken before food is eaten. However, if this results in a gastrointestinal upset, they should be taken after food.

Oral levodopa (L-dopa) should be taken after meals to lessen the likelihood of gastrointestinal side effects, such as nausea and vomiting. However, those who have been taking L-dopa for a long time may not suffer these side effects.

Domperidone (anti-emetic) is routinely used in conjunction with anti-Parkinson's drugs.

For more information, see the PDS booklet *The Drug Treatment of Parkinson's*.

Constipation

This problem occurs as a result of:

- reduced physical activity/mobility
- reduced peristalsis, causing delayed gut transit time
- poor fibre intake, due to difficulties chewing fibrous foods or following a texture-modified diet, eg purée diet

- poor fluid intake, due to problems such as urgency and frequency of micturation or incontinence
- a side effect of some anti-Parkinson's drugs, in particular anticholinergics

Dietary advice is aimed at increasing the bulk and softening the stool. This is first-line treatment and usually works for most people with Parkinson's. Fluid and fibre play a very important part in the management of chronic constipation.

Sufficient fluid: about two litres of fluid per day (eight to ten cups or six to eight mugs), in the form of fluids such as water, cordial fruit juice, vegetable juice, tea, coffee, smoothies or drinking yoghurt.

Sufficient fibre: in the form of fibre-rich foods that are easy to manage, eg high-fibre choices of breakfast cereals, wholemeal bread, easy to peel fruit (such as bananas, satsumas or dried fruit) and by including vegetables, peas, beans and lentils as meal components. However, the common practice of adding bran to foods should not be encouraged as this is more likely to create problems than solve them.

The information sheet *Constipation and Parkinson's* is available from the PDS.

Oral nutrition support (ONS)

The dietitian should advise on ways to increase energy intake through the use of energy-dense foods. Fortifying meals with high fat, sugar or protein foods, such as full-fat milk, skimmed powder, butter and/or the prescription of oral sip feeds, may be appropriate. Meals may need to be divided into six small, energy-dense meals if patients suffer from long 'off' periods (where the patient has severe periods of immobility or freezing) or excessive daytime sleepiness or unintended sleep episodes, due to the tendency of dopaminergic medications to induce a sedative side effect (Aldrich, 1994).

Clinical experience has shown that some patients have exceeded 3,000kcal per day and still managed to lose weight. Calculating these patients' requirements is based on Schofield's equation. Add a weight-gain factor of at least 600–1,000kcal to the basal metabolic rate (BMR) to promote weight gain, if necessary, or 25–35kcal/kg ideal body weight (NICE 2006 Nutrition Support for Adults), especially if the patient is underweight. Regular dietetic review and imaginative use of oral sip feeds is necessary to optimise nutritional intake.

Enteral nutrition support (ENS)

If the person with Parkinson's is designated nil-by-mouth (NBM), due to severe dysphagia, or is unable to maintain adequate nutritional intake to prevent malnutrition, a percutaneous endoscopic gastrostomy (PEG) may be inserted for long-term enteral feeding. Establishing nutritional requirements is based on the same principles as in ONS. The use of a PEG will need to be discussed in detail with the MDT and patient/carers before it becomes an option.

Increased risk of falls and bone health

Malnutrition and weight loss can cause general weakness and increase the risk of falls. Ensure the patient is eating sufficient amounts of calcium-rich foods to maintain bone structure. People with Parkinson's have been found to have a defect in the renal synthesis of 1,25-dihydroxyvitamin D (1,25-[OH]₂D) (Sato et al, 1997). Literature suggests that Parkinson's patients should be supplemented with vitamin D (1-alpha-hydroxyvitamin D3 – the more active form of vitamin D), which can help to increase bone density and dramatically lower the risk of fracture in these patients (Sato et al, 1999). This is necessary for patients who are bedbound or immobile.

Weight gain

If an individual living with Parkinson's becomes sedentary but still has a normal appetite and continues to consume the same amount of food, weight gain can occur.

Perlemoine et al (2005) and Tuite et al (2005) have observed significant weight gain in patients following deep brain stimulation (DBS) surgery. Weight gain of 21lbs and BMI increase of 4.7kg/m² six months after DBS, and an increase in fat mass, were also observed by Tuite et al (2005) and Macia et al (2003). This weight gain is due to reduced energy expenditure as a result of subsidence of chronic tremor by up to 44% (Varma et al, 2003). This indicates that there is a need for proactive management of body weight in Parkinson's patients undergoing DBS. Dietary guidance should focus on the need to reduce fat-rich and sugar-rich food choices, rather than more nutrient-dense foods. Consumption of fruit and vegetables should be increased and use of reduced-fat milk and dairy foods encouraged.

Cognitive decline

Cognitive decline becomes increasingly possible as the condition progresses. Confusion is common and may be accompanied by delusions and hallucinations. Drug dosage to control motor dysfunction may have to be reduced in order to produce a more settled psychological state.

The consequent worsening of motor symptoms is likely to increase the risk of eating and swallowing difficulties, necessitating dietetic involvement and possibly active nutritional support via the enteral route, eg naso-gastric tube (NGT) or PEG feeding.

Dietary protein manipulation

L-dopa is a type of amino acid called large neutral amino acid (LNAA). In order for the L-dopa to be absorbed adequately, it must attach itself to carrier molecules in the wall of the intestine, which then carry it across the intestinal wall to the blood. Therefore anything that also uses this carrier system can compete with L-dopa.

L-dopa disappears from the blood very quickly, usually about 60–90 minutes after being administered. It must be absorbed from the small intestine into the bloodstream, cross the blood-brain barrier and then be converted, by enzymes, to dopamine in the brain.

Factors such as a heavy meal (a meal high in fat or protein) or constipation can delay the emptying of the stomach contents into the small bowel, therefore preventing adequate L-dopa absorption. The major site of interference between L-dopa and protein, in particular of large neutral amino acids (phenylalanine, tyrosine and tryptophan), is at the blood-brain barrier (Karstaedt & Pincus, 1992). As a result, it has been suggested that reduction, manipulation or redistribution of dietary protein intake may help to counteract the decrease in the long-term effectiveness of L-dopa and so help to provide symptom relief.

Some patients benefit from taking L-dopa at least half an hour before a meal or an hour after to avoid competing with protein for absorption. The following measures have also been advocated and researched extensively.

Protein restriction Restricting protein intake to 7–10g during the day maximises absorption of the drug and minimises motor fluctuations. Most should be consumed in the evening, when reduced motor functions are less likely to disrupt a person's lifestyle.

Riley and Lang (1998) report that this approach is well tolerated and beneficial. Pare et al (1992) reported that healthy, well-motivated individuals could maintain an adequate intake of most nutrients, despite restricting dietary intake in the daytime, as long as they received sufficient dietetic education and support. However, this type of intervention may not be appropriate if the patient is already malnourished and/or requires the use of oral sip feeds to maintain weight.

Protein reduction Researchers have suggested that these patients benefit from not exceeding their recommended daily allowance (RDA) for protein (Frankel et al, 1989) or eating no more than 50g/d (men) and 40g/d (women) (Tsui et al, 1989). However, it is not only the total amount of protein that is important but how it is distributed throughout the day (Carter et al, 1989). It is also important to increase the proportion of dietary carbohydrate to protein to a ratio of 5:1; thought to yield an optimum ratio between plasma neutral amino acids and L-dopa (Berry et al, 1991).

Protein redistribution It is well established that the use of protein redistribution diets (PRD) can benefit this group of patients (Carter et al, 1989; Frankel et al, 1989; Pincus et al, 1987; Juncos et al, 1987). Total protein intake can be evenly distributed between six small snack-meals.

Karstaedt & Pincus (1992) have suggested that the long-term use of a protein-restricted diet is a safe and simple technique to extend the usefulness of carbidopa/L-dopa therapy in advanced Parkinson's. However, do remember that these are experimental techniques and that the benefits have not been sufficiently established for them to be regarded as standard practice. They may be a viable option in some instances, when symptom control on medication is failing or inadequate, but in any patient where nutritional intake is already inadequate (particularly likely in patients with advanced symptoms), there is a considerable risk that such dietary manipulations could seriously compromise nutritional status.

It is advisable to liaise with your MDT, in particular the PDNS if you have one, who can advise whether the above measures will be of benefit. In some cases, the patient may be becoming resistant to L-dopa and would benefit from other forms of management, for example an apomorphine challenge and subsequent

apomorphine pump insertion. Ensure that your aims of dietetic intervention are explicit to the MDT when manipulating protein with any individual.

Antioxidants

It has been suggested that high dietary intakes of antioxidants may be protective against the development of Parkinson's. However, this remains speculative; while some studies have reported findings consistent with this effect (de Rijk et al, 1997), others have failed to confirm this (Logroscino et al, 1996; Morens et al, 1996). Further research is needed (Ben-Shlomo, 1997).

Once the condition has developed, there is no evidence that taking supplemental doses of antioxidants slows the progression of the disease or enhances the effects of anti-Parkinson's drugs.

It had been hypothesised previously that supplementary vitamin E could be of significant benefit in slowing down the progression of the condition. However, the recently published NICE Guideline for Parkinson's disease: diagnosis and management in primary and secondary care (2006) has recommended that vitamin E should not be used as a neuroprotective therapy in Parkinson's, due to the lack of evidence. Patients who are concerned about their intake of these nutrients should be reassured that a well-balanced diet will meet their antioxidant needs and that food sources of these nutrients (particularly fruit and vegetables) may be better, and probably safer, than supplements. See the PDS booklet *Complementary Therapies and Parkinson's Disease* for more information.

Co-enzyme Q10

People living with Parkinson's often take supplementary co-enzyme Q10, as it is thought to slow down the progression of the disease. Due to the lack of scientific evidence, the NICE Guideline for Parkinson's disease (2006) has recommended that co-enzyme Q10 should not be used as a neuroprotective therapy, except in the context of clinical trials. Co-enzyme Q10 can be found in organ meats, beef, soya oil, oily fish and peanuts (very small amounts).

End-stage Parkinson's

In the absence of any curative treatment, the management of Parkinson's remains largely palliative, despite the huge advances that have been achieved in medical knowledge.

The palliative stage of Parkinson's is defined as:

- inability to tolerate adequate dopaminergic therapy
- unsuitable for surgery
- the presence of advanced co-morbidities

(MacMahon & Thomas, 1998)

Medication may be reduced due to lack of drug efficacy and increasing sensitivity to unwanted effects, such as hallucinations. Active and aggressive nutrition support may also be withdrawn if it is causing discomfort or undue distress. Close liaison with the palliative care team is advised at this stage. It is therefore very important that there is good, effective and open communication within the MDT.

Case study

Background

Mr X was diagnosed with Parkinson's in 1987.

Referred to MDT Parkinson's clinic in day hospital in 2002.

Dietitian carried out initial nutritional assessment and has had patient on caseload since; most recently for first hospital admission.

Other medical history

2005 TIA

2006 Fall – wrist fracture

Signs and symptoms

constant drooling	no direct eye contact
poor gait	expressionless face
reduced mobility	quiet speech
tremor	unable to communicate fully
tilts when sitting	coughs on normal fluids

Reason for hospitalisation

(not been hospitalised previously)

Review medication/simplify medication regime

Assess worsening

Assess mobility

Treat constipation – BNO x 11 days

Assess confusion – drug-induced hallucinations and confusion

Review ADL

Case study (continued)

Nutrition

November 2002

Initial assessment: BMI: 22

Problem: Steadily losing weight due to reduced food and fluid intake (very slow eater)

Action: Food/fluid enhancement
Healthy eating
x2 supplement drinks/day

Monitoring: Monthly initially

March 2003

Review: BMI: 24

Problem: Communication difficulties, drooling

Action: Referral to speech and language therapist, continue nutrition support

Monitoring: Quarterly until February 2006

February 2006

Review: BMI: 26

Problem: Fall, fracture left wrist
Reduced ability to eat and drink
Increased strain on wife

Social: Wife main/only carer
Live in own home

Adaptations: Handrails
Stair lift
Wheelchair

Wife is Mr X's advocate. She does most things to assist Mr X. The main problem occurs when she wants a break or is unwell. She has refused planned surgery when no one available to care for husband at home.

She reports that the daily hospital visits and feeding Mr X is exhausting, stressful and time-consuming.

Plan

- Home with simplified medication regimen for others to use, eg respite carers
- Improved eating and drinking due to continued intake of thickened fluids (syrup consistency) and eats more due to decreased confusion (which was caused by medication)
- Weight steady
- Reviewed physio exercise regime
- More aids to eating and drinking via the OT
- Carer support via local carers group

Relevant resources from the PDS

Booklets

Complementary Therapies (code B102)
Looking After Your Bladder and Bowels in Parkinsonism (code B060)
Parkinsonism (code B060)
Parkinson's and Dental Health (B045)
Parkinson's and Diet (code B065)
The Drug Treatment of Parkinson's Disease (code B013)

Information sheets

Antioxidants (code FS67)
Co-enzyme Q10 (code FS74)
Communication (code FS06)
Constipation and Parkinson's (code FS80)
Eating, Swallowing and Saliva Control in Parkinson's (code FS22)
Fatigue and Parkinson's (FS72)
Motor Fluctuations in Parkinson's (FS73)

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notes

notes



The GP's guide

to Parkinson's disease

Introduction

The good news for the GP is that there is a lot more you can do for your patients with Parkinson's, particularly when it comes to the non-motor symptoms of the condition; these are often more troublesome to patients than the motor features – bradykinesia, hypokinesia, rigidity and resting tremor – that doctors often concentrate on.

Non-motor symptoms are wide ranging and can include depression, dementia, sleep disturbance, incontinence, dysphagia, constipation, impotence, hypotension and sweating. The GP has a crucial role in controlling these non-motor symptoms, as well as the motor symptoms.

Behavioural disorders, such as pathological gambling, hypersexuality and compulsive eating, can also be side

effects of certain Parkinson's drug treatments, so significant behavioural changes should also be monitored.

It must be remembered that each patient is part of a family unit. Other members will be affected by the patient's Parkinson's. The spouse invariably becomes the carer and it is important to support them too.

Patients and carers are central to the management of the condition. Openness, explanation and honesty (in situations where you can't help) will make a major difference. Palliative care for the final days needs to be organised to ensure that a patient's dignity is maintained at the end of their life.

Background

Dr Parkinson described the condition in 1817 on the basis of observations made from the window of his London home, from consultations and from people he approached in the street. This would suggest that the diagnosis is straightforward but, of course, this is not always the case, particularly as our responsibility is to detect disease processes at an early stage in order to introduce appropriate therapy and refer on to other members of the multidisciplinary team (MDT). Awareness is the first rule of diagnosis so it is important to have some concept of the prevalence of the disease and its age range.

The condition occurs in all ethnic groups and there is a 1.8 times greater risk of Parkinson's in men. The prevalence in the general population is one in 500 – over 120,000 people in the UK are affected by Parkinson's. The mean age of presentation is 65 years. However, it is important to remember that one in 20 of all newly diagnosed patients (about 10,000 per year in the UK) are under the age of 40. It is estimated that the prevalence will increase in the next 50 years because of our ageing population. The important message is that this is not an uncommon disease.

Pathology

The pathological basis for the symptoms is the loss of nerve cells in the pigmented substantia nigra, pars compacta and the locus coeruleus of the midbrain. Cell loss also occurs in the globus pallidus. The loss of dopaminergic cells in the substantia nigra leads to striatal dopamine depletion.

Dopamine activates receptors in the direct pathway to the motor cortex and represses inhibitory receptors in the indirect pathway (via the thalamus). Depletion leads to decreased activity in the direct pathway and increased activity in the indirect pathway, reducing thalamic stimulation of the motor cortex. The depletion of other neurotransmitters may also play a part in the development of other non-motor symptoms, such as depression.

The cause of Parkinson's remains uncertain but it is likely to be due to a combination of genetic risk factors

and environmental agents. Symptoms have been associated with exposure to certain chemicals, which suggests that long exposure to an unrecognised environmental toxin may play a role. Endogenous toxins may also be involved, as dopamine readily oxidises to produce free radicals.

While genetic influences also may contribute, early studies failed to find similar disease patterns in mono and dizygotic twins. However, striatal abnormalities have been shown to be present (by positron emission tomography) in non-affected twins. In addition to the potential of genetic susceptibility factors, about 5% of cases of Parkinson's are directly inherited and are usually manifest as early-onset Parkinson's (less than 40 years of age). To date, ten genes associated with inherited Parkinson's have been identified.

Diagnosis

A definite diagnosis of Parkinson's is difficult. It is important that there is an early diagnosis. If the condition is suspected, a patient should quickly be referred – untreated – to a neurologist or a geriatrician with a special interest in Parkinson's. There may be a local 'movement disorder clinic'. The NICE Guideline on the diagnosis and management of Parkinson's says referral time should be no more than six weeks and should not exceed two weeks in cases where the condition is severe or complex.

Signs and symptoms suggestive of Parkinson's are:

- bradykinesia (slow movements)
- tremor
- hypokinesia (poverty of movement)
- rigidity

The condition is diagnosed following a detailed clinical examination. Often the specialist will use the 'brain bank criteria'. There are no laboratory tests or easily available imaging tests to help make the diagnosis. While Single Photon Emission CT (SPECT) scanning may assist in making the diagnosis, this is only available in some centres. It is more likely to be used to exclude other conditions that may have similar symptoms.

Patients with Parkinson's should be reviewed regularly and the diagnosis reconsidered if atypical features appear. The rate of onset is extremely variable and some years may pass before the patient or their relatives appreciate what is happening. This is especially true if tremor is not an early symptom.

There are some conditions that have symptoms similar to Parkinson's and are referred to as 'parkinsonism'.

Essential (familial) tremor is a faster tremor (about 7–8Hz). There is a postural element to the tremor, which can help to differentiate from Parkinson's rest tremor. There are no other neurological signs and the disability is never profound.

Post-encephalic parkinsonism can be distinguished by the history and there are usually features of dementia at an early stage.

Other conditions include **cerebrovascular parkinsonism, progressive supranuclear palsy (PSP), multiple systems atrophy (MSA), corticobasal degeneration** and **Wilson's disease**.

Neuroleptic drugs, taken for a prolonged time, can induce symptoms of parkinsonism. These include

chlorpromazine, thioridazine, trifluoperazine, fluphenazine, haloperidol, pimozide, risperidone, quetiapine and **anti-emetics**, eg prochlorperazine and metoclopramide. All these drugs reduce dopamine

levels and withdrawal of the drug is likely to result in the symptoms resolving.

Follow-up

Ideally, patients with Parkinson's should receive a follow-up by a Parkinson's specialist every 6–12 months to optimise the treatment and reassess the diagnosis. It is not unusual, as the illness evolves, for the diagnosis to change. If the GP has a special interest then the patient can be followed by using a local shared care protocol.

If there is a Parkinson's Disease Nurse Specialist (PDNS), they can co-ordinate optimal care with the patient, carer, GP and specialist. The PDNS revolutionises care by bringing it into the community and the patient's home. All patients with Parkinson's should have access to a PDNS.

Maintaining independence is a high priority, along with home safety. Occupational therapy and physiotherapy

follow-up will facilitate independence. Speech therapy will help to preserve speech and swallowing.

The GP can co-ordinate care by using a computerised register, to ensure patients are not referred on and then forgotten about.

Medication is usually proved by the GP, who is well placed, with the PDNS, to monitor compliance issues related to repeat prescribing. A medication review will ensure that no other medication is exacerbating the condition. Do not stop medication abruptly as it can cause neuroleptic malignant syndrome, which can be dangerous.

Motor symptoms

Patients with Parkinson's become slower in all movements (bradykinesia) and gradually the characteristic parkinsonian rigidity takes possession of the limb, usually on one side – both sides will be affected as the condition progresses. On the affected side, the arm stops swinging when walking and the leg feels heavy.

Hypokinesia (poverty of movement) manifests as loss of facial expression, loss of arm swing and difficulty with movement.

In the majority of patients, but not all, the tremor appears not when the limb is in motion but when at rest, or perhaps when carrying out a task such as holding up a newspaper. It is a fine, rhythmic movement – about two to five per second – and may appear in the thumb and index finger ('pill-rolling') or at the wrist. The leg also, when inadequately supported, will shake in the same way. The tremor is aggravated by fatigue, emotional stress or the knowledge that the tremor is being looked at. It usually only affects one side of the body initially.

Clinical examination should, as usual, begin with the observation of the patient as he/she approaches the examiner. The face, the stance and gait are all good indicators of Parkinson's.

The arms and legs are not paralysed. The muscle tone is increased with the classic 'lead pipe' or 'cog-wheel' rigidity. Movements tend to be slow and restricted in range.

The tendon reflexes are normal or even a little brisk and the planter reflexes are flexor. If reflexes are brisk, this raises the possibility of atypical parkinsonism.

Imperceptibly, the natural mobility of the patient's face fades and this becomes a little set and, later, a 'masked' appearance develops. Although the voice tends to lose its natural inflexions and eventually becomes very weak, mental alertness is unimpaired for many years. Although the lack of facial expression can give the wrong impression about the mental state, many patients have unrecognised depression.

Non-motor symptoms (NMS)

Early recognition of NMS is essential. The GP or PDNS can assess and monitor continuously, providing specific advice and support for the person and their family, as well as ensuring referral on to the MDT.

The Parkinson's Disease Society (PDS) has produced a *Non-motor symptoms questionnaire* with 30 yes/no questions relating to the month prior to the consultation. This can be given to patients before their consultation to aid recognition of NMS and allow them to be discussed.

Neuropsychiatric symptoms

Anxiety

Anxiety is common and can be a preclinical indicator. Presentation can be in the form of panic attacks, compulsive eating, punding (the repetitive performance of meaningless tasks) and other obsessive compulsive behaviours or generalised anxiety and can often be related to drug-induced motor fluctuations.

Apathy

Apathy is now known to be a particular symptom of Parkinson's, independent of depression and fatigue, and responds minimally to dopaminergic drugs, perhaps indicating the involvement of other neurotransmitter pathways.

Depression

Depression occurs in about 45% of people with Parkinson's and appears to be related to the degeneration of dopaminergic neurones in limbic and pre-frontal systems. Depression may present with feelings of guilt, helplessness, remorse or sadness. A structured evaluation and the use of a depression rating scale can help to quantify the problem when making a referral to psychiatric services for a correct diagnosis and treatment.

Psychosis and visual hallucinations

Hallucinations and other forms of psychosis occur in about 40% of individuals with Parkinson's who are on dopaminergic therapy. Psychotic symptoms can take the form of vivid, complex visual hallucinations of people and animals. Auditory and olfactory hallucinations are less common and may be associated with visual hallucinations or present independently. Delusional thinking can also occur. Presence of these symptoms may indicate that the diagnosis needs to be reviewed as the patient may be developing dementia.

Mild psychotic symptoms, if tolerated by the person with Parkinson's, need not be actively treated. If they are troublesome, management includes gradually withdrawing anti-Parkinson's medication that might have triggered the psychosis and, if not effective, then considering the use of atypical antipsychotics, (as well as checking for concurrent infection or constipation). Typical antipsychotics are not recommended as they exacerbate the motor symptoms of Parkinson's.

Impulse control disorders (ICD) affect a very small percentage of patients. It may be seen more often in younger, early onset patients, and seems to be a result of treatment with dopamine agonists, rather than a specific non-motor symptom. This can manifest as compulsive gambling, hypersexuality, compulsive eating, punding and other obsessive compulsive behaviours. Dopamine dysregulation syndrome, where the patient takes increased doses of medication, with traits similar to drug addiction, is also associated with ICD.

Dementia

At least 40% of patients will develop cognitive changes severe enough to warrant a diagnosis of dementia. This may be dementia with Lewy bodies (DLB), which is usually diagnosed when the symptoms of dementia are manifest within one year of the onset of the Parkinson's motor symptoms. Dementia in Parkinson's is progressive and characterised by a severe dysexecutive syndrome, with impairment of visuospatial abilities and marked cognitive impairment, impaired concentration, excessive daytime sleepiness, visual hallucinations and delusions.

Although cholinesterase inhibitors have been used successfully in treating individual people with Parkinson's dementia, further research is recommended to identify those patients who will benefit from this treatment.

Sleep disturbances

Most people with Parkinson's will have problems with sleep. The causes are multifactorial but degeneration of the sleep regulation centres in the brainstem and thalamocortical pathway is implicated. A full sleep history should be taken. The merits of good sleep hygiene should be advised. The PDS information sheet *Sleep and Night-time Problems in Parkinson's* is a useful source of information for patients. A review of all medication and avoidance of any drugs that may

affect sleep or alertness, or may interact with other medication should also be considered.

Restless legs syndrome (RLS)

RLS will disturb sleep but usually responds to a low dose of dopamine agonists, clonazepam or levodopa.

Rapid eye movement (REM) sleep behaviour disorder (RBD)

This is characterised by loss of the normal skeletal muscle atonia during REM sleep, resulting in people physically acting out their dream (often violently) and can precede the development of the motor symptoms in up to 40% of patients. Clonazepam in small doses of 0.5–2mg may help.

Hypersomnolence

Excessive daytime sleepiness and dozing affects up to 50% of patients with Parkinson's. The condition itself, poor sleep and anti-Parkinson's drugs are causative factors. Excessive daytime sleepiness can occur early in the condition and predate the diagnosis. 'Sudden onset of sleep' is now considered to be a side effect of dopamine agonists, rather than a dysfunction of sleep. Modafanil may reduce this problem.

Autonomic disturbance (dysautonomia)

Autonomic dysfunction is common in Parkinson's, due to the underlying pathophysiology of the condition affecting the catecholaminergic neurones of the autonomic nervous system. The pathophysiology is complex and includes degeneration and dysfunction of the nuclei mediating autonomic functions and degeneration of cholinergic, monoaminergic, and serotonergic nuclei. Symptoms include: urinary dysfunction, constipation, erectile dysfunction, orthostatic hypotension, weight loss, dysphagia, excessive sweating (hyperhidrosis) and excessive saliva (sialorrhoea).

Urinary dysfunction

Bladder dysfunction can affect up to 40% of individuals. The earliest and most commonly reported complaint is nocturia (waking at night one or more times to void) followed by urgency, frequency and urge incontinence.

Where there are refractory or persistent bladder problems, referral to a urologist should be considered, after exclusion of urinary tract infection (where there is an abrupt change in voiding pattern) or diabetes mellitus (where frequency and polyuria are prominent). Referral to a continence adviser may also be helpful.

Constipation

Constipation occurs frequently, affecting over 50% of people with Parkinson's, which is significantly higher than in the normal population (around 15%). It is one of the most common non-motor symptoms and can precede development of the disease. The initial management of constipation due to colonic dysmotility includes increasing dietary fibre and fluid intake (at least eight glasses of water per day) and increasing exercise.

Sexual dysfunction

The most commonly reported sexual problem for men with Parkinson's is erectile dysfunction. For women, difficulty with arousal (genital sensitivity or lubrication), orgasmic difficulty, dyspareunia or vaginismus are the primary problems.

Orthostatic (postural) hypotension

Orthostatic hypotension can occur in up to 48% of people with Parkinson's. It is defined as a fall in systolic blood pressure of over 20mm mercury on standing. Patients who are experiencing orthostatic hypotension may complain of dizziness, visual disturbances, falling or fainting. It can be due to central or peripheral autonomic dysfunction but it should be remembered that it can also occur as a result of Parkinson's medications, antihypertensives or co-morbidities, such as anaemia. Taking a lying to standing blood pressure should be part of a first visit assessment and then as required, if the patient complains of dizziness, visual disturbances, falling or fainting. This can be helped by increasing salt and fluid intake and raising the head of the bed. Fludrocortisone and midodrine may also be helpful.

Weight loss

Unintended weight loss is common, occurring in over 50% of individuals. Moderate or severe dyskinesia can be the cause but if significant loss occurs, other medical causes, eg malignancy, endocrine causes, dysphagia or poor diet, should be considered and referral to the appropriate discipline instigated.

Dysphagia

Swallowing difficulties usually relate to disease severity and may affect all phases of the swallow process. There is a risk of aspiration pneumonia, malnutrition and dehydration. Dysphagia poses a major problem to

the taking of medications that are critical in the successful management of Parkinson's. There should be early referral to a speech and language therapist for assessment, swallowing advice and, where indicated, further instrumental investigation.

Hyperhidrosis

Excessive sweating may occur as an end-of-dose 'off' phenomenon or while in the 'on' motor state. It is usually associated with dyskinesias.

Sialorrhoea

Excessive saliva or drooling occurs in 70–80% of people with Parkinson's. Apart from social embarrassment and soiling of clothing, sialorrhoea may also be associated with perioral infection. General management should include referral to a speech and language therapist for full assessment of swallowing ability and advice.

Treatment

Unless the GP has a special interest in the condition, treatment is best initiated by a Parkinson's specialist in liaison with the PDNS, using a local shared care protocol that the GP can refer to. The GP can then prescribe Parkinson's medication but only if a robust local shared guideline is available. Ideally the monitoring will be carried out by a PDNS.

Communication by phone between GP, PDNS and Parkinson's specialist will often smooth out any issues regarding responsibility and reluctance to prescribe drugs that a GP has no experience of prescribing.

Ideally, your patient should have access to physiotherapy, occupational therapy and speech and language therapy. Sadly these services are often not available.

The obvious treatment is to give the patient dopamine, but this is seriously emetic and cannot cross the blood-brain barrier when taken orally, so the aim is to use other approaches to increase brain dopamine levels.

Levodopa

Levodopa (L-dopa) is a dopamine precursor that is converted to endogenous dopamine within the brain by the enzyme dopa decarboxylase. The two common forms of L-dopa do this by combining with benserazide (which inhibits the actions of extracerebral dopa decarboxylase and therefore the peripheral effects of increased dopamine levels) as co-beneldopa

Sensory disturbances

Pain

Pain is common and can occur in up to 50% of people with Parkinson's. Patients may complain of sensory-type pains, which include paraesthesias, burning dyesthesias, coldness, numbness and deep aching within a nerve (neuropathic pain). Pain may be related to motor fluctuations or early morning dystonia, 'off' phase dystonia and, occasionally, 'on' dystonia, the latter being particularly difficult to treat. It can also be a result of musculoskeletal pain, secondary to parkinsonian rigidity and hypokinesia. Pain should always be evaluated and treated appropriately.

Olfaction

Olfactory dysfunction eventually affects up to 90% of people with Parkinson's and is a potential pre-clinical marker of the condition.

(Madopar[®]), in addition to carbidopa as co-careldopa, (Sinemet[®]). These drugs remain the mainstay of therapy and it is important to titrate the dosage to the patient's requirement.

The problem with L-dopa is that, in the longer term, the timing of each dose becomes critical, as there is frequently loss of effect before the next dose is absorbed. This can give rise to unexpected involuntary movements. In addition, patients experience sudden switches from normal movement (being 'on') to immobility (being 'off').

In time, the majority of patients on this drug will experience these adverse effects. Manipulation of the dosage, time of administration and type of preparation will help. In addition, attention should be paid to diet, as a high protein diet can interfere with the absorption of L-dopa from the gastrointestinal tract, and some patients benefit from taking their medication about 45 minutes before meals.

Dopamine agonists

An alternative strategy is to use drugs that have a dopamine-like action. The dopamine agonists stimulate dopamine receptors (among other actions) and can be used either alone or in conjunction with L-dopa. They produce fewer long-term side effects but they are much more likely to cause hallucinations in older patients. In addition, they have to be introduced

very gradually, as they do cause nausea, sickness, ankle swelling and dizziness related to low blood pressure. They have to be used with care but are very useful. Preparations include bromocriptine, cabergoline and pergolide (ergot derived). While some of these can have a side effect of heart valve fibrosis and reddening of the legs, others, including pramipexole, ropinirole and apomorphine, do not.

Rotigotine is delivered once daily by skin patch but its place in therapy is not yet established.

Apomorphine can only be administered subcutaneously and is helpful in patients who have severe fluctuations in their symptoms. With appropriate training, it can be self-administered and there is now a preparation for continuous subcutaneous infusion with a syringe driver.

Other drugs

Amantadine – The action is uncertain but it is likely to promote dopamine action by inhibiting the excitatory amino acid glutamate. It is relatively mild in effect but is useful in reducing drug-induced dyskinesia.

MAO-B inhibitors (selegiline and rasagiline) – This drug blocks the enzyme monoamine oxidase type B (MAO-B), which breaks down dopamine in the brain. It can be used on its own in the early stages of the condition or in conjunction with L-dopa. In this situation, it reduces the required dosage and prolongs the action of the L-dopa.

Catechol-O-methyl (COMT) inhibitors (entacapone and tolcapone) – COMT inhibitors work by blocking an enzyme called catechol-O-methyl transferase (COMT), which breaks down L-dopa. As a result they slow the destruction of L-dopa in the body. COMT inhibitors are therefore prescribed for use with L-dopa to prolong the duration of action.

Anticholinergics (eg trihexyphenidyl) – These were the first drugs to become available for the treatment of Parkinson's. While they tend to help the tremor, they are no longer recommended due to high risk of side effects, especially in the elderly, and concerns about their effect on cognitive function.

Antidepressants – As depression is present in up to 45% of people with Parkinson's, these are often important in the management of the condition. There are no specific rules for their use and GPs should use drugs they are familiar with. Selective serotonin-reuptake inhibitors, eg citalopram, are possibly the most useful but there is a rare adverse interaction with selegiline and rasagiline (hypertension and CNS excitation).

Drugs that are best avoided in Parkinson's

Prochlorperazine
Metoclopramide
Perphenazine
Flupentixol
Chlorpromazine
Fluphenazine
Haloperidol
Pimozide
Sulpiride
Trifluoperazine

Surgical treatments

A very small percentage of patients with extra-pyramidal movement disorders benefit from surgical treatment. The most common procedure is the implant of electrical stimulators in the midbrain in an operation called 'deep brain stimulation' (DBS). In carefully selected patients, the results are excellent, greatly relieving the symptoms of the condition for some years.

Relevant resources from the PDS

Booklets

Looking After Your Bladder and Bowels in Parkinsonism (code B060)

Parkinson's and Diet (code B065)

The Drug Treatment of Parkinson's Disease (code B013)

DVD

Being There – a resource for the newly diagnosed (code V012)

Questionnaire

Non-motor Symptoms Questionnaire (code B117)

Information sheets

Apomorphine (APO-go) (code FS26)

Dementia and Parkinson's (code FS58)

Dementia with Lewy Bodies (code FS33)

Depression and Parkinson's (code FS56)

Eating, Swallowing and Saliva Control in Parkinson's (code FS22)

Gambling and Parkinson's (code FS84)

Hallucinations and Parkinson's (code FS11)

Parkinson's and Hypersexuality (code FS87)

Low Blood Pressure and Parkinson's (code FS50)

Muscle Cramps and Dystonias (code FS43)

Pain in Parkinson's (code FS37)

Parkinsonism (code FS14)

Pill Timers (code FS53)

Restless Legs Syndrome and Parkinson's (code FS83)

Sleep and Night-time Problems in Parkinson's (code FS30)

Useful websites and further reading

GPnotebook

A concise synopsis of the entire field of clinical medicine, focused on the needs of the general practitioner.

www.gpnotebook.co.uk

National Institute for Health and Clinical Excellence

The NICE Guideline for Parkinson's disease: diagnosis and management in primary and secondary care.

www.nice.org.uk/CG35

Clarke C (2006) *Parkinson's Disease in Practice*, 2nd revision, Royal Society of Medicine Press Ltd

Jones, Roger et al (2003), *Oxford Textbook of Primary Medical Care*, Oxford University Press

notes

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The nurse's guide

to Parkinson's disease

Introduction

Both Parkinson's Disease Nurse Specialists (PDNSs) and registered nurses are vital in the care of people with Parkinson's and make a real difference to people's lives. They are often looked to for help at times of great difficulty by patients and their families.

As a nurse, your contribution is crucial in providing people with Parkinson's with high-quality care and treatment. The importance of a highly skilled and educated nursing workforce is well recognised by healthcare commissioners and people with Parkinson's themselves.

This section is written by an experienced nurse specifically to guide you in delivering 'best practice' in Parkinson's disease management. We hope you find this resource helpful.

The publication *Competencies: an integrated career and competency framework for nurses working in Parkinson's disease management* is also available from the Parkinson's Disease Society (PDS). It describes the knowledge and skills required by nurses to manage the care of people living with Parkinson's disease in any healthcare setting and offers signposts for good practice. The PDS, Parkinson's Disease Nurse Specialist Association (PDNSA) and Royal College of Nursing (RCN) have collaborated as one body to produce these competencies to maintain the highest level of standards, competence and professional integrity.

nurse

Introduction

While it is not inevitable that people with Parkinson's will develop bowel and bladder problems, dysfunction is experienced by many.

Constipation occurs frequently in Parkinson's, affecting over 50% of individuals, which is significantly higher than in the general population – around 15% (Sakakibara et al, 2003). It is one of the most common non-motor symptoms and can precede development of the disease. Faecal incontinence, when it occurs, is usually due to overflow around faecal impaction.

Bladder dysfunction in Parkinson's can affect up to 40% of individuals (Winge & Fowler, 2006). The earliest and most commonly reported complaint is nocturia (waking at night one or more times to pass urine), followed by

urgency, frequency and urge incontinence. The early development of severe bladder dysfunction, such as urgency, frequency and incontinence, may indicate an alternative diagnosis, such as multiple system atrophy (MSA).

Bowel and bladder dysfunction is a source of discomfort for any person and can add to the distress of a patient with Parkinson's, affecting their quality of life. Many patients are embarrassed about discussing their bowels and bladder so, as a nurse, building an open and trusting relationship is important. A willingness to discuss individual difficulties with patients and carers can lead to positive steps to alleviate them.

Bowel dysfunction

Identifying bowel dysfunction

Constipation is defined as less than three bowel movements a week (Winge et al, 2003). It is the most common bowel problem in Parkinson's and has several causes. There is evidence of autonomic failure due to the presence of Lewy bodies in the gut wall, which impair contraction of the colon and result in constipation. Other causes include:

- reduced physical mobility
- inadequate fibre and fluid intake due to chewing and swallowing problems
- problems emptying the bowel due to weak abdominal straining and the anal sphincter not relaxing (functional outlet obstruction)
- medications such as anticholinergics, iron or analgesics

Assessing bowel function

Constipation not only impairs quality of life but also affects dopaminergic drug absorption, making the symptoms of Parkinson's worse, so it is important to check if there are any concerns with bowel function. The following factors should be considered when carrying out a nursing assessment:

- How often do they open their bowels and what is their usual stool type? (eg The Bristol Stool Scale)
- Do they have an ability to sense bowel fullness?
- Do they get pain before or with a bowel movement?
- Is there any blood or mucus?
- Do they strain or have a sense of incomplete emptying?
- Do they take any laxatives?
- Have they or do they use digital stimulation for evacuation of stool?
- Do they get urgency or can they hold on?
- Have they had any urge or passive incontinence?
- Can they control flatus and distinguish flatus from stool?
- Are they using pads?
- Is there any skin irritation?
- Is there an obstetric history or other relevant past medical history?
- Do they have any problems with bladder control?
- Do they have a physical difficulty with toilet access/ability to use the toilet independently?

Treatment and management of bowel dysfunction

The aim is a predictable and effective bowel evacuation. Information may be given to the patient regarding the following, but referral to a dietitian or continence nurse should be considered if there is not an improvement in symptoms on the follow-up evaluation.

Fluid intake

Patients with Parkinson's may try to cut down on fluids in an attempt to avoid continence problems; this should be discouraged as it can lead to constipation. Increasing dietary fibre and fluid intake (at least eight glasses of water a day) should be encouraged. Many people experience a laxative effect when hot drinks are taken.

Medications

If attention to diet, fluid intake, exercise and toilet access fails to alleviate constipation, laxatives or suppositories should be considered. Occasionally, severe constipation will require treatment by enema or manual evacuation. The use of laxatives is not specific to Parkinson's and the choice of laxative should be determined by the cause of constipation.

Diet

Eating times should be regular and a diet with adequate fibre and roughage (from vegetables, fruit, bran-based cereals and wholemeal bread) encouraged.

Many people with Parkinson's disease find eating a very slow process and, because of muscle rigidity, may have chewing and swallowing difficulties. A dietitian can advise on how to achieve a manageable, balanced diet that will help to prevent constipation.

Exercise

The muscle rigidity and bradykinesia (slowness of movement) symptomatic of Parkinson's restrict the patient's ability to engage in the physical activity and exercise that is helpful in preventing constipation. They should be encouraged to move about as much as possible, to carry out regularly any form of exercise that they can manage, and to keep as active as their circumstances allow. This will stimulate the bowel and help to prevent constipation.

Position and habit

Good posture while sitting on the toilet is important. Sitting with the upper body slightly forward, the forearms resting on the thighs with knees above the hips will assist the opening of the bowels. Patients should allow time for defecation and not put off the urge to go to the toilet. Setting aside time to go to the toilet after meals can help to develop healthy bowel habits.

Bladder dysfunction

Identifying bladder dysfunction

Nocturia is the earliest and most common lower urinary tract symptom reported by individuals with Parkinson's. The International Continence Society defines nocturia as one or more night-time voids. Nocturia contributes to fatigue, memory deficits, depression, increased risk of heart disease, gastrointestinal disorders and, at times, traumatic injury through falls. Identifying nocturia, determining the cause and treating it effectively are keys to improving patients' quality of life.

In individuals with Parkinson's, nocturia is usually followed by symptoms of urinary frequency and urgency as the condition progresses. This is thought to be due to neurogenic detrusor overactivity – previously called 'detrusor hyper-reflexia'. Detrusor

overactivity of neurogenic origin appears to result from disinhibition of the ponto-mesencephalic micturition centre.

Where there are refractory or persistent bladder problems, referral to a person with urological expertise should be considered. Other management approaches include the exclusion of urinary tract infection and diabetes mellitus. Sometimes, anticholinergic agents are used, but since these drugs cross the blood-brain barrier they must be used with caution as they may induce a toxic confusional state. Other drugs may be available that do not cross the blood-brain barrier.

Mild autonomic dysfunction is common in the later stages of Parkinson's, but early presentation of

bladder symptoms (in particular urinary urgency and urinary frequency, in addition to urinary incontinence and incomplete bladder emptying) should alert the clinician to the possibility of a diagnosis of MSA.

Assessing bladder function

During the nurse's assessment, the following should be covered:

- Whether there is any frequency, urgency, hesitancy, nocturia or incontinence
- The onset and duration of symptoms
- Whether there is a relationship to being 'on' or 'off'
- What fluid is taken and when (consider caffeine and alcohol intake)
- Any relevant past medical history
- Problems with mobility, bradykinesia and dexterity
- What the person's expectations are (eradication or reduction of the symptoms)

A urine sample should be checked for leukocytes and nitrates, to eliminate infection. A specimen will need to be sent for microbiology, culture and sensitivity if positive. If the person continues to complain of urinary frequency and urgency and there is no underlying infection, a pre- and post-void bladder scan should be performed by a competent practitioner. When the post-void residual is less than 150ml, information on bladder training should be given. If more than 150ml, a referral to the specialist continence service or urologist should be made for further advice and management.

Treatment and management of bladder dysfunction

Fluid intake

Concentrated urine can irritate the bladder so it is important to maintain a good fluid intake of 1.5–2 litres (eight to ten drinks) a day.

Bladder training

This involves keeping a bladder diary on frequency of urination and then attempting to suppress the urge to urinate, extending the times between visits to the toilet when possible. This can be a challenge, so support from specialist continence services is important for success.

Intermittent catheterisation

This is useful in patients who have incomplete bladder emptying (residual urine over 100ml). The person may be able to do this for himself or herself or the carer may do it for them. Factors to consider are the person's mobility, dexterity, cognitive function and motivation. When it is clinically indicated, the patient should discuss the advantages and disadvantages with the specialist continence service or urologist.

Indwelling or suprapubic catheters

As Parkinson's progresses, some patients may choose this option to improve their quality of life. This, again, should be discussed with the specialist continence service or urologist.

Mobility

Check the patient's degree of mobility, as the level of akinesia, bradykinesia and rigidity all affect the individual's ability to reach the toilet. Ensuring that there is easy access to the toilet, a hand-held urinal or discreetly placed commode may help in certain situations. The occupational therapist (OT) will be able to advise on obtaining these items, as well as toilet seat raisers and grab rails. In certain circumstances, it may be possible to get a grant for household/bathroom adaptations – the OT can also assist with this.

Clothing

Removal or adjustment of clothing may be difficult. Clothes may be adapted to help in maintaining continence. For example, zip fasteners or buttons may be awkward for a patient to manage. The use of Velcro for fastenings may help. The OT can often advise on suitable clothing.

External appliances

There are many types of products available, including pants and pads or urinary sheaths for men. Advice from a continence nurse specialist and liaison with the district nurse is important to get the most appropriate equipment.

Conclusion

Determining the causes of bowel and bladder dysfunction and treating it effectively are key in improving patients' quality of life. The assessment and management of bowel and bladder problems in Parkinson's require multidisciplinary input.

A nurse is often one of the professionals who has regular, close contact with the person with Parkinson's

and their family or carer. The nurse will have the ability and opportunity to carry out regular holistic assessments and evaluations, particularly when there are changes in their condition. This means that nurses are in a good position to make an appropriate and timely referral to the continence team or relevant person when problems with continence are highlighted.

Key points

- Bowel and bladder dysfunction are experienced by many people with Parkinson's.
- Constipation not only impairs the quality of life of patients but also affects dopaminergic drug absorption.
- Where there are refractory or persistent bladder problems, referral to a person with urological expertise should be considered.
- Early presentation of bladder symptoms (in particular urinary urgency, frequency and incomplete emptying) should alert the clinician to the possibility of a diagnosis of multiple system atrophy (MSA).

Useful contacts

The Disabled Living Foundation (DLF)

380–384 Harrow Road
London W9 2HU
Helpline: 0845 130 9177 (Mon–Fri, 10am–4pm)
www.dlf.org.uk

Bladder and Bowel Foundation

SATRA Innovation Park
Rockingham Road
Kettering
Northants NN16 9JH
Counsellor Helpline: 0870 770 3246
Tel: 01536 533255
www.bladderandbowelfoundation.org

National Association for Continence

www.nafc.org

The Royal College of Nursing Continence Care Forum

20 Cavendish Square
London W1M 0RN
Email: kath.wilkinson@bradford.nhs.uk
www.rcn.org.uk

Introduction

Many people with Parkinson's disease suffer from disorders in their speech (collectively referred to as dysarthria) and swallowing (referred to as dysphagia). Up to 49% report speech disturbances and 50–80% experience a degree of dysphagia (Oxtoby, 1982; Leopold & Kagel; 1996). The symptoms of

bradykinesia and rigidity mean that people with Parkinson's also tend to give fewer non-verbal cues, such as facial expressions and hand gestures. All these factors can lead to the person with Parkinson's being embarrassed, upset and socially isolated.

Communication difficulties in Parkinson's

Speech

Deterioration in speech is a common manifestation of Parkinson's that increases in frequency and intensity with the progression of the disease. It is important to consider referral to a speech and language therapist (SLT) sooner rather than later to maximise the person's learning ability. The referral can be from a variety of professional disciplines, including nurses who are involved with continuing assessment and management of the person with Parkinson's.

What can be a problem?

The specific type of dysarthria associated with Parkinson's is known as hypokinetic dysarthria. The main features that make it distinct from other types of dysarthria are:

- breathy or harsh voice
- monotony with reduced loudness and pitch range
- difficulties in initiating speech
- variable rate
- short rushes of speech
- imprecise consonants

These features have been categorised into four main groups by Marigliani et al (2001), which can help towards identifying the predominant communication disorder as part of a functional assessment in Parkinson's. Separating the features into manageable categories also helps when explaining the problem to the patient.

Voice

There is reduced respiratory support for speech as a result of muscle rigidity, which in turn results in

reduced volume and a breathy, whispery or harsh voice quality. There is often disturbed resonance, which is often hypernasal a result of reduced ability of the soft palate to seal off the nasal cavity.

Fluency

Speech can lack fluency due to a 'stuttering' speech pattern, frequent pauses, word blocks, and repetition of syllables, sound or words.

Articulation

Slowed movement of the tongue and lips results in imperfect articulation. Difficulties changing pitch and volume result in 'flattened' speech, without natural melody or rhythm. A listener's impression is of a progressive reduction in volume but increase in rate.

Language

While some people with Parkinson's will develop dementia, most will experience changes in intellectual function. Depression is seen in 50% of people with Parkinson's (Metman in: Wolters et al, 2006). A reduction in general cognitive function and depression affects language ability. There may be problems with auditory comprehension, topic maintenance and initiation of conversation, inappropriate cessation of sentences and limited eye contact, facial expression and body language.

Treatment of speech problems

The primary aim is to teach simple strategies to encourage conscious attention to speech. Early referral to a SLT is important in order that the person with Parkinson's may learn and retain these skills before their disease has progressed to a stage where their cognitive ability is affected. The approach

to treatment will vary according to the individual's speech pattern assessment by the SLT and their ability to learn new strategies. Techniques range from exercises to improve facial expression and breathing control, speed of speech and stress intonation and the Lee Silverman Voice Treatment (LSVT), employed to increase voicing and improve articulation. Nurses can be aware of the patient's exercises, to help reinforce the lessons learnt, and make use of the PDS information sheet on SLT.

It is important to be aware that speech can be affected by timings of Parkinson's medication. Nurses can make patients aware of this by encouraging them to keep an 'on/off' diary to pinpoint problem times. Picking the optimum time to speak will also help. Performing two tasks simultaneously (eg walking and talking) is difficult for people with Parkinson's, because smooth automatic movement is impaired as the contribution of the basal ganglia is reduced.

Other ways to help your patient with communication is by **not**:

- forcing them to speak if they don't want to
- talking for them
- interrupting them
- insisting that they pronounce each word perfectly
- getting irritated when they cannot communicate
- ignoring them (the 'does he take sugar?' scenario)
- isolating them

Swallowing difficulties in Parkinson's (dysphagia)

Dysphagia eventually occurs in up to 50–80% of people with Parkinson's (Marks et al in: Playfer & Hindle, 2001). The SLT has a key role in the management of swallowing problems, helping to minimise the risk of aspiration, malnutrition and dehydration. Dysphagia poses a major problem to the taking of medications that are critical in the successful management of Parkinson's.

Swallowing difficulties in Parkinson's usually relate to disease severity and may affect all phases of the swallow process.

Signs of dysphagia include:

- drooling
- weight loss

In severe dysarthria, individuals may benefit from communication aids such as:

- voice amplifiers – for use in conversation or on the phone
- pacing boards – a board divided into blocks that the person points to while speaking to help them break down speech into manageable units
- alphabet word chart
- pen and paper
- portable keyboards with speech output

Writing

People with Parkinson's experience small, spidery, illegible writing called micrographia. They start off normally but progress across the page to micrographia and writing becomes difficult to read beyond a sentence, which means communication is difficult. If speech is a problem as well, other means, such as a Lightwriter, should be considered. Writing with block capitals does help, as does making a conscious effort to lift the hand from the page, or using a thick/padded pen or felt tip pen. Sometimes tremor interferes, making the writing look 'shaky'. Stopping and trying to relax beforehand can help, though this is time-consuming.

Referral to the OT is helpful as they can further advise on all aspects of handwriting.

- fear of swallowing
- a 'gurgly' voice
- coughing before, during or after swallowing
- disturbed intake of medications
- reduced social contact
- history of chest infections
- bronchopneumonia

Treatment of swallowing problems

Speech and language therapy

Assessment of the swallow should be carried out by a SLT. Procedures such as videofluoroscopy (modified barium swallow) or fiberoptic endoscopic evaluation of swallowing safety (FEES) may be used to look at the

swallow in more detail. Explanation of the normal swallowing mechanism and the effect of Parkinson's on it are valuable in helping the person deal with problems. Management of swallowing problems may involve the use of oro-facial exercises, learning specific swallow manoeuvres, modifying food thickness and co-ordinating meal times with 'on' times.

Drizzling and difficulty swallowing saliva is reported by up to 78% of people with Parkinson's (Marks et al in: Playfer & Hindle, 2001). The nurse can make the person aware that this occurs as a result of failing to swallow frequently enough or autonomic dysfunction, suggest simple measures to help alleviate this (eg prompting to swallow) and ensure a referral to a SLT has been made. The cause of the problem is not excessive saliva production but pooling of saliva due to a combination of an impaired swallow mechanism, head-down position and poor oral muscular control. The SLT can advise on head control, lip closure and awareness. Swallowing prompts, such as a bleeper badge, may help.

How can a nurse help?

A nurse is often one of the professionals who has regular, close contact with the person with Parkinson's and their family or carer. The nurse will have the ability and opportunity to carry out a holistic assessment and evaluation regularly, particularly when there are changes in their condition. They are in a pivotal

Dietitian

The involvement of the dietitian is important, should the person be identified as nutritionally at risk by anyone involved with the patient. After a detailed assessment, the dietitian will advise strategies such as eating little and often, taking snacks between meals and the addition of nutritional supplements to help maintain adequate levels of hydration and nutrition. There may be times when the person cannot swallow safely or meet their nutritional requirements. In this circumstance, alternative feeding (eg nasogastric or percutaneous endoscopic gastrostomy tube – PEG) may need to be considered. It is important that this is a team decision that will provide actual benefit to the patient. The wishes of the person with Parkinson's and their family and carers should be taken into account.

position to make appropriate and timely referral to the SLT, where problems with speech, swallowing or communication are highlighted, and the dietitian, where nutritional intake is not adequate, and offer practical advice where appropriate.

Conclusion

Speech, swallowing and communication problems are very common in Parkinson's. The treatment involves the development of strategies that will maintain

function, as the disease progresses, and the introduction of aids as necessary.

Key points

- Communication and swallowing problems in Parkinson's occur as a result of the disease process and can lead to the person with Parkinson's being embarrassed, upset and socially isolated.
- Treatment is multidisciplinary and patient-focused.

Introduction

Complementary therapies are non-medical treatments that may be used in addition to or alongside conventional treatments and drugs. Sometimes they are referred to as alternative therapies. Complementary therapies do not offer a cure for Parkinson's but may help to ease symptoms and make coping with Parkinson's easier.

Patients with Parkinson's often turn to complementary therapy and non-prescribed medication with the hope of improving their quality of life.

Mental and physical benefits include postural control, fitness, relaxation, social interaction and personal development. Those used for relaxation have been found to be particularly helpful, as it is known that stress can exacerbate some of the symptoms of Parkinson's.

The Department of Health acknowledges that there are now numerous complementary therapies available in the UK and that they could feature in the range of services that local NHS organisations provide.

Points to consider

It is important that patients considering complementary therapies inform their healthcare team and do not discontinue use of any prescribed medicines – they should be used in addition to, not instead of, conventional medicine.

The nurse has an important role in encouraging the person with Parkinson's to take responsibility for their health and wellbeing, and should provide support

and advice when patients are considering using complementary therapies.

The PDS booklet *Complementary Therapies and Parkinson's Disease* is a valuable resource that explains what complementary therapies are, how they are regulated, how to find a reputable therapist and other points to consider. It also has an extensive index of complementary therapies, from acupuncture to yoga.

Conclusion

As the use of complementary therapies is common among people with Parkinson's, further studies using a rigorous scientific method are needed to determine the safety and efficacy of alternative therapies, and to improve

the knowledge of patients and healthcare professionals of their potential benefits. The PDS has supported research into some complementary therapies, such as reflexology, acupuncture and conductive education.

Key points

- Complementary therapies do not offer a cure for Parkinson's but may help to ease symptoms and make coping with Parkinson's easier.
- Further studies using a rigorous scientific method are needed to determine the safety and efficacy of alternative therapies in Parkinson's.
- The nurse has an important role in providing support and advice when patients are considering using complementary therapies.

Introduction

The initial treatment of Parkinson's, Tarsey (2006) suggests, begins with diagnosis, patient education and then discussion of when and which drug treatments to initiate. Drug therapy may not be used in the early stages of the condition and the decision to start treatment and which option to use should be considered together with the doctor, the person with Parkinson's and their family. The nurse has a valuable role at this time in providing clear, accessible information and support to the person and their family. Sometimes people need time to consider the options. Providing information, such as the PDS booklet *The Drug Treatment of Parkinson's Disease*, can help the person with Parkinson's make an informed decision.

Drugs will not stop the progression of the disease but will usually decrease the symptoms. People with Parkinson's usually take medication for the rest of their lives; stopping medication at any time will mean a return of the symptoms. The choice of drug treatment is specific to that individual and will take into account clinical and lifestyle characteristics and patient preference (after being informed of the short- and long-term benefits and drawbacks of the suggested drug). Once started, a drug regimen will not always stay the same. The patient's individual, specifically timed drug regimen is as vital as the dose. As the condition progresses, increasing doses and different combinations of drugs may be tried.

What kinds of drug treatments are available?

The most effective drug in the treatment of Parkinson's, and one of the oldest, is levodopa (L-dopa). Despite the increasing number of anti-Parkinson's agents developed over the last 30 years, it remains the most effective anti-Parkinson's treatment.

However, it is known that long-term use of L-dopa is associated with motor complications, including dyskinesias and motor fluctuations. These motor complications affect as many as 30–50% of patients after two years of L-dopa therapy (Poewe in: Olanow 2004). This has led to the development of treatment strategies that provide continuous dopaminergic receptor stimulation (CDS); including dopamine agonists, catechol-o-methyltransferase (COMT) inhibitors and monoamine oxidase (MAO) inhibitors.

Dopamine agonists act directly on post-synaptic dopamine receptors. They are less effective than L-dopa. One of them – apomorphine – can be administered as a subcutaneous infusion. COMT and MAO inhibitors prevent the metabolism of dopamine and, hence, extend its availability.

Other treatments for Parkinson's include amantadine (an antiviral agent that has anti-Parkinson's potential and helps to reduce drug-induced dyskinesia, although its exact mechanism is not clear) and anticholinergic drugs (the oldest anti-Parkinson's class of drugs, used to reduce tremor, but not often prescribed today).

To date, all the drugs used to treat Parkinson's are symptomatic and there is no treatment proven to cure Parkinson's or delay its progression. Around the world, there is active research into identifying an agent that will be neuroprotective and slow the progression of neuronal loss that occurs in Parkinson's.

Drugs currently used in Parkinson's

Levodopa (L-dopa)

L-dopa has been the standard symptomatic therapy for Parkinson's for more than 30 years. L-dopa is the precursor of dopamine, the neurotransmitter deficient in Parkinson's. L-dopa is metabolised into dopamine after oral administration by the enzyme dopa decarboxylase (DDC). Dopamine, which cannot cross the blood-brain barrier, accumulates in the periphery, stimulating the area postrema ('vomiting centre'), causing nausea and vomiting.

To prevent the peripheral conversion of L-dopa to dopamine, it is combined with a peripheral dopa decarboxylase inhibitor (DDCI) – in the case of Madopar; benserazide and Sinemet; carbidopa. This not only helps reduce dopamine-related side effects but

increases the amount of L-dopa that crosses the blood-brain barrier.

Intravenous and enteral infusions of various L-dopa solutions have been under investigation for over 30 years. The most recent development is duodenal infusion via a percutaneous endoscopic gastrostomy tube (PEG).

In general, it is better to start with low doses of L-dopa and increase the dose slowly to minimise side effects such as nausea, vomiting and hypotension. The lowest dose of L-dopa that gives a satisfactory clinical response should be used to reduce the development of motor complications.

Current formulations of L-dopa

Generic name	Brand name
Co-beneldopa	Madopar (oral)
Co-careldopa	Sinemet (oral)
Co-careldopa	Duodopa (intestinal gel)

There are a number of formulations of Madopar and Sinemet containing different amounts of the drugs:

Madopar	Levodopa (mg)	Benserazide (mg)
Madopar 62.5 capsule	50	12.5
Madopar 125 capsule	100	25
Madopar 250 capsule	200	50
Madopar 62.5 dispersible scored tablet	50	12.5
Madopar 125 dispersible scored tablet	100	25
Madopar CR (125) capsule	100	25

Sinemet	L-dopa (mg)	Carbidopa (mg)
Sinemet 62.5 scored tablet	50	12.5
Sinemet 110 scored tablet	100	10
Sinemet 275 scored tablet	250	25
Sinemet plus (125) scored tablet	100	25
Half Sinemet CR (125) scored tablet	100	25
Sinemet CR (250) scored tablet	200	50

Controlled release (CR) preparations are released slowly, over six to eight hours. They should not be broken in half, crushed or chewed. They are useful for night-time control, on retiring to bed, but are not as predictable in their release during the daytime. Patients prescribed half Sinemet CR should check they are not given Sinemet CR by mistake and should not be asked to break the tablet.

Dispersible Madopar (but not the capsules) can be dissolved in water. The idea is that, as a soluble, form it will be absorbed quickly (20 minutes on an empty stomach) and can be used as a 'kick start' or 'rescue'

when a quick response is needed. It can also be used when swallowing is difficult, but it does not last as long as standard tablets or capsules. Once dispersed, as with all dispersible preparations, there will be a chalky/gritty residue left in the glass. This does not contain any drug and is only the agent used to release the drug.

There is no dispersible form of Sinemet but the tablet (except CR) can be crushed and mixed with liquid or yoghurt to make swallowing easier or to get quicker absorption and response, as above.

Duodopa	L-dopa (mg/ml)	Carbidopa (mg/ml)
Intestinal gel	20	5

Duodenal infusion of L-dopa is a recently licensed therapy in the UK, though has been used throughout the rest of Europe for more than ten years.

The indications for use of duodenal L-dopa are for advanced Parkinson's patients with severe motor fluctuations when available combinations of current Parkinson's medications are unsatisfactory. The person must be responsive to L-dopa and be able to manage the portable pump and intestinal tube(s). A positive

clinical response to nasogastric infusion is required, before insertion of a PEG.

Advantages of L-dopa

L-dopa is the most effective drug in the treatment of Parkinson's. Its efficacy can be enhanced by the use of co-administration of a catechol-O-methyl transferase (COMT) inhibitor, which reduces methylation of L-dopa in the gut, increasing its absorption and its half-life.

Disadvantages of L-dopa

L-dopa is effective throughout the course of Parkinson's but, as an effect of disease progression and loss of the dopaminergic cells, its effects are changed. Long-term treatment with L-dopa is associated with motor complications such as dyskinesias (drug-induced, involuntary movements, including chorea and dystonia) and motor fluctuations (end of dose, unpredictable 'offs', freezing episodes). Motor complications develop faster in young-onset Parkinson's. Altering the delivery of L-dopa, the use of dopamine agonists, amantadine and, in some cases,

functional surgery can help to improve drug-induced dyskinesias. Patients can also experience fluctuations in non-motor symptoms.

There is evidence of an increased incidence of malignant melanoma in those treated with L-dopa. It is thought that malignant melanoma cells possess a unique biochemical pathway for converting L-dopa to melamine, which could precipitate development of a preclinical melanoma. However, the observed effect is weak – around one excess case per 3,500 patients with Parkinson's per year.

Dopamine agonists

Dopamine agonists (DA) directly stimulate post-synaptic dopaminergic receptors in the striatum. They are effective when used alone or as adjunct treatment, but eventually patients will need supplementation with

L-dopa. Treatment with DA is started at low doses and titrated over several weeks or months to achieve therapeutic benefit.

Oral and transdermal preparations

Generic name	Brand name
Bromocriptine	Parlodel (oral)
Cabergoline	Cabaser (oral)
Pergolide	Celance (oral)
Pramipexole	Mirapexin (oral)
Ropinirole	Requip (oral)
Rotigotine	Neupro (transdermal patch)

Ergot derived

Non-ergot derived

Advantages

DAs have a longer duration of action than L-dopa and there is evidence that DAs produce fewer motor complications than L-dopa if used early on in the disease process. Some DAs can be used as monotherapy, as well as adjunct therapy.

Disadvantages

On starting a DA, nausea and vomiting can occur but can be alleviated by the use of domperidone for the titration period. There have been reports of excessive daytime sleepiness with DAs and patients should be warned of this.

DAs are associated with dose-dependent neuropsychiatric side effects, especially hallucinations and psychosis, which are more common in elderly people. Ergot derivatives (ergolines pergolide and cabergoline) have also been associated with the rare complications of pleura, pericardial and retroperitoneal

fibrosing serositis. The NICE Guideline for Parkinson's disease (2006) recommends that if an ergot-derived dopamine agonist is used, the patient should have a minimum of renal function tests, erythrocyte sedimentation rate (ESR) and chest radiograph performed, before starting treatment and annually thereafter. In view of this, a non-ergot-derived agonist should be preferred, in most cases.

A potential class effect of DAs is impulse control disorder. This affects a very small percentage of people treated with DAs. Symptoms can include an increase in risk taking, increased libido, hypersexuality and pathological gambling. The nurse has an important role in explaining to the patient that changes in behaviour can occur. Changes in behaviour should be closely monitored and changes in medication made if necessary as the effect is usually reversible on reduction or discontinuation of the drug.

Subcutaneous DA preparations

Generic name	Brand name
Apomorphine	APO-go

Apomorphine is a potent D1 and D2 dopamine agonist, given subcutaneously either as intermittent injection or, more usually, as a daytime infusion.

Advantages

Rapid, reliable response. Effective in management of severe motor complications.

Disadvantages

Increased risk of neuropsychiatric complications – hallucinations, euphoria, increased libido, confusion, personality changes, agitation and psychosis. There is formation of skin nodules in some patients and orthostatic hypotension, haemolytic anaemia and eosinophilia can potentially occur. Its initiation should be restricted to expert units with facilities for appropriate monitoring.

MAO-B inhibitors

Generic name	Brand name
Selegiline	Eldepryl (oral) Zelapar/Zydis (buccal)
Rasagiline	Azilect (oral)

Selegiline and rasagiline are monoamine oxidase type B inhibitors (MAO-B inhibitors). They slow the metabolism of dopamine, thereby increasing its level in the striatum.

Advantages

Few side effects. MAO-B inhibitors may be used to reduce motor fluctuations in people with later Parkinson's.

Disadvantages

Selegiline acts as a stimulant as it is metabolised to amphetamine-like metabolites, so should be avoided

later in the day and withdrawn very slowly to avoid withdrawal symptoms.

Rasagiline is not metabolised to amphetamine-like metabolites.

There is potential for interaction with SSRIs in both selegiline and rasagiline, with the risk of central nervous system side effects.

COMT inhibitors (drugs that block the metabolism of dopamine)

Generic name	Brand name
Entacapone	Comtess (oral)
Tolcapone	Tasmar (oral)
L-dopa/Carbidopa/Entacapone	Stalevo (oral)

Catechol-O-methyl transferase (COMT) inhibitors work by reducing the methylation of L-dopa. This increases L-dopa half-life, resulting in more stable plasma L-dopa concentrations. They are ineffective when given alone.

Two COMT inhibitors are available: entacapone and tolcapone. Tolcapone was the first COMT inhibitor to enter clinical practice in England and Wales but its European product licence was withdrawn in November 1998 after three cases of fatal hepatic toxicity. However, after further clinical experience and research, it has recently been re-introduced in Europe. It is currently licensed for use in patients for whom entacapone has failed and requires intensive monitoring of liver function. It is available in a 100mg tablet.

Stalevo, introduced in November 2003, is a triple combination of L-dopa, carbidopa and entacapone in a single tablet. It is available as 50, 100 and 150mg L-dopa strengths.

Advantages

When used with L-dopa, this leads to a 30–50% increase in L-dopa half-life, resulting in more 'on' time.

Disadvantages

Side effects are related to those of increased L-dopa levels: dyskinesia, nausea and vomiting, visual hallucinations and orthostatic hypotension. They can be managed by lowering the dose of L-dopa before or after commencement of COMT. Other reported side effects include abdominal pain, loose stool or severe diarrhoea that can be managed by reducing or discontinuing COMT.

Antimuscarinic (also called anticholinergics) – drugs that block the action of acetylcholine

Generic name	Brand name
Trihexyphenidyl (previously Benzhexol)	Broflex, Artane, Agitane (oral)
Orphenadrine	Disipal (oral)
Benztropine	Cogentin (oral)
Procyclidine	Kemadrin, Arpicolin (oral)

Anticholinergics have been used to treat Parkinson's for over 100 years. They were introduced in the late 19th century after Charcot's work with hyoscine (scopolamine). Anticholinergics are less commonly prescribed these days. Their effect on bradykinesia and rigidity is of little value but they can be useful in the treatment of severe tremor, but they are not a drug of first choice, due to limited efficacy and the tendency to cause neuropsychiatric side effects.

Advantages

Useful for treating young people with early Parkinson's and severe tremor.

Disadvantages

Not drugs of first choice due to limited efficacy and the propensity to cause neuropsychiatric side effects. Can cause dry mouth, blurred vision and constipation.

Miscellaneous – amantadine

Generic name	Brand name
Amantadine	Symmetrel (oral)

Amantadine is an antiviral agent found by chance to be effective in symptomatic treatment of Parkinson's. How the drug works is unclear but there are several proposed mechanisms of action:

- It enhances the release of dopamine and inhibits its re-uptake.
- It has antimuscarinic (anticholinergic) properties.
- It has antiglutamatergic properties.

Advantages

It has antidyskinetic effects and is available as a syrup, as well as a tablet. It can have a stimulating effect so can help with tiredness (but should be avoided late in the day as it will then cause insomnia).

Disadvantages

Its effect is mild and short-lived. It can cause confusion and hallucinations, especially in the older patient. It can cause ankle oedema and sometimes brings a mottled colour to the legs (livedo reticularis) – this is unsightly but harmless.

Withdrawal of amantadine can be difficult and should be done gradually.

Nursing issues of drug management in Parkinson's

Nurses are involved in drug administration either in hospital or in the community. MacMahon & Thomas (1998) point out that the timing of doses and compliance with a complex regimen of drugs and diet may be critical, and the involvement of a skilled nurse will ease the burden on the person with Parkinson's. Nurses are also key in educating people with Parkinson's, their carers and professionals involved in their care about the dangers of sudden cessation of drugs.

Changes to prescribing regulations mean that Parkinson's Disease Nurse Specialists (PDNS) can obtain a qualification allowing them to be an independent prescriber.

Timing of medication

As responses to drugs are variable, treatment regimens differ from person to person. To get the right balance between benefit and any side effects, the individual will need to understand and be involved in which drugs are being used and why drug timing is so important.

The timing of the drugs is important in order to achieve continuous dopaminergic stimulation (CDS) for the optimal control of symptoms and to reduce the incidence of motor complications. If a person with Parkinson's is unable to take their prescribed

Parkinson's medication at the right time for them, there is a disruption to their dopamine levels. This may lead to a worsening of their symptoms, which can take some time to stabilise again.

Errors and delays can happen when a person is admitted to a hospital, nursing home or going on holiday. When admission to a home or ward occurs, it is important for staff to be aware of why the timing of these drugs is so important and to make sure medication times are accurately documented. When going away, the person with Parkinson's should ensure they have enough medication supplies and have worked out a transient timing regime with their doctor or specialist nurse to deal with different time zones or long-haul flights.

Allowing patients to control the exact timing of their medication can be empowering. It can, however, be problematic when it becomes associated with an uncommon disorder called dopamine dysregulation syndrome (previously called hedonistic homeostatic dysregulation).

Patients may exhibit an increase in libido and hypersexuality or pathological gambling associated with dopamine agonist treatment – this is referred to

as impulse control disorder. Its management is complicated and the nurse should be aware of the syndrome in order to provide appropriate management and support.

Education and compliance

Nurses have an important role in not only sharing their knowledge with the person with Parkinson's and their carer but by encouraging patients to take responsibility for their health and wellbeing.

A diagnosis of Parkinson's can be a frightening thing. Education is essential in order to give the person with Parkinson's a sense of control and understanding of the disease. In the earlier stages of the diagnosis, too much knowledge can be alarming. Selective information is usually more helpful and the PDS has many publications that can help the person and their family understand more about Parkinson's and the drugs used to treat symptoms.

Patients must be taught to recognise the symptoms of Parkinson's and the side effects of drug treatments in order to become 'expert' in managing their condition, and the nurse is ideally placed to help with this. Compliance with drug regimens will suffer if the patient does not understand drug side effects or the different symptoms of the condition and how they respond to their drugs.

Patients can take part in their local Expert Patients Programme (EPP), which can help them to manage their symptoms. The EPP was set up in 2002 as one of a range of new policies and initiatives to modernise the NHS and to emphasise the importance of the patient in the design and delivery of services. The EPP is a national Community Interest Company (CIC) course, designed to help people manage life with a long-term condition. It is delivered by tutors who are themselves living with a long-term condition and can help people to, among many things, manage their medication and improve their quality of life.

Dietary considerations

When dopaminergic drugs are first started, the manufacturer and pharmacy information sheets advise taking the drugs after food, in order to help alleviate the common early side effects of nausea and vomiting.

These symptoms are attributed to dopamine accumulating in the periphery and stimulating the area postrema ('vomiting centre').

Most people quickly develop a tolerance to drug-induced nausea and vomiting and can eventually take the medication without food. Some people need to take an anti-emetic, such as Domperidone, until tolerance has developed. Domperidone is the only oral anti-emetic recommended for people with Parkinson's, as it does not easily cross the blood-brain barrier and block dopaminergic receptors, causing extrapyramidal symptoms (ie symptoms of Parkinson's).

Many patients find that their dose of L-dopa is less effective or may fail altogether after a meal. There are several reasons for this. One is the competition between protein and L-dopa for absorption from the gastrointestinal tract into the bloodstream. In such cases, it is recommended that the L-dopa be taken not less than 30 minutes before or 60 minutes after meals. Sometimes redistribution of the protein intake is recommended. Dopamine agonists are not affected in this way. Another cause is the slowing of gastric emptying, which delays drug absorption and can cause unpredictable drug absorption. The most common cause of this is large, high-fat meals. Again, taking the medication not less than 30 minutes before or 60 minutes after meals may help.

Neuroleptic malignant syndrome

Neuroleptic malignant syndrome is a rare, life-threatening reaction in people exposed to neuroleptic medication. It can also occur in Parkinson's patients for the same reason or after sudden withdrawal of anti-Parkinson's drugs.

It is characterised by hyperthermia, muscle rigidity, altered level of consciousness, autonomic instability and elevated serum creatine kinase (CK) level. Onset of symptoms is about one to nine days. The major complications are respiratory, renal and cardiovascular failure; it carries a significant mortality.

The nurse has an important role in ensuring that patients and professionals understand that anti-Parkinson's medication should not be withdrawn abruptly or allowed to fail suddenly due to poor absorption (eg gastroenteritis, abdominal surgery) in order to avoid the potential for neuroleptic malignant syndrome. Similarly, the practice of withdrawing patients from their anti-Parkinson's drugs, so called 'drug holidays', to reduce motor complications has been abandoned because of the risk of neuroleptic malignant syndrome.

Nurse prescribing

The role of a PDNS is diverse, encompassing a wealth of knowledge and skills, including the monitoring and management of medication. Changes to prescribing regulations have meant that some PDNSs are now qualified to prescribe independently.

The ability to prescribe will further improve the care of people with Parkinson's by making it easier for them to get the medication they need when they need it.

Conclusion

At present there is no pharmacological agent that slows down the progression of Parkinson's. The ultimate aim is to develop a cure for the condition, ie to allow a person with Parkinson's to live a life free from symptoms.

Nurses have an important role in providing information on drug treatments, helping the patient to make an informed decision on how to manage their symptoms. Nurses are key in helping the patient manage complex drug changes or, in the later stages of the disease, to withdraw treatment as toxicity may become a problem.

Key points

- There is a wide range of drugs available to treat the symptoms of Parkinson's, which are tailored to the individual.
- Sudden discontinuation of treatment should be avoided as it can result in neuroleptic malignant syndrome, which can be fatal.
- Timing of drug regimens is important and should be adhered to in hospital and nursing/residential homes or when on holiday.
- Nurse prescribing enhances the service given to a person with Parkinson's.
- Nurses have a key role in helping the patient manage complex drug regimens.

Introduction

The main disabling feature of Parkinson's is akinesia (absence of or reduced functionality of movements), which results in difficulty in performing day-to-day activities. Akinesia comprises most or all of the following deficits:

- Slowness of movement (bradykinesia)
- Poverty of movement (hypokinesia)
- Difficulty initiating movement
- Progressive fatiguing and diminishing amplitude of repetitive, alternating movements
- Difficulty in performing two simultaneous or sequential motor acts

With disease progression, a flexed posture develops, gait is affected and postural instability occurs, often resulting in falls.

Along with regular reviews by the neurologist, PDNS or link nurse, consideration from the time of diagnosis should be given to referring people with Parkinson's to a physiotherapist and occupational therapist (OT). A physiotherapist has a key role in maximising functional ability and minimising secondary complications, using movement rehabilitation. An OT has a role in helping individuals manage the practical aspects of everyday life.

Mobility problems specific to Parkinson's

Gait

Initial gait impairment is seen as a reduction in stride length and gait speed. A reduction in knee flexion results in the common picture of dragging the foot. In more advanced cases, the person is severely flexed forward and will 'chase' their centre of gravity in order to stop falling (festinant gait).

'Freezing' can occur with any movement but is most troublesome when it involves gait. It is particularly evident on gait initiation and turning or moving in narrow spaces. Freezing can occur in both 'on' and 'off' states. In the 'off' state, it is usually responsive to manipulation of Parkinson's medication. Management of freezing when 'on' is more difficult and not always responsive to drug manipulation.

Freezing can also be exacerbated by anxiety. When freezing occurs, it can often be helped by the use of various techniques that involve the use of cueing strategies. These can be external (visual, auditory, proprioceptive) or internal (cognitive).

Visual cues – Stepping over a visual cue on the floor. For example, white strips of tape can aid step length and initiation problems in confined spaces. A coloured marker at eye level can provide a visual prompt to maintain large steps in a corridor. Sometimes, if a

cluttered room is the problem, the OT can give advice on how to reduce hazards in the environment.

Auditory cues – Metronomes can be worn to aid gait initiation. Counting out a rhythm or singing and walking in time with this, or a vocal instruction to step, can also be beneficial.

Proprioceptive cues – Taking a step back before starting to walk, rocking gently from side to side or marching on the spot before stepping.

Cognitive cues – Breaking down a movement sequence (such as turning over in bed) into component parts. Each component part acts as a cue that can be used to initiate and maintain movement.

Using these strategies when 'on' will make the task more successful.

How do cueing strategies work?

Cueing strategies work by bypassing the dysfunctional basal ganglia. It is thought that, normally, the basal ganglia, in conjunction with the supplementary motor area, triggers the action of sequential motor movements. When the contribution of the basal ganglia is reduced (as in Parkinson's), this process is interrupted and smooth automatic movement is impaired. The use of external (eg visual) and internal

(cognitive) cues enhances cortical mechanisms to activate and sustain movement (possibly via the pre-frontal regions of the brain) and compensates for reduced basal ganglia input.

Balance

When standing, the person with Parkinson's can have a tendency to topple forwards. Posturography studies of Parkinson's patients (on a multidirectional mobile platform who are deliberately thrown off balance) show an inability to produce a quick and strong enough postural response to stop themselves from falling.

Why this occurs is not clear, but it may be connected to reducing muscle strength, slower psychomotor speed and reduced planter sensation, as a result of loss of pressure receptors in the feet. There is also a growing recognition that a fear of falls can have a negative effect on postural control.

Balance control may be improved by cognitive strategies, such as concentrating attention on visual information and other cues, to bypass the dysfunctional mechanism. The general idea is that the malfunctioning automatic programme is substituted with a conscious motor programme.

Posture

In Parkinson's, when standing, there is flexion at all joints, giving the person a stooped or simian posture. The most effective way to preserve musculoskeletal flexibility is regular exercise. Individuals should be encouraged to continue their normal activities, rather than shy away from them, as well as taking part in formalised exercise programmes. Such exercise classes aim to achieve better posture by minimising musculoskeletal limitations and postural deformities in order to preserve independent function. Additional benefits include improved cardio respiratory fitness, general feelings of wellbeing and a reduction in falls.

The PDS booklet and video *Keeping Moving* is a very helpful resource. Many of the Society's branches also organise regular exercise groups. Information regarding these can be found by calling the PDS Helpline.

Referral to a physiotherapist is more beneficial to the individual early on in the disease process. A physiotherapist can help to prevent future physical complications and maximise the person's functional capacity and role in society. Areas that can be addressed include gait re-education and improvement of balance, flexibility and movement initiation.

Other key issues in the management of mobility in Parkinson's

Falls

Falls are a major source of hospitalisation and institutionalisation in the UK. In the UK, two-thirds of people with Parkinson's fall at least once each year, and many of them are at risk of falling again. The most devastating complication of falling is fracture, in particular the neck of the femur. The risk of this can be reduced by 80–100% by the correct use of hip protectors (Bloem et al, 2003).

Factors specific to Parkinson's that can cause falls include:

- longer disease duration
- an advanced stage of disease
- postural instability
- freezing
- small steps (festination)
- dyskinesias

- loss of arm swing
- fear of falling again, once a fall has occurred

The NICE Guideline on falls (2004) recommends that older people be asked routinely whether they have fallen in the past year, about the frequency, context and characteristics of the fall(s) and that this should be part of the nurse's written assessment. Individuals at risk of falling and their carers should be offered information orally and in writing about what measures they can take to prevent further falls. The PDS produces an information sheet, *Falls and Parkinson's*, which provides further details.

When the individual reports recurrent falls within the year, the NICE guidance is that they should be offered a multifactorial falls risk assessment. The nurse is in a good position to make such an assessment and refer to the falls service, physiotherapist or OT, all of whom

will help in the assessment of activities of daily living. They can advise on ways to make the home safe and manageable and how to improve posture and balance and thus mobility, helping towards preventing or reducing the risk of falls.

Orthostatic (postural) hypotension

Orthostatic hypotension was found in a recent UK community study by Allcock et al (2003) to occur in 48% of people with Parkinson's, and was often the cause of falling.

Orthostatic hypotension is a physical sign and not a disease. The American Autonomic Society and The American Academy of Neurology reached a consensus in 1996 that to measure properly for orthostatic hypotension, the person should be supine for at least ten minutes before taking the reading. The person should then stand up and the reading taken within three minutes of standing. If there is a fall in blood pressure greater than or equal to 20mmHg systolic or to less than 90mmHg systolic on standing, the person has orthostatic hypotension. Patients who are experiencing orthostatic hypotension may complain of dizziness, visual disturbances, falling or fainting. It can be due to central or peripheral autonomic dysfunction or as a result of Parkinson's medications, antihypertensives or co-morbidities such as anaemia.

It is important to raise awareness with the individual about things that will lower the blood pressure. An ideal time is during nurse consultations, either over the phone or in clinic. This could include:

- rapid postural changes (especially in the mornings when getting out of bed when the supine blood pressure is at its lowest)
- the effects of food and alcohol (which can cause splanchnic vasodilation and postprandial hypotension)
- hot weather/baths (which can cause cutaneous vasodilation as a result of impaired thermoregulation)
- physical exertion (which can cause skeletal muscle vasodilation not opposed by sympathetic vasoconstriction)
- avoiding straining at micturition or defecation, playing wind instruments or singing (which raises intrathoracic pressure, ie inducing a Valsalva manoeuvre, causing postural hypotension)

Nurses can suggest the following to help maintain blood pressure:

- a 30–40 degree elevation of the head of the bed at night (as this may reduce salt and water loss by stimulation of the renin-angiotensin-aldosterone system)
- increasing dietary salt and fluid intake, eating small meals and avoiding alcohol
- the use of compression stockings (to at least thigh height)

Giving the person literature such as the PDS information sheet *Low blood pressure and Parkinson's* is useful for further information and reminders.

If these measures do not help, pharmacological treatment should be considered. This can include the reduction or discontinuation of antihypertensives or diuretics, reviewing anti-Parkinson's treatments and considering the use of other drugs to raise the blood pressure, such as fludrocortisone. Persisting or troublesome orthostatic hypotension should be referred on to a unit with expertise in falls and syncope.

Feet

Feet must be kept in good condition if the patient is to retain mobility. Foot problems, such as calluses, corns or ingrowing toenails, can affect balance. An early referral to a podiatrist, where necessary, is advisable and can be initiated by the nurse.

Vision

Many people with Parkinson's experience poor vision. It is important to ensure they have had a recent eyesight test to rule out easily treated problems. Typically, their vision is normal but they often experience blurred or double vision. It is now known that vision is affected in Parkinson's and is associated with abnormalities in ocular motor control and the ability to discriminate contrasting colours. Problems with vision can be a cause of poor mobility and falls, and should be investigated and, where possible, treated. Practical interventions that the nurse can suggest include good lighting in all areas, assuring good colour contrast between floor or wall and transition areas, avoiding clutter and low-lying, low colour-contrast furniture and avoiding confusing patterns on floor coverings.

Pain/dysesthesias

Pain can occur in up to 50% of people with Parkinson's (Drake et al, 2005). Treating pain in Parkinson's begins by adequately treating the symptoms of Parkinson's itself. This is because the pain may be related to motor fluctuations, early morning dystonia or akathisia (an inner feeling of restlessness leading to an inability to keep still) – problems that are often responsive to appropriate dopaminergic treatment. Musculoskeletal pain, which can be secondary to rigidity, and hypokinesia may be responsive to simple analgesia.

The nurse can encourage the person to keep a diary of when the pain occurs and the type of pain (neuropathic, burning or paraesthetic), which helps to clarify what type of pain is being treated. Referral to a pain clinic for analgesic advice should be considered by the nursing and medical team and, although the use of deep brain stimulation for pain in Parkinson's has been explored, further investigation is required before its use becomes routine.

Conclusion

The aim is to maximise functional ability and minimise secondary complications to keep the person with Parkinson's safe, independent and socially integrated for as long as possible. Nurses often have regular, close contact with the person with Parkinson's and their family

or carer. The opportunity to regularly carry out holistic assessment and evaluation, particularly when there are changes in their condition, results in appropriate and timely referrals to the physiotherapist, OT or other specialist teams.

Key points

- The management of mobility problems in Parkinson's requires a multidisciplinary approach.
- Consideration from the time of diagnosis should be given to referring people with Parkinson's to a physiotherapist, occupational therapist or multifactorial falls service.
- The mobility problems specific to Parkinson's affect gait, balance and posture.
- Other issues in the management of mobility in Parkinson's include falls, postural hypotension, foot and visual problems and pain management.

Introduction

Parkinson's is now seen not only as a motor disorder but also as a movement disorder with non-motor symptoms (NMS) that can affect cognition, behaviour and mood.

The neuropsychiatric problems of Parkinson's range from anxiety to frank dementia and psychosis and can be more disabling than problems with motor function. As the nurse may be the first port of call for distressed relatives, there is a need to be aware of the problems that can occur, to offer appropriate information, support and referral to the multidisciplinary team.

Cognitive impairment and dementia, depression, anxiety, apathy, sleep disturbance, behavioural disturbances and visual hallucinations are the most common mental dysfunction in Parkinson's. Cross-sectional studies have shown that more than 60% of Parkinson's patients will have at least one psychiatric symptom and, in addition, 50% will have cognitive impairment, 30% dementia and 38% visual hallucinations (Aarsland & Ehrt in Wolters 2006).

Mental dysfunction in Parkinson's

Cognitive impairment

Cognitive impairment refers to changes in intellectual function. There is increasing recognition that cognitive impairment in Parkinson's presents early in the disease process. The range of cognitive impairment seen in Parkinson's relates to frontal lobe function with deficits in planning, sequencing and working memory.

The effect of such difficulties can have a profound effect on daily life. The management and treatment of cognitive dysfunction should be multidisciplinary. Education of the patient and family is crucial. Patients are often relieved that there is a reason for their problem and they are not 'losing their mind', and family can understand behaviours and develop plans to accommodate them. Involving the OT is important, as they can help with cognitive assessment and appropriate interventions to manage day-to-day living.

Pharmacological treatment of cognitive impairments in Parkinson's has coincided with the treatment of dementia. Although cholinesterase inhibitors have been used successfully in individual people with Parkinson's dementia, further research is recommended to identify those patients who will benefit from this treatment.

Dementia

Dementia is not a typical feature of early Parkinson's but many people with the condition will have mild cognitive impairment. A significant number of people with Parkinson's (up to 50%) will, over time, develop cognitive changes severe enough to warrant a diagnosis of dementia.

Traditionally, dementia developing more than one year after the onset of the motor features of Parkinson's is referred to as Parkinson's disease with dementia (PDD). Patients who present with dementia within one year of the onset of motor features are classified as having dementia with Lewy bodies (DLB).

PDD is progressive and characterised by a severe disturbance of the ability to plan (dysexecutive syndrome), marked cognitive slowing and intellectual function with impairment of visuospatial abilities and memory.

DLB is a primary dementing disorder characterised by cognitive fluctuations (resembling a chronic confusional state), visual hallucinations and mild parkinsonism. Neuropathologically, it is characterised by the presence of neuronal inclusions, called Lewy bodies, in various brain regions.

Differentiating DLB from PDD on clinical grounds alone is almost impossible; the most obvious difference is early onset of dementia in DLB, whereas dementia usually occurs after 8–10 years of motor symptoms

in PDD. The relationship between PDD, Parkinson's disease and DLB is unclear but many consider them to be a continuum rather than discrete entities.

Rarely, dementia may arise due to other treatable illnesses. Dementia is also a feature of disorders such as normal-pressure hydrocephalus, Whipple's disease or dementia pugilistica. Therefore, all people with dementia require careful evaluation of their medical condition, and treatment and investigations to clarify the diagnosis, with attention to potentially treatable conditions.

Depression

Depression is common in Parkinson's and can predate the motor symptoms of Parkinson's by several years. Recent community-based studies suggest that major depression occurs in up to 10% of Parkinson's patients, while up to 50% suffer some form of depression (Metman in: Wolters, 2006). The development of depression creates an added burden for people with Parkinson's and their carers and its impact on health-related quality of life is high, but optimal treatment remains uncertain.

It is unclear how much the depression in Parkinson's is due to damage to the serotonergic neurotransmission system, as well as limbic noradrenergic and dopaminergic systems, or a result of psychosocial effects of chronic disease. The NICE Guideline for Parkinson's (2006) suggests that the inconsistent relationship between mood changes and the severity of motor symptoms indicates that depression should not simply be considered a reaction to motor disability.

Assessing depression in Parkinson's is challenging as many of the symptoms of depression overlap with the motor features of Parkinson's. The main characteristic features of depression are low mood, loss of interest and enjoyment, and fatigue. There is also a disturbance of cognitive function and thought processes, which may result in poor concentration and memory, excessive worry, feelings of worthlessness, hopelessness and guilt, negative views of self and life, and thoughts of suicide. Any suicidal thoughts should prompt an urgent referral to psychiatric services for evaluation.

Routine screening for depression is justified, as it is common in Parkinson's. There are several self-reporting scales that are useful tools in monitoring and evaluating depression in Parkinson's: the Geriatric Depression Scale and Beck's Depression Inventory.

Drug and therapy treatment of depression in Parkinson's is not sufficiently evidenced and there is an urgent need for further research. There are case reports suggesting that some antidepressants may make Parkinson's motor symptoms worse and there are established, but rare, interactions between some antidepressants and dopaminergic therapy for Parkinson's, eg MAO-B inhibitors and antidepressants. Currently, selective serotonin reuptake inhibitors (SSRIs) are the most common class of drug used in clinical practice for people with Parkinson's.

Anxiety and apathy

Anxiety disorders are common in Parkinson's and can be a preclinical indicator of the disease. Anxiety can present as panic attacks, phobias or generalised anxiety, and can often be related to drug-induced motor fluctuations.

Medication is not recommended for every anxiety disorder but SSRIs and beta-blockers have been used. Psychotherapies such as cognitive behavioural therapy (CBT), where the person looks at problems from a different perspective, can be helpful.

Apathy is now known to be a particular symptom of Parkinson's, independent of depression and fatigue, and responds minimally to dopaminergic drugs, perhaps indicating involvement with other neurotransmitter pathways.

Neuropsychiatric sleep disturbance

As many as 98% of patients with Parkinson's will suffer from sleep disturbances at some time but, in spite of this, they are often underdiagnosed and undertreated (Dhawan et al, 2006). Sleep difficulties have an impact not only on the quality of life of the person with Parkinson's but also the carer, and should not be underestimated.

The causes of sleep disturbance are multifactorial but degeneration of the sleep regulation centres in the brainstem and related thalamocortical pathways are implicated. The neuropsychiatric problems of sleep disturbance include:

- depression-related insomnia
- REM behaviour disorder (RBD)
- vivid dreams or nightmares
- hallucinations
- panic attacks

Depression-related insomnia Depression, which is common in Parkinson's, affects sleep quality. It can lead to REM behaviour disorder (RBD), insomnia and nocturnal hallucinations. Active treatment with sedating and antidepressant therapy with/without psychiatric counselling support can help improve sleep quality.

REM behaviour disorder (RBD) RBD is a parasomnia characterised by loss of the normal skeletal atonia during REM sleep. This allows those affected to act out dreams, which can be vivid and usually frightening. Actions may range from mild restlessness to more severe movement, in which patients can vocalise, leap out of bed or attack their sleeping partner while acting out a dream.

Urgent treatment is warranted as RBD is potentially dangerous for the patient and their partner. Relief can be found by the use of the benzodiazepine clonazepam, although the mechanism is unknown. The symptoms of RBD occur in about a third of patients with Parkinson's and may predate the diagnosis of Parkinson's in up to 40% of patients (Chaudhuri et al, 2006).

Vivid dreams, nightmares and hallucinations

Other psychiatric sleep symptoms, such as distressing dreams or hallucinations, require that alternative diagnosis be considered (multiple system atrophy, DLB or progressive supranuclear palsy). Vivid dreaming is common in patients being treated with dopaminergic drugs and is not always a significant problem. If the dreams are distressing or getting worse, they could be a prodrome of daytime hallucinations and should be followed clinically by a review of all medication, with avoidance of any drugs that may affect sleep or alertness, or may interact with other medication.

Panic attacks Panic attacks can occur during 'off' states, with some patients feeling that they are going to die. If this is the case, treatment strategies should be aimed at decreasing 'off' time, after looking at the patients 'on/off' diary. Some forms of anxiety may also manifest themselves as panic attacks.

Behavioural disturbances

Parkinson's is associated with several types of behavioural disturbances that seem to be a result of dopaminergic treatment, rather than a specific non-motor symptom. These include:

- hypersexuality
- disinhibition

- mania and hypomania
- pathological gambling
- abuse of dopaminergic drugs
- obsessive-compulsive behaviour and punting

Optimal management includes prudent use of dopaminergic and psychiatric medications and non-pharmacological therapies. Education and support are also very important for the patient and carer, to help them understand and cope with the problem.

Hypersexuality Aberrant sexual behaviour and hypersexuality is more common in men with Parkinson's. It forms part of the impulse control disorder syndrome, which is linked to dopaminergic drug treatment in susceptible patients.

Disinhibition This refers to inappropriate social and interpersonal behaviours and can be a characteristic of another condition or an independent syndrome. The impulse behaviour can be dangerous or merely socially embarrassing.

Mania and hypomania Patients with a medical history of bipolar disorder may experience an exacerbation of these symptoms in response to dopaminergic treatment, while some patients develop these symptoms as a result. Mania is a mood disorder characterised by an elevated, expansive or irritable mood and an inflated sense of self-confidence, self-esteem or grandiosity. Other features include flight of ideas, hyperactive thoughts and talking, and a decreased need for sleep. In hypomania, the symptoms are the same but less severe. Manic and hypomanic people act impulsively and become excessively involved in pleasurable, risk-taking behaviours (eg gambling or sexual activity).

Pathological gambling The desire to gamble impulsively becomes destructive, causing severe financial and relationship problems. In Parkinson's, men are more affected than women. It forms part of the dopamine dysregulation syndrome.

Abuse of dopaminergic therapy – dopamine dysregulation syndrome Some patients develop a routine of excessive use of dopaminergic replacement therapy. It is more common in young onset Parkinson's males. It forms part of the dopamine dysregulation syndrome, which is linked to dopaminergic drug treatment in susceptible patients.

Impulse control disorder is a potential class effect of dopamine agonist therapy but can also occur with L-dopa. This affects a very small percentage of people treated with dopamine agonists. Symptoms can include an increase in risk-taking, increased libido, hypersexuality and pathological gambling. Management includes reduction of dopaminergic treatment as the effect is usually reversible on reduction or discontinuation of the drug, or switching from one dopamine agonist to another.

Obsessive-compulsive behaviour This is linked to, but not the same as, obsessive-compulsive disorder (OCD), which occurs in about 2% of the population, although some people with Parkinson's do have OCD (Marsh in: Menza & Marsh, 2006). In obsessive compulsive behaviour, the obsessions can be persistent images or impulses, the compulsive behaviour senseless and ritualistically carried out in a driven manner to combat the anxiety brought on by obsessions. An example would be an obsession with dirt, with a compulsion to continually wash hands.

Punding This refers to stereotypical behaviour in which there is repetitive performance of meaningless tasks. This can manifest itself in a variety of ways. There may be repetitive handling, examination or sorting and arranging of objects. Patients tend to find the behaviour calming and become irritable if forced to stop. In severe cases, patients will stay awake all night, neglecting food and sleep.

Psychosis and visual hallucinations

Psychotic symptoms in Parkinson's include hallucinations, delusions and their associated behavioural changes. They can happen at any stage in the disease process. Up to 50% of people with Parkinson's can develop psychotic symptoms and 30% may experience hallucinations within the first five years (NICE, 2006).

Hallucinations are defined as abnormal perceptions in any sensory modality in the absence of an external stimulus. They can occur at any time of day and the content is usually recurrent. Delusions are defined as fixed, false, idiosyncratic and unshakeable beliefs that are maintained despite incontrovertible evidence. They are usually paranoid in content, focusing on a single subject, such as spousal infidelity.

Occasionally, auditory hallucinations can occur but up to 40% of patients with Parkinson's have visual hallucinations, which are usually benign (Chaudhuri et

al, 2006). As the disease progresses, delusions, paranoid thoughts and delirium (a disordered state of mind with incoherent speech and hallucinations) become more frequent.

The appearance of psychotic symptoms requires careful evaluation. Psychotic symptoms may occur as part of delirium. Delirium can occur in advanced dementia or a co-morbid mental illness. It can be induced by toxic confusional states, and intercurrent causes, such as infections, metabolic disturbances, drug interactions, constipation, dopaminergic treatments or falls with subdural haematoma, need to be excluded.

The aetiology of psychotic symptoms in Parkinson's is complex. They may arise from the neuro-transmitter disturbances of Parkinson's itself but can also be caused by any of the drugs used to treat motor symptoms. The NICE Guideline for Parkinson's (2006) suggests that the initial treatment of psychosis should include a general medical assessment and treatment of any potential causative factor. Mild psychotic symptoms, if tolerated by the person with Parkinson's, need not be actively treated. Otherwise, consideration should be given to withdrawal of any recently added medication that may have triggered a psychotic reaction. There are drugs that are particularly prone to trigger psychosis, such as anticholinergics selegiline and amantadine. In more severe psychosis, use of atypical antipsychotics should be considered. Typical antipsychotics are not recommended as they exacerbate the motor symptoms of Parkinson's.

Psychosis is one of the leading causes of nursing home placement in Parkinson's patients. It can affect the quality of life of the person and their family and be more disabling than the motor symptoms of Parkinson's.

Psychotic symptoms are distressing and may be frightening to people with Parkinson's and their carers, who may not appreciate that they are symptoms of illness. It is essential to explain the nature of these symptoms, and the nurse in the role of educator and supporter is ideally placed to do so. The PDS has produced information relating to many of these problems that is useful for patients and their carers.

The dopamine dysregulation syndrome (previously called homeostatic hedonistic dysregulation), recognised in younger onset patients, seems to be a result of dopaminergic treatment, rather than a specific non-motor symptom.

Conclusion

Cognitive impairment and dementia, depression, anxiety, apathy, sleep disturbance, behavioural disturbances and visual hallucinations are the most common mental dysfunctions in Parkinson's.

Nurses can make a difference to people affected by the neuropsychiatric problems in Parkinson's as they can offer support, information and ensure the person is involved with the appropriate members of the MDT.

Key points

- The neuropsychiatric symptoms of Parkinson's can affect the quality of life of the person and their family and be more disabling than the motor symptoms of Parkinson's.
- More than 60% of Parkinson's patients have at least one psychiatric symptom.
- The PDS has a wealth of information available that can provide supporting information.
- Nurses can make a difference to people affected by the neuropsychiatric problems in Parkinson's.

Introduction

Sexuality is one of the most complex aspects of being human and many people experience sexual difficulties in their lives.

There are many reasons – physical, psychological and social – why people with Parkinson's might experience problems within their sexual relationships. For some, the recognition that life with a diagnosis of Parkinson's will never be the same can cause a total disruption to what individuals perceived as normal. Diminishing communication skills, fluctuating mood, a negative self-image and social isolation can cause distress, not

only for the person with Parkinson's but also for their sexual partner.

It has been recognised for some time now that neurological disease and trauma cause sexual dysfunction. In people with Parkinson's, sexual dysfunction is not uncommon: 50% of men and women may have a sexual problem (Chandler & Brown, 1998), but 50% do not, so it is important to remember that having Parkinson's does not mean that sexual dysfunction is inevitable.

What can be a problem?

In both men and women with Parkinson's, there may be a decrease in sexual interest, desire, arousal and orgasm. Not all problems can be explained by Parkinson's or drug side effects.

The management of sexual dysfunction in a person with Parkinson's must include an initial screening for other underlying causes. Things such as diabetes, excessive alcohol intake, antihypertensive drugs, depression and anxiety can also be the cause of impotence and sexual dysfunction. Listening is very important in order to help with anxieties about sex and relationships.

Female sexual dysfunction

"I can't move around a lot, so it's just a case of he does all the work and ... it can be very painful because when I am taut, my muscles go tight."

(Parkinson's disease: the effects on womanhood, Schartau et al, 2003)

Female sexual dysfunction is a common health problem. In one of the first studies devoted entirely to sexuality in women with Parkinson's by Welsh et al (1997), definite differences were found when compared with an age-matched population. These women reported greater anxiety or inhibition, vaginal tightness and involuntary urination (related to sexual activity). There was a pre-occupation with health problems that interfere with sex, and dissatisfaction with body

appearance, although this was not statistically different from the control group. Overall, the women with Parkinson's were less satisfied with their sexual relationships and with their partners. There are other reports of difficulty with arousal (genital sensitivity or decreased mucosal lubrication), orgasmic difficulty, dyspareunia or vaginismus.

Anecdotal evidence from newsletters published by the PDS indicates that women with Parkinson's have their own specific concerns about sexuality that may not be recognised or anticipated by healthcare professionals. It is important that treatment of these problems involves a sensitive discussion with the woman and screening for any other physical causes. Treatment options include psychosexual counselling, oestrogen therapy for vaginal dryness and testosterone therapy for low libido. Sildenafil (Viagra) has been successful in non-Parkinson's females, although it is not yet known if it will be of benefit to women with Parkinson's.

Male sexual dysfunction

The most commonly reported sexual problem for men with Parkinson's is erectile dysfunction. Causes include cardiovascular disease, diabetes, hypertension, hypercholesterolaemia, smoking, spinal cord injury, prostate cancer, surgery, psychiatric disorders and the use of particular drugs, such as

alcohol, antihypertensives and antidepressants. Erectile dysfunction could also be the initial manifestation of autonomic dysfunction.

It is estimated by Singer et al (1989) that the prevalence of erectile dysfunction in men with Parkinson's is greater than the general population; at 60% compared to 37.5% in an age-matched, healthy, non-parkinsonian group.

Patten (1996) states that impotence is a source of great anxiety and frustration and may be responsible for divorce in 50% of couples, where one person has a chronic neurological illness.

As in female sexual dysfunction, the treatment approach for erectile dysfunction needs to be multidisciplinary, due to its complex nature. There are several therapeutic options to enhance erectile function that enable intercourse, resulting in an improved quality of sex life. This can include the use of psychosexual counselling, external vacuum devices, surgically implanted penile prostheses or drug treatments. Drugs can be given locally (intracavernosal or urethral) or orally.

Oral medications such as sildenafil (Viagra), which increase blood flow to the penis, are well tolerated in Parkinson's. However, as the drug causes vasodilation, it can lower blood pressure substantially. This can be a danger in patients with orthostatic hypotension, as in multiple system atrophy (MSA), where the hypotension can be severe, causing collapse.

MSA can be difficult to distinguish from Parkinson's, especially in the early stages. It is important, therefore, to monitor lying and standing blood pressure before prescribing sildenafil to men with Parkinson's and to make them aware of the symptoms of orthostatic hypotension. Symptoms of orthostatic hypotension include feeling dizzy, vague or light headed, blurred vision, angina-type pain and generally feeling fatigued or unwell.

There is a possible role for the dopamine agonist apomorphine in erectile dysfunction. As well as improving motor symptoms, this drug, as a side effect, can induce penile erection in men with Parkinson's. However, further research of this option is needed.

Other causes of sexual dysfunction

Physical limitations

Some of the problems associated with sexual dysfunction can be linked to motor function, for example, reduced mobility. A couple may desire intercourse and begin, only to be disrupted by a sudden onset of Parkinson's symptoms, eg dystonia, rigidity or pain, leading to frustrations on both sides. Adjusting drug therapy to decrease unwanted involuntary movements and optimise mobility can be useful. Timing lovemaking to take place during optimal motor function is also something to consider, as well as different approaches to intimacy.

Stress, tiredness and depression

It must be remembered that, in any relationship, these factors are likely to reduce sexual desire. Anecdotal evidence would suggest that carers (particularly female carers) also experience difficulty in switching from the role of carer to lover. Research by Jamieson (1999) found that sexual dysfunction in a partner is strongly related to the level of impairment in the person with Parkinson's. While this may be related to the physical symptoms, it is possible that stress also plays a part.

Depression occurs in approximately 50% of people with Parkinson's and can result in symptoms of tiredness and loss of libido. A study carried out by Jacobs et al (2000) found that depressed and unemployed patients were often dissatisfied with their present sexual relationship, less able to enjoy a small flirtation and likely to feel lonely more often.

Listening and encouraging discussion of the problem, referral for formal counselling or treatment with antidepressants may be useful and should be considered.

Hypersexuality and sexual delusions

Even in the face of an inability to perform, hypersexuality can coexist. It is known that there is a dose-dependent relationship between hypersexual behaviour and anti-Parkinson's drugs, including L-dopa, selegiline and dopamine agonists.

Hypersexuality and sexual delusion can be a problem in both sexes. It takes many forms, for example an increase in libido or desire to act out sexual fantasies that do not necessarily take place within the constraints of the current personal relationship. Often the individual

can imagine that their partner is having covert affairs or is constantly masturbating. Some hallucinate that their partner is involved in sexual acts with other people or animals (zoophilia).

How can a nurse help?

While it is important that a nursing assessment be carried out to identify possible causes for problems within a relationship, perhaps the most important thing nurses have to offer is time to listen. Being given the opportunity to express concerns freely for the first time may be a great relief to the person with Parkinson's and their partner. One person who spoke to a nurse felt that they provided a 'shoulder to cry on' (Schartau et al, 2003).

Areas where practical support can be offered

Communication Verbal and non-verbal communication skills may be affected in Parkinson's. If speech is affected then some people become reluctant to initiate and maintain conversations so it is important to give the person time to express themselves. Avoiding excess background noise, maintaining eye contact and not rushing the person to respond will lessen their anxiety and keep them engaged.

If the person also lacks facial expression, communication can be more difficult. Simple facial exercises can help to keep tone in the facial muscles.

Self-image Self-esteem can be low because of difficulties with communication, poor posture, excessive sweating and drooling. Involvement of a physiotherapist can help with posture and some patients find yoga or tai chi helpful. Many of the local PDS branches run exercise sessions. Excessive drooling can be helped by reminding the person to swallow frequently, and sipping iced water can also elicit a swallow reflex (a speech and language therapist can help with these problems).

As possible causes include large doses of L-dopa or dopamine agonists, management is aimed at reduction or withdrawal of treatment but, of course, this may be at the expense of an increase in their Parkinson's symptoms.

Excessive sweating can occur, predominantly in 'off' periods and in 'on' periods with dyskinesias. It is important, therefore, to optimise patients' drug treatments. Awareness that personal hygiene needs may be increased and avoidance of tight, synthetic fabrics, which encourage sweating, can be suggested.

Social isolation There is a tendency for some people with Parkinson's to withdraw from society – to become introverted. Loss of social understanding within the family group, peer group and workplace can lead to feelings of reduced self-worth and a reluctance to socialise. A key factor causing this reluctance is that, for many affected people, Parkinson's is an obvious illness. People can feel that they stand out in a group and are embarrassed for themselves, their friends and family. It is important to remember that even though individuals may be unable to function fully in roles they previously fulfilled, these roles should not be denied them completely.

Mood fluctuations It will be natural for a person with Parkinson's to feel depressed and frustrated with their condition at times. Changes in mood can be related to medication levels – when a person is 'on' they feel better, but when 'off', feelings of anxiety and pessimistic thoughts can predominate. It is important to optimise treatment but also explain why the fluctuations may happen and that they will pass.

Conclusion

There are many reasons – physical, psychological and social – why people with Parkinson's might experience problems within their sexual relationships. Nurses have an important role in the support of people with Parkinson's experiencing relationship difficulties. In a community study carried out by Jarman et al (2002), PDNSs were shown to improve the sense of wellbeing in people with Parkinson's. A nurse is often one of the professionals who has regular, close contact with the person with Parkinson's and their family or carer.

The nurse will have the ability and opportunity to regularly carry out holistic assessment, evaluation and appropriate referral when there are changes in their condition needing further expertise (PDS et al, 2006). The challenge for the nurse is to be aware of ways of working to ensure best practice and to access expert care and support for people with Parkinson's.

Key points

- Sexual dysfunction is common in women and men with Parkinson's, but it is not inevitable.
- Clinical and nursing management must involve screening and correcting any other underlying causes of impotence and sexual dysfunction.
- Erectile dysfunction in men with Parkinson's can be the initial manifestation of autonomic dysfunction.
- Anti-Parkinson's drugs are one of the main causes of hypersexuality in Parkinson's.
- Nurses have an important role in the support of people with Parkinson's experiencing relationship difficulties.

Relevant resources from the PDS

Booklets

Looking After Your Bladder and Bowels in Parkinsonism (code B060)

Competencies: An integrated career and competency framework for nurses working in Parkinson's disease management (code B115)

Complementary Therapies and Parkinson's Disease (code B102)

Parkinson's and Diet (code B065)

Sex and Intimate Relationships (code B034)

The Drug Treatment of Parkinson's Disease (code B013)

Questionnaire

Non-motor Symptoms Questionnaire (code B117)

DVDs

Being There (code V012) – For people who have been recently diagnosed with Parkinson's

Keeping Moving – An exercise programme for people with Parkinson's disease (code V011 – DVD and booklet)

Information sheets

Apomorphine (APO-go) (code FS26)

Clothing (code FS31)

Communication (code FS06)

Constipation and Parkinson's (code FS80)

Dementia and Parkinson's (code FS58)

Dementia with Lewy Bodies (code FS33)

Depression and Parkinson's (code FS56)

Eating, Swallowing and Saliva Control in Parkinson's (code FS22)

Ecstasy and Parkinson's (code FS47)

Equipment and Disability Aids (code FS59)

Falls and Parkinson's (code FS39)

Foot Care and Parkinson's (code FS51)

Gambling and Parkinson's (code FS84)

Hallucinations and Parkinson's (code FS11)

International Travel and Parkinson's (code FS28)

Keeping a Diary: People with Parkinson's (code FS69)

Low Blood Pressure and Parkinson's (code FS50)

Muscle Cramps and Dystonias (code FS43)

Pain in Parkinson's (code FS37)

Parkinson's and Eyes (code FS27)

Parkinson's and Hypersexuality (code FS87)

Parkinsonism (code FS14)

Physiotherapy and Parkinson's (code FS42)

Pill Timers (code FS53)

Restless Legs Syndrome and Parkinson's (code FS83)

Sleep and Night-time Problems in Parkinson's (code FS30)

Speech and Language Therapy (code FS07)

Telling People About Parkinson's (code FS88)

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The occupational therapist's guide to Parkinson's disease

Introduction

To be effective when working with people who have Parkinson's, an occupational therapist (OT) needs to have a general understanding of the common functional difficulties associated with the condition. It is beneficial to apply a basic conceptual framework for understanding the basis of the range of functional issues experienced by people with Parkinson's. Provision of practical interventions to promote function, including use of various Parkinson's-specific cognitive and sensory coping strategies, together with interventions based on the more generic knowledge and skills of the OT profession, will facilitate addressing issues relating to functional impairments and overall quality of life.

On an individual level, Parkinson's is a very variable condition, with each person experiencing a personal collection of the common features. Symptom intensity

tends to fluctuate and will, as a result, mean that certain functional tasks can be performed with ease at some times, but be difficult or even 'impossible' at other times, not uncommonly on the same day. Clinical experience shows that sensitivity to functional facilitation through the use of various cognitive and sensory management strategies is also individual. The reason for this has not yet been established but the life-long interests, habits and life experiences of an individual with Parkinson's may perhaps combine to make one person more responsive to a specific sensory input, while another responds most dramatically to another modality. Alternatively, additional neurological pathology, or subtle changes in brain chemistry, may be responsible for the variability of response. It is possible that a combination of all these factors are involved.

OT

Checklist

- ✓ Use appropriate assessment and communication strategies for Parkinson's disease.
- ✓ Consider teaching use of cueing techniques for improving performance of problematic motor tasks – cues may be used in the modalities of visual, auditory, cognitive or proprioceptive 'inputs'.
- ✓ Encourage use of mental rehearsal as a preparation for challenging activities.
- ✓ Provide prompts and reminders, such as cue cards, or an association with a specific location or feeling to prompt recall and application of specific management techniques.
- ✓ Use carefully chosen and well-introduced assistive aids, equipment, adaptations and technologies to promote independence and reduce strain on carers.

Assessment

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:

- The Unified Parkinson's Disease Rating scale (UPDRS) – Part 3 ADL score
- PDQ39 (a 39-question Parkinson's Disease Quality of Life measure)
- PDQ8 (an eight-question Parkinson's Disease Quality of Life measure)
- Hoehn & Yahr Staging of Parkinson's Disease scale (H&Y)
- The Webster scale
- Schwab and England Activities of Daily Living scale

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 personal relevance of the domains measured into account.

There is currently no comprehensive, standardised, Parkinson's-specific OT assessment. The following assessment tools are sometimes considered appropriate by OTs for use with people who have Parkinson's:

- Assessment of Motor and Process Skills (AMPS)
- Canadian Occupational Performance Measure (COPM)
- Nottingham Extended Activities of Daily Living Assessment

In daily clinical practice, OTs use a wide range of standardised and in-house assessment formats, with no single uniform assessment currently being used in the UK.

Priorities for therapy

It is encouraging, and perhaps in part due to the impact of the whole-person approach promoted as a core philosophy of the OT profession, that use of a person-centred approach is becoming increasingly mainstream in health and social care. A person-centred approach is very appropriate for people with

The confounding effect of 'doing an assessment'

Observation of the functional performance of a person with Parkinson's – as in an assessment session – is unlikely to be representative of actual abilities within the context of that individual's daily life. Atypical performance and uncharacteristic behaviours are commonly elicited by the presence of an observer. Tasks performed out of context (eg bed transfers performed in the mid morning) will rarely reveal difficulties being experienced with actual performance.

Paradoxically, it is common for performance under observation to be far smoother than usual or more difficult, or even virtually impossible. People with Parkinson's are often quick to fatigue during performance of just one or several routine activities, adding a further barrier to accurate assessment. Time of day and time since last dose of anti-Parkinson's medication also influence ability. In addition, actual performance tends to vary over the 24-hour period. Perhaps such variability is, in part, due to changes in time of day, mood, context and degree of motivation at the time of actual performance. For all these reasons, use of the assessment methods outlined below are recommended.

Assessment methods suitable for people with Parkinson's

Assessment needs to be well structured (logical and relevant) and to be assessor-led, as patients tend to make little spontaneous elaboration and may not state all aspects of a problem, unless asked directly. Functional difficulties will often only be revealed by asking for details about elements of ability, if common functional difficulties are initially denied (for this, an OT needs an awareness of functional issues related to Parkinson's).

Parkinson's. Often, someone with Parkinson's will have a major priority at a particular time. They may also have difficulty fully attending to anything that does not address their main 'short-list' of priorities. Using the COPM as a basis for assessment, or by starting an initial assessment by 'brainstorming' a list of main

concerns and goals, ensures that key personal issues are considered. A close relative or friend may be able to assist in this process if appropriate. During the course of intervention, and in subsequent contacts, opportunities to identify new issues and goals should be included once original concerns have been addressed.

Where non-ADL priorities predominate, it may be necessary to 'retreat' until other issues have been

addressed. At times, it may be necessary to change tack, more carefully tailor an approach to the current goals or needs of an individual, or to yield to resistance (eg as when an individual has 'made up their mind' to have brain surgery to address their symptoms).

Checklist

- ✓ Gather as much background information as possible prior to conducting an assessment. If referral details are minimal, consider seeking further information about reasons for referral to OT from the source of the referral.
- ✓ Use appropriate communication strategies for all contacts (see Communication Issues section on page 70).
- ✓ Discuss functional abilities and then observe performance.
- ✓ Explore range of ability to conduct specific tasks, eg at different times of day and night, and in different settings.
- ✓ Consider functional impact of the 'on/off' phenomenon, if anti-Parkinson's medication has been in use for several years.
- ✓ If dyskinesias occur, it can be helpful to establish if this is bi-phasic (occurring near the start and again near the end of an anti-Parkinson's medication dose interval) or peak dose (occurring at the mid point of the dose interval).
- ✓ Establish list of main concerns and prioritise intervention goals.
- ✓ Observe behaviour indirectly, thus minimising the confounding effect of the 'sense of being watched'.
- ✓ Sensitivity to personal stamina level, as well as to personal agenda, will need to be taken into account during the assessment process.
- ✓ Accommodate for communication problems and other difficulties with interviews by allowing extra time, to manage delayed verbal responses (associated with bradyphrenia), and/or take breaks to manage fatigue (perhaps splitting an assessment into two or more sessions).

Communication issues

Possible problems with communication for people with Parkinson's are numerous and may include difficulties such as:

- reduced volume and clarity of speech
- absent or reduced social/non-verbal language and gestures
- reduced facial expression and loss of prosody (the emotional intonation, stresses and emphasis that give words their depth of meaning)
- tiring quickly during conversation
- stooped posture, loss of eye contact and difficulties controlling saliva
- increased response times and difficulties keeping up with frequent changes of subject
- rapid (festinating), unintelligible speech
- reliance on others to speak on one's behalf
- difficulties using the telephone
- shrinking handwriting (micrographia) or scrawly, illegible writing

Useful communication strategies

- Use a quiet environment, or at least minimise distractions as much as possible.
- Allow extra time for responses.
- Announce each change and end of topic discussed, and introduce each new subject.
- Provide polite verbal prompts to promote optimum posture, volume and clarity of speech.
- Split sessions or take breaks to manage fatigue.
- Provide brief written reminders as memory aids where relevant.
- If possible, avoid having important conversations during episodes of intense dyskinesia (individuals will usually have an idea of how long an episode of dyskinesia will last). As dyskinesia can be very physically tiring, returning to pursue a conversation once it has passed should be considered.
- Encourage sitting down when using the telephone. Consider use of a headset, eg if holding the phone while writing a message is a problem.
- Teach handwriting strategies if improved clarity of writing is desired.
- Consider ergonomics and computer adaptations, eg resetting to reduce mouse difficulties due to tremor, if a computer is used.

Apathy and motivation

As motivation, initiative and problem-solving skills are affected by having Parkinson's, people with the condition may be less adaptable than others in coping with their health changes and symptoms. With a highly complex condition such as Parkinson's, specific support and guidance for managing health and coping with symptoms is generally required. Therapists need to be aware that extra attention will need to be paid to facilitating adaptation and adopting change. Some suggestions for assisting in this area are listed below.

Methods for increasing engagement in therapy and raising motivation

- Acknowledge ambiguity about change. It is important to acknowledge that change is not easy, while balancing this by reflecting back any comments that have been made about '... wanting to remain independent ... cope better etc', eg comments about wanting to improve performance
- of a specific task, but fearing being unable to do so because of 'the Parkinson's'.
- Expressions by the therapist of empathy and understanding of how people feel aids engagement and assists development of a therapeutic relationship.
- Provide education, particularly related to research or other people with similar difficulties and ways that problems have been successfully managed. Education, given one-to-one initially, allows key points and information to be paced according to individual main concerns, style and stamina.
- It is of value to give opportunities to talk through experiences, beliefs and fears related to the diagnosis, as well as any concerns about specific symptoms and about what the future holds. It may also help to promote a more optimistic outlook to explore understanding about how Parkinson's is progressive, but is not a terminal condition.

- Build confidence by relaying tales of success of others in similar circumstances (obviously this must be done without giving names or other personal information).
- Exposure to peers with positive experiences may help to raise motivation. Contact with peers who have gained benefits and confidence in the use of symptom-management strategies can be of great value in raising willingness to try different methods.
- Give constructive feedback on progress during supervised practice and further positive reinforcement at follow-up contacts, to facilitate change.

- Do not attempt to change or teach too much too fast: addressing one or two issues per session is generally sufficient. The simple principal of doing one thing at a time applies to OT intervention, as well as to conducting other cognitive and motor activities.

An effective therapist has the ability to transmit their belief in an individual's potential ability to succeed.

Use of these approaches will promote willingness to try out new methods of performing familiar tasks, which had been easily conducted before the development of Parkinson's.

The benefits and frustrations of aids and equipment

Items that are most useful to people with Parkinson's are those with familiar modes of use. Handrails, for example, can be very useful on stairs and in other suitable locations. Items that are used spontaneously, such as chair-raising units or a half-length satin sheet (to aid moving in bed), will also generally be used.

Frustrating items include those that demand the learning of novel processes, skills or ideas. Even

simple but unfamiliar items (ie not encountered in the past), such as a long shoe-horn or a button hook, can be a source of considerable confusion and frustration for patient and OT alike. Adjusting to a new car, new home, new computer, new TV or microwave oven can therefore present a considerably greater than usual challenge to someone who has Parkinson's.

Learning and memory

Evidence from research shows that new learning in Parkinson's subjects 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 is provided that elicits a memory), but recall, in the absence of any form of external stimulus, is generally impaired.

Recall aids can help the day-to-day application of coping strategies for problematic movements, after having been learnt in a therapeutic context. Therapists should therefore consider using cue cards, visual markers/stripes or associations with emotions, or objects in the environment, eg look across the room at a picture on the far wall and aim for this to reduce the tendency of freezing at the doorway when walking into the room. Or, when feeling nervous when going to turn around, think 'Don't panic. Feet first' to aid recall of management techniques.

Involvement of as many senses as possible, from intellectual to proprioceptive, can enhance learning considerably. For example, various mobility strategies can be taught through the use of the methods that will follow.

On a practical level, sometimes internally recalled associations may be used as a 'handle' to retrieve a memory. Some patients report that they think of the therapist who taught them a movement strategy before remembering the movements to use.

Teaching methods for promoting learning and use of adaptive movement strategies by people with Parkinson's

- Discuss any issues and, if relevant, discuss ways that people with similar difficulties have resolved the same issue.
- The therapist initially demonstrates a movement strategy that will improve ease of doing a movement, to provide a visual frame of reference (ensure the patient watches performance of movements, by giving verbal prompts to look at the section of the body being moved if this is not done spontaneously).

- Follow demonstration with practice by the patient, initially with the therapist providing verbal cues to guide performance. Use brief, clear descriptions of actions/instructions, emphasising key words to provide a verbal frame of reference.
- Use guided mental rehearsal (asking the patient to imagine doing each element of a movement sequence while remaining still) if getting started is proving quite difficult.
- Physically facilitate limb and body movements if needed, to give proprioceptive feedback about movements being learnt, thus aiding the learning process.
- Use a backward-chaining approach (focusing on achievement of the final stage(s) of a sequence

initially and building up skill in reverse order, until a complete run-through is achieved) if needed.

- Patients should be encouraged to talk through key elements of their movements aloud while performing them, thus providing their own cues for the movement sequence.
- A cue card can be provided to be put in a place where it will be seen when doing an activity, hence aiding transfer of a newly learnt movement strategy into daily life.
- Finally, patients may learn to internalise key words if able and if preferred.

Education

By providing time for discussion and education about the effects of insufficient and fluctuating levels of dopamine in accessible language that is appropriate to the individual, observable and often dramatic functional benefits can be achieved. People with Parkinson's may already realise that using their attention more consciously, for example, enables them to perform tasks with greater ease and better 'flow'. Once understood and reinforced, greater application of this approach will usually emerge.

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 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 learnt can be of ongoing value. Clinical experience shows that use of metaphorical and allegorical language can greatly aid understanding of any unfamiliar ideas that need to be conveyed.

When teaching strategies for pre-linguistic movement skills and activities (such as rolling and bed mobility, sit-to-stand, swallowing, stride length, turning around, volume or clarity of voice), use of a multi-sensory approach, as described in the section on learning and memory, is beneficial.

Current knowledge of the role of the basal ganglia and its dysfunction, as seen in Parkinson's, provides a rationale for the use of cognitive and sensory management strategies – the three main principles of which are as follows:

- Conscious attention is required for the performance of well-learnt motor skills and movement sequences that had been performed automatically prior to the onset of Parkinson's. By employing a high level of attentional resources, as used for performance of a new 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.
- Dual-task performance should be avoided wherever possible. The 'auto-pilot' system, which allows performance of multiple well-known tasks, is impaired in Parkinson's. Thus, simultaneous activities – such as speaking and walking, dressing while listening to the radio, standing and swallowing tablets – compete for attentional resources, seriously impairing performance of the most automatic, least attention-demanding task (eg maintaining balance). Doing two things at once should be avoided where at all practical, eg sit to comb hair, swallow tablets, dress or write. Don't walk and talk at the same time. Cut out auditory distractions when doing a difficult task. Avoid daydreaming or planning another activity (like what to have for lunch) while performing a movement task. Learning to use conscious attention during routine tasks will generally enhance the quality of performance of the task while attention is sustained.
- Use of cognitive and sensory cues and triggers can be utilised to guide the flow of motor performance and ideas.

Attention

Concentration on the task at hand is absolutely essential for enhancing performance. Where concentration or comprehension is reduced, attention can be facilitated by giving verbal prompts, turning off distractions such as TV and radio and strictly avoiding chatting to the person with Parkinson's when they are performing a challenging task. The application of focused attention (like in the original learning phase of acquiring a new

skill) can be tiring, but will help to increase speed and flow of movements performed if applied in short bursts at times when the flow of movements is reduced. The application of conscious attention is essential for the enhancement of motor performance, when using the cognitive and sensory techniques described below.

Intrinsic cues and triggers

For those in the early and middle stages of Parkinson's, several internally generated cueing methods can be taught to enhance functional ability. 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.

Positive attitude/emotional set

Expectation of frustration and failure at the outset of engaging in a task can be common where experience of poor performance reinforces such ideas. As the basal ganglia has strong links with the limbic system, which is associated with emotion, a constructive attitude and expectation of success ('I will...'), can 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 can be of great benefit to discuss this in some detail where appropriate. Using mental rehearsal provides a more constructive preparation for a difficult action or task.

Mental rehearsal

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 people with 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. Sports people and musicians commonly use this technique to improve their performances.

Internal dialogue

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, such as 'Big steps. Big steps' can increase stride length dramatically. Nouns and verbs seem to be the most effective, eg 'Grip button ... find hole ... push button into hole ... and pull'. This type of commentary appears to employ knowledge and skill remaining intact in the higher regions of the brain and to bypass dysfunctional basal ganglia mechanisms. Where this technique is found to be effective, it can be very reassuring for patients to prove to themselves that the simple use of internal commentary can enhance motor performance, as people with Parkinson's can be in great fear of 'losing their mind' when so many daily activities lose their spontaneous nature. 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

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 are 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 line (like at the end of a running track) can sometimes give sufficient stimulus to trigger restart of walking. Here, distraction helps to break over activity and the loss of co-ordination between the anterior and posterior leg muscles. Freezing is a phenomenon of Parkinson's often brought on by distraction, or when moving through an unfamiliar, or visually complex space (see Visual environmental on page 74).

Extrinsic cues and triggers

The use of external sensory stimuli may be the most effective way to facilitate performance of motor skills in some cases, and can also aid communication. The need for conscious attention and concentration throughout performance remains of paramount importance when using externally generated cues and triggers, just as with internally generated cues.

Visual environment

Layout of the environment has a strong influence on the flow of mobility for those with Parkinson's. This is particularly the case where contrast-sensitivity and subtle visio-spatial disturbances occur. An OT can facilitate mobility around the home and other frequently used environments by advising on the repositioning of furniture to simplify the visual impact of its layout. Central (coffee) tables should ideally be moved to the side of the room, thus allowing direct access from

armchair to door, TV and other frequently visited areas within the room. Patterned floors and carpets may present special challenges in 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. Use of a staggered threshold (where floor covering is continued through a doorway ending in the shape of a doormat inside the entrance to the next room) can also be helpful, if there is different coloured or textured flooring in two rooms that are used frequently by someone who freezes at doorways.

In cluttered, crowded and unfamiliar places, pausing to plan a route and negotiate obstacles safely, as far ahead as can be seen, can aid ease of walking. Further pauses to survey and plan again will be necessary as the next area comes into view.

Visual cues

Evidence from research shows that people with Parkinson's are unusually sensitive to visually complex stimuli. For example, the classic freezing at doorways and where colour or pattern of flooring changes, eg carpet to lino, seems to be the result of a kind of 'visual overload'. Paradoxically, enhancement of motor function is often most dramatically demonstrated by use of visual cues. (See also the section about visual disturbances and management ideas.)

Floor markers

Increased stride length can be facilitated by strips of coloured tape (eg two-coloured hazard tape or plain masking tape) applied to the floor in areas where freezing or difficulty negotiating a turn in a corridor regularly occur. Strips of adhesive tape approximately 45cm (24in) in length, can be stuck to the floor in troublesome places. Strips need to be of a colour that contrasts with the surface below, and should be placed parallel at intervals to match the normal stride length for the individual (assess distance using paper or card strips laid on the floor if desired). 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 (in the absence of orthopaedic or other complications): the lines of the steps, like strips applied to the floor, seem to act as cues to maintain the flow of gait.

Cue cards

Brief written directions (as the example below) 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.

To fasten buttons

Sit down and say to yourself:

"Grip button ...
find hole ...
push button into hole ...
and ... pull."

**Example of a simple cue card
(cue cards can be laminated for
improved appearance and durability)**

Auditory cues

The sound of the 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 disease. Here, we seem to see voluntary, internally generated cues being relayed back into the brain via auditory pathways – to reach parts that other thoughts cannot reach. Auditory cues may also be provided in a variety of other forms, as below.

Verbal commands

Concise instructions, spoken by the carer, therapist etc, may be used to cue (prepare for), trigger (initiate) and maintain 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.

Experimentation with individuals will reveal whether auditory cues are required only to initiate a movement sequence, or if it is necessary to continue repeating the cues throughout the activity (especially 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, yet a verbal command such as 'One, two, three ... stand' can act as a preparatory cue and then trigger standing up.

Other verbal commands can be devised according to individual needs. Always keep commands clear, brief and well sequenced. With a little training and practice, carers may be able to progress from giving physical assistance with transfers and walking to giving verbal prompts only.

Metronomes

Studies on the value of using metronomes have been conducted for overcoming start-hesitation (or ignition failure, as this has been called) and freezing (motor blocks occurring during movement). Encouraging responses to the sound of a metronome were noted where the individual is sensitive to this form of stimulus. Modern, compact, commercially available metronomes can be 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 studies, the beat-rate was set at 110–120 beats per minute for women and 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 become a distraction, which could impede progress). If considering purchase of a metronome for use as described, remember to consider design and dexterity requirements when making a choice. They can be purchased from suppliers of musical instruments and accessories.

Music and rhythm

The beneficial effects of using music and rhythm to trigger and maintain flow of voluntary movements have been noted by some physiotherapists, who include dancing (waltz style) to music at the end of group exercise classes for Parkinson's patients. Use of this mode of auditory stimulus may become more popular in the future. Conductive education also employs rhythmical facilitation and is used by some people with Parkinson's for management of difficult movements and activities.

Checklist

When teaching concepts and techniques such as those outlined above, aim to:

- ✓ engage conscious attention/focus on the task in hand
- ✓ increase understanding of the basis for functional difficulties
- ✓ provide a small range of alternative techniques (which can be experimented with) to address specific functional issues
- ✓ where relevant, demonstrate movement strategies to provide a visual frame of reference
- ✓ involve as many senses as possible in the learning process, with opportunities for practice of these
- ✓ provide feedback on performance in an honest and supportive manner as a form of positive reinforcement. By facilitating any level of success, confidence and motivation will be raised.

In general, where difficulties are encountered, it is beneficial to:

- ✓ encourage the breakdown of complicated sequences into smaller parts
- ✓ encourage application of attention through use of verbal and visual prompts
- ✓ allow sufficient time, and use prompts when switching to a separate task or subject, as it has been shown that Parkinson's inhibits shifting of both mental and motor set (switching from one idea or motor plan to another)
- ✓ supply recall aids (cue cards, prompt sheets and short written reminders), where possible, but avoid overloading with these

The use of cognitive and sensory attentional strategies seems to utilise alternative pathways for reaching a goal. To use an analogy, it is as if a messenger travelling into the unconscious mind (with a message for the body) finds the commonly used, direct pathway blocked and so is unable to deliver the message to the movement control centre. However, by using an alternative route, or taking 'a long way round', the message can get through after all. The exact mechanisms being employed when using alternative pathways is not yet fully understood. It is believed that

messages are rerouted, 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 supports the findings of the RESCUE project: that cognitive and sensory attentional strategies can be extremely beneficial, and are inexpensive and simple to use. They therefore provide a valuable intervention resource for OTs in the treatment of people with Parkinson's and sometimes also in other Parkinson's syndromes.

Interventions for some common functional and daily-living issues associated with having Parkinson's

Poor medication compliance

Optimising management of anti-Parkinson's medication will improve function and self-management in all areas of daily life. Consider usual routine and who manages this, including timings, especially times of doses that are 'easy to miss' or are regularly taken late. Physical processes and dexterity, opening of containers of medication etc should also be considered. Access to water and ability to drink at dose times, likewise. A 'nosey'-type cup can be used if neck rigidity inhibits ease of drinking, especially for taking the first dose of the day. A wide selection of medication management and reminder systems – pill boxes with multiple chambers to hold separate doses (some with built-in alarm clocks that beep, flash or vibrate) – can be obtained via pharmacies or from specialist equipment suppliers. If problems keeping to advised medication times are identified, careful assessment of the person's management of their medication regimen is essential for the selection of an appropriate aid. A local Parkinson's Disease Nurse Specialist (PDNS) or pharmacist may be available to help if medication compliance is a problem.

Dossette-type medication boxes may be useful, but check that dexterity is sufficient at medication times to open and extract medications, including removal of a clear plastic seal included by the pharmacy, if medications are dispensed into systems of this style.

Alarm watches with multiple pre-set alarm functions, in audible and vibrating styles, are available. A standard travel alarm clock can also be useful to remind about

doses that are easy to miss, eg a dose not taken at a meal time or due while out at a social event. Pill reminder alarms may also be suitable, eg a vibrating pocket alarm may suit people who are hard of hearing. It is also discreet for use in public or work environments, such as libraries, meetings and teaching sessions. Medication will need to be carried in a suitable container.

One type of pill timer is a carousel. This is a programmable automatic medication dispenser with a dose-reminder alarm, which holds up to 28 doses, dispensing up to four doses a day for a week. If more than four doses daily are taken, it may suit to use another type of dispenser for the most easy-to-remember doses, such as mornings and bedtimes, with the four doses for the central part of the day being kept in the carousel dispenser. Some types of this device can be linked to telecare systems used with community alarm systems. If linked like this, the carousel will automatically generate a pre-recorded phone call giving a prompt in a known voice to go and take the dose, if a dose is not removed from the dispensing chamber within a specified period of the alarm having sounded. As this is a battery-operated system, batteries will need replacement after several months' use and people should be aware that if a carousel begins to behave erratically, it is probably a sign of worn-out batteries. It may be worth keeping a small supply of medications or a spare key at home, for use in situations such as the carousel being filled and locked at a local pharmacy.

Mood, motivation and initiative

Consider and address the impact of anxiety, which may inhibit the ability to engage in activity and cause distress, eg fear of falling, anxiety about eating and drinking in public or gait and balance problems may all raise anxiety levels in day-to-day life. Where possible, teach movement strategies to manage difficulties that aggravate anxiety. Also consider the benefit of small aids. Improved function tends to alleviate anxiety and promote re-engagement in public life.

Depression may occur with anxiety or on its own. Mood swings may occur as part of an 'on/off' pattern. Mood may improve as a result of satisfaction achieved through mastery of one or more troublesome symptoms, as well as by addressing functional issues that are causing anxiety (as above). Motivation and the ability to independently resolve practical difficulties is commonly reduced. Provide support and encouragement for people to identify and to reach achievable goals.

Cognition and perception

Consider and address the impact of difficulties with life management and organisational tasks or roles that may need to be addressed. Explore the use of management strategies, sources of social contact, support and the need for advocacy, establishing support networks where required. Ensure the patient is known to the local PDNS or community matron, if available, and give the patient information about activities at their local PDS branch.

People with Parkinson's have reported that visual hallucinations tend to be less intrusive if labelled by

themselves as such, when experiencing them.

Education about this side effect of anti-Parkinson's medication may help to increase insight and reduce distress.

Delusions in the form of bizarre or obsessive ideas, often in combination with hallucinations, can have a major impact on the ability to cope with daily life. If distressing delusional ideas are reported, discuss the need for a medication review and adjustment with the PDNS, or GP if possible.

Visio-spatial problems

Some people with Parkinson's-type conditions report visual problems, including the following:

- Reaching for an object or placing an item on a surface due to difficulty judging distances. Often things appear closer than they actually are. As a result, it is not uncommon for items to be misplaced and fall off the edge of a worktop or table. People should be advised to speak to their GP about whether they should continue to drive if they have any problems with judging distances etc.
- Walking down steps, kerbs, stairs and using escalators, again, due to difficulties with judging distances.
- Eyes tiring quickly if kept focusing at a set distance – perhaps with 'blank patches' temporarily appearing over text, or part of an object being looked at for a sustained period of time 'going blank', such as part of a plate of food 'vanishing' during a meal.
- When reading, finding that the same line is read again and again, or poor visual attention – where the eyes seem to be distracted by other areas of the page, especially when reading pages with a variety of text styles and pictures, eg newspapers or magazines.
- Increased sensitivity to contrasting colours and bold patterns. This may cause difficulty walking through an area with a lot of strong colours or bold patterns on the floor, increasing any tendency to shuffle, freeze and/or feel the need to step over 2D shapes, as if they were 3D objects.
- Double vision – sometimes only affecting moving objects, lines of a certain angle, when looking through net curtains or at objects at a certain

distance. Double vision often reduces during good 'on' time when levodopa medication is being used.

- Judging the speed or path of moving objects – as when moving among people in busy places, using escalators, driving or crossing roads.
- Difficulties with figure/ground discrimination – such as when picking up an object that it is positioned on a background of the same colour as the object.

Self-management strategies

It can be helpful to explain to people who report the kind of visual problems outlined above that, by making extra use of their mind and sense of touch (as below), the brain will be able to use the extra information to locate items being dealt with more accurately.

As well as having regular eye tests and using glasses and other treatments, as advised by an optician or ophthalmologist, the following suggestions can make management of vision-aided tasks easier:

- When reaching for items, expect them to be further away than they appear to be, eg while standing up, move an extra step closer to the item before reaching for it. Also, make sure to stand in front of the area being reached to, rather than off to one side.
- When placing an item on a surface, reach out with the free hand and touch the surface first to check the distance, eg touch the front of a table or worktop before placing a cup on it with the other hand.
- When pouring cold liquids into a cup or glass, use the free hand to hold the empty vessel while it rests on the worktop or table, as this will help the brain to aim more accurately when pouring.

- When pouring hot liquids, do not hold the cup but, if possible, place it in the sink or on the draining board, so that any spills will flow safely down the drain.
- When going down steps or a kerb, a walking stick or walking pole with a non-slip tip can be useful as a 'depth gauge' if placed on the next level before moving the leading foot down. Where handrails or banisters are available, they can be used as a guide when descending steps or stairs.
- If reading is difficult, use plain-coloured card to mask off the area below the line being read, and move the card down to reveal the next line when ready. It is easiest to do this sitting at a table with the book,

- magazine or paper laid out on the table and with good lighting from above or from over one shoulder.
- Rest the eyes regularly by looking away from a plate of food or a page, eg to an area across the room, for a short while after each paragraph or two. A tinted plastic sheet – most commonly tinted blue or green – placed over a page of text, may help to reduce glare and contrast, enabling reading with less effort.
- Where possible, reduce the number of contrasting colours on the floor and encourage removal of clutter in areas used regularly at home. This is especially helpful where shuffling or freezing regularly occur in the same area.

Hand function

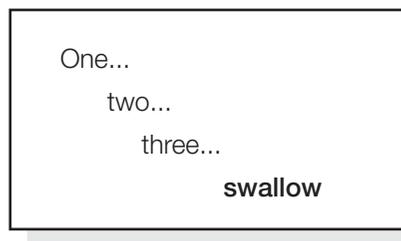
Manual dexterity and co-ordination are often impaired, while the degree of ability may also fluctuate, adding uncertainty and frustration for people with Parkinson's and those around them.

Eating and drinking are often slower and messier and may demand greater effort, which can lead to loss of pleasure in food and withdrawal from previously enjoyed family and social activities involving food or drink.

Referral to a speech and language therapist should be considered where difficulties are reported with swallowing, and coughing when taking tablets, food or drinks. Good sitting posture, adequate lighting and as few distractions as possible are recommended if mealtime problems occur. Some of the following small aids may also be useful in reducing difficulties with eating and drinking, where relevant:

- Dycem™ square or rectangle used as a plate mat
- Raised-edge/lip-edge plate, or a suitably-sized shallow straight-edged flan dish
- One-way valve straw may be useful if too much effort is needed to use a standard straw comfortably
- Flexible/elbow straws may suit if weakness or (severe) tremor inhibits holding a cup safely
- 'Nosey' cups/cut-away mugs (left, right or two-handed) may be very useful if limited neck mobility prevents easily draining a cup, or frequent coughing occurs when drinking
- Dyna fork (fork/knife combo) helps if co-ordination between knife and fork is impaired

- Spork/splade (spoon/fork combo) helps if food tends to be dropped between the plate and mouth
- Weighted cutlery may sometimes help to dampen an action tremor, but may exacerbate fatigue and thus cancel out the benefit
- If starting the swallow is a problem, using a cue card, as shown here, may be beneficial if read silently when ready to swallow



Kitchen tasks may entail problems relating to poor dexterity, impaired balance and rapidly becoming fatigued. Some of the following ideas may help to improve ease and safety of working in the kitchen. If relevant, consider use of small aids etc, as below:

- Latex® netting – a small square or two makes easy-to-use jar openers by aiding grip (like using a tea towel). This generally works more easily than less familiar styles of opening device.
- Consider the need for a perching stool to support balance as hand function in people with Parkinson's tends to improve when sitting.
- Wire mesh or chip baskets can help if lifting and straining pans of vegetables is a problem.
- Consider the need for a high-level trolley, or other ways to reduce walking and carrying simultaneously.

- A ring-puller gadget will be of benefit if difficulty with opening modern ring-pull cans of food is reported (available from most kitchen equipment suppliers).
- Lever taps or tap turners may be needed to facilitate independence.
- Pacing the preparation of meals, eg by doing some preparation earlier in the day, so that there is less to do when actually cooking the meal, will help with fatigue.
- Use of labour-saving devices and convenience foods where appropriate.

Dressing is generally slower, more tiring and may cause poor balance if done in a standing position. People with Parkinson's often report that putting on a set of clothes can take from 30 minutes to two hours or more daily. The fastening of a regular man's shirt alone is, not uncommonly, reported to take up to 30 minutes. In some cases, provision of assistance may be the most appropriate course of action, especially if the process of dressing takes a very long time, or leaves the person so exhausted that it takes a significant part of the day to recover.

For those who wish to dress themselves more easily, use of the strategies below will usually be much more effective for people with Parkinson's than the use of unfamiliar dressing aids.

Chip and PIN cards cause difficulties where tremor, delayed movement times, double vision or impaired memory affect the ability to use a number-pad.

If requested, banks can issue 'chip and sign' cards to customers who cannot use PIN-based systems. These cards prompt the retailer to ask for a signature for verification, instead of requesting the entering of a PIN code.

Handwriting typically diminishes in size (micrographic). In addition, script often slopes towards the far corners instead of going straight across the page. A more 'spidery' or 'scrawled' style of script may also be evident.

Oliveira et al (1997) studied micrographia in people with Parkinson's disease, focusing on the effects of providing external cues. The team, based in Oxford, were able to demonstrate the benefits of using visual or auditory cues, which, they suggested, encouraged people with Parkinson's to write less automatically; thus improving the size and clarity of their handwriting.

Tips for bigger writing*

In a one-off session, after an initial sample of writing has been produced, try out the following advice:

- If possible, sit comfortably and in an upright position at a table, with good lighting from over one shoulder or from above.
- Try using a fibre tip pen, or a modern gel ink pen, as these 'flow' most smoothly.

Dressing strategies

- Collect all the clothes you plan to wear and lay them in the correct order for dressing.
- Sit down on a chair or the bed, close to your stack of clothes.
- Concentrate on dressing, avoiding distracting thoughts, sounds or conversations.
- Before putting on each item, imagine yourself doing it.
- Describe each body movement while you are dressing, eg 'Put right hand into this sleeve and pull up' or 'Grip button ... find hole ... push button into hole ... and pull'.
- Stand to pull up pants/trousers, making sure your body is well balanced.
- Sit down to do up all buttons and fastenings.

REMEMBER!

- Do only one task at a time.
- Concentrate fully on the task.
- Describe each movement to yourself as you do it.

Adapted from Morris, Kirkwood, Iansek (1996)

- A pen grip (a short triangular or cylindrical tube that slides over the lower end of a pen or pencil barrel) may 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 pad of writing paper).
- Concentrate and avoid rushing when writing. Avoid distractions such as TV, radio, background music etc.
- Think 'BIG' often while writing.
- Pay close attention to forming each letter.

- Aim up to the line above, on each upward pen stroke.
- Follow the line to guide writing straight.
- Stop to stretch from time to time: press palms together, open arms out wide and then return to your writing. Do this regularly during long pieces of writing.
- And finally, don't forget to keep thinking 'BIG'.

If writing style remains rapid, these strategies will be less effective. It may then help to think 'Big and slow' to focus attention on writing less automatically. For scrawly or spidery writing that does not really shrink, thinking the words 'Smooth' or 'Slow and smooth' may be more helpful.

Mobility and gait disturbances

An initial period of experimentation will be needed to discover which method(s) works best for each person. Once the use of a suitable cueing strategy has been established, an individual will be able to restart walking or maybe avoid freezing by using their preferred method(s). Cues work in real time and are a compensatory mechanism that use 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'. People with Parkinson's sometimes experience 'freezing' when doing activities other than walking or when starting a movement, eg when beginning to speak, when raising a cup to drink, or starting to get out of bed. Difficulty getting started, sometimes called start-hesitation, can often be overcome using a similar approach to coping with episodes of freezing.

All the strategies described below involve providing a stimulus or 'cue' to trigger the start or restart of movement.

The weight shift method (proprioceptive cue)

- Upon freezing, instead of trying to move forward again, first STOP. It is not uncommon for the upper body to still be mobile when the legs are 'frozen'. This can trigger a fall as a result of being unable to engage saving reactions, such as taking a step forward as the centre of gravity reaches the edge of the base of support.

- Next, gently shift the majority of weight sideways to one leg/foot. This will break the pattern of incorrectly co-ordinated and over-active leg muscles, which is associated with freezing during walking.
- Once weight has been transferred gently to one foot, it will generally be easy to then take a step forward with the other leg to restart walking.
- A verbal cue may help, said silently, aloud or by a companion, such as: 'Shift weight to left leg and step with right foot.' (Reverse left and right if this suits the situation.)

Consider triggers of freezing if it occurs repeatedly in the same locations at home or in other regularly used environments. Thresholds at doorways, contrasting coloured rugs, mats, corners, narrow spaces, eg between furniture, free-standing toilet aids, poorly stabilised wheeled commodes, etc may cause regular freezing in the bathroom. If so, remove the rug or mat, or reposition it well away from the usual route taken through the room or area. Use fixed rails and securely anchored aids and equipment where required. Items which wobble during use tend to raise anxiety and elicit increased tendency to freeze with subsequent use.

Auditory methods for unfreezing and management of other gait problems

- Upon freezing, STOP.
- Decide which foot to move first.
- Then listen to yourself or someone else saying: 'One, two, three, step...', or a similar phrase.
- Restart walking by moving the chosen foot first, on hearing the trigger word (eg 'step' or 'go'), spoken silently or aloud by the person him/herself or said by someone else.

- Whichever method is used, a clear commanding tone of voice will be the most effective to get movement restarted.

Other strategies to manage freezing involve using rhythm (either in the mind or aloud), by singing or humming a tune as walking, or by counting steps or chanting 'one, two, one, two, one, two...' or 'left, right, left, right...' and moving with the beat.

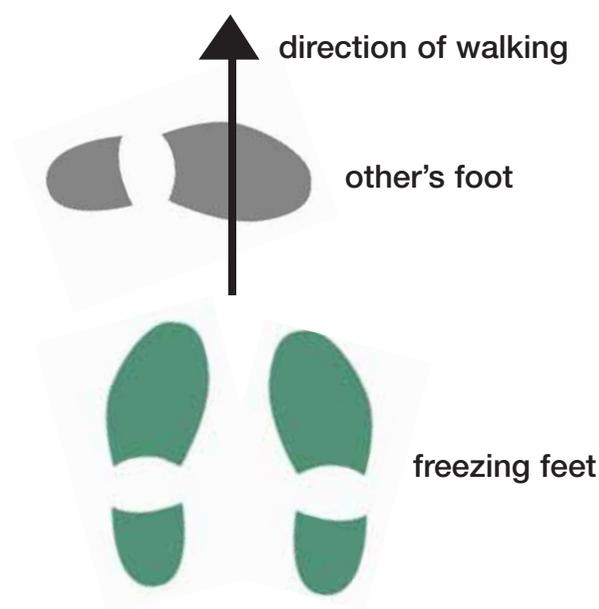
It may also help to use rhythm when approaching an area that tends to cause freezing regularly, letting the person pass the 'trouble spot' without freezing.

Using rhythm when walking may increase stride length, if there is a tendency to shuffle. Chanting 'BIG STEPS' or 'LONG STEPS' silently or aloud can also help to increase stride-length for some people.

Festination of gait describes the tendency for shuffling steps to get faster and faster, with stopping being difficult or 'impossible'. Festination is a particular problem for some people with Parkinson's when using slopes, ramps and walking downhill. Use of self-generated or externally produced rhythmical sound such as chanting 'one, two, one, two', singing a song with a suitably regular beat, or using music or a metronome, may be of benefit in regulating stride and thus inhibit festination ('falling into step' with an external rhythm or beat is a phenomenon common to all group-dwelling creatures).

Visual cues for starting and unfreezing

- Someone else can assist by placing one of their feet at a right angle in front of the closest foot of someone who has frozen.



- Stepping over such an obstacle (with a verbal prompt such as 'step over my foot' if needed) may trigger the restart of walking.

If freezing in the same place occurs regularly, floor strips may solve these 'motor blocks' in that area. Floor strips are of particular use in doorways, corners of corridors or in a narrow area, such as between furniture. Contrasting coloured sticky tape can be used, eg masking tape. (NB: Strips will need to be renewed with fresh tape from time to time as they tend to get scuffed by vacuum cleaning, etc.)

Outdoor and community mobility

Freezing in busy places, eg supermarkets, libraries and town centres, may discourage people with Parkinson's from participating in previously enjoyed pursuits. To promote continued participation in public life, a disabled person's parking permit should be considered, to allow best use of limited stamina, 'on' time and to allow car doors to be opened as wide as possible to aid getting in and out.

Where difficulties with moving in busy or unfamiliar environments are reported:

- build confidence in the use of personalised management strategies for freezing
- encourage realistic pacing of activity
- teach the 'map reading' approach (see below) for walking in busy or unfamiliar places

A wheelchair for use outdoors may suit some people who are very unsteady, or who tire very quickly when walking, to enable continued participation in society. Use of Shop Mobility and other wheelchair loan schemes at many public recreation facilities and in some large shops, as well as pre-arranged assisted-transit facilities at airports, should all be considered for ease of mobility, when appropriate.

Map reading approach – for ease of walking in complex environments

Allow time to pause, look and plan the immediate route ahead at regular intervals. To do this:

- 1 Pause** – step to one side, eg just inside a doorway or out of the main flow of other people (so as not to cause an obstruction). Touch something solid, like a wall or lamppost, to aid balance.
- 2 Look** at the area ahead, check for obstacles, eg boxes, lampposts, children, trolleys, uneven ground, turns in a pathway, etc.
- 3 Plan** – plot the exact route to be taken as far as can be seen.
- 4 Walk** – set off to walk to that point.

Repeat this 'Pause, Look, Plan and Walk' strategy as often as needed, as each new area comes into view.

In addition, when walking along a busy street, walk along near the shop-fronts, well out of the way of lampposts and other street furniture. When facing oncoming people in this manner, there is minimal decision-making about which side to pass each other on, and so also less gait difficulty.

Strategies for difficulties in starting an action/start-hesitation

If starting an action is a problem, mentally rehearsing doing the action without difficulty and involving as many senses as possible during the imagined practice will aid subsequent performance of the action.

Recalling a memory of doing an action with ease, such as remembering drinking in a former situation, will prime neural circuits which are the same as those used for actual performance of that specific task.

Imagining or remembering doing the action(s) in detail, as in the example below, and without any difficulty is essential for this method to be effective. If failure is anticipated, it will be reinforced neurally.

To get up from an armchair, when 'feeling stuck'

- 1 First, imagine moving to the front of the seat.
- 2 Next, imagine placing feet close to the chair and slightly apart.
- 3 Hands ready to push down on the armrests...
- 4 And then, imagine the feeling of pushing down through legs and arms, and rising up easily, into a standing position.
- 5 After having briefly run through the actions in the mind, prepare for real action with a 'one, two, three ... stand', or other phrase to suit, followed by the actions just imagined.

Methods for reducing the risk of falls

By employing some of the strategies below, it is usually possible to reduce the frequency of falls and near-falls.

Fixed rails (including extra stair rails, newel rails and grab rails by steps and other awkward locations) and toilet frames, if needed, should be floor-fixed as a tendency for these to 'wobble' exacerbates gait problems such as freezing and poor balance. It can sometimes help to fix a grab rail horizontally on the wall opposite the top of the stairs as a target to aim towards if freezing on the top step of the stairs is reported.

For tasks usually done in a standing position, such as washing at a basin or working in the kitchen or greenhouse, a perching stool (adapted by adding a latex netting cover, if a non-slip surface is required) may be useful, especially if one hand is being used by

the individual to aid balance when working in a standing position.

If dizziness or light-headedness is experienced on rising from lying or sitting (signs of possible postural hypotension), a doctor may be able to help manage this. In addition to using any medication prescribed, it is recommended that the steps listed below are followed if any feelings of light-headedness remain.

- After lying or sitting for a while, always rise slowly and in stages.
- Before getting up, march legs a few times on the spot and flex ankles up and down a few times to exercise calf muscles and thus pump extra blood through the system.
- Rise carefully and pause to concentrate on feeling well balanced and clear in the head before walking off.

Some general strategies for improving gait and balance

Strategies such as the methods below can be taught to enable people with Parkinson's to enhance their general stability during walking.

- Make it a habit to concentrate on walking and avoid non-essential talking while moving along. If possible, pause to speak and touch something solid, eg a wall or lamp post, to aid balance while talking.
- When turning a corner, turning away from a cupboard or turning to sit down etc, always turn feet first.

Remember when turning...

FEET FIRST!

A cue card, to prompt turning steadily. A similar cue card can be made up and supplied to be placed where it will be easily seen in a room such as the kitchen or bathroom.

- If a tendency to 'miss the turn' when changing direction, eg from a corridor into a room, is troublesome, breaking up the route and stopping at points where turns are needed before turning (feet first) and walking on may help.
- In a wide, spacious area, walking in an arc to change direction is safer than an abrupt or pivoting turn.
- When looking or reaching up, prepare stance with feet shoulder width apart and one foot a pace in front of the other beforehand.
- If a walking aid such as a stick or a wheeled walking-frame is found to be useful, encourage use to improve balance. Liaise with physiotherapist about suitable walking aids if possible.
- Use of lighting on night visits to the toilet is strongly recommended. An automatic night-light or two, or a touch light by the bed can be helpful.
- Good lighting on stairs is also recommended.
- Extra banister rails, spiral (newell) rails for corners on stairs and grab rails by steps or by the toilet can be very helpful. The need for fixing these in frequently-used environments should be considered.

Encourage review of the floors around the home and frequently used environments:

- Reducing the number of contrasting colours and textures from rugs and mats in frequently used areas will improve the flow of walking.
- Ensure floors are clear of clutter and trailing flexes.
- Consider re-arranging furniture to reduce narrow spaces, such as when coffee tables are kept in the centre of a living room, to ease the flow of walking in that area (consider the need for help to move furniture, as this poses a risk to balance).
- If choosing new carpet or flooring, select plain, short-pile styles if possible.

Carrying even small, light, items when walking can distract from fully focusing on balance. So, where possible, promote the use of alternatives. Instead of carrying items in the hands, consider the use of:

- pockets in clothing or in an apron
- a lightweight shoulder bag (ideally with a strap long enough to be worn diagonally across the chest, so it won't slip off the shoulder)
- a body-belt bag, worn around the waist – for carrying small items such as pens, keys, mobile phone and glasses. One with a wide opening and a large tag on the zip will be easiest to use
- a small backpack (if possible, the user should sit or ask for help to put it on and off. Also for shoulder bags)
- trolleys – high platform-style trolleys are often useful but are not always suitable as they may increase a tendency to 'break into a run' (festination of gait).
If considering the use of a trolley, assess gait in small spaces and observe posture. The trolley should not be held too far ahead of the body and should be set at a height to avoid stooping. Shops, railways and airports often provide trolleys for customer use
- a net bag on walking frames

or encourage asking someone else to carry items, eg on stairs.

Dyskinesia – If a medication review is unable to 'damp down' dyskinetic episodes, it may help to advise about ways to pace routines and plan for coping with episodes, considering positions, eg sitting or lying, and activities, like dancing or walking, that help or exacerbate uncontrolled movements. Walking at a slightly increased speed and in

time to a regular beat when dyskinetic may improve gait and reduce the likelihood of falling.

If a tendency to fall is reported, regular calcium supplements may be recommended to maintain the strength of bones and reduce the risk of fractures associated with falling. A blood test may need to be arranged by a supervising doctor prior to considering calcium supplements.

If falls sometimes occur, it is advisable to **carry a means of calling for assistance**. A whistle, telephone community-alarm button (or similar 'fall alert' pager), the button part of a cordless doorbell (short range, battery-operated) or a mobile phone may suit the situation. Encourage the use of an appropriate alerting device, including when visiting the toilet at night.

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

Some methods for addressing poor posture

- Encourage improved awareness of poor posture and strategies to improve it.
- Consciously straighten up regularly, starting from the hips if sitting or the knees if standing.
- Check and correct posture regularly, or ask a companion to prompt to 'straighten up' from time to time.
- Practise standing with the back against a suitable blank piece of wall. Try to stand as straight as possible with the heels as near to the wall as is comfortable. Make contact between the back of the head and the wall when able. Hold this position for a

brief time, once or twice daily. Gradually build up to holding this position for one minute or so each time.

- Lie as flat as is comfortable on the back (supine), for 10–20 minutes during the day to maintain length of ligaments and avoid development of contracture.
- Use as few pillows as possible at night.
- Ensure suitable seating is available.
- Consider using a car safety-restraining strap, if a passenger tends to lean towards the driver when travelling by car.

The Alexander technique may be helpful for improving day-to-day movement. 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).

In a randomised, controlled trial, three groups of people – one receiving lessons in the Alexander technique, another receiving massage, and the third having no additional treatment – all diagnosed with idiopathic Parkinson's disease, were examined. Measures were taken pre- and post-intervention, and at follow-up six months later. People who participated in a course of 24 lessons in the Alexander technique showed improvements compared with the group that didn't receive additional treatment. Improvements were shown in self-assessment ratings using the Parkinson's Disease Disability Scale at the best and worst times of the day. Secondary measures included the Beck Depression Inventory and an Attitudes to Self-Scale. The comparative improvement for the Alexander technique group was maintained at six-month follow-up.

For more details, see the PDS booklet *Complementary Therapies and Parkinson's disease*.

Transfers

Sit-to-stand transfers from chairs, toilet and bedside commonly present difficulties for people with Parkinson's. It is not, therefore, uncommon for physical assistance to be required by people with Parkinson's when rising from a seated position. Generally, appropriate elements of the movements to rise from sitting are performed but are done so in the wrong order, possibly leading to a series of failed attempts

before managing to fully get up. Use of suitably worded verbal cues may be of benefit. A carer may be able to give verbal cues instead of physical assistance using this type of approach. 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.

Method for getting up from an armchair

Move bottom to front of seat.

Place feet close to chair and slightly apart.

Put hands ready to push down on armrests.

And ... push down through legs and arms.

One, two, three and UP.

Example of a cue card to aid rising from sitting

Car transfers NB: All drivers who have been diagnosed with Parkinson's should be advised to notify the Driver and Vehicle Licensing Authority (DVLA) and their car insurance company of their condition. Each individual's fitness to drive will be assessed by the DVLA and if permission to continue driving is granted, this will be reviewed at a specified interval (generally every one to three years).

Allow space for the car door to be as fully opened as possible (a disabled parking permit will usually enable access to suitably sized parking space). Consider the use of foam seat wedge if the seat slopes backward, adding to difficulty rising or causing discomfort. A flexible fabric turning-disc with a non-slip base placed on the seat before travel may be of use when turning to get legs in and out of a car. A portable handgrip that slots into a suitable door-latch striker plate (fitting most cars) on the side away from the door hinge can be helpful. It works on both driver and passenger sides and allows holding onto something with both hands (with the inner door handle or sill of a fully lowered window being employed on the other side) when entering and

Seating

Well-proportioned seating is especially necessary for people with movement disorders and acquisition of a suitably sized armchair should be considered, or made to measure if such a seat is not available. Chair raisers may suit some situations so the need for this should be assessed when possible. Powered riser-recliner-type chairs 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. Consider using the

exiting a car. The handgrip is portable and can be easily taken on journeys in various cars, eg taxis.

Toilet transfers As already stated, free-standing toilet aids are rarely suitable for people with Parkinson's. As Parkinson's is a long-term, degenerative condition, installation of fixed grab rails to aid toileting should be considered where difficulties are identified. Use of additional height, as provided by various forms of raised toilet seat, should be avoided whenever possible, as this will tend to exacerbate any tendency towards constipation, which is common in people with Parkinson's. Consider the need for clothing adaptations to aid going to the toilet, eg fitting a small split ring (as used on a key ring) to trouser zip fobs makes using the zip easier.

Bath transfers Where difficulties are reported, consider the need for supervision during transfers in and out of the bath. A non-slip mat should be recommended. Well-placed grab rails may help with stability when stepping in and getting out. A wide shower board, or possibly a swivelling bath-top seat may suit people who use an over-bath shower fitting. A powered bath aid may suit those having major difficulty when needing to bathe, eg due to incontinence.

Showering A level-floor shower (wet room) with seating and handrails would suit many people with mobility problems associated with Parkinson's. A half-height, fixed or free-standing screen can be used to prevent the feet of an assistant getting wet when helping, if using level-floor shower facilities. In shower cubicles, if solid walls are accessible, fixing a wall-mounted folding seat and handrails to suit, or using a corner seat and grab rails will often be beneficial.

management strategy to aid rising from an armchair already outlined.

Dyskinesia occurring when sitting in an armchair, eg when relaxing in the evening, may cause sliding forwards on the seat and possibly falling out of the seat altogether. In this case, a deep pressure-relief foam cushion with a ramped (thicker) front edge may help if used on the chair (in place of the seat squab if suitable). A piece of Latex-covered string netting or other non-slip material may be required to anchor the

ramped cushion to the surface below. A one-way glide fabric band or Latex netting on top of the seat cushion may help if dyskinesia is only mild to moderate in intensity.

When rising from a dining-type chair without arms, start by turning 90° towards the direction to be taken

while seated. The top of the back of the chair and the nearest edge of the table on the other-hand-side can then be used to aid rising. But do not use the edge of a table with a central leg/pillar, as it will tip up.

For management of bed mobility problems, see the 'Night-time issues' section below.

Early morning and self-care routines

Functional abilities will be improved once the first dose of anti-Parkinson's medication has been absorbed. It therefore helps to wash and dress after taking the first dose of the day. Establishing usual times of

waking, getting up and taking the first dose of anti-Parkinson's medication will help to ensure that where non-optimal use of medication is identified, this can be reviewed with the supervising PDNS or GP.

Fatigue

People with Parkinson's often find that they tire quickly following relatively short periods of (limited) physical exertion. The following methods may help fatigue management:

- Use of labour-saving and energy conservation opportunities.
- Prioritisation of how to best use limited reserves of energy.

- Delegation of some tasks to optimise use of time and energy.
- Pacing of activity, by balancing periods of activity and rest through the course of the day, and over the course of the week, will allow regular recuperation times and minimise episodes of intense exhaustion resulting from delaying resting for too long.

Poor saliva control

Excess saliva building up in the mouth troubles some people with Parkinson's, often causing social embarrassment. This situation is due to a reduction in frequency of automatically swallowing saliva as it is produced, rather than because of an excess in saliva production. Improving posture will improve the ability

to control saliva to some extent. Developing the habit of swallowing a couple of times when saliva is felt to be building up will better control this problem than using a handkerchief to absorb secretions, which also contributes to the development of dehydration, unless extra fluid is taken to replace what is lost.

Night-time issues

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 trigger admission to a care home, while for those with a frequent need for assistance at night, this may cause 'intolerable' stress on their carer.

People with Parkinson's tend to 'travel across the mattress' when turning in bed and so may need more space than usual. A powered, profiling bed or mattress elevator is sometimes purchased or provided for people with Parkinson's. However, as bed mobility difficulties tend to arise from rigidity of the trunk and subsequent difficulties with rolling, problems often persist despite the help of automatically raising the head end of the mattress.

It may be possible to reduce or eliminate nocturnal episodes of confusion and hallucinations by keeping a

light on at night, having a radio playing softly or keeping the windows open for night sounds to enter the bedroom, thus reducing the effects of lack of sensory stimulation during the night.

Strategies to promote night-time mobility and independence

The following strategies may help to promote increased independence in people with Parkinson's during the night. Introduction of one or two of these methods will generally be sufficient to improve function at a particular time. Additional strategies can then be introduced as needed as, over time, the condition progresses.*

- Consider using a bed-side grab rail to aid turning and rising. These are available in various styles to suit a variety of beds and situations, eg bed-stick, bed-lever, rise-easy bed aid and mattress elevator with integral grab rail. If used, it is important that the rail is fitted correctly at the shoulder level of the bed occupant to provide a comfortable grip.
- Teach movement methods for turning over, adjusting position in bed and getting out of bed. If a bed aid is used, ensure the person has been shown how to use it comfortably.
- An ergonomic movement sequence, as used by people who have lower back pain, usually suits people with Parkinson's who find turning and getting out of bed difficult (see example cue card below).

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

Example of a cue card for prompting turning over and getting out of bed, starting from lying on the back

- Teach bridging (when lying on the back, bend knees up and raise hips off the mattress) then moving a small distance sideways, before lowering hips again. Alternating movements of the three main sections of the body to move across the mattress, shifting one section of the body at a time (head and shoulders being one section, hips another section and feet being the final section) will enable easier repositioning away from the edge of the bed or to straighten up if lying at an angle across the mattress.
- Encourage getting into bed by sitting on the bedside, shuffling the bottom well back and lifting legs onto the bed before lying down (getting into bed knees first tends to become increasingly awkward as Parkinson's progresses).
- Consider the need for facilities (commode, urinal) to pass urine nearer the bed during the night, if the journey to the toilet is via stairs or too far for convenience or safety, in the case of poor balance.
- Encourage the use of lighting when getting up to go to the toilet at night, eg a touch-light or automatic night light(s).
- Consider the use of satin night wear or a satin, half-length sheet as shown opposite (but not both together as this would be too slippery).

Using a satin half sheet

Many people with movement difficulties find that using a satin sheet positioned across the top two-thirds of their bed makes it much easier to move, as the satin reduces friction and adds ease to their movements. It is important not to have the satin covering the bottom third of the bed, as this allows the feet to grip on the standard sheet below when moving.

Sometimes full-length satin sheets are used to aid moving in bed but these tend to be less beneficial as the feet tend to slide about, so leg muscles cannot give the power required to aid movement.

- Ordinary satin from a dressmaking fabric supplier is all that is needed, costing approximately £5 a metre.
- Buy enough to lay over the top and sides of the mattress, plus an extra 46cm (18in) minimum for each side to tuck well under the mattress.
- Alternatively, stitch a patch of satin onto one side of a sheet (within the dotted area shown on the diagram opposite). By leaving approx 23cm (9in) of standard sheet along the outside edge(s) of the mattress, the

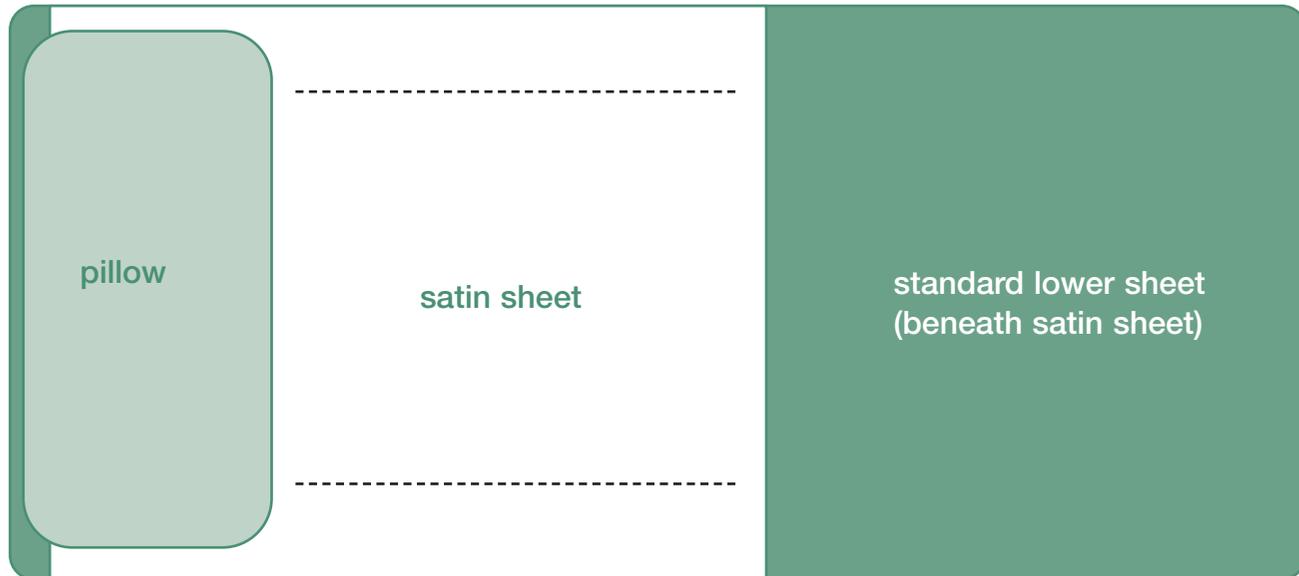
possibility of a short person slipping off the bedside when getting in or out is reduced.

- Hem cut edges if possible, to avoid ends fraying.

Usually satin is machine washable at 40°C. It is quick-drying and, if desired, it can be ironed on a cool temperature setting.

NB Hazard warning!

Consider whether the use of satin would cause the person to slide off the bed, as could occur, with a short person using a high bed. If so, avoid using satin, or use the satin patch method described.



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Diagram showing how to position a satin sheet on a single bed

Relevant resources from the PDS

Booklets

Competencies: An integrated career and competency framework for nurses working in Parkinson's disease management (code B115)

Complementary Therapies and Parkinson's Disease (code B102)

Keeping Moving: An exercise programme for people with Parkinson's disease (code V011 – and booklet or code B074 – booklet only (free of charge))

Looking After Your Bladder and Bowels in Parkinsonism (code B060)

Sex and Intimate Relationships (code B034)

The Drug Treatment of Parkinson's Disease (code B013)

Information sheets

Falls and Parkinson's (code FS39)

Foot Care and Parkinson's (code FS51)

Handwriting and Parkinson's (code FS23)

International Travel and Parkinson's (code FS28)

Low Blood Pressure and Parkinson's (code FS50)

Occupational Therapy and Parkinson's (FS97)

Pain in Parkinson's (code FS37)

Physiotherapy and Parkinson's (code FS42)

Pill Timers (code FS53)

Speech and Language Therapy (code FS07)

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The pharmacist's guide to Parkinson's disease

Introduction

Drug therapy is a key component of the overall management of Parkinson's. Furthermore, a patient's drug therapy often requires careful adjustments to obtain optimal effect – the drugs used cause a wide range of side effects and many have significant interactions with other drugs.

But before commencing drug therapy, it is important that an accurate diagnosis of Parkinson's disease is made. Recent guidelines have reinforced the view that this should be done by a specialist with expertise in the differential diagnosis of the condition. A patient with suspected Parkinson's disease should be referred, untreated, to a specialist. If the symptoms are mild, they should be seen within six weeks, but new referrals in later disease with more complex problems should be seen within two weeks.

A significant proportion of patients given a diagnosis of Parkinson's by their GP, in fact, have some other cause for the symptoms they are experiencing. A number of drugs can produce parkinsonism

(see table below) and other conditions can present a picture similar to that of Parkinson's. It should be noted that essential tremor (sometimes misdiagnosed at Parkinson's) is ten times more prevalent than Parkinson's.

Drugs which may produce parkinsonism

Cinnarizine
Flunarizine
Pethidine
Sodium valproate
Amiodarone
Lithium
Methyl dopa
Metoclopramide
Phenothiazines
Calcium-channel blockers
Selective serotonin reuptake inhibitors (SSRI)

Drug therapy

Drug therapy does not cure the condition and there is very little evidence that it can slow disease progression. However, substantial improvement in symptoms may be achieved with the drugs currently available. Unfortunately, these drugs often produce unwanted side effects, so it is important to balance the benefits of therapy against the adverse effects that a patient may experience. In the early stages, when symptoms are still quite mild and are having little effect on a patient's mobility and quality of life, it is often best to withhold drug therapy. Clearly, the patient and their family should be key influencers in deciding the appropriate point to start drug treatment. A prerequisite for this level of agreement is access to information and

help in gaining an understanding of the condition and the treatments that may be appropriate. Information, such as that in the Parkinson's Disease Society's (PDS) booklet *The Drug Treatment of Parkinson's Disease*, can be a great help to the person with Parkinson's in making an informed decision.

Treatment is usually lifelong but changes in the types and combinations of drugs, dosages used and administration schedules will be necessary. This may be due to altered symptoms associated with disease progression or the development of adverse effects and intolerance to the drugs. Generally, drugs used to treat Parkinson's fall into one of a number of groups,

depending on their mode of action. These are briefly discussed below. When necessary, more detailed information should be sought from standard resources (eg British National Formulary, Martindale, SPCs) and

specialist sources of information focusing on the management of Parkinson's.

Drug groups

Levodopa

Levodopa (L-dopa) is converted in the body to dopamine, the neurotransmitter that is depleted in certain parts of the central nervous system in Parkinson's. L-dopa is administered in an attempt to build up levels of dopamine. Dopamine itself is ineffective if administered since it does not pass across into the brain. L-dopa is always given combined with another drug, called a peripheral dopa-decarboxylase inhibitor, to reduce the extent of peripheral metabolism to dopamine. There are two oral preparations available:

Co-careldopa (L-dopa + carbidopa) [Sinemet®]

Co-beneldopa (L-dopa + benserazide) [Madopar®]

A special gel formulation of **co-careldopa [Duodopa®]** is also available for administering directly into the duodenum as an infusion via an external pump. This treatment requires surgical intervention. It is very expensive (approximately £28,000 annually) and very few patients in the UK are receiving this form of therapy.

L-dopa has been in use for more than 30 years but still remains the most effective drug available for treating Parkinson's. However, the patient may experience side effects, including dyskinesia (uncontrolled or excessive movement). These effects are more common after a patient has received this drug for a few years and may also lead to other motor complications, including motor fluctuations (periods when the patient is 'on' and can function well, alternating with periods when the patient is 'off' and their weakness substantially restricts mobility).

A further problem that often occurs after some years is 'end-of-dose' deterioration. This results in the drug's effects lasting for a progressively shorter time. Adjustments in dosage regime, the use of different formulations or the addition of adjunctive therapy are different ways of trying to regain good control of symptoms when these problems occur. Other side effects include nausea, anorexia and postural hypotension, which may be more troublesome in the early days of treatment. These effects are

less troublesome if the dosage is increased slowly.

The anti-emetic domperidone may be given if necessary to reduce the severity of nausea and vomiting.

Domperidone is the only anti-emetic drug recommended for people with Parkinson's. Other drugs, such as prochlorperazine and metoclopramide, will worsen symptoms by blocking dopamine receptor sites in the brain.

A wide range of L-dopa preparations are available, including controlled-release and dispersible preparations; the relevant SPC or other authoritative text should be used, if necessary, for details of dosages and administration schedules of these. The dispersible formulation can provide a quicker onset of effect. For this reason, it is sometimes deployed as a 'rescue' therapy when patients experience 'off' periods. The duration of beneficial effect is less than that with standard formulations. The controlled-release products are sometimes useful when fluctuations in response occur with ordinary preparations.

Dopamine receptor agonists

These drugs have a direct effect on post-synaptic dopamine receptors in the striatum, mimicking the effects of naturally occurring dopamine. The older drugs in this class are derivatives of the ergot alkaloids and have the potential to cause serious adverse effects (fibrotic reactions). Dopamine agonists that are not derivatives of ergot are also available and do not cause this problem.

Ergot derivatives

Bromocriptine [Parlodel®]

Cabergoline [Cabaser®]

Pergolide [Celance®]

Non-ergot derivatives

Apomorphine [APO-go®]

Pramipexole [Mirapexin®]

Ropinirole [Requip®]

Rotigotine (transdermal patch) [Neupro®]

Dopamine agonists are used as monotherapy, especially in younger patients and those with symptoms that are not too severe. They are also used as adjunctive therapy with L-dopa when L-dopa alone is no longer providing a satisfactory level of control. Dopamine agonists may also allow a reduction in dosage of levodopa with a subsequent decrease in its adverse effects.

The dosage of dopamine agonists should be increased gradually to minimise the severity of side effects. Generally, ropinirole and pramipexole are preferred when initiating treatment in new patients as these drugs do not produce the serious fibrotic reactions that can be associated with bromocriptine, cabergoline, lisuride and pergolide. Dopamine agonists tend to cause fewer motor complications than L-dopa but neuropsychiatric adverse effects (eg hallucinations and psychosis) and changes in behaviour can be more of a problem.

Apomorphine can only be administered by subcutaneous injection or infusion, though other routes of administration are being tested. It is only used in advanced Parkinson's, which cannot be controlled with other drugs. Since apomorphine is highly emetogenic, co-administration of domperidone is necessary, starting at least a couple of days before the apomorphine itself. The optimal dosage of apomorphine has to be ascertained for each patient, balancing beneficial effects against any side effects that occur. If more than ten injections daily are needed, consideration is given to infusing apomorphine during the daytime via a small portable syringe driver, designed to enable the dose rate and size of any bolus doses to be set accurately.

A transdermal patch containing the dopamine agonist rotigotine has been developed. This route of administration avoids first-pass hepatic metabolism and obviously avoids any potential problems with absorption from the gastrointestinal tract. Transdermal rotigotine may be suitable for patients suffering with dysphagia, which can be a significant symptom with Parkinson's and can create difficulties in swallowing tablets. However, allergic skin reactions may occur and these should be monitored.

Monoamine oxidase-B (MAO-B) inhibitors

The enzyme monoamine oxidase-B (MAO-B) inactivates dopamine in the brain, reducing the levels available for neuronal transmission. Inhibitors of MAO-B reduce this breakdown, increasing the amount of dopamine

available. There are two MAO-B inhibitors available for treating Parkinson's disease in the UK:

Selegiline [Eldepryl®]

Rasagiline [Azilect®]

MAO-B inhibitors are used with L-dopa to reduce 'end-of-dose' deterioration, which is often a problem when Parkinson's has progressed. These drugs are occasionally used as monotherapy in the early stages of the disease but generally other forms of treatment are preferred. Selegiline can be administered as ordinary tablets or as freeze-dried tablets, designed to dissolve on the tongue.

Selegiline and rasagiline can cause dry mouth, constipation and headache, but the insomnia that can occur as a side effect with selegiline is not produced by rasagiline. This is because selegiline produces an amphetamine metabolite in the body whereas rasagiline does not. Patients should be advised to avoid taking the selegiline during the late afternoon or evening to reduce the likelihood of insomnia. However, here is also a selegiline preparation called Zelapar, which comes in the form of freeze dried tablets designed to dissolve on the tongue.

Catechol-O-methyl transferase (COMT) inhibitors

Another enzyme, catechol-O-methyl transferase (COMT) metabolises both L-dopa and dopamine in the body. Administering a drug that blocks this enzyme increases the availability of L-dopa and prolongs its therapeutic effect. Two COMT inhibitors are currently available:

Entacapone [Comtess®]

Tolcapone [Tasmar®] (use is tightly controlled due to potential toxic effects on the liver)

In addition there is a combination preparation of **co-careldopa plus entacapone [Stalevo®]**

Tolcapone was the first COMT inhibitor used in clinical practice, but reports of fatal liver damage led to it being withdrawn from use in 1998. However, it has now been re-introduced, but only for patients who do not respond to entacapone. In these patients, liver function tests must be carried out regularly to identify early signs of hepatotoxicity. If this occurs, the tolcapone must be stopped straight away.

COMT inhibitors are not used as monotherapy, but as adjunctive therapy in patients on L-dopa who are experiencing 'end-of-dose' deterioration that cannot be controlled by adjustments in L-dopa dosing.

These drugs can cause nausea and vomiting, dry mouth and abdominal pain. Entacapone colours the patient's urine reddish-brown and tolcapone intensifies urine colour. Patients should be warned of this effect. The dosage of L-dopa may need to be reduced since its increased bioavailability, resulting from the administration of a COMT inhibitor, may lead to orthostatic hypotension and adverse motor effects.

Glutamate inhibitors

Amantadine [Symmetrel®] is not as effective as other drugs used to treat Parkinson's. There has been uncertainty about its mode of action but it seems likely the antagonist effect on glutamate is responsible for the drug's effect on Parkinson's disease. Amantadine may also have effects on dopaminergic and cholinergic pathways.

This drug has relatively weak effects on symptoms but may improve bradykinesia, tremor and rigidity, providing these are not too severe. It is probably more useful in treating dyskinesias that occur in later stages, as the disease progresses (see also under L-dopa). Often, the beneficial effects of amantadine decrease

over a few months, reducing the usefulness of this drug. It may impair a patient's ability to concentrate and sometimes causes dizziness and difficulties in sleeping. Livedo reticularis and oedema may also occur.

Anticholinergic drugs

Anticholinergic drugs are little used now in the treatment of Parkinson's; they are more effective in managing drug-induced parkinsonism. However, these drugs are occasionally useful in Parkinson's when tremor is the main symptom; they have little effect on hypokinesia, bradykinesia and rigidity. Drugs in this class include:

Benzatropine [Cogentin®]

Orphenadrine [Disipal®]

Procyclidine [Kemadrin®, Arpicolin®]

Trihexyphenidyl (formerly called benzhexol)
[Broflex®, Artane®, Agitane®]

Anticholinergic drugs produce a range of troublesome adverse effects, including dry mouth, blurred vision and constipation, as well as significant neuropsychiatric effects. For this reason, and the lack of efficacy in treating the more problematic symptoms of Parkinson's, these drugs have very limited value in treating this condition.

Pharmaceutical care issues

There are many pharmaceutical care issues that should be considered to ensure patients gain maximum benefit from their drugs and keep the risk of problems to a minimum.

A study carried out in three primary care trusts (St Helen's, Brighton and Hove City, and Coventry) demonstrated the value of pharmacists providing regular consultation sessions for Parkinson's patients (and/or their carers). During these sessions, patients were able to discuss their experiences with their medication and any concerns they had about the condition. The pharmacists provided support and counselling on their treatments, including side effects and potential interactions. Advice was also given for optimising dosage timing and, if appropriate, practical aids were provided to reduce problems with drug administration.

The most frequent problems which pharmacists identified were:

- uncontrolled and unmanaged symptoms
- the occurrence of side effects
- the need for review of dosage or treatment regimen

A total of 336 consultations were carried out in the study, resulting in nearly 600 identified 'interventions'. Three-quarters of the identified problems could be addressed by the pharmacist, without referral. More than 80% of patients felt the consultations were helpful and 70% felt they were gaining greater benefits from their drug therapy as a result.

The results of this study, plus the government's wish to make better use of pharmacists' expertise in drug therapy, should provide opportunities to further improve the drug management of patients with Parkinson's. In 2006, the Department of Health launched a framework for establishing Pharmacists with Special Interests (PhwSI), stating that such a development should build on pharmacists' core roles

and provide opportunities to maximise the contribution pharmacists make in specialist areas to ensure patients received the highest quality of care.

The Department of Health has also introduced a new contractual framework for NHS community pharmacy services. This has increased the range of services that pharmacists can offer. The Department of Health document specifically cites providing support to people suffering with long-term conditions, and carrying out Medicines Use Review (MUR). Parkinson's disease would clearly fall within the remit of the framework.

Concordance, compliance, communication

Much has been written about compliance and concordance, both of which are highly relevant to patients receiving medication for Parkinson's. As confirmed by the study carried out in community pharmacies, patients need to understand all aspects of their medication in order to maximise benefits and minimise risks. It is very important that patients are involved and are influential in decision-making. Good communication is essential in order to achieve this, and it is crucial that healthcare professionals recognise and understand those aspects of Parkinson's that may potentially compromise this (eg effects on speech, altered body language such as expressionless face, etc).

Dose timing

Many patients find that they are able to optimise control of symptoms by 'experimenting' with the time of doses (within the range prescribed). The patient should be advised to seek professional advice before doing this. Such patients are often anxious about anything that may then interfere with their individualised dosage timings.

Situations that cause particular concern are stays in hospital, where staff who are unaware of the complexities of treating Parkinson's often insist on administering medication at times in line with the ward's routine. Pharmacists can help to prevent this by explaining to nursing and medical staff the need for sticking to the times that the patient has found to be best, and by marking the prescription clearly with these. In many cases, it may be possible for the patient to self-medicate while in hospital, which helps to solve the problem.

If the patient does not have sufficient supplies of medication to take to hospital, it is important that the

pharmacist requests products that are the same or therapeutically equivalent. Changes in formulation type may affect bioavailability and control of symptoms.

Food and L-dopa

Nausea (and sometimes vomiting) may occur in the early days of treatment with L-dopa preparations. Taking doses after food often reduces this problem. In severe cases, the anti-emetic domperidone may be taken. Patients should be reassured that nausea and vomiting usually subside after taking the medication for a while. Once a patient reaches this stage, it may be preferable to avoid taking L-dopa preparations at meal times to ensure good and reliable absorption of the drug.

It should be noted that the bioavailability from controlled-release tablets of co-careldopa (Sinemet® CR) is increased when taken with food. Patients should also be made aware that the tablets should only be taken in the format provided due to the potential altered pharmacokinetics of drugs ground into powder, for example, to aid oral administration to a person with Parkinson's. Patients who have problems swallowing should consult a healthcare professional who can advise on other drug formulations.

Adverse effects

All the drugs used to treat Parkinson's have the potential to cause a range of adverse effects. This overview of pharmaceutical care is far too brief to include details and readers are advised to consult other texts for details. However, attention is drawn to the occurrence of sudden onset of sleep, which has been associated with taking L-dopa preparations and dopamine receptor agonists. Patients must be warned of the possibility of experiencing this effect with these drugs and told to avoid any activities where such an occurrence would present a danger (eg driving). Patients should only undertake such activities when they have been taking the medication for long enough that they can be sure they are not susceptible to sudden onset of sleep.

Studies have also shown that a small percentage of people with Parkinson's taking certain dopamine agonists will develop 'dopamine dysregulation syndrome'. It is important that advice is sought if the behaviour of someone with Parkinson's changes, for example, they may spend more, show aggressive

outbursts, develop an increase in risk-taking behaviour, an increase in sexual desire or develop other obsessive behaviours. Studies have highlighted that drug reduction or withdrawal can, in many cases, reduce excessive behaviours.

Drug interactions

The range of potential interactions between drugs used in the treatment of Parkinson's and other medications is vast, and beyond the scope of this publication. Basic information on these interactions can be found in Appendix 1 of the British National Formulary. It is important that pharmacists are always mindful of potential interactions with these treatments and some of the clinical effects can be severe.

In some cases, one drug should be stopped for a number of weeks before starting another, eg selegiline should not be commenced until five weeks after stopping treatment with the antidepressant fluoxetine. This interaction can result in hypertension and CNS excitation.

Withdrawal of therapy

If any of the drugs used for treating Parkinson's are to be stopped, it is important that this is done gradually. Abrupt withdrawal of certain drugs can result, albeit rarely, in neuroleptic malignant syndrome. This is a very serious condition that may cause death from complications of the respiratory, cardiovascular or renal system.

Relevant resources from the PDS

Booklets

Complementary Therapies and Parkinson's Disease (code B102)

The Drug Treatment of Parkinson's Disease (code B013)

Information sheets

Drug-induced Parkinsonism (code FS38)

Eating, Swallowing and Saliva Control in Parkinson's (code FS22)

Gambling and Parkinson's (code FS84)

Hallucinations and Parkinson's (code FS11)

Parkinson's and Hypersexuality (code FS87)

Pill Timers (code FS53)

Motor Fluctuations in Parkinson's (code FS73)

Further reading

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notes

pharmacist



The physiotherapist's guide to Parkinson's disease

Introduction

Physiotherapy or physical therapy can be defined as: 'A healthcare profession which emphasises the use of physical approaches in the promotion, maintenance and restoration of an individual's physical, psychological and social wellbeing, encompassing variations in health status.' (CSP, 2002)

Physiotherapy primarily addresses the physical components of rehabilitation, essentially, to maximise the functional capacity of a person and their role within society. Where people receiving physiotherapy have a longer-term condition, such as Parkinson's, physiotherapy is generally regarded as an active, ongoing process and one that should be client-focused in its approach and regularly reviewed.

Physiotherapy might incorporate only education and advice, ensuring maintenance of a current level of fitness and ability, or involve exercises specific to the needs of the person with Parkinson's to regain movement, prevent falls, maximise respiratory function or reduce pain. It also has a role alongside medical and surgical intervention to enhance the person's potential with these interventions.

In addition to physiotherapy, other physical adjuncts to therapy may include approaches such as the Alexander technique, yoga, conductive education or pilates – techniques that not only promote movement, but also are linked with social wellbeing.

The principles of physiotherapy for people with Parkinson's

- Early implementation of an exercise programme to prevent deconditioning and other preventable complications.
- Utilisation of a meaningful and practical assessment procedure to allow monitoring and identification of rehabilitation priorities.

- The identification of deterioration and timely, appropriate intervention.
- The opportunity for targeted therapy for restoration or compensation of function.
- The involvement of patients and carers in decision-making and management strategies.

(Turnbull, 1992)

The following section is an updated review of the information produced by the Parkinson's Disease Society (PDS) Working Party of Physiotherapists (Handford et al, 1997). Our thanks go to the previous authors.

The aim of this section is to provide physiotherapists with enough information to be able to understand, assess, plan and appropriately manage the effects of Parkinson's on people with the condition and their carers.

The evidence for this section of the pack is based on information from the following projects:

- The PDS part-funded Physiotherapy Evaluation Project (UK) that took place in 2000 (Ashburn, 2004), which provided information on the core areas of physiotherapy practice, plus a model by which it might be delivered.
- The Guidelines for Physiotherapy Practice in Parkinson's Disease (Plant et al, 2001), answering frequently asked questions about delivery of services for people with Parkinson's.
- During 2002/3, AGILE (a physiotherapy clinical interest group for physiotherapists working with older people) promoted these Guidelines to ensure working clinicians understood how to deliver the theoretical information in practice. From this informal consensus work came four recommendations for physiotherapists working with people with Parkinson's (Ramaswamy & Jones, 2005),

these being:

1 Physiotherapists should locate the aim of the episode of care as being either (1) maintenance of the patient's current movement capability, (2) management of complex problems or (3) palliative care.

2 Physiotherapists should ensure their baseline assessment comprises a comprehensive set of data against which to monitor change with disease stage.

3 Physiotherapists should use an appropriate outcome measure to evaluate the impact of a specific intervention on aims of treatment.

4 Physiotherapists should relate treatment strategies to problems identified at assessment.

These recommendations are for therapists who are unfamiliar with dealing with people with Parkinson's. They give guidance on the assessment components, management strategies and measures of assessment and outcome most useful in their treatment.

- The RESCUE project – a multi-centre study on the effects of cueing.
- Association of Physiotherapists in Parkinson's Disease: Europe (APPDE), providing international networking opportunities and the support for research. It also produces resources for physiotherapists with an interest in Parkinson's.

- The Clinical Practice Guidelines for physical therapy in patients with Parkinson's, ie the 'Dutch Guidelines' (Keus et al, 2005).

- The American Association of Neurology's Parkinson's disease guidelines (AAN, 2006).

- NICE Clinical Guideline on Parkinson's disease: diagnosis and management in primary and secondary care (NICE, 2006).

This section on the role of the physiotherapists in Parkinson's is not documented in true academic style. Clinicians who specialise in this branch of neurological physiotherapy have written it for other practitioners. For this purpose the content combines research evidence with clinical expertise and advice where proof is unavailable at this current time.

It is not intended as a stand-alone text and throughout the section there are references to look up, recommended reading plus websites containing more detailed information.

The information provided is not prescriptive in nature; it is written to form the basis of a clinician's understanding of Parkinson's disease and to start the process towards making clinical decisions.

Movement abnormalities in Parkinson's disease appropriate for physiotherapy intervention

The movement and postural problems in Parkinson's are numerous and complex. Below are some difficulties that a survey of PDS members identified (Oxtoby, 1982).

	Percentage
Walking	67
Turning in bed	63
Sitting down and getting up	54
Bathing	53
Getting in and out of bed	50
Freezing	48
Climbing stairs	44
Initiating walking	41
Walking through doorways	39

The survey was pivotal in highlighting the need for physical intervention in people with Parkinson's.

The problems experienced by people with the condition are usually caused by a combination of factors and, while several may be experienced at one time, the most debilitating problem as reported by the individual will vary according to their perception and needs. A combination of mobility problems and postural instability that can occur in the later stages of the condition may result in falls.

The three main symptoms of Parkinson's all cause movement problems:

Bradykinesia is a cardinal symptom of Parkinson's, affecting 78% of people with Parkinson's, and is an area that can be influenced by physiotherapy (del Olmo and Cudeiro, 2005; Darmon et al, 1999; Morris et al, 1994a). It is caused by a reduction in speed and an inability to maintain the amplitude of a movement. While bradykinesia often refers to just the reduction in

speed, hypokinesia may be used to describe a reduction in amplitude. Akinesia occurs in the form of initiation problems, freezing mid-movement, thought or speech, and termination problems.

Rigidity is an increase in muscle tone and is described as 'lead pipe'. Tone is increased throughout the range of movement and is completely different from the 'clasp knife' spasticity of strokes. In the wrist and elbow, the rigidity may be combined with or interrupted by tremor, giving a 'cogwheel' feel to it. The difference in this type of increased tone is that it is caused by the lack of sufficient neurotransmitter (dopamine). This results in a body-wide effect, as opposed to a lesion affecting upper motor neurone inhibition and transmission to a specific muscle (or group of muscles), as seen in spasticity. Although the tone of people with Parkinson's can be affected by physiotherapy intervention in the short term, there is no evidence to demonstrate the efficacy of normal movement strategies having a long-term effect on decreasing the effects of rigidity. It is suggested that physiotherapists concentrate on maintaining the available range of movement, especially in the major limb joints and the trunk, in order to minimise the effects of rigidity.

Tremor affects 70% of people. Some neurologists define Parkinson's as 'tremor-dominant' or 'tremor non-dominant'. It frequently starts in one hand then spreads to the other and, later, more widely throughout the body. Tremor in Parkinson's is characteristically at a frequency of about five per second; when it involves the thumb, it has a 'pill-rolling' effect. Tremor is worse at rest, usually lessens with intentional movement and is absent during sleep. Obvious tremor can be a great handicap to someone when it does not improve on movement. Difficulties can arise when eating and drinking and some may find a manually-based occupation more difficult to manage, which can affect their role and chosen lifestyle.

Of the clinical signs reported by people with Parkinson's, tremor may be the first obvious symptom to appear. As Idiopathic Parkinson's Disease (IPD) usually starts as a unilateral process, a person may report that they had noticed for some time that when they were tired, their walking had become slower or one leg felt stiffer, or their writing had become smaller and less legible, etc.

These are signs of unrecognised bradykinesia and rigidity. Some people with Parkinson's experience non-motor symptoms such as pain, altered temperature control or loss of sense of smell, etc before they experience physical symptoms.

Physiotherapists are often the first people to recognise the symptoms of the condition through their subjective and objective assessment skills. The length of time from diagnosis is often not an accurate reflection of the onset of the condition; this is an important factor in determining the stage of the disease and, therefore, the aims of physiotherapy at that stage.

Postural instability is a later-stage symptom, characterised by a combination of balance issues and autonomic changes that can lead to a susceptibility to falls and injury. This requires careful assessment by the multidisciplinary team, and instigation of the necessary intervention, which is most likely to be multifactorial in nature. This is not to say that balance problems will not be picked up in the earlier stages in the tests for proactive and reactive balance responses.

Dyskinesias (or abnormal involuntary movements) are common side effects of medication. They can, in severe cases, be very disabling and add to the risk of injury. People with Parkinson's can often temporarily and consciously improve both movement and posture. However, since the symptoms of the condition and the ageing process cannot be switched on or off at will, it is reasonable to assume that there are other factors influencing movement in Parkinson's.

Factors unrelated to Parkinson's may also affect movement, for example the ageing process. Over the years, muscles lose mass and, if not used effectively, can become weaker. The range of movement at the joints and the speed of walking also both become reduced. It should be noted that an active 65-year-old may well be fitter than an inactive 30-year-old. However, old age increases the risk of disabling condition, which can also affect movement and gait. Anyone used to treating older people will know that there may be problems unrelated to the main illness which may make life difficult for people with Parkinson's, for example low chairs/beds, inappropriate walking aids, buttons and zips that cannot be done up/undone.

Key points

- Perception of difficulty when performing an activity, plus requirements to live the chosen lifestyle, will dictate what aspect of the condition the person with Parkinson's finds most debilitating – tailor your assessment and intervention accordingly.
- The three main symptoms of Parkinson's disease are:
 - bradykinesia
 - rigidity
 - tremor
- Physiotherapy strategies have the longest lasting effect on bradykinesia.
- Effects of medication, mood and fatigue levels can cause motor fluctuations during the day.
- Postural instability and falling occurs later in the disease process.
- Parkinson's disease will not explain all symptoms – assess thoroughly and do not be dismissive of other factors.

The basal ganglia: implications for physiotherapists

We would recommend that this subsection and the next are read in conjunction with the information on basal ganglia (BG) and cognitive, perceptual and emotional processes in the occupational therapy (OT) section.

As physiotherapists, it is important to be aware of the component parts of the BG and their normal mode of working. Appreciation of these will assist recognition of the resultant dysfunctions that might be seen in Parkinson's and, hence, dictate the strategies used in treatment to overcome or minimise the problem.

The BG is a collection of nuclei, mainly situated near the base of the brain, that communicate particularly with the cortex, thalamus and cerebellum. The BG is referred to collectively as the automatic processor ('cruise control') of the brain (Kirkwood, 2006), and to perform normal activities of daily living the BG needs to be functioning normally. This requires the ability to converse with the thalamus and, hence, with the cerebellum to work in balance to provide a co-ordinated movement.

The BG comprises:

- striatum (caudate nucleus and putamen) – with connection from most parts of the brain, including a strong link to the limbic system and globus pallidus. Physiotherapists, therefore, need to be aware of the range of emotional and cognitive issues experienced by people with Parkinson's as it may affect the outcome of treatment
- globus pallidus (internal and external), a nucleus of particular importance for people with Parkinson's. The reduced output from the GPe leads to problems with retrieval of stored, well-learned movement patterns from the supplementary motor area (SMA). This leads to problems when planning and initiating movement and so is the basis on which cueing strategies can work
- subthalamic nucleus – thought to help select actions
- substantia nigra (pars reticulata and pars compacta), part of which houses the production system of dopamine, a necessary neurotransmitter for motor function and its subsequent 'rewards' and which

undergoes a neuro-degenerative process in Parkinson's. A decrease in dopamine results in decreased thalamic inhibition, eventually causing bradykinesia. As dopamine also has a modulatory role in the central nervous system (CNS), a change in background tone is noted from the signs of rigidity and tremor. This explains the pharmacological ideal of replacing the deficient dopamine

The BG has direct and indirect pathways, which may be excitatory or inhibitory (Flaherty and Gabriel, 2004). From a simplistic view, the direct pathway activation inhibits BG output while indirect pathway excites BG output. Where it becomes complicated, however, is that dopamine has the opposite effect on the cells of these pathways, so is excitatory to the direct pathway and inhibitory to the indirect (Rothwell, 2004).

Some theorists hold the view that for each motor movement pattern performed – for example, walking, turning, running, writing – we have a motor set alongside cognitive sets that control the flow of thoughts and ideas, allowing changes of topic to be followed (Deecke, 1996; Morris et al, 1994b). If either of these 'sets' cannot be accessed, it could hinder efficient, automatic function; it is thought that dopamine allows each set to be opened and closed.

The BG controls well-learned, long and complex movement sequences (Morris, 1997) by co-ordinating or ensuring the following actions:

- pre-movement planning and preparation
- initiation of movement
- sequencing and timing of movement
- maintaining cortically selected movement amplitude, ie the frontal cortex is involved in the choice of movement, after which the BG takes over
- habit building

(Graybiel, 2006)

By allowing the shifting of motor and cognitive sets, BG dysfunction therefore results in:

- impaired performance of well-learned motor skills and movement sequences
- problems maintaining sufficient movement amplitude
- difficulty in performing more than one task simultaneously (dual-tasking)
- difficulty in shifting motor and cognitive sets
- slower mental processing
- perseveration in thought and action

Ideas on how these might be best tackled are described later in this section.

Key points

The basal ganglia controls well-learned, long and complex movement sequences by co-ordinating or ensuring the following actions:

- Pre-movement planning and preparation
- Initiation of movement
- Sequencing and timing of movement
- Maintaining cortically selected movement amplitude, ie the frontal cortex is involved in the choice of movement, after which the BG takes over
- Habit-building
- Allowing the shifting of motor and cognitive sets

(Graybiel, 2006; Morris, 1997)

The limbic system: implications for physiotherapists

The most noteworthy areas of the limbic system for physiotherapists that might affect intervention and carry-over are as follows.

Amygdala – an area that predominantly produces and responds to non-verbal signs of anger, defensiveness, avoidance and fear. From the perspective of the physiotherapist, it might affect people with Parkinson's in two ways – their responses to such signs in others may be slow or their own mask-like face might negate an appropriate response from others.

Hippocampus – an area important in maintaining new information so that it may be transferred into a memory. This area is naturally shrunken and depressed in people with mood changes. It is therefore important to consider the amount of information you are expecting a person to take in during a treatment session; it may take more sessions until the information has been retained and embedded as a learned memory.

Fornix – acts as the intermediary link across many areas of the BG and CNS.

Cingulate gyrus – an area that co-ordinates sensory input with emotions and emotional responses to pain, and regulates aggressive behaviour. This area allows a person to decide whether a response is necessary and, if a stimulus is not sufficient, they will take no action. For this reason, the outcome of physiotherapy interactions must be a jointly agreed aspect, considered 'worth the effort' of the person with Parkinson's. If pain is an overriding feature of the condition, the therapist must work to alleviate this to ensure the emotional set allows

concentration for the rest of the session, giving the person with Parkinson's the sense that the work is worth the reward.

Parahippocampal gyrus – an area linked with recognition of names and faces. As the disease progresses and with age, this area becomes less effective; hence it is important to consider treatment in the home environment, which is more familiar.

Hypothalamus – a region of the brain that controls a number of body functions; it serves the limbic, endocrine and autonomic nervous systems. By balancing body homeostasis and hormonal production, it organises non-verbal responses to things such as aggression, fear, anger and sexuality. The physiotherapist should monitor responses in the person with Parkinson's. For example, if they are going red and sweaty with frustration, this may not always be an indicator of a response to effort. We need to bear in mind that some people with Parkinson's have altered autonomic nervous system (ANS) symptoms and may perspire more. An alteration in this system might result in other autonomic symptoms that can be a cause of embarrassment or discomfort to a person with Parkinson's.

Another point to consider is the effect of dopamine on some of the areas of the limbic system. In combination with other neurotransmitters, such as serotonin, dopamine has an important influence over the brain's 'reward' mechanism and, hence, will either drive or hinder an activity, depending on the level of success. Be aware of this when goal-setting – make them achievable so that the focus to maintain activity remains strong.

Key points

- The BG and limbic systems are anatomically intertwined and, hence, their actions cannot be easily subdivided into either motor or psychological domains.
- The action of the neurotransmitters affecting the areas instigates interplay of both structures.

Disease progression

Disease progression is graded by:

- **the disease stages** – to establish whether they are in the early, mid or late stage of the disease; useful when quantifying a stage for research purposes
- **clinical stages** – practically useful for a clinician to quantify whether the person with Parkinson's is in the diagnosis, maintenance, complex or palliative stage

Progression of Parkinson's disease is graded either by clinical stages (MacMahon & Thomas, 1998) or by the Hoehn and Yahr disease stage scale (Hoehn & Yahr 1967). It is useful to classify the stage of the disease to establish the strategies required for current disease management, as well as to determine the plans for the mid term and long term.

Disease staging

During the 1960s, two neurologists studied the traits of 856 patients with Parkinson's, investigating the pattern of disease progression through a 15-year period. Using an arbitrary scale (I–V), they classified the level of disability exhibited by their case mix (as below). Although biased to the physical orientation of the disease and with limitations for clinical use, the scale is recognised internationally and used to select/demarcate patients in research. It also provides the margins with which the stages of the disease are classified.

Hoehn & Yahr scale

Stage I	mild unilateral signs and symptoms
Stage II	bilateral symptoms with minimal disability
Stage III	equilibrium impairment; general dysfunction noted
Stage IV	severe symptoms; limited mobility; support necessary at home
Stage V	cachexia; dependent; immobile

(Hoehn & Yahr, 1967)

Some people further subdivide the scales into smaller denominations, denoted by decimalisation, rather than Roman numerals.

In general:

Early phase	H&Y 1–2.5
Mid phase	H&Y 2–4 (it is within this phase that people with Parkinson's show the signs of falls risk)
Late phase	H&Y 5

Clinical staging

Diagnosis
Maintenance
Complex
Palliative

This method of recording the stage of Parkinson's is useful to physiotherapists as it exhibits fluidity according to the state of the patient. It follows the predicted ideology that intervention earlier on in the disease process will focus on establishing educational needs and health gain. As the disease progresses, intervention promotes maintenance until involvement becomes palliative in nature, to provide comfort encompassing both the person with the condition, as well as their family/main carer (MacMahon & Thomas, 1998).

While it appears that therapists on the European mainland use the Hoehn and Yahr disease staging more frequently (Keus et al, 2004), within the UK, the tendency is to also recognise the benefit of the more flexible approach that the clinical staging classification system offers (Ramaswamy & Jones, 2005).

An example of its use would be where a person is admitted to hospital, unable to cope due to an infection. Previously, if they were managing in their own environment with minimal assistance and minimal medication to control their symptoms, they would have been classified as 'Maintenance'. The onset of the infection might progress them clinically to the 'Complex' stage, prompting clinicians to negotiate a temporary increase in social support, as well as possible increased doses of medication until the infection is cleared. The temporary services necessitated by the worsening of their condition can be withdrawn at this stage and the person will return to being classified as 'Maintenance'.

The following sections cover assessment, physiotherapy interventions and outcome measurement throughout the progression of the disease. Please also refer to your local Parkinson's Disease Physiotherapy Assessment Form.

Assessment tools and considerations

There are, at present, no suitable assessment forms for use by physiotherapists of which the validity and reliability have been tested and proved. Depending on clinical expertise, the therapist can choose from various tools when assessing someone with Parkinson's.

An **Assessment Framework** (Schenkman & Butler, 1989). This model is based on the World Health Organisation's International Classification System (Üstün et al, 2003) and provides the therapist with a means to identify various types of impairments and how they relate to a patient's functional problems. This allows them to formulate an appropriate treatment plan.

A comprehensive **assessment proforma**, such as that devised by Sue Franklyn (1986). Proformas can be very useful for clinicians who do not see people with Parkinson's regularly. One problem identified with such proformas is that while they ensure major aspects of the condition are assessed and allow future comparisons of status from one assessment to the next, they do not promote clinical decision-making abilities from the clinician. This ability to develop a theory from recorded data is what separates a specialist from a technician. In addition, a specialist will also modify the direction of the assessment depending on the responses from the person with Parkinson's, something a proforma does not make allowance for.

The Dutch Guidelines (Keus et al, 2005) provide four Quick Reference Cards (QRC), based on the current available evidence, the first two of which are relevant to assessment; **QRC1: History Taking** and **QRC2: Physical Assessment**, which suggest a baseline of evidence-based themes of questioning and assessment. The Dutch Guidelines are available in

English on the Centre for Evidence Based Physiotherapy website: www.fdg.unimaas.nl/epid

Ideas from other sources. For example, as part of an informal consensus of AGILE clinicians' views in their daily practice with people with Parkinson's (Ramaswamy & Jones, 2005), specific assessment topics were identified and tabulated for the four clinical stages of Parkinson's. Evidence-based sections have also been identified to classify regularly asked clinical questions in the Guidelines for Physiotherapy Practice in Parkinson's disease (Plant et al, 2001).

Other considerations

Consider whether the assessment should be recorded by the physiotherapist only, for example, if the person with Parkinson's is presenting at an outpatient department for a specific musculo-skeletal problem or as part of multi-professional documentation, as appropriate for a person requiring multiple interventions and monitoring for their long-term condition.

Unlike the treatment regime, the timing of the assessment should ideally be at varying times of the day and during the cycle of medication to try to capture the best and worst times for the person with Parkinson's. This is not always possible, so a clear idea of problems faced should be drawn out with careful questioning. Issues such as stress, anxiety, fatigue and the wearing off of medication all affect the symptoms assessed.

Sometimes, a relevant carer/family member's presence is required during the assessment to confirm answers, especially if the person with Parkinson's is confused or forgetful. It provides the opportunity to gauge the relationship and level of dependency; the significant

other may be a little overprotective, inadvertently causing the person with Parkinson's to become more dependent. Be sensitive to the wellbeing of the carer. NB: An assessment tool called the Carer Strain Index, which will identify any problems, can be found in good outcome measures databases or books.

While it might be easy to subdivide the areas for assessment into subsections, the act of clinically assigning decisions to each of the subsections is more

difficult, as there may be more than one reason for a pattern of behaviour or inability to respond. In the following section, some thoughts are explored to provide the beginning and basis of reasoning; it is not exhaustive and may not reflect what you see with all patients. A bias is placed on assessment of the four core areas to be addressed by the physiotherapist: posture, balance, transfers and gait (Ashburn, 2004).

Key points for assessment

- Posture – including joint range and muscle length
- Functional gait – including freezing and indoor and outdoor mobility
- Balance and falls – including problems with turning
- Transfers
- Bed mobility
- Muscle strength and power
- Pain
- Condition of feet and footwear
- Effects of Parkinson's on functional ability, wellbeing and quality of life

Posture – including range of joint movement

The tendency in Parkinson's is for posture to become increasingly flexed – known as simian posture: the head pokes forward at the chin, the thoracic spine becomes kyphosed, the pelvis is pushed towards posterior tilt as flexion increases at the hips and knees and the person with Parkinson's ends up on the forefoot. As the trunk muscles become increasingly rigid, the active range of movement is reduced so that both trunk rotation and extension activity become increasingly limited, affecting the counter-rotational ability of the thorax on the pelvis until they rotate in the same direction.

The degree of lack of trunk rotation is directly attributed to the severity of the disability (Lakke, 1985). In rare cases, the neck muscles can be particularly

affected, causing very abnormal neck flexion. If the head extends rather than flexes, the diagnosis is more likely to be progressive supranuclear palsy (PSP) rather than idiopathic Parkinson's disease. The reduced active range of movement results in joint stiffness and muscle architecture alteration, which may be limited to a specific muscle group or joint (Leiber, 2002). For example, trunk flexion is likely to result in lengthening of sarcomeres of the erector spinae muscle, making the muscle contraction relatively more ineffective. As attainment of the inner range becomes more difficult, the person with Parkinson's will no longer be able to maintain an upright position for long periods of time. Gradually some muscles become shortened and contracted, eg the plantarflexors of the foot, making heel strike increasingly difficult.

The abdominals and hip flexors cause their opposing muscle groups to become stretched, weakened and less effective.

Assessment should distinguish whether the imbalance is permanent, through a fixed shortening, or whether subsequent intervention may be able to correct or improve this problem.

Poor posture also contributes to breathing, speech and swallowing problems. In the more severely affected

patients, stiffness and contracture can make lying flat difficult and uncomfortable. Not uncommonly, a scoliosis develops, initially due to dystonic contraction or perhaps contracture of para-spinal muscles. In later stages, bony changes can compound this. From the physiotherapist's point of view, seating and a thorough assessment of the person's ability to maintain an erect position for as long as possible are important.

Key points

- The classical posture of a person with bradykinesia and rigidity is a flexed, simian posture.
- The classic posture of a person with dyskinesia is scoliotic.
- Both postures influence all aspects of movement and mobility.

Functional gait – including freezing and indoor and outdoor mobility

There are a number of different ways of describing the Parkinson's gait. The stooped posture with hip and knee flexion, small shuffling steps, lack of trunk rotation, heel strike and reduced arm swing is well documented (Thaut et al, 1996; Murray et al, 1978; Knutson, 1972). In some people, the shoulders are maintained in extension and elbows in flexion to compensate for the forward lean at the trunk. Toe clearance during the swing phase is decreased as a result of reduced active hip flexion.

The step and stride lengths are significantly shorter than normal. The double support phase is increased from 11% to 25% of the gait cycle (Knutsson, 1972). As a result of a decrease in both amplitude and speed of movement, people with Parkinson's walk significantly more slowly. However, these features are characteristic of almost all abnormal gait patterns, eg arthritic lower limb joints/post stroke. It is only when looking at the angular displacements in Parkinson's that it can be distinguished from other abnormal gait patterns. Full details of the alteration to the gait pattern can be read in the articles by Giladi (2001a & b), Knutson (1972), Lewis et al (2000), Morris (2005,

2000, 1996), Murray et al (1978), Nieuwboer (2001) and Rochester et al (2004) and can be reviewed with visual examples on the RESCUE CD-Rom, which also provides an extensive reference list of physiotherapy-related articles on gait disturbances.

A physiotherapist's assessment of reduction in forward motion should include observation of the extent and effect of:

- rigidity and bradykinesia
- reduced or absent trunk rotation
- increased flexion of the knees, reducing the strength of the push-off and reducing the range of body movement over the supporting limb

If the person with Parkinson's experiences dyskinesias, the gait pattern can be so erratic that assessment is difficult, and the treatment plan follows alleviation of current symptoms.

While the recording of gait is often based on visual observation, there are tools that can be used in a clinical setting to assess a person's safety while on their feet. The Tinetti Gait Scale (Tinetti, 1986) is a useful observation tool for picking up problems with

gait that might lead to risk of falling. The Timed Up and Go provides a more functional view (Podsiadlo & Richardson, 1991) of a sequence of tasks, of which gait is just one part.

It is also important to assess the ability of the person to walk in different directions, such as sideways and backwards as well as forwards, and this can be assessed using the Four Square Step Test (Dite & Temple, 2002). There is also a specific Freezing of Gait Questionnaire (Giladi, 2000).

People with Parkinson's can experience other mobility problems, including:

- initiation difficulties, where the person cannot set off
- freezing, which occurs during the course of an activity, resulting in the person coming to a sudden standstill
- termination difficulties, where the person is unable to moderate their checking reactions to stop while walking. The phenomenon of 'festinating gait' is an observable version of this and observed as short, shuffling, 'running' steps, where the person with Parkinson's ends up on their toes and has little control to stop themselves.

A person with Parkinson's may exhibit none or all of these symptoms.

Key clinical points in the classic bradykinetic and rigid gait

- Reduced stride and step length
- A slower, more shuffling gait pattern, with flexion of trunk and hips
- Reduced trunk rotation and arm swing
- Increased double stance phase
- Decreased ability to perform heel strike on initial contact, following the swing phase
- Reduced toe clearance for the swing phase
- Akinetic problems such as:
 - initiation difficulty
 - freezing during an activity
 - termination difficulties
- There is no discernible gait pattern in people with Parkinson's who have dyskinesia

Balance and falls

The ability to balance is affected in the later stages of Parkinson's (typically H&Y stage III). Most aspects of daily life involve the act of multi-tasking, such as walking and talking, walking while carrying etc, which people with Parkinson's find increasingly difficult as the condition progresses (Rochester, 2004).

The effect of muscle rigidity, functional range of movement, strength, posture, bradykinesia and defects in balance strategies make it very difficult for muscles to react as quickly as normal to rapid changes in body

position. This causes postural instability, which in turn impairs righting and equilibrium reactions, increasing the chance of falling. Intrinsic causes of falling might include postural hypotension, visual defects and cognitive problems. Extrinsic causes might include medication, footwear and the environment. The percentage of people with Parkinson's who are reported to fall or be at risk of falling is as high as 50–60% (Bloem et al, 2001).

While many falls occur in a backward direction, a large proportion also happens when a person with

Parkinson's is turning. In order to turn 180° safely, an individual requires independent mobility, good ground clearance, stability, continuity of movement and good posture; someone without Parkinson's will be able turn 180° in two to three steps, and a older person without Parkinson's in five steps or fewer (Simpson et al, 2002). When walking in a straight line, the eyes can be on an immovable object, the feet remain a good distance apart and there is good stable contact with the ground. Problems arise for people with Parkinson's when turning because they are unable to see where they are heading and the moving stimuli as they turn can cause freezing. One leg may get in the way of the

other as they begin to turn; there is no heel strike, no rhythm of gait, no stable base or dynamic stability. Someone with Parkinson's may take more than four steps to turn and turns on the spot. The physiotherapist should be aware that many people with Parkinson's will be able to turn in one direction more safely and with fewer steps than the other; some patients may freeze when simply thinking about turning (Stack et al, 2004).

For further information, refer to the NICE Guideline on assessment and prevention of falls in older people (2004) and PDS information sheet *Falls and Parkinson's*.

Key points

- Dual-tasking can threaten balance.
- Impaired proactive and reactive responses result in difficulties with balance.
- Falls might be as a result of intrinsic and/or extrinsic causes.
- Turning is a particularly hazardous activity.

Transfers

The ability to transfer smoothly, efficiently and independently can be affected in people with Parkinson's. This is observed when assessing how the person rises from a chair, gets in and out of a car and gets up off the floor. The problem is usually due to a combination of posterior pelvic tilt posture (limiting their ability to flex forwards) and slowed timing of the

sequences involved in the action of sit to stand; when the person stands up, their centre of gravity is too far back in relation to their feet and they can fall backwards (Morris, 2000).

Because of the high risk of falls, people with Parkinson's need to be assessed for their ability to rise from the floor (Keus et al, 2005).

Key points

- Sit to stand is compromised in 54% of people.
- On and off the floor needs to be assessed.

Bed mobility

As the condition progresses, finding a comfortable position, turning, and getting in and out of bed become difficult. Lack of neck and trunk rotation, the loss of the ability to reproduce automatic movement and a fear of rolling off the bed often lead to difficulty in rolling. This is particularly the case when the person with Parkinson's has dementia or is easily confused. These people are at special risk of developing pressure sores and becoming incontinent.

The need to get in and out of bed also occurs at a time of the day when bradykinesia and rigidity are at a peak and the task is complex (Morris, 2000).

Bed mobility is assessed as part of the Lindop Parkinson's Assessment Scale (LPAS) (see reference section), in later stages of the condition in the Parkinson's Assessment Scale (PAS) (Nieuwboer et al, 2000), and has been described more fully in the Dutch Guidelines.

Key points

The following actions can all be problematic for people with Parkinson's:

- Getting comfortable
- Turning while in bed
- Getting in and out of bed

Muscle strength and power

A secondary effect of a reduced active range of movement is muscle weakness, which is often reported as decreased stamina when carrying out activities of daily living.

Strength is the ability of a muscle to exert a force against a resistance. While power also results in the ability of a muscle to exert a force against resistance, it has the added element of being explosive in nature, requiring both sufficient muscle mass and quick timing of nerve response to permit a required movement. Either, if not both, of these can be diminished in people with Parkinson's, hence reducing power.

The clinical relevance of the physiotherapist differentiating between the two comes when assessing functional activity; some activities require strength, some require power but most require a

combination of the two. Decreased range of movement may limit strength and power so must be taken into account during the assessment.

A clinical example of where these are important would be in the action of moving from sitting to standing. If a person was sitting in a chair of a good height with a sturdy seat, their legs and arms need only have sufficient strength to enable them to stand up against gravity. If, however, the seat was low or soft, they would need power to stand, timing the forward lean at the hips with antigavity extensor activity, as well as recruiting greater numbers of muscle fibres to overcome the added lack of support from the seated surface. Your assessment will differentiate whether the person is weak, has problems due to bradykinesia or rigidity, or all of these.

Key point

Muscle strength and power are essential for normal activities and therefore should be assessed in terms of either function and/or in major muscle groups.

Pain

Pain can be a problem for people with Parkinson's. It can vary in intensity and the effect it has, and is reported along a spectrum from 'unpleasant' sensations to 'severe and intractable' in nature, sometimes overshadowing motor symptoms. It has been reported as being experienced by 20–70% of people but, most recently, a figure of 40% has been quoted (NICE, 2006). NICE classifies pain according to the following categories:

- Musculo-skeletal, often secondary to parkinsonian rigidity and hypokinesia
- Dystonic, associated with dystonic movements and postures, which often occur in the feet during the 'off' period

- Primary or central, with burning or paraesthetic pain not associated with a dermatomal or root territory, which is not explained by a musculo-skeletal or dystonic cause
- Neuropathic – pain in the distribution of a nerve or root with associated signs
- Akathisia-related with an inner feeling of restlessness, leading to an inability to keep still

Differentiating between the causes of pain through assessment may be difficult if the person with Parkinson's cannot distinguish between such things as pain from dystonia as opposed to stiffness etc. Form your questions carefully and try to discern a pattern that will help you to differentiate between them.

Key points

- While pain is experienced in a high proportion of people with Parkinson's, physiotherapists must still consider other causes.
- A thorough assessment can identify the origin of the pain and indicate treatment options.

Condition of feet and footwear

As muscle tone alters during the course of the condition, it is important to assess the appropriateness of the footwear worn, as well as the mobility of the foot. Shoes should adequately support the foot while allowing acceptance and response to the base of support. Poor examples of footwear are seen where variable oedema is accommodated by the wearing of

larger-sized shoes or less supportive slippers. Plus, some people prefer fashion over function.

The condition of the feet can greatly affect a person's ability to bear weight and mobilise, and should be part of the assessment, especially where it is suspected that a person has been unable to maintain foot hygiene due to tremor or lack of flexibility to cut their toenails.

Key points

Assessment should include:

- condition of the feet
- condition and appropriateness of the footwear
- mobility of the foot and ankle

Effects of Parkinson's on functional ability, wellbeing and quality of life

During the assessment process, the physiotherapist should be considerate of the various aspects of the condition in relation to the impact it has on the person with Parkinson's. By the nature of our profession, physiotherapists concentrate mainly on the physical manifestations of disease processes and disorders and, as seen throughout the assessment section, each of these cardinal signs of Parkinson's can affect the ability to generate normal movement.

It is also important to listen to the perception of the patient, as it indicates how the condition is manifesting itself on their lifestyle and, hence, their quality of life. They might report a problem from one of the signs that you cannot influence greatly with physiotherapy, for example the effects of a tremor, or may report that

they feel unable to do an activity when you have assessed them as physically capable of doing it. Don't forget to take into account the effects of the time of day, timing of medication, mood and fatigue, to name but a few issues, as well as the concerns of the family and carers.

The physiotherapist also has the task of assessing at which point in the condition the ability to dual-task or multi-task becomes hazardous. During the earlier stages of the condition, it is important that the person is allowed to live as full a life as possible. However, once taking on two or more tasks starts to cause a balance impairment, the physiotherapist should assess how the person with Parkinson's can moderate their lifestyle.

Key points

- The various aspects of Parkinson's can affect a person's wellbeing and mood.
- Each cardinal sign can affect normal movement.
- Assessment allows the therapist to consider the impact on the lifestyle of the person with Parkinson's.

Treatment

Having assessed the patient, the main areas of intervention for physiotherapists usually involve production and/or retrieval of normal, automatic movement patterns; although there will be times when you will need to call on your basic counselling skills during the treatment session. Before you start a treatment, however, consider carefully what aspects from the assessment you have the skills and knowledge to influence and how you can measure the changes brought about through your input. (This will be considered further in the section on outcome measurement.) Also, consider whether your goals are agreed with and whether it is important to the patient that they are achieved.

The requirements of physiotherapy intervention will alter according to the clinical stage the person is at. During the earlier stages, greater emphasis is placed on education and self-management and the patient should be encouraged to continue being active and participate in sporting activities for as long as possible. Hands-on intervention gradually increases during the middle stages, until the patient's support network is offered education in comfort and manual handling during the period of palliation (Keus et al, 2005; Ramaswamy & Jones, 2005).

A single course of physiotherapy is likely to be inadequate for patients, as they will have the condition for the rest of their lives. For this reason, all people

with Parkinson's should be encouraged to undertake a programme of home exercises. Friends, relatives and carers may be able to help encourage this.

Being a long-term and complex condition, it is impossible for the physiotherapist to work alone to deal with all aspects of the disorder, and it is very important to ensure good liaison and communication between all parties (professionals, volunteers and family) when caring for and treating the person with Parkinson's. Areas where the multidisciplinary approach is used are increasing, with physiotherapists becoming more involved in Parkinson's disease clinics and home visits through community rehabilitation services, in addition to hospital admission intervention.

Unless the patient has dementia or acute confusion, they will not usually have a problem learning functional movement patterns, although the process may be slow in comparison to someone without Parkinson's. A balance must be found, however, if teaching movements and strategies through repetition. If the movement is practised so frequently that it becomes automatic, it will be saved in the Supplementary Motor Area (SMA), the area of the brain that is difficult to access for people with Parkinson's, and therefore the movement becomes difficult for the patient to reproduce. Some repetition has to occur, however, as people with Parkinson's can also have difficulty performing novel tasks, especially as the disease progresses.

Key points

Aims of physiotherapy intervention, as agreed goals with the patient, are:

- to maintain and improve levels of function and independence and, hence, influence their quality of life
- to correct and improve abnormal movement patterns
- to prevent contracture and minimise muscle weakness and joint stiffness
- to correct and improve posture and balance
- to maintain a good breathing pattern and effective cough
- to educate both patients and carers about Parkinson's disease
- to augment the effects of drug therapy

Treatment plans by physiotherapists must take into account:

- the effects of basal ganglia dysfunction
- drug-induced movement disorders
- age-related changes, including co-morbidity
- fear of falling
- disuse on functional performance

Physiotherapists can teach and encourage compensatory strategies, as well as providing education and support for patient and carer as a means of dealing with these issues.

(Morris & Iansek, 1997)

Concepts and projects to inform intervention

METERS (Plant et al, 2000) – **M**ovement **E**nablement **T**hrough **E**xercise **R**egimes and **S**trategies. This is based on the concept that there are four core areas to be addressed to promote, maintain and use quality functional performance. This should be the basis of clinical practice and research. The four core areas are gait, balance, posture and transfers.

The guidance is for:

- general exercise (core flexibility, strength, balance training, endurance, co-ordination work plus relaxation)
- specific/group exercise

The recommendation, however, was for a combination of all forms of exercise.

The informal consensus project conducted through AGILE (Ramaswamy & Jones, 2005), based on the contents of the UK Guidelines for physiotherapists and Parkinson's disease (Plant et al, 2001), highlighted the fact that in clinical practice, physiotherapists would ensure intervention was used to monitor, improve or maintain the following:

- disease status
- quality/safety of walking
- balance and avoid fall risk
- posture
- functional performance, including transfers
- fitness and endurance
- dexterity and writing
- negotiating expectations from physiotherapy
- monitoring cognition
- determining quality of life

Models of intervention explored by Morris (2000) and Schenkman (1989).

The latter particularly concentrates on an understanding of pathophysiology, impairments and disabilities and, through thorough assessment of these, the physiotherapist can treat/work on achievement of functional tasks.

More proof is emerging for the success of physiotherapy in maintaining and accessing automatic movement patterns through the choice of appropriate **cues and cueing strategies** (Lim et al, 2005; Rochester et al, 2005; Howe et al, 2003; Thaut et al, 1996; Morris et al, 1994a). Where possible, family and carers may need to provide prompts, so should be included in and involved with any treatment programme, especially as the condition progresses. Physiotherapists will need to be involved in training individuals in functional tasks in the home, community and workplace, teaching strategies in many of these situations.

The most comprehensive work on cueing to date took place in a three-armed multi-centre trial (Belgium, Netherland and UK) that researched gait-related rehabilitation strategies for cueing in the laboratory and home. The **RESCUE project** evaluated different types of cues (auditory, visual, somato-sensory) and cueing parameters (spatial and temporal). Within the home, the cues for dual-task performance were conducted three times a week; 30-minute durations for three weeks.

Although the intervention was for a short duration, the main results from the trial indicated that the **gait parameters of walking speed, step length and step frequency could all be improved** and, most importantly, that rhythmical cueing in the home can be safe and resulted in no increases in the number of falls. This is often a dilemma with physiotherapists, who find that families worry that if the person with Parkinson's is helped to become more mobile, they will be at greater risk of falling.

The trial highlighted that the best cueing modality was through auditory input, and there was an increase in overall activity with a decrease in fatigue levels in the participants.

More information about this work can be found on the RESCUE website:
www.rescueproject.org

The Dutch Clinical Practice Guidelines (Keus et al, 2005) suggest:

- specific treatment goals in their Quick Reference Card (QRC) 3
- treatment strategies in QRC 4

Each is divided into early, mid and late phases, according to the H&Y scale.

Required physiotherapy skills for treatment of people with Parkinson's

Depending on your assessment, you will need:

- basic skills to assess the state of the person's muscle architecture and the changes that can occur, causing imbalance, maybe leading to pain etc. Review the exercises you will use to correct these, then maintain and improve where able
- knowledge of exercise physiology, to provide balance and strengthening exercises
- musculo-skeletal skills to mobilise stiff joints – particularly the thoracic and lumbar spine, gleno-humeral joints, hips and ankle/foot areas. Maitland-type mobilisation often increases both range and proprioception for the patient, making mobility easier to achieve. You may need to start a session with passive stretching, but always incorporate activity after this, to let the person feel the movement they have gained
- pain-relieving modalities, such as mobilisation and exercise. Massage, acupuncture, ice, heat and transcutaneous electrical nerve stimulation (TENS) may be useful adjuncts.
- respiratory skills, to monitor the condition of the chest and treat where appropriate as the rib cage

can become rigid, limiting tidal volume and respiratory function in general. In the palliative stage, swallowing difficulties and increasingly flexed posture can compromise respiration

- basic understanding of ergonomics, in case you are required to review the workplace and home environment (including the garden, garage etc), advising on things that will affect function and quality of life
- knowledge of resources available locally, so that the education provided aims towards the person self-managing and taking responsibility for their condition as much as possible

In the later stages, intervention will be towards positioning and pressure care, teaching manual handling techniques to carers, plus assessing the environment for hazards and the need for additional equipment/support

It is important to recognise your own limitations and access outside support agencies (including the voluntary sector) and other appropriate professionals to refer on to.

Cueing and movement strategies

There are two particular strategies that, given the nature of the motor deficit, are likely to be particularly helpful in Parkinson's disease – cueing and compensatory movement strategies (Kamsma et al, 1995).

The use of cues or triggers and compensatory movement strategies is becoming more widely used in the treatment of Parkinson's as it provides a non-automatic drive for movement amplitude and timing; this in turn addresses one of the issues of the BG's inability to maintain appropriate amplitude and timing of sequential movements.

Again, it is recommended that this section be read with the corresponding occupational therapy section, where you will find further illustrations of the use of cues and cueing strategies. More information, plus visual examples, can be viewed on the CD-Rom developed by the RESCUE Consortium.

Clinically, a variety of cues can be tried to regain movement:

Intrinsic cues

Attention

Emotional set

Mental rehearsal

Internal dialogue

Visualisation

'Manual shift'

Extrinsic cues

Facilitate attention

Effect of visual environment

Visual cues

Auditory cues, including music and rhythm

Somato-sensory cues

Where people with Parkinson's have problems automatically reproducing functional movements, these movements should be broken down into much simpler component parts, put into the correct sequence and conscious control then used to reproduce the whole task. For example, with regard to walking, assessment will indicate which component of the gait cycle is problematic, so you may end up practising weight transference onto the stance leg or concentrating on heel strike on the swing leg etc.

Prompts, whether verbal, visual or sensory, can be used to remind patients what they should be doing, and sometimes a combination of these approaches may be required.

Intrinsic cues and triggers

On the whole, this type of cue is chosen for someone in the early/middle stages of Parkinson's, when they can learn how to generate their own cues. In some situations, overlapping cueing strategies can work well, while some are better used on their own. Different cues or strategies may be useful at different times of the day, and if one becomes less effective over time, then another can be assessed for and used. Different methods work better for different people so it is important to try a few first, before deciding that they do not work. It is also good to work on these with your OT colleagues as they may have ideas and solutions where you do not.

Attention Tasks require concentration to complete. By providing verbal prompts or removing distractions – eg turn off the television, stop talking while they are concentrating – the patient can focus their attention more effectively.

Emotional set It is important to approach a task when in the right frame of mind, with a positive attitude and ability to focus on an activity or conversation. A good example of emotion-influencing motor performance is when people who have fallen become petrified of moving unassisted, although physically able.

Mental rehearsal provides a more constructive preparation for a difficult action or task, allowing the patient to run through the subcomponents of the task in their mind first. It acts as a primer, preparing the body to put thought into action.

Internal dialogue is when a person talks through the actions as they are performing them. This strategy,

as well as mental rehearsal, is a form of cueing classically utilised in conductive education training. For example, the patient can be taught to talk themselves through instructions for moving from sitting to standing, eg 'I come forward in the chair ... tuck my feet back under my knees ... lean forwards ... and push up from the chair'. The patient can say the instructions silently to themselves or speak aloud, depending on their needs.

Visualisation is a way of using imagery to access movement. The classic example is telling someone to visualise a door threshold to step over if they freeze at the doorway, or imagine how satisfied they will be on completing a task.

Manual shift requires recognition by the person that they are off the beaten track. This might be in terms of motor sequencing or thought processes, so if they realise they are no longer able to follow a conversation, they either need to ask what is being spoken about or catch a few words that will allow them to understand the topic and rejoin the conversation.

Extrinsic cues and triggers

These tend to be more useful for people entering the later stages of the condition, when they might have limited ability to remember the cues and triggers that they have been shown. The use of external stimuli might facilitate a better response.

Facilitate attention Attention is necessary to perform a task; if the person cannot focus sufficiently, the therapist draws their attention back to the task, either by calling their name, decreasing distractions, tapping them, etc.

Effect of visual environment People with Parkinson's may have an alteration in their visuo-spatial fields, which can present a challenge to their function. This is most noticeable in people who freeze, especially when there is patterned carpet or a cluttered environment. Uncluttering the environment is paramount and, where finances allow, changing the flooring to solid colour, flowing from room to room, is beneficial.

Visual cues While some visual stimuli overload the system, causing a halt in movement, others ironically enhance motor function. These might be in the form of strips of coloured tape, spaced at intervals of approximately one and a half times the foot size of the

patient (which are only needed in problematic areas). Other aids that provide visual cues include a device that gives a steady pulsed light emission, which is attached to glasses, walking frames or a stick with a laser light beam (activated by the patient when needed) and cue cards containing a simple sequence of instructions to be followed (see OT section for details). Visual cues have been found to be most effective with people with bradykinesia or during the 'off' phase if freezing is a problem.

Auditory cues can be used to initiate and maintain performance of a motor task or movement sequence. They can be in the form of succinct verbal command,

a metronome or the use of music and rhythm. Auditory cues have been found to be most effective in people prone to freezing, during the 'on' phase.

Somato-sensory cues An example of this would be teaching an accentuated heel strike to initiate a forward step. More recently trialled in the RESCUE study is the use of a vibratory stimulus to indicate a rhythm, to dictate timing of movement.

Gait

Gait disturbances in advanced Parkinson's

Parkinson's features

Hypo/bradykinesia



Gait disturbances

Shorter steps, slower, less arm swing, festination

Rigidity (with abnormal posture)



Reduced joint motion, flexed posture

Disturbed postural response



Fear of falling, hesitated gait, festination

Disturbed automatic motor tasks



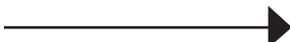
Start hesitation, freezing of gait

Disturbed autonomic function



Weakness, light-headed unsteadiness

Involuntary movements



Dystonia or dyskinesias

Research has shown that the most important components of gait to be preserved are stride length and heel strike. Improvement in these two areas will also improve ground clearance and cadence (number of steps taken over a set time). More detail can be found on the RESCUE CD-Rom.

Dual- or multi-tasking must be considered when treating problems of gait, as most functional tasks have a component of walking as part of the activity.

Freezing during gait

Freezing occurs when the sequence of a movement is interrupted – this is seen particularly during walking as

gait is a series of complex movements, strung together in a sequence (RESCUE, 2005). Freezing is often preceded by festination. This is a sudden episode of an involuntary increase of the stepping rate ('hastening'), together with a minimisation of step length, but without coming to a halt. Freezing can be best described as the feeling of being 'glued to the floor' and is often accompanied by trembling of the legs.

When considering working on gait with people who freeze, it has been found useful to adapt the frequency of steps, ie lower the frequency of freezing, compared with hastening the pace for people with bradykinesia (Willems et al, 2006).

Freezing while in an 'on' phase

- Freezing episode is of a shorter duration
- The pattern has a more rhythmical influence of festination
- Medication does not help
- Freezing may respond better to auditory (temporal) rhythmic cues

Freezing while in an 'off' phase

- Freezing episode is of a longer duration
- The pattern is more slow and halting; more to do with hypokinesia
- Medicine can help
- Freezing may respond better to visual cues

Falls

As noted in the assessment section, falling occurs in a high proportion of cases. Further information can be found in the NICE Guideline on the assessment and prevention of falls in older people (2004) and the PDS information sheet *Falls and Parkinson's* (FS39), but some of the main reasons why people fall, which can be affected by therapy intervention, are as follows:

- Parkinson's symptoms resulting from rigidity, hypokinesia and bradykinesia can be minimised, permitting better quality of movement. For some people, it is sufficient to educate them about this symptom so they can monitor at what time of the day they feel less able; their lifestyle can then be altered accordingly. Cueing strategies can be taught to improve movement patterns and the performance of functional tasks.
- Additional physical problems – people with Parkinson's are limited by the symptoms of the condition but may also have other conditions that affect mobility and balance. This is especially the case if the person is elderly. Postural hypotension can be particularly problematic and has many causes.
- The fear of falling has dramatic effects on step length, stride length and confidence in the ability to move safely.
- Effect of medication. Parkinson's medication acts on the central nervous system and is therefore prone to

causing alterations throughout the body. Medication can cause nausea and vomiting, postural hypotension, confusion and hallucinations, especially when new or when a dose is increased. Patients may be on additional medication for other conditions, which may cause further interactions leading to a fall. Review of medication is required over the course of the disease progression, as new drugs will become available and old ones may become less effective. If a patient is admitted to hospital, it is important that their normal regimen is followed and that medication is not dispensed according to set drug rounds, as it can impede their mobility severely, putting them at risk of falls or freezing.

- Hazards in and around the home – these often restrict the stride length and gait pattern of someone with Parkinson's, especially if other Parkinson's symptoms, such as alteration to vision and spatial awareness, result in difficulty negotiating obstacles. Objects that move suddenly, such as pets and small children, are particularly hazardous to people who find it difficult to accommodate their gait pattern so check responses in these situations. When ground clearance starts to become an issue during the gait cycle, advice regarding location of furniture and floor coverings may be necessary to further minimise the risk of falls.

Treatable causes of falls

- Certain Parkinson's symptoms
- Additional physical problems
- Fear of falling
- Medication
- Hazards in and around the home

Rehabilitation in early onset Parkinson's

Most physiotherapists will come across people with Parkinson's in the older age group. However, the condition also affects a proportion of younger people aged between 18 and 40 (Quinn et al, 1987). This is known as early-onset Parkinson's or young-onset Parkinson's. The younger person is more likely to exhibit motor fluctuations and dyskinesias, caused by prolonged use of dopaminergic treatment. They may require multiple drug combinations to control symptoms as the condition progresses (Pantelatos & Fornadi, 1993).

While a wide range of services should be accessible to all individuals with Parkinson's, there is particularly poor availability of support in health service provision for the younger age groups (Birtleson, 2003, 2002).

Again, although physiotherapy management with all people with Parkinson's must consider the choices and lifestyle of the person, those with early-onset Parkinson's may have difficulties related to relationships of a sexual nature, as well as a change in their role within the family circle; there might be work-related issues if their occupation is affected by the symptoms, plus there may be a knock-on effect on their participation in a lifestyle of their choice as the condition progresses. This is often more obvious and distressing than in someone with the onset later in life who is retired and with fewer family commitments with regard to financial impact, independence etc. The physiotherapist forms part of the much-needed support network that is required for the young-onset person with Parkinson's, particularly if they are still in work and/or raising a family.

Long-term management

Physiotherapists need to recognise the importance of developing long-term management programmes to run in conjunction with short-term courses of treatment.

How a long-term management programme is organised depends on service availability, staffing levels or the ability of a person to pay privately for ongoing intervention where NHS provision is not available. The following points need to be considered when setting up a programme:

Where – The most appropriate place to continue management into the longer term is in the home. However, it is better to bring a patient into the department than not to monitor at all.

When – People with Parkinson's need monitoring regularly from the point of diagnosis (NICE, 2006). The frequency of this will depend on disease progression and the problems being experienced by the person. Monitoring may need to be done no more than once or as many as four times a year.

How – It may be appropriate for some patients to refer themselves as and when problems occur. However, some people, especially older people, are often reluctant to ask for help, so it may be more

effective to have an 'at risk' register for people who will need reassessing.

Good communication is essential between the various professionals involved with a person. If someone is being managed in the community, professionals could use patient-held records in which to write comments and observations; these can then be read and added to by the next professional to see the patient. Wherever the professionals who are managing a patient are based, it would be a good idea to appoint a key worker who would then be responsible for co-ordinating the help and treatment given to a patient and their carers/relatives. This role might be undertaken by a Parkinson's Disease Nurse Specialist, a community matron or a social services care manager.

In the process of managing a person with Parkinson's in the longer term, a balance must be struck between maintaining a positive outlook, yet not raising the person and their family's expectations unrealistically (NICE, 2006). A physiotherapist is a good person to manage this as they have advanced problem-solving skills and, even if they are physically unable to solve a problem encountered, they usually know someone who can help and, hence, will refer accordingly.

Key points

Aims of long-term management should be:

- to maintain the patient at the highest level of functional independence for as long as possible
- to monitor the patient objectively and at regular intervals so that relevant intervention can be directed according to changing needs
- to prevent or reduce mobility problems and deformities
- to be alert to problems, such as speech and swallowing difficulties, drug intolerance or failure, and to refer patients on to the appropriate professionals and services
- to educate and support the patient, relatives and carers in the management of the condition

Outcome measurements

The Core Standards of Physiotherapy (CSP, 2005) state that an outcome measure must be used to evaluate a change in a patient's status.

As a clinician, it is important to measure the outcome of your intervention as a means of reflecting on your own effectiveness, and the information can be used to inform audit and service development.

A wide range of outcome measures exists, depending on what you or a team are trying to measure. There is also a growing evidence base for use of appropriately selected measures, reflecting the bio-psycho-social manifestation of any long-term condition on the individual's quality of life (Bowling, 1995).

In general, the aim of physiotherapy intervention is to enable the patient to achieve maximum independence and quality of life through various interventions. While a simple measure of efficacy might be the increase in step length through the use of a visual marker, the impact/outcome of interventions should also be measured in terms of the ability of the recipient to execute an activity, as well as the capacity to function in their chosen environment (Üstün et al, 2003).

Try not to confuse assessment tools with tools to measure the outcome of intervention, although

sometimes, such a tool may act to serve both purposes. If appropriate, you can use a category in an assessment tool where full scores were not achieved and use this as the basis for your intervention, measuring the success of the patient at achieving a better score following treatment. Sometimes, as is the case in long-term, progressive conditions, the aim of intervention may be maintenance or even prevention of deterioration at a slower rate than if there was no physiotherapy input (Ramaswamy & Jones 2005).

Outcome measurement, as recommended from the informal consensus project (Ramaswamy & Jones, 2005), can be done to negotiate the client's expectations and monitor any of the following:

- disease status
- quality/safety of walking
- balance and avoid fall risk
- posture
- functional performance (including transfers)
- fitness and endurance
- dexterity and writing
- cognition
- quality of life

Where possible, a validated, reliable tool should be used to measure the outcome of intervention.

However, few exist that are sensitive to our intervention. Also, to measure the entirety of what a physiotherapist treats, you will need to use more than one tool.

Below are just a few examples of the tools clinicians use in practice.

<p>Generic physical tools Functional Independence Measure (FIM)</p>	<p>Generic quality-of-life tools SF-36 EQ-5D</p>
<p>Disease-specific tools to measure general function Unified Parkinson's Disease Rating Scale (UPDRS), particularly mobility section 3</p>	<p>Confidence Falls Efficacy Scale (FES) Assessment of Balance and Confidence (ABC)</p>
<p>Stage specific Hoehn & Yahr scale Clinical staging</p>	<p>Patient-specific goals Goal Attainment Scale (GAS) Treatment and Evaluation by the Le Roux method (TELER)</p>
<p>Mobility-specific tools Berg balance scale (BBS) Problem-orientated Assessment of Mobility Timed walks Falls diary History of falling Timed up and go test Elderly Mobility Scale (EMS) Parkinson's Assessment Scale Lindop Parkinson's Assessment Scale Freezing of gait questionnaire</p>	<p>Disease-specific quality-of-life tool PDQ-39 PDS non-motor symptoms questionnaire</p>

There are more measures than these, and all provide quantitative data about the severity, stage or impact of Parkinson's. Most do not, however, take into account environmental, social and contextual factors, or personal

relevance of the domains measured. These outcome measures can be accessed through websites, literature searches and outcome measurement texts.

Key points

Measurement is encompassed through some of the following areas:

- Promotion of increased activity and independence
- Increased self-efficacy and reported feelings of wellbeing
- Optimisation of independence through adaptation or support
- Resumption of valued roles
- Where appropriate, increase in specifics such as decreased pain levels, increased range of movement and flexibility, endurance, etc

Conclusion

Publication of the National Service Framework (NSF) for Long-term Conditions, other NSFs and the NICE Guideline for Parkinson's have resulted in support for ongoing research and evidence-based practice for physiotherapists working with people with Parkinson's. As mentioned in the introduction and the reference section, we have provided information to support CPD

and clinical decision-making. In the UK, the CSP clinical interest groups who specifically support Parkinson's-related issues are Physiotherapists working with Older People (AGILE), Association of Chartered Physiotherapists Interested in Neurology (ACPIN) and, within Europe, Association of Physiotherapists in Parkinson's Disease: Europe (APPDE).

Relevant resources from the PDS

Booklets

Complementary Therapies and Parkinson's disease (code B102)

Keeping Moving: An exercise programme for people with Parkinson's disease (code V011 – DVD and booklet or code B074 – booklet only)

Living with Parkinson's – a guide for people of working age affected by the condition (code B077)

Information sheets

Falls and Parkinson's (code FS39)

Foot Care and Parkinson's (code FS51)

Pain in Parkinson's (code FS37)

Physiotherapy and Parkinson's (code FS42)

Speech and Language Therapy (code FS07)

Useful websites

AAN: American Academy of Neurology

Various guidelines for people with or dealing with Parkinson's, but with a medical bias.

www.aan.com/professionals/practice/guidelines

ACPIN: Association of Chartered Physiotherapist Interested in Neurology

www.acpin.net

AGILE

Chartered physiotherapists working with older people.

www.agile-uk.org

APPDE: Association of Physiotherapists in Parkinson's Disease: Europe

www.appde.eu

CEBP: Centre for Evidence Based Physiotherapy

www.fdg.unimaas.nl/epid

Guidelines for Physiotherapy Practice In Parkinson's Disease

Plant R et al (2001), Institute of Rehabilitation, Newcastle upon Tyne and Parkinson's Disease Society, London

hces.unn.ac.uk/guidelines

National Institute for Health and Clinical Excellence

The NICE Clinical Guideline on Parkinson's disease: diagnosis and management in primary and secondary care.

www.nice.org.uk/CG035

RESCUE

Information from the international, multi-centre trial investigating the use of cues to improve walking and mobility in people with Parkinson's.

www.rescueproject.org

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notes

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The social worker's guide to Parkinson's disease

Introduction

As Parkinson's disease is a fluctuating condition that can affect all aspects of daily living, social workers need to be aware of the wide-ranging impact it can have on the lives of those affected by it, including families and carers.

Symptoms will vary from person to person so it is important to treat each person with Parkinson's as an individual and acknowledge the expertise people have about their condition.

People with Parkinson's can experience difficulties meeting their personal and social care needs because of the range of effects symptoms can have. These can be very unpredictable, changing day to day, hour to hour or minute to minute.

Difficulties your client may experience can include:

- bowel and bladder problems
- difficulty with food and fluid intake
- problems with movement and mobility
- depression

- anxiety
- tiredness and fatigue
- sleep disorders
- confusion
- pain
- hallucinations
- communication difficulties
- drooling and swallowing problems
- handwriting difficulties
- skin and perspiration problems

These symptoms, along with the three major symptoms of tremor, rigidity and slowness/poverty of movement, require a multidisciplinary approach when assessing personal and social needs. Multidisciplinary teamwork is essential if a social worker is to acquire a rounded picture of an individual's situation.

This section outlines best practice for social workers to be used alongside any criteria specific to your area.

Assessment – communicate and engage

Social workers are required to carry out an assessment of need in order to establish the balance between need, risk and resources for intervention. In community care, assessments may make the difference between people living independently or in a residential establishment (Coulshed & Orme, 1998).

Assessment is an ongoing process and, because of the fluctuating nature of Parkinson's and the wide variation in symptoms, it may be helpful for people with Parkinson's to access assessment and reviews more frequently, in order to acquire a comprehensive assessment of need.

Assessment is a two-way process and it is important that social workers empower people

with communication difficulties to fully participate in the assessment process, together with their carers (*The Exchange Model*, Smale et al (1993) may be helpful). An holistic assessment is required and it is essential to look at the social situation beyond the individual and the here and now. The social worker's role is to develop and establish a package of care that supports choices and needs, while also recognising and negotiating the conflicts that choices and needs can create. The social worker also needs to possess the ability to change approaches if the situation changes over time (Smale et al, 1993).

The content of the care package is determined by the criteria for access to social care services (called Fair

Access to Care Services), and the eligible needs of the person identified in the course of the assessment.

Some, but not all, people with Parkinson's can experience problems with communication. McCall (2006) suggests that 50% of people with Parkinson's will experience some communication challenges over time. Quiet speech, poor articulation, slurring, loss of rhythm and intelligibility, and lack of non-verbal cues, facial expression and body language can create challenges when engaging with clients. People with Parkinson's may require aids, not only in order to participate fully in the assessment process but also to maintain social relationships and reduce the risk of social isolation.

Social workers should initiate an assessment by a speech and language therapist or occupational therapist, where communication difficulties are encountered, to provide support during the assessment process. People from some ethnic minorities may

require the engagement of an advocate from the same community in order to be able to participate fully.

It may be helpful if a diary is kept by the person with Parkinson's or a carer; this may help the assessment process and provide a record of daily activities. However, this may not always be possible as a common symptom of the condition is difficulty with handwriting.

Social workers should use personal skills such as listening and maintaining eye contact (although this may not be appropriate for people from certain ethnic communities). Vocal techniques, such as short and precise sentences and emphasis on key words, may be helpful, as well as allowing adequate time for responses.

For further information on communicating with people with Parkinson's, see the PDS booklet *Working Together Locally*.

Implications for care packages

Many people with Parkinson's do not require help with personal care. However, if an assessment highlights the need for support with personal care, it is important that social workers who are organising and producing a care plan ensure that the fluctuating nature of Parkinson's is taken into account. For example, a home care worker arriving at a client's home at an agreed time may find the person with Parkinson's is unable to move or to participate in meeting their own care needs. However, this situation can change given time and, therefore, it is important to build some flexibility into the care plan to take into account the unpredictable nature of Parkinson's. It is the social worker's responsibility to plan, implement, monitor and review care packages. Monitoring and review should include regular assessment in order to establish whether new needs have been identified and how these can best be met.

Domiciliary care staff, day centre staff and staff in nursing and residential homes, or other workers, can obtain information and possibly access training and information days provided by the Parkinson's Disease Society (PDS). A Parkinson's Disease Nurse Specialist (PDNS) may be available to assist social care staff in furthering their understanding of Parkinson's.

Medication

Research carried out by the PDS in 2006 found that the late administration of drugs has an adverse effect on the condition. If a person with Parkinson's is unable to take their prescribed Parkinson's medication at the right time for them, there is a disruption to their dopamine levels. This may lead to a worsening of their symptoms, which can take some time to stabilise again. It is therefore important to ensure that home care workers who are supervising the taking of medication arrive at visits on time. The social worker should ensure that home care agencies are aware of this need and that visits have been arranged to ensure that medication is taken on time.

People with Parkinson's who have problems remembering to take their medication may benefit from aids such as pill timers. Non-adherence to medication routines presents a risk to people with Parkinson's and, where this has been identified, social workers should arrange appropriate care provision to eliminate risk. People with Parkinson's who live alone may have difficulties with bottles and blister packs or may be unable to collect their medication from a pharmacy. The PDS produces information on aids to help with medication, and local pharmacies may provide a delivery service.

Medication can have significant side effects and impact on the provision of care. Social workers should ensure that home care agencies are made aware of any significant difficulties or challenges.

Abnormal involuntary movements (dyskinesias) can cause difficulties and pain for the person with Parkinson's and may be quite alarming for social care staff witnessing it for the first time. The 'on/off' effect can be extremely distressing and can cause difficulties for social care staff. The 'on/off' effect may also lead to misinterpretation and clients may be perceived as difficult or unco-operative.

Social workers should be aware that hypersexuality can be experienced by the person with Parkinson's. This is a possible side effect of some medications and can affect both men and women. It is important that social care agencies and their staff are made aware of this problem so that, should hypersexuality become an issue, action can be taken to manage the situation.

Another side effect of some medication can be an increase in gambling or other compulsive behaviour. Up to 10% of people are affected and this can have serious consequences of both a financial and social nature. Help and support can be obtained from the PDS Helpline or PDNSs, who can provide advice with regard to the side effects of Parkinson's medication.

Psychological challenges

Depression is the most common psychiatric problem in Parkinson's and is experienced by up to 50% of people with the condition. People who are newly diagnosed are particularly likely to be affected while they are coming to terms with the condition, although no two people with Parkinson's are the same and the cause(s) of depression will vary. Changes in brain chemicals probably play an important role. These may make people with Parkinson's more vulnerable to depression triggered and maintained by important life changes, ill-health or stress. The social worker is well placed to recognise changes in mood and refer on if necessary.

Some people living with Parkinson's experience cognitive challenges. McCall (2006) highlights the fact that up to 40% of people with Parkinson's develop dementia. People can regularly experience problems with confusion, memory loss and concentration.

Dementia with Lewy bodies (DLB) is a condition that has similarities to both Alzheimer's disease and Parkinson's. Of those with DLB, 75% will also develop symptoms of Parkinson's. Therefore, people with DLB will experience problems with concentration and attention, memory, language, recognition, the ability to carry out simple actions and the ability to reason.

People living with Parkinson's who are experiencing mental health or psychological difficulties may require specialist support from mental health professionals, as recommended by the NICE Guideline for Parkinson's disease. Specialist support workers, mental health charities and voluntary organisations may be able to offer additional support and information. Social workers should consider whether specialised residential care or supported housing may be appropriate – specialised day care or counselling services should be considered as a means of supporting people who are experiencing mental health problems as a consequence of Parkinson's disease.

The PDS has produced the information sheets *Dementia*, *Dementia with Lewy Bodies* and *Depression and Parkinson's*.

Aids and adaptations

In order for people with Parkinson's to remain independent in their own homes, major adaptations may be required in order to create space for equipment or access to areas of the home.

The National Service Framework (NSF) for Long-term (Neurological) Conditions stresses the importance of community rehabilitation and support (Quality requirement 5) and the need for health and social services 'to work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home' (Quality requirement 8). Social workers should make a referral to an occupational therapist in order for a full assessment to be carried out, to ensure that the correct aids and adaptations are acquired and grants and funds can be accessed, if applicable. Local authorities may help

with disabled facilities grants, and home improvement agencies may help with care and repair.

The PDS's Mali Jenkins Fund can provide grants (subject to means testing) of up to £1,500 for the purchase of aids and equipment. The Disabled Living Foundation can provide advice and guidance on purchasing equipment and goods. Local authorities can supply information on grants available for services such as insulation, repair and replacement heating systems.

It may be appropriate to consider rehousing if the person with Parkinson's requires more support or supervision. Social workers should work with housing officers in order to access warden-controlled or supportive accommodation, or seek alternative housing from the voluntary, private or charitable sectors.

Carers

Yarrow (1991) found that the principle source of care and support for people with Parkinson's is family and/or friends. However, a recent report from the PDS highlighted the fact that only one-quarter of carers had received a carers' assessment.

The NSF for Long-term (Neurological) Conditions includes a quality requirement for carers of people with long-term neurological conditions to have access to appropriate support and services, which recognise their needs both in their role as carer and in their own right (Quality requirement 10).

The Carers (Equal Opportunities) Act 2004 places a duty on local authorities to inform carers of their right to a carers' assessment. The assessment should take into account work, lifelong learning, leisure and the carer's opportunities to pursue these. It is important that assessments incorporate support from housing, health, education and other local authorities in providing support to carers.

Support for carers is vital if they are to be able to continue in their caring role. As Parkinson's progresses, it

is likely that the person being cared for will require more help with practical and personal care tasks. Social workers should ensure that carers receive the information they require in order to make informed choices about the type of support that is available and the financial implications, which are particularly important for those who are likely to be self-funding.

The starting point for the carer's assessment should be the carer him/herself and they should be encouraged and enabled to play an active part in the assessment process. If a carer cannot fully participate in the assessment process, an advocate may be helpful. Information and Support Workers (ISW), disability advocates or Age Concern advocates may provide extra support and guidance to carers. If the carer is from an ethnic minority community, the engagement of an advocate from the same community may be particularly helpful.

The assessment should clarify whether the carer is eligible to receive support, what support is needed and establish whether carers' needs can be met by social

services or other service providers. Where social services do not have a responsibility to provide services to the carer, alternative sources of support should be considered such as carer organisations or voluntary and charitable organisations. The PDS has produced information for carers on carer's assessments: The Carers (Equal Opportunities) Act and the Carer's Emergency Scheme.

Yarrow (1991) highlights the desire of carers for people with Parkinson's to have access to an emergency support system, should they become ill or have to go into hospital. It may offer reassurance to both the carer and person with Parkinson's if a plan can be arranged to provide support and care, should an emergency occur.

Continence

Problems with continence may be experienced. Help can be obtained from PDNSs or referral to a specialist continence adviser may be beneficial. Social workers should be aware that additional home

Social workers should provide information on:

- home care services
- respite services
- emergency support services
- benefits and eligibility criteria, particularly carer's allowance
- carers' support workers, who may be able to provide support locally
- carers' groups and organisations
- training that may be available locally to provide both support and education to carers

Carers should be made aware of their right under legislation to receive direct payments in order to purchase the support that they have been assessed as needing.

care visits may be necessary in order to assist with continence care. Think too about the individual's ability to attend day services, participate in social activities and retain dignity and respect.

Domestic care

Because of the nature of Parkinson's, clients may require support with domestic care, as well as with personal care needs. Research has shown the importance that older people place on domestic care (Clarke et al, 2000) so the provision of some domestic help may alleviate anxiety and stress, which can exacerbate the symptoms of Parkinson's. Domestic care can also support and maintain informal caring networks and may improve the subjective experience of people with Parkinson's, their families and carers.

It is important that the domestic and practical needs of people with Parkinson's are acknowledged and supported by social workers, particularly when the needs identified are outside the criteria laid down by local authorities. Clients may experience problems with maintaining their property and gardens. Occupational therapists may be able to provide adapted tools, or additional support may be required from housing departments, voluntary maintenance and gardening schemes or from alternative sources, such as the probation service.

End-of-life care

Planning end-of-life care is vital in promoting dignity, and is an important role for all health and social care professionals. The NSF for Long-term (Neurological) Conditions states that a range of palliative care services should be provided that 'offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care' (Quality requirement 9).

A key element is to determine what a person's wishes are regarding where they would like to be cared for. This is known as advanced care planning and is a vital

process in understanding individual concerns, values, goals and preferences. For more information go to www.endoflifecare.nhs.uk

A national care strategy is being developed to deliver increased choice to people near the end of their life about where they are cared for, and die. This will involve improving networks and co-ordination between services, training for professionals and investment in community-based palliative care services (*Our Health, Our Care, Our Say: Making it Happen*, 2006).

Falls

Because of mobility, movement, balance and postural difficulties, people with Parkinson's are susceptible to falls and stumbles. Sagar (1991) notes the high risk to people with Parkinson's from falling after moving from sitting to standing. It is important to consider ways of alleviating the risk of falls. Occupational therapists, PDNSs and physiotherapists can assist in isolating and reducing the risk of falls. Emergency alarm systems can provide help if a fall should occur and it is helpful if people with Parkinson's are provided with a pendant or similar device, in order to enable them to call for help if necessary. Risk of falls, particularly at night, should be considered and acknowledged by social workers during the

assessment process. If falls become frequent, it may be appropriate to consider specialised housing, residential or nursing care, or an increase in home care support.

Mobility aids may assist people with Parkinson's in moving around at home. Again, physiotherapists can advise on suitable aids. Rehabilitation services may be able to provide holistic support with mobility. Disability charities and organisations, such as the Disabled Living Foundation, can provide information and guidance about the purchase of equipment, such as scooters, to help with outdoor mobility.

Finances

Yarrow (1991) acknowledges the extra costs incurred by people with an illness or disabilities, compared with their relatively low incomes. Burchardt (2003) identifies the fact that disability affects other members of the household. In single-earner households, even where the earner is not the person with the illness or disability, one in five earners leave employment; Burchardt argues that this is often in order to pursue a caring role.

It is imperative that social workers assist people with Parkinson's, their families and carers in accessing all available benefits. Many people are unaware they are

eligible for benefits which are not means tested (Disability Living Allowance and Attendance Allowance). PDS ISWs can provide help and guidance in claiming and accessing benefits and the Society produces a wide range of information on levels of benefits and eligibility criteria. Referral to finance and benefits teams or Citizens Advice Bureau/disability advocacy service can also help with maximising income. Social workers should also offer and provide advice about direct payments to all people with Parkinson's who require support at home.

Living alone

Many people with Parkinson's live alone very successfully. However, the challenge of living alone with a chronic condition may add to feelings of social isolation. Depression is a common problem in Parkinson's and it may be difficult for someone with Parkinson's who lives alone to recognise the signs of depression. It may become difficult to maintain key social relationships because of problems with mobility, transport, communication, etc. Means of communication such as telephones may require adaptation or, if the client is on a low income, social workers should consider the auspices of the Chronically Sick and Disabled Persons' Act.

In order to reduce social isolation, social workers should consider social activities such as day care, day centres or community activities, along with befriending, support from PDS ISWs, or volunteer networks, where available. Carers may also experience feelings of social isolation. Referral to carers' support workers or carers' groups and organisations may be helpful. The PDS may have a local branch which can offer the opportunity to meet others with Parkinson's and to develop social networks.

Meal provision

Diet is acknowledged as an important factor in the management of Parkinson's (Leader & Leader, 2001). People with Parkinson's require access to appropriate food and drink every day as they can be particularly affected by constipation, weight loss and changes to appetite. Access to Shop Mobility schemes or a volunteer, support worker or social care worker may enable the person with Parkinson's to shop independently and maintain social networks.

An assessment should consider whether Meals on Wheels or a frozen meal service may help to maintain a

balanced diet if the person with Parkinson's has difficulty preparing meals. The use of kitchen utensils and ovens may present a risk to some people with Parkinson's. If this is the case, referral to an occupational therapist should be considered.

Ensuring that supervision at meal times is incorporated into a care package can help to alleviate risk for people who experience swallowing problems. A speech and language therapist will also be able to help if this is an issue.

Nursing or residential care

As Parkinson's progresses, the client may be assessed as requiring nursing or residential care. People with palliative stage Parkinson's may be eligible to receive their care under the auspices of continuing care and it is important that social workers recognise this and initiate the necessary assessments promptly.

Others may require support and information on nursing and residential homes, fees, charges, etc. The PDS has produced the booklet *Choices: A Guide to the Health and Social Care Services*, which outlines the basis of charging for placements in residential and nursing homes. It is vital that social workers provide local information regarding the financial implications of a placement in respect of property, top-up fees, personal allowances, etc. The Society's ISWs and PDNSs can provide information and support to people at the time of choosing and transition to nursing or residential care. It is important that appropriate

assessments are carried out by relevant health and social care professionals to ascertain the type of care required. The person with Parkinson's and their families and carers may need ongoing support from social workers to help them through the process and to empower them in making informed choices about their care and future. Hospital discharge should not be rushed and people with Parkinson's and their carers should be allowed time to consider their options fully.

At the yearly review, you should take into account the fact that many people with Parkinson's feel isolated in nursing and residential settings. Care home staff should be encouraged to identify any changes or additional support that may be required, such as physiotherapy, exercise or specialist support.

Risk

People with Parkinson's may find themselves in vulnerable positions, either physically, mentally or financially. They may be at risk of harm from illness, due to disability or self-harm, or may find themselves at risk of abuse from carers or others. It is important that risk assessments are carried out to ascertain the degree and type of risk and whether the person with Parkinson's should be considered as a vulnerable adult. Social workers are required to take action

to reduce risk of significant harm, for example occupational therapy assessment, GP referral, protection under specific legislation and increase in formal provision of support services or mental health assessment. (For further information about the analysis of risk in social work practice, see O'Sullivan, 2002.) Where financial vulnerability is suspected, legal representation may be required, for example a solicitor acquiring power of attorney or contact made with the

police. The PDS can provide information on finances, financial advisers, insurance and pensions. Other forms of support can be obtained from an agency such as

Age Concern, which can provide advocates to help with financial tasks such as paying bills and organising finances.

Social activities

People with Parkinson's should be made aware of the support and services that the Parkinson's Disease Society can offer, including local branch meetings.

Transport

Many people with Parkinson's continue to drive for a long time following diagnosis. Social workers should offer support about DVLA conditions, vehicle adaptations, access to a Blue Badge, Motability Schemes and Vehicle Road Fund Licence exemptions. For people who do not have access to their own transport, information should be made available about community transport schemes, mobility schemes and charitable or voluntary organisations that can help with transport and costs. Yarrow (1991) found that most

people with Parkinson's found public transport either impossible to use or not available to them. Support may be required to enable a person with Parkinson's to attend hospital appointments, pursue hobbies, maintain social contacts, shop, etc. People with Parkinson's may be eligible to reclaim transport costs for hospital appointments or may be able to access motability schemes. CSWs can assist with arranging and locating suitable transport and completing forms.

Younger carers

Often, younger people with Parkinson's have children. The PDS produces books and information for younger people and children to explain how Parkinson's affects people and answer the common questions that children may have about their parent or family member.

There may be cases where children have adopted a caring role within the family; this should be acknowledged and acted upon by social workers. It is important for social workers to consider the role of children within the family and to look at any tasks or activities that they are undertaking to support their parent or carer. The Carers (Recognition and Services) Act 1994 offers all carers, including young carers, the opportunity to have their needs assessed at the same time as the

recipient of care is being assessed or re-assessed. However, evidence has shown that young carers are frequently excluded from the assessment process (Dearden & Becker, 1997). Support for children who are undertaking a caring role within the family may be obtained from young carers projects (for further information see Dearden & Becker, 1995). It is important to consider the role of children during the assessment process. It may sometimes be appropriate for the assessment of the child to be completed under the auspices of the Children Act after referral to a children and families team.

Younger people

Parkinson's is often considered to be a condition that affects older people. However, one in 20 of those diagnosed is under the age of 40 (McCall, 2006). Parkinson's in younger people can have a significant impact on family life. Roles may change and there may be financial implications for families around issues of employment and the increased costs, which evidence has shown affect disabled people (Burchardt, 2003). However, many people continue working following diagnosis and successfully manage full-time work.

McCall (2006) highlights the fact that younger people who have been diagnosed with Parkinson's are more likely to suffer from depression, so consideration of the psychological implications of Parkinson's is important. Support may be available from counselling services, family therapy or PDNSs. A mental health assessment may also be helpful where depression is a significant problem. Younger people who are feeling socially isolated or wish to meet other people and families in similar situations may like to become involved with the PDS's Younger Parkinson's Network or access day services designed to meet the needs of younger people. It is important that social workers ensure that needs are assessed age specifically.

Evidence has shown that direct payments schemes can help younger disabled people regain control over their lives (Stainton & Boyce, 2004). The Independent Living Fund may also be able to help younger people with Parkinson's to fund their care.

Social care implications for younger people are similar to those of older people. However, financial concerns may be increased if the person is supporting a family and paying a mortgage. It is important that there is access to support and advice about claiming welfare benefits and in maintaining or finding employment opportunities. Specialist employment support workers, Job Centre Plus and associated agencies may be able to offer advice to people who are experiencing difficulties with continuing or finding employment. The fluctuating nature of Parkinson's may make finding and sustaining employment or training problematic. However, with adequate support, many younger people with Parkinson's continue to work, many with the co-operation of their employers, who have a statutory duty to provide 'reasonable' support and adaptations where necessary. Further information, advice and support is available from the Disability Rights Commission.

Voluntary agencies such as the Citizens Advice Bureau can help with claiming benefits, as can finance and benefits teams from the Work and Pensions Service. Disability advocates may also be a useful source of support. ISWs from the PDS can offer support and advice regarding welfare benefits and assist with completing forms. The Society also provides a range of rights and benefit information sheets and has a rights and benefits advisory service. An employment guide is also available.

Useful contacts

Disabled Living Foundation

Helpline: 0845 130 9177 (Mon–Fri, 10am–4pm)
Email: advice@dlf.org.uk
www.dlf.org.uk

Action on Elder Abuse

Helpline UK: 0808 808 8141
Helpline ROI: 1800 940 010
Email: enquiries@elderabuse.org.uk
www.elderabuse.org.uk

Contact the Elderly

Freephone: 0800 716543
www.contact-the-elderly.org

Disability Rights Commission

Telephone: 0845 6046610
Textphone: 0845 6046620
www.drc-gb.org

Relevant resources from the PDS

Booklets

Choices: A Guide to the Health and Social Care Services (code B079)
Employment Guide (code B103)
Looking After Your Bladder and Bowels in Parkinsonism (code B060)
Living with Parkinson's – a guide for people of working age affected by the condition (code B077)
Parkinson's and Diet (code B065)
The Carers' Guide (B071)
Various books for children
Working Together Locally (B100)

Information sheets

Dementia and Parkinson's (code FS58)
Dementia with Lewy Bodies (code FS33)
Depression and Parkinson's (code FS56)
Eating, Swallowing and Saliva Control (code FS22)
Falls and Parkinson's (code FS39)
Living Alone with Parkinson's (code FS29)
Pill Timers (code FS53)
Parkinson's and Hypersexuality (code FS87)
Gambling and Parkinson's (code FS84)
Equipment and Disability Aids (code FS59)

Rights and benefits information sheets

Attendance Allowance (code WB2)
Carers' Allowance (code WB8)
Council Tax Benefit (code WB12)
Disability Living Allowance (code WB3)
Employment and Support Allowance (code WB16)
General Information (code WB1)
Help with Getting Around (code WB10)
Housing Benefit (code WB13)
Incapacity Benefit (code WB6)
Income Support (code WB7)
Insurance (code WB18)
National Health Service Costs (code WB9)
Pension Credit (code WB5)
Pensions and Financial Advice (code WB17)
The Social Fund (code WB15)
Working Tax Credit (code WB4)

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notes

social worker



Communication and Parkinson's disease

A commonly occurring feature of Parkinson's disease is communication impairment – between 75% and 89% of people with the condition will experience a reduced ability to communicate (Logemann et al, 1978; Mutch et al, 1986). It is one of the many complex aspects of this neurodegenerative condition that needs careful, knowledge-based management within a multidisciplinary setting.

The prevalence of Parkinson's rises with age, from 1.5 per 1,000 people below the age of 80 to two per 1,000 in those over 80. For older people, who are often faced with reduced mobility and social contacts, the ability to communicate gains even greater importance – as a link to others and as a way of maintaining emotional stability and a sense of wellbeing (Casper et al, 2000). For younger people with Parkinson's,

communication is often a lifeline to retaining independence and quality of life, through work and social interaction.

With neuropharmacological and neurosurgical treatments reported as having only a variable and unpredictable impact on improving speech production (Pinto et al, 2004), speech and language therapists are faced with an ongoing and exciting challenge to bring evidence-based, effective treatment methods into their clinics, as well as to inform the research process.

This section aims to assist this process by describing:

- the nature of the speech and language presentation in Parkinson's
- progression throughout the course of the condition
- evidence-based treatment methods and applications

The nature of speech and language presentation in Parkinson's

Non-verbal

Communication can be affected on several levels. Reduced facial mobility can be a significant feature of the condition – although the patient is able to move their facial muscles, hypokinesia or poverty of movement makes a change in movement difficult or slow. A reduction in facial muscle activity results in a 'mask-like' facial expression, which gives an impression of flat affect, despite an apparently normal experience of emotion. This is likely to contribute to the perception of depression, anxiety and detachment. Communication partners, sensing this, may withdraw, leading to a breakdown of communication and isolation for the person with Parkinson's (Pentland et al, 1987). In some cases, eye contact may be disrupted: a reduced eye blink reflex may be experienced or eyes can be fixed closed for several seconds. Gestural

movements, including head nodding and shaking, may also be reduced. In addition, writing may become very small (micrographic) and eventually illegible, cutting off another means of communication.

Motor speech

Described as hypokinetic dysarthria by Darley in 1969, the most commonly reported perceptual features are:

- reduced loudness
- monoloudness and monopitch
- breathiness and harshness
- reduced prosody
- imprecise articulation

(Logemann, 1978; Johnson & Pring, 1990; Hammen & Yorkston, 1996)

The physiological and neuropathological mechanisms underlying speech in Parkinson's are still being

determined but it is clear that laryngeal and phonatory impairments are a predominant feature. Studies have found vocal fold bowing is a consistent laryngeal finding in patients with Parkinson's – a recent study found 87% of patients presented with bowing of vocal folds (Blumin et al, 2004).

Laryngeal impairments have been attributed to reduced laryngeal muscle activation or muscle atrophy, stiffness or rigidity of vocal folds and/or respiratory muscles and a general reduced drive of amplitude to the muscles of the speech mechanism (Ramig et al, 2001).

Whatever the underlying causes, patients with Parkinson's will often present these features and it is important that we understand their typical presentation, as well as assessing them as individuals.

Reduced loudness

People with Parkinson's often present with a soft, weak voice that may just be audible in a one-to-one situation but will be lost in a noisier environment. They may often be aware that they are having to repeat themselves more frequently but do not associate this with a reduction in their volume. They are more likely to assume their communication partner has a hearing problem.

This is the result of a problem in sensory perception of effort, which prevents them from accurately monitoring their spoken output and a difficulty in self-generating the right amount of effort for adequate loudness (Fox et al, 2002). They will therefore often believe they are shouting when they are not. Speech may start at an adequate volume but gradually fade to become unintelligible.

Monoloudness and monopitch

Difficulty in varying volume and pitch leads to a lack of inflectional changes and emphasis in speech and contributes to reduced intelligibility. Singing may also be difficult.

Breathiness and harshness

The occurrence of breathiness and harshness have been noted frequently as perceptual features (Darley et al, 1969; Logemann et al, 1978), with a breathy voice quality sometimes also being described as continuous.

Prosody

Word stress can be reduced and syllabic stress may sometimes be inappropriate or syllables may be omitted from multisyllabic words. Rate of speech can

be either too rapid, sometimes with accompanying repetition of syllables or words, referred to as palilalia, or can be very slow. Sometimes, just as difficulty in initiating walking can occur, there may be difficulty initiating speech – or 'freezes' – when there may be inappropriate silences in the middle of a sentence. This can be very distressing for the person with Parkinson's, and carers need to be helped with strategies to 'repair' the conversation.

Imprecise articulation

This is typically present in conversation although in single word testing, performance can be normal. The imprecision is likely to result from the range of movements being narrowed and laryngeal and oral co-ordination being reduced, leading to distortions and omissions of phonemes.

Neuropsychological functioning

It has been estimated that 40–60% of people with Parkinson's experience decreased cognitive functioning (Mahler & Cummings, 1990) and while for some this may be part of a global process of dementia, many others experience a particular pattern of deficits specific to Parkinson's.

These deficits may be very subtle and sometimes undetectable in a straightforward conversation. They include slow thinking and slow learning, problems shifting cognitive sets, problems internally cueing and with procedural memory (Lees, 1994; Brown et al, 1988; Fimm et al, 1994). There may also be a reduction in pragmatic communication skills in areas such as conversation appropriateness, turn-taking and sometimes word-finding difficulty (Murray et al 2000).

It is essential, when planning treatment, that these impairments are recognised and that learning theories and compensatory strategies are brought into each programme. Depression is also a common feature, affecting 40–50% of people with Parkinson's (Goetz et al, 2002), and needs to be recognised and addressed as part of overall management and through multidisciplinary working.

Progression of speech and voice symptoms in Parkinson's

There has been limited research on how speech presentation changes during the progression of the condition but a study by Holmes et al (2000) found that initial symptoms were of vocal dysfunction – monopitch, monoloudness, low loudness and soft, breathy voice. It suggested that these characteristics deteriorate with the progression of the condition, most likely as a result of increasing rigidity and bradykinesia

and their impact on the laryngeal and respiratory musculature. Tremor was the sole voice feature associated only with later stage Parkinson's and this, also, was seen to deteriorate. It is therefore useful for clinicians to be alert to these early signs, both diagnostically and also to encourage early referrals, as treatment outcomes are likely to be better if initiated at early or mid stage rather than at end stage.

Evidence-based treatment methods and applications

In the 1980s and 90s, speech and language therapy for people with Parkinson's was rare – an initial study by Oxtoby et al (1982) estimated that of the 75–89% of people with speech problems, only 3–4% ever received therapy. This was further updated in 1999 by another survey of members of the Parkinson's Disease Society, where access to speech and language therapy was found to have increased to 20% (Yarrow, 1999) – still a low figure.

Treatment took place (and, in some cases, still does) typically once a week for a small number of weeks, and was then followed up by reviews later in the year. Treatment was either individually or in groups. Many aspects were included – for example articulation, breathing, rate and prosody – and efficacy data indicated limited success, particularly for long-term follow-up.

However, in the past ten years, there have been some exciting developments in treatment methods, with sound efficacy data showing long-term improvements – as much as two years post-treatment (Ramig et al, 2001) – and neural correlates showing the effects on regional blood flow following treatment (Liotti et al, 2003).

One such method is known as the Lee Silvermann Voice Treatment (LSVT) (Fox et al, 2002) and directs attention to phonation (voice) as a key element.

The essential concepts are:

- exclusive focus on voice, specifically vocal loudness
- stimulation of high-effort productions with multiple repetitions
- intensive treatment delivery (four individual sessions a week for four weeks)
- enhancing sensory awareness of increased vocal effort and loudness

- quantification of behaviours

By combining principles of skill acquisition and motor learning – keeping it simple, high-effort, with multiple repetitions and a focus on sensory awareness – the programme is specifically tailored to people with Parkinson's. It has been successful for people with a range of cognitive impairments, including mild to moderate dementia and also mild to moderate depression. Interestingly, there is also preliminary evidence that facial expression is improved through this intensive programme (Spielman et al, 2003).

While LSVT is designed to be administered individually, some therapists have started to incorporate elements of the programme into group settings (Manor et al, 2003), again with successful preliminary findings. While there are still unanswered questions and more research is needed, LSVT is currently the treatment method with the most sound and positive evidence base and, as such, clinicians should have access to the accredited courses. It then needs to be incorporated into the wider picture of communication management in Parkinson's. This involves:

- detailed assessment and recording for pre- and post-treatment analysis
- advice/work with carers and communication partners on strategies and tips for improving communication
- addressing hearing impairment/partner's hearing
- awareness of drug regimen and effects on speech, eg end-of-cycle effect
- evaluation of need for alternative augmentative communication aid in later stages and advice
- multidisciplinary working, advising colleagues
- continuous professional development of condition and current interventions
- treatment exercises to achieve and maintain intelligibility

Augmentative and alternative communication systems (AAC)

Assessing the communication abilities and needs of somebody with Parkinson's may sometimes lead to consideration of AAC. Technology in general can improve quality of life; for the increasingly computer-literate ageing population and younger people with Parkinson's, technological advances can facilitate improved communication and social links.

Careful assessment is the first step, to establish whether a low-tech aid (such as an E-Tran frame/communication chart) or high-tech aid (such as a text-to-speech aid) is appropriate and whether further specialist expertise from a communication aid centre may be helpful. A common symptom of advanced Parkinson's is cognitive impairment. Therefore it is important to assess carefully and try out any aid prior to purchase. It is especially important to involve the carer and give them the opportunity to practise using the aid before buying.

Amplifiers may be considered if articulation remains relatively clear. An article in *RCSLT Bulletin* (September

2001) by Frenchay AAC department describes the benefits they can bring to a range of conditions. Again, careful assessment and testing is needed to establish whether they would enhance communication and which type of amplifier is most appropriate (eg wireless or non-wireless amplifier), also assessing how easy it is for the person to operate the volume controls.

Encouraging the use of the internet/email is sometimes appropriate and advice from occupational therapy colleagues and organisations such as AbilityNet on adaptations to seating/posture, as well as how to customise the computer/keyboard/mouse, can be helpful.

Telephone use and any adaptations to enhance use, such as those provided by BT, should be assessed and the patient provided with contacts/information relevant to their needs.

Swallowing in Parkinson's disease

Swallowing disorders have been reported in as many as 95% of people with Parkinson's (Logemann et al, 1975; Blonsky et al, 1975). Although the severity, even in the later stages, is not usually great enough to require non-oral feeding (Lieberman et al, 1980), it remains a significant feature of the condition, which demands careful assessment and management.

Presentation

Videofluoroscopic studies have demonstrated motility disorders in all phases of the swallow – oral, pharyngeal and oesophageal (Logemann et al, 1988). The main features are :

- disturbed lingual movement with characteristic 'rocking' or 'pumping' tongue movement back and forth
- reduced tongue base retraction, with residual food subsequently remaining in the valleculae (This is significant as a possible cause of erratic absorption of tablets and reduced response to medical treatments.)
- reduced range and co-ordination of tongue movements with decreased ability to chew,

control bolus and move posteriorly

- the above disturbances in lingual function lead to increased oral transit time
- delayed triggering of the pharyngeal swallow
- reduced laryngeal closure and/or elevation
- aspiration (various levels reported in the literature from just laryngeal penetration to frequent aspiration). Also included is silent aspiration, where the patient shows no coughing/awareness or overt signs of food or liquid having passed below the level of the vocal folds

Management of eating and drinking

As with all neurodegenerative conditions, careful assessment and monitoring is important. The accompanying features in Parkinson's disease of cognitive impairment and depression, as well as drug-cycle effects, also need to be considered in the overall assessment and management strategy.

Assessment starts with the clinical evaluation and can be supplemented by further investigation, such as cervical auscultation/modified barium swallow

videofluoroscopy/Fiberoptic Endoscopic Evaluation of Swallowing (FEES).

Management of swallowing disorders in Parkinson's has traditionally been through compensatory strategies such as the following:

- Maximising body posture and head position, to be as upright and central as possible. (Liaise with physiotherapy and occupational therapy colleagues on positioning and optimum seating.)
 - Giving advice on adapting consistencies, linking with the dietitian to ensure that the most nutritional and safest-to-swallow consistencies are provided. Oral phase impairment with lingual disorders are likely to make chewing and hard consistencies difficult to manage, although this has to be assessed on an individual basis. Assessment with thickeners may also be needed if thin fluids are difficult to manage.
 - Bolus size should be considered. Some studies have found that increased bolus size reduces pharyngeal delay, possibly due to increased stimulation of the sensory receptors (El Sharkawi et al, 2002).
 - Liaising with dietitian and multidisciplinary team on food and fluid intake – slowness, fatigue and lack of concentration may affect intake and smaller high-calorie snacks may be more appropriate.
 - Giving a verbal, timely oral routine to the swallow is sometimes helpful, particularly where cognitive deficits are present.
 - Trying strong flavours or ice-cold drinks to help trigger the swallow.
 - Alerting carers/staff to the signs of aspiration and ensuring they are informed of emergency measures for choking.
 - Alerting carers/staff to the likelihood of food pocketing and to oral hygiene issues and being aware of medications that may cause dryness.
- If patients complain of food sticking in the pharynx, try different techniques such as altering head posture or taking solid followed by liquid swallows/dry swallows to clear residue building up in pharynx.
 - Teaching carers 'safe feeding' techniques if the person with Parkinson's is unable to feed themselves, because a dependency upon others for feeding has been shown to put people at higher risk of aspiration pneumonia (Langmore et al, 1998).
 - Emphasising the importance of good oral hygiene with regular dental check-ups (Langmore et al, 1998).
 - Medication – no Parkinson's medications are currently available in syrup form and controlled-release tablets cannot be crushed. Dispersible Madopar can be dissolved and thickened, if easier to swallow. In cases of severe dysphagia, an apomorphine injection or nasogastric feeding with dispersible Madopar may need to be considered. Other methods of administering medications for Parkinson's are being investigated at present.

Ensure clear verbal and written advice is available to carers/staff, based on individual assessment – these suggestions are, by necessity, general and need to be adapted for each individual.

In addition to these compensatory strategies, there has been anecdotal evidence from patients and, more recently, a study (El Sharkawi et al, 2002) that showed that swallowing improved following LSVT. Pre- and post-treatment evaluation by videofluoroscopy showed a 51% overall reduction in the number of swallowing motility disorders. It was suggested this may be due to improved neuromuscular control and an overflow of effort from the increased activity of the programme.

Saliva management

Drooling, sometimes described in medical literature as hypersialorrhoea, is a relatively common symptom for people with Parkinson's and can be both distressing and embarrassing.

Drooling has been found to be the result of swallowing difficulty rather than production of excess saliva (Proulx

et al, 2005) and there are a number of strategies – therapeutic, pharmacological and surgical – available. The speech and language therapist needs to assess the severity and impact on the patient of the drooling – often present in the later stages – and liaise with medical and health colleagues for ways to reduce it, continuing to monitor and evaluate as appropriate.

Initially, **therapeutic** methods, such as addressing posture and head positioning with physiotherapy colleagues, can be used, as can using cues to remind patients to swallow – some therapists have tried an electronic reminder, such as the metronome brooch (Marks et al, 2001). If a lot of fluid is being lost through drooling, the importance of compensating for this by extra fluid intake needs to be emphasised to patient and carer(s).

Pharmacological – Hyoscine patches are often tried first, although they can have side effects of confusion and hallucination, particularly among older people. Sublingual atropine has been shown to reduce saliva production effectively, both objectively and subjectively, but there can occasionally be side effects (Hyson et al, 2002). These are simple to administer as drops, given orally under the tongue, and are a non-invasive and inexpensive option.

Botulinum toxin injections into the parotid/submandibular gland can be given to reduce saliva, with some effect, for people with severe drooling (Lipp et al, 2003), the down side being that the effects wear off and repeat injections are needed every few months. The Botulinum toxin may also spread into the pharyngeal musculature and cause difficulty with swallowing.

Surgical excision of the salivary glands or duct rerouting has been used in some cases but, as a surgical procedure, is not usually a preferred option for older, later-stage Parkinson's patients.

Speech and language therapy checklist

Name :

Date of assessment :

1 Communication environment

2 Communication needs

3 Patient perceptions on their communication

4 Physical

- tremor
- rigidity
- bradykinesia
- posture/symmetry
- gait
- balance

5 Speech

- hearing
- vision

Summary dysarthria assessment:

- intelligibility
- voice
- volume
- respiration / ss / ___ secs
/ ah / ___ secs
- prosody
- facial expression/gaze
- palilalia
- initiation difficulties
- freezing
- strategies used

6 Cognition and language

- memory
- orientation
- insight
- self-monitoring
- writing

7 Dysphagia

- consistencies
- appetite
- weight loss
- chest infections
- nutritional/aspiration risk
- posture
- saliva management

8 Medication and drug cycle

- Variability of:
- physical state
 - speech
 - swallowing
 - cognition
 - best time of day
 - wearing-off effect
 - 'on/off' syndrome
 - factors affecting variability

Recording

	Decibels
/ah/ normal volume	
/ah/ loudest volume	
Counting aloud 1-20	
Reading aloud sentences	
Picture description/conversation	

Recommendations:

Useful contacts

AbilityNet

Network of local centres around the UK
Tel: 01926 312847
www.abilitynet.org.uk

Frenchay Communication Aid Centre

SLT Department
Frenchay Hospital
Bristol
BS16 1LE
Tel: 0117 975 3946
www.cacfrenchay.nhs.uk

Find a Voice

49 Beaver Lane
Ashford
Kent
TN23 5NU
Tel: 01233 640443
www.findavoice.org.uk

Relevant resources from the PDS

Information sheets

Communication (code FS06)

Computers, the Internet and Useful Websites (code FS60)

Eating, Swallowing and Saliva Control in Parkinson's (code FS22)

Handwriting and Parkinson's (code FS23)

Speech and Language Therapy (code FS07)

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notes

notes



Parkinson's
Disease Society



To stop their condition getting out of control,
people with Parkinson's need their medication
on time – every time

Whether in a hospital or care home setting, effective medicines management is crucial to the wellbeing of people with Parkinson's.

Poor medicines management can lead to the worsening of symptoms and increased care needs.

The Parkinson's Disease Society has advice and support to help you meet medication management standards for Parkinson's patients.

Best practice for managing Parkinson's medication can also be applied to other conditions.

Act now...

Contact us for a 'Get it on time' campaign pack, to talk to local people with Parkinson's about their experiences of hospital or nursing home stays, or for best practice advice.

Email campaigns@parkinsons.org.uk or call 020 7963 9332.

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