

Coping with the symptoms of Parkinson's disease

Parkinsonism is one of the most common clinical groups of conditions within residential care. In 2003, it was estimated that the incidence of Parkinson's disease (PD) was 2 in every 1000 people, increasing to 1 in every 100 for elderly people and 1 in every 10 residents in nursing homes (Parkinson's Aware in Primary Care, 2003).

PD is not a new disease; it was first described in 1817 by Dr James Parkinson in an essay titled the 'The Shaking Palsy'. He described the cardinal symptoms as akinesia (loss of movement), a rest tremor, cog-wheel rigidity and postural abnormalities.

Gazzaniga et al (2002) describe how in the 1950s, PD became the first disease to be linked to neurotransmitter deficiencies. Celebrities including Ray Kennedy and Michael J Fox have raised public awareness of the disease as they have young-onset PD. The cause of 'true' idiopathic PD, which results in a reduction in the neurotransmitter dopamine, is unknown. There is thought to be a weak genetic link, perhaps exacerbated by unknown toxins accumulating in the environment (McCall and Williams, 2004). Nazarko (2005) notes that 'the incidence of PD is rising in line with the population ageing'.

Medical treatment

Medication remains the main treatment of PD. In the 1960s, many people's lives were transformed by the administration of levodopa (L-dopa), which replaced the missing neurotransmitter dopamine, providing major improvements to physical problems. Scadding and Gibbs (1994) note that quality of survival has undoubtedly been improved by L-dopa treatment, although the life expectancy is still in the region of 10 years from the onset of symptoms.

Julie Swann discusses how parkinsonism affects residents and offers some practical ways of overcoming problems with daily living.

Unfortunately, medication can result in side-effects such as dyskinesia (jerky uncontrollable movement) and hallucinations. Medication, therefore, needs careful monitoring. It should not be assumed that signs of deterioration are a natural progression of the disease – they could be related to the medication itself.

In addition, some other types of medication, especially sedatives, can cause symptoms that mimic parkinsonism symptoms. Sometimes, by simply altering the medication, we can reduce the symptoms. Care staff have a vital role to play in monitoring any changes of symptoms.

For further details on the medical treatment of PD, readers can refer to Nazarko (2005).

Understanding residents' problems

PD causes stiffness and slowness of movement, which progressively worsens over time. The movement pattern of the tremor experienced is similar to that of rubbing in flour with your fingertips, or the former pre-industrial method of making pills – hence it is termed as a 'pill-rolling' tremor. Tremor is initially present on rest, disappearing with action. People with PD have difficulty walking, loss of balance, slow movement, poor coordination and fatigue.

Rose (1990) was diagnosed with PD at the age of 18 years and her insightful book describes her experiences, which include problems with medication. As knowledge of the illness has developed and professionals have gained more experience of dealing with problems, identification of coping strategies have developed. *Table 1* details the different roles of health-care



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professionals in helping patients with PD and their carers.

Effects of symptoms

Imagine that you want to perform an action but your body won't move, or you want to smile but your muscles don't work – you would feel trapped inside your body. This is experienced by many sufferers of parkinsonism. Many also have problems with walking and their feet can get 'stuck'. Posture is flexed (kyphotic) and balance reactions are lost. Walking is slow and shuffling, with loss of arm swinging.

As a result of akinesia and facial rigidity, the sufferers can look vacant and depressed. It can be very difficult to communicate with a person with a mask-like face, as there is no facial expression to interpret. Staring eyes and reduction of blinking are common.

On-off phenomena

Some people may have periods of mobility and periods of immobility, commonly called the 'on-off' phenomena. People may have periods of 'freezing', in which they are totally immobile, then a short period of reasonable movement patterns, followed by a period of dyskinesia. When planning activities, it is sensible if passive activities are carried out during the 'off' period and participative activities during an 'on' period. 'On' periods occur for about 30 minutes after L-dopa medication is administered.

Speech

Volume, timing, articulation and pronunciation of speech can be affected, resulting in difficulty judging how a person is feeling and misinterpretation of emotions. Speech is often quiet and may at times be inaudible or appear jumbled, simply because voice production is poor. This may be accompanied with excessive saliva production or drooling, as tongue and swallowing movements are impaired.

Sheila Scott (2005) offers tips to help when communication difficulties are present:

- Give the person time to speak and to respond in a conversation
- Maintain eye contact
- Don't pretend to understand if you don't, but instead ask the person to repeat the comment in another way

- Don't complete the end of the sentence for the person
- Don't speak above noise
- Use short sentences and stress key words.

She summarizes:

'Stress is easy to recognize in a person's voice, so it is important to relax. Above all, have patience and don't interrupt.'

Writing

Small writing is a common symptom in PD. Encourage larger pen strokes and try the person with different writing implements, such as felt tips (not as much pressure is required) or medium-nib ballpoint pens (do not show up tremor as much). A clipboard will prevent paper from slipping.

Eating

Parkinson's Aware in Primary Care (2003) states that in some people, the protein in food seems to interfere with the absorption and effectiveness of L-dopa, so the doctor may suggest that daytime intake of protein is restricted (but not the overall amount of protein). Because of impairment of movement, chewing can be difficult and appropriate food should be given with a dietician's advice, if necessary.

Eating can take a long time and food may become cold if a full plate is given. Try smaller portions and offer seconds. Some adapted plates have a hollow base that can be filled with hot water and sealed tightly to prevent leakage and scalding.

Fine finger movements may be difficult and enlarged lightweight handles are preferable. One hand may be more affected than the other and use of a plate guard or straight-sided bowl with non-slip material is advisable. If there is a tremor on movement or dyskinesia, then a swivel spoon can be tried for soups and puddings. Encourage only partial loading of food onto cutlery.

There are many different types of drinking vessels, from ones with enlarged handles to feeding cups with spouts. Tabards are useful as they can be changed easily.

Dressing

Several problems and solutions are provided in Swann (2005) that are relevant to residents suffering from parkinsonism.

A gradual change of clothing style is advisable. Avoid small fastenings and tight garments. Front-fastening loose garments with raglan sleeves, large buttons, zips with large pulls and velcro are easier to

Table 1.

HOW HEALTH-CARE PROFESSIONALS CAN HELP IN PARKINSON'S DISEASE

Professional	Help and advice on
Counsellor/Psychologist	<ul style="list-style-type: none"> ■ Adjustment ■ Developing coping strategies
Dietician	<ul style="list-style-type: none"> ■ General diet ■ Preparing and presenting food to cope with swallowing problems
Falls coordinator (nurse, occupational therapist or physiotherapist)	<ul style="list-style-type: none"> ■ Removing obstacles in the environment ■ Provision of hip protectors (garments)
Nurse (district nurse, health visitor and Parkinson's disease specialist)	<ul style="list-style-type: none"> ■ Understanding the illness ■ Support for carers ■ Clinical knowledge of medication and side-effects ■ Incontinence advice and provision of garments
Occupational therapist	<ul style="list-style-type: none"> ■ Equipment for personal care ■ Advice on alternative techniques ■ Suggestions on activities and maintenance of leisure ■ Wheelchairs
Physiotherapist	<ul style="list-style-type: none"> ■ Maintaining movement ■ Teaching mobility coping strategies ■ Retaining good posture and modifying poor posture ■ Improving breathing techniques
Speech and language therapist	<ul style="list-style-type: none"> ■ Communication ■ Swallowing problems, including strengthening facial muscles

put on and remove. Scarves or a cravat can help if drooling is severe.

If shuffling is a problem, then encourage leather-soled shoes, as these are easier to walk with and elastic or Velcro-fastened shoes are easier to manage. Natural fibres are more comfortable to wear.

Toileting

Ensure that strategically placed handrails are available in communal toilets and en suites, with toilet paper and towels within reach. It may be difficult to extract toilet paper, but interleaved paper may be easier, or even a box of tissues. A male resident may benefit from the installation of bilateral vertical rails, to aid standing over a toilet.

Initiating movement patterns

The film 'Awakenings' (recently shown on television) graphically shows the effect of L-dopa on people with parkinsonism as a result of an outbreak of encephalitis in the 1920s. It demonstrated akinesia, yet how quick automatic reflexes were retained. The main character was immobile in a chair, yet caught a ball that was thrown to him. Methods of using this pathway will be discussed in the next article, which will concentrate on specific tips to use when people are undertaking personal care activities. It will provide some exercises to be used in movement to music or individual exercise sessions.

Box 1.

HOW CARE STAFF CAN HELP

- Encourage self-management for as long as possible
- Advise relatives on easier-to-manage clothing styles
- Arrange for the provision of assistive equipment to help with self-care
- Allow extra time to do tasks and concentrate on one task at a time
- Plan daily routines around any daily fluctuation of function
- Report any side-effects or changes in mobility or behaviour
- Encourage good posture and walking pattern
- Encourage participation in social activity
- Reinforce physiotherapy and speech therapy exercises

One neurological consultant I knew encouraged his rehabilitation staff to sing when walking with patients. This is not as strange as it sounds: a rhythmic tune, such as a marching song, can overcome the loss of voluntary movement and make it automatic. You may notice an improvement not only in gait pattern, but also in arm swinging. Gazzaniga et al (2002) describes a patient who used a stick, which he would kick to help him initiate walking.

Psychological problems

Although it can be difficult to determine mood because of loss of facial expression, depression is common in PD. Nazarko's articles in this magazine will discuss the psychological aspects of PD.

Conclusion

Decades ago, owing to immobility, many people became bed-bound and nursing care was the main form of treatment for PD. The introduction of L-dopa and subsequent medication has given increased mobility, but at a cost: major side-effects include dyskinesia and 'on-off phenomenon'. Care staff must be aware of the side-effects of medication and report any fluctuation in condition. Some of the impairments of cognitive function can be a result of the side-effects of drugs.

Equipment and mobility aids are often met with resistance with any deteriorating condition, as they are visible signs that activities are no longer independently possible. Therapists working in conjunction with care staff can assist to maintain function and help people to overcome areas of difficulty, primarily by alteration of techniques and encouragement to use adaptive equipment. *Box 1* summarizes how care staff can help residents with PD. **NRC**

Gazzaniga MS, Ivry R, Mangun GR (2002) *Cognitive Neuroscience: The Biology of the*

Further information

- Parkinson's Disease Society
215 Vauxhall Bridge Road
London SW1V 1EJ
Helpline (freephone): 0800 800 0303
(Mon–Fri 9.30am–5.30pm)
Tel: 020 7931 8080
www.parkinsons.org.uk

- European Parkinson's Disease Association
www.epda.eu.com/patientInfoLeaflets.shtm

Additional websites on Parkinson's disease:

- www.parkinsonsdisease.com
- <http://james.parkinsons.org.uk>
- http://hcd2.bupa.co.uk/fact_sheets/html/Parkinsons_disease.html
- www.bbc.co.uk/health/conditions/parkinsons1.shtml
- www.parkinson.org/site/pp.asp?c=9dJFJLPwB&b=711.17

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KEY POINTS

- **Parkinsonism is one of the most common clinical groups of conditions within residential care.**
- **Awareness of the side-effects of medication is essential.**
- **Allow plenty of time for personal care activities to be undertaken.**
- **Plan activities around an individual's function if fluctuations occur from medication.**