

The misconceptions and reality of Parkinson's disease

Parkinson's disease is a progressive, fluctuating, neurological condition – the cause of which remains unknown. Recent evidence draws attention to environmental factors (such as drinking from well water, and farming and the resultant exposure to insecticides) that are associated with an increased prevalence of the disease and are the subject of intense research (Clough et al, 2003).

More than 120 000 people have Parkinson's disease in the UK, and it is estimated that 10 000 people are newly diagnosed each year (Ben-Schlomo, 1997). The incidence of the disease increases with age and as the population in the UK ages, the prevalence of the disease is expected to rise.

As the number of people living longer increases, new and varied challenges are arise for health-care professionals. People will expect flexible services both at home and in care home settings, and their demands will be more exacting, with heightened awareness and expectations (Disability and Rehabilitation Education Foundation, 1995).

What is Parkinson's disease?

Parkinson's disease is a common neurological condition. It is the fourth most frequent neurological disorder after epilepsy, stroke and dementia. It is also a very individual condition that affects each person in different ways.

The disease, unlike many other neurological illnesses, is one of the few for which specific drug treatment is available. The treatment, although not a cure, does bring degrees of control over the disease process and improves quality of life, but it can result in frustrating and misunderstood

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Caring for people with Parkinson's disease is a rewarding challenge. Sheila Scott gives an update on the impact of the disease, side-effects, and current treatment options.

Table 1.

CONDITIONS THAT MIMIC PARKINSON'S DISEASE

Multiple system atrophy*
Progressive supranuclear palsy
Lewy body dementia
Corticobasal degeneration*
Dystonia Parkinsonism
Cerebrovascular disease
Essential tremors

* Indicates conditions referred to as 'Parkinson's plus' syndromes

side-effects which adversely impact upon the quality of life.

For those caring for people with the disease, understanding the nature of the condition and the impact of treatment is often their biggest challenge.

Symptoms

The cardinal symptoms of Parkinson's disease are tremor, rigidity and slowness of movement (bradykinesia). Many textbooks also now include postural instability as an associated feature of the disease as it progresses (Playfer and Hindle, 2001).

Notably, these cardinal symptoms are also present in conditions which mimic the disease. These are classified under the term 'Parkinsonism'. *Table 1* illustrates the more complex of these. It is important that these neurological conditions, and other conditions such as drug-induced Parkinsonism, are eliminated during diagnosis.

The cardinal symptoms of Parkinson's disease arise as a result of the selective loss of neurones which produce dopamine in the area of the brain known as the substantia nigra. This loss of dopaminergic activity to the striatum causes excessive motor inhibitory output. The striatum is the largest part of the basal ganglia. This area receives information about the position and movement of the body from several parts of the brain and transmits it to the substantia nigra.

Yet even this accepted neuropathological description of the disease has given rise to challenges. Parkinson's disease is a complex condition and other neuropathways may also contribute to the overall deficits that occur (Clarke, 2001). In turn, this further complicates treatment.

The onset of the disease is slow and insidious. For many, the presence of these main motor symptoms may be pre-dated by depression, constipation, disturbance of olfactory function (sense of smell), and aching and stiffness in the limbs.

Diagnosis and outlook

Cardinal symptoms

The diagnosis of Parkinson's disease is based on the presence of cardinal symptoms. This makes it a major challenge. The presence of two of these clinical features is essential for diagnosis. Diagnosis on tremor alone is not acceptable.

Misperceptions abound about Parkinson's. Many people regard tremor as the most disabling feature of the disease. While this may be distressing to watch, for most people living with the disease it is both the slowness of movement and rigidity that have the most affect on their daily activities.

Effect on activities of daily living

In addition to the cardinal symptoms, people with Parkinson's disease are increasingly unable to cope with activities of daily living, and as such become more and more dependent on carers. The disease impacts upon wellbeing, sense of purpose,

independence, participation and personal and sexual relationships.

The loss of mobility and bowel and bladder disturbances are distressing but rarely misconstrued by carers. The 'fluctuations' and loss of communication and swallowing functions, however, are often the cause of much misunderstanding.

The term 'motor fluctuation' means that after a number of years of levodopa treatment (trade names: Sinemet, Bristol-Myers Squibb, Hounslow; Madopar, Roche, Wellwyn Garden City), people may find that the smooth control of symptoms that their drugs once gave them is no longer dependable. When these fluctuations occur, people may initially find that the effects of their regular dose do not seem to last until the next dose is due (this is known as 'end-of-dose deterioration', or more simply, 'early wearing-off').

As the disease progresses, people may find that their symptoms reappear quickly and unexpectedly – a sensation that some have described as the 'on-off effect' (see later). Others find that they start to develop involuntary movements which initially occur when the level of levodopa in the bloodstream is at its peak, but may appear at any time later on. These are known as dyskinesias (see below) (Donaghy, 1997).

Living with the disease

The 'on-off' effect

Sudden fluctuations in motor function are known as the 'on-off syndrome'. The person can switch very rapidly from having minimal symptoms, to slowness of any movement with feelings of fatigue and exhaustion.

- **'Off':** When the medication is not working and the symptoms return, including slowness of movement and rigidity
- **'On':** When the drugs are working and movements are relatively normal. Many younger people can predict when an 'off' period is likely to occur. The periods vary in length, depending on the individual's response to levodopa, and can last from 5–10 minutes to several hours. The likelihood and frequency of this phenomenon occurring increases with the length of time the person has been taking levodopa.

Lack of understanding of this particular effect causes problems when a person is admitted to care. The 'on-off' syndrome can



Talk to the client with Parkinson's disease – include them, do not talk about them.

be very frustrating not only for the person with Parkinson's, but also for a professional who is unaware of fluctuations that this disease can cause. The person experiencing it can seem to be purposefully obstructive, uncooperative and demanding.

Dyskinesias

Dyskinesias are abnormal involuntary movements of the arms, legs, hands or body, caused by too much levodopa rather than too little. They vary in pattern from hardly visible twitches and jerks, to extreme writhing and twisting of the whole body. Notably, these are different to tremors, which are more likely to occur when the person is 'off'. Dyskinesias are more likely to present when the person is 'on' and the drugs are working.

Freezing

Many people with Parkinson's experience what is known as 'freezing'. This is where they have difficulty in performing a series of movements or sequences and temporarily become unable to move.

It is thought that freezing is related to duration of the condition and the prolonged use of levodopa. It tends to occur later on in the progression of the condition, and usually becomes more frequent and severe. However it is not entirely related to levodopa treatment, as untreated people can also experience freezing.

Activities to improve motor skills, such as marching on the spot, counting or walking over masked tape on the floor can often help a person start moving again if they have frozen. Physiotherapists can also do much to help those with freezing problems.

Eating

Eating dysfunction is a serious problem and one which causes great anxiety in care settings. Junior staff are often given the responsibility of assisting at meal times. Sometimes, however, their lack of experience can exacerbate an already difficult situation (Scott, 2002).

Eating difficulties can cause considerable embarrassment for the client. The physical difficulties of rigidity and slowness may also influence the manipulation of cutlery, further slowing the eating process and drawing attention to difficulties in what, for most of us, is an enjoyable and sociable activity.

Clients will often complain of an altered sensation of taste (usually metallic) which masks all flavour. Furthermore, unsightly eating and choking problems can cause further social separation.

Weight loss is a common feature of Parkinson's, arising from the increased metabolic demand of the tremor, rigidity and dyskinesias, reduced appetite, swallowing difficulties and depression.

Communication

Parkinson's disease can affect all types of communication:

- Speech
- Handwriting
- Body language
- Facial expression.

The loss of these skills can have a profound effect on clients' abilities to make themselves understood in a care setting. These communication difficulties can also create a misleading impression of the individual because they can sometimes incorrectly be interpreted as being difficult, deaf, or unintelligent, for example.

Research has also shown the negative effect that reduced facial expression has on the impression formed by health professionals of people with Parkinson's, compared to people with ischaemic heart disease (Pentland et al, 1987). Those with Parkinson's were thought to be more anxious, hostile, suspicious, unhappy, bored, tense, less intelligent, more introverted and passive, while those with ischaemic heart disease were considered to be compliant.

Loss of communication increases isolation and social embarrassment, and clients with the condition often become increasingly hesitant to participate in social activities within the home. Communication is affected in up to 50% of those with the condition, and this increases as the disease process progresses. Commonly, the voice is quiet and hesitant with little tune. Coupled with the loss of body language and facial expression, this can be the cause of much isolation, frustration and distress.

People with Parkinson's describe how it 'hurts to smile' or how 'even a hug can be difficult' (Parkinson's Disease Society, 1998). This again has an adverse affect upon staff who, when receiving little in the way of response or feedback often devote less time to that person (Parkinson's Disease Society, 2002).

In addition to communication problems, up to 80% of people with the disease will present with problems of dysphagia (swallowing). This can respond to levodopa treatment through an improvement in general mobility, but is often the cause of considerable anxiety and fear, not just for the client but also for his or her family and carers.

Drooling occurs in 70% of cases. This is often caused by the loss of automatic swallowing, combined with poor head posture and lip seal. Swallowing is characteristically piecemeal, with tongue bunching and repetitive attempts to swallow. Antimuscarinic drugs, while reducing tremor and rigidity also cause a dry mouth in some clients which is uncomfortable and further affects communication skills.

Treatment

There is a range of anti-Parkinson drugs available. It is important to remember that the disease is a very individual condition and what suits one person will not suit another. Clients will be on a different combination of drugs, of differing dosages, taking them at different times of the day.

The drug treatment also needs to be adjusted as the condition progresses and can often become quite complicated. Many clients may also have other conditions for which they will be taking medication that will further complicate the picture. However, the individual nature of the drug timing must not get lost as a result. When tremor is a distinctive or dominant cause of disability, surgical intervention may be considered as the preferred option over medical management. Drug-resistant tremor responds consistently well to surgery (Clarke, 2001).

Drug administration

Unfortunately, many clients in care homes do not receive their drugs at the individual times prescribed for them (Parkinson's Disease Society, 2002). Having managed their drugs successfully at home for a long time, they often find that their drugs are taken away from them and are only given at routine drug rounds. This upsets the disease, resulting in increased care needs. If an inflexible medication scheme is imposed, staff will probably have to provide a higher level of care.

The benefits of self-administration, where possible, or a patient-centred distribution of drugs are numerous. It saves staff time and energy in caring for the resident with Parkinson's disease. It not only enables the client to maintain dignity, self-respect and independence but also creates a firm base of communication and understanding between the health-care professional and the person with the disease.

If self-administration is not possible, drugs still need to be provided at the prescribed times for the individual. One solution that has worked in some settings is for a client to have a pill timer that rings to remind staff of the drug regime.

Side-effects of drugs

When someone with the disease starts anti-Parkinson drugs treatment, the symptoms often improve dramatically to the extent that they seem to disappear. After a time many people eventually begin to experience side-effects, especially fluctuations in the effectiveness of their medication. This can present a very confusing picture to staff, and it is important to be aware of this.

Drugs to be avoided

Some drugs are contraindicated because they generally make the symptoms worse. Unfortunately, some of these drugs may sometimes be used in a care setting to treat complications that may arise. In particular, certain drugs used to combat sickness or dizziness, including metoclopramide (trade name: Maxalon, Shire Pharmaceuticals, Hampshire), and propchlorperazine (trade name: Stemetil (Castlemead Healthcare Ltd, Ware), cause a drug-induced form of Parkinsonism and exacerbate symptoms in people with the disease.

The only oral anti-sickness drug that can be taken safely is domperidone (trade name: Motilium, Sanofi-Synthelabo, Guildford). Those on apomorphine will also usually be prescribed domperidone to overcome the problems of sickness and nausea that are a side-effect of apomorphine.

Many anti-psychotic drugs are also contra-indicated. These may be used to treat a confused patient or one with hallucinations (which can occur as a side-effect of the Parkinson's drugs). Although these drugs may be useful for other clients, they are to be avoided in people with Parkinson's disease. If absolutely necessary then some of the newer, so-called 'atypical anti-psychotic drugs' are preferable because they have fewer side-effects.

Selegiline, one of the anti-Parkinsonian drugs, can also have adverse interactions with pethidine which is used for pain relief during or after surgery.

Caring for clients

Figure 1 gives a list of key questions that care home staff should consider. Figure 2 is a practical 'checklist' for nurses working in this field.

Parkinson's disease nurse specialists

The establishment of Parkinson's disease nurse specialists throughout the UK means that health-care staff in care homes will have access to specialist help. These nurse specialists aim to:

- Work closely with other members of the multidisciplinary care team, meeting with them regularly and participating in team meetings
- Be involved in direct client contact throughout the course of the disease, from diagnosis to palliative care
- Use counselling skills where appropriate to identify problems with clients and facilitate their resolution or acceptance
- Plan and document care on an individual basis
- Advise clients on adjustment of medication (within a protocol) after discussion with either patients or colleagues
- Liaise with other health-care professionals and voluntary organizations according to the client's individual needs
- Liaise with professional and voluntary organizations for the provision of a comprehensive Parkinson's disease service
- Apply relevant research to ensure sound, evidence-based practice.

Conclusion

The role of the nurse or key worker is vital in good caring practice. If they have an understanding of the disease, they can do much to alleviate the symptoms and improve quality of life for the client.

Above all, every health-care professional who is involved in the care of a client with Parkinson's disease must be aware of the importance of professional communication and personnel factors that can positively and adversely affect the delivery of care. **NRC**

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Figure 1.

DISCUSSION POINTS FOR CARERS

- What ages are affected by Parkinson's disease?
- Does it only affect older people?
- If younger people are affected, will their care needs be different?
- Reflect on your personal experiences of health needs:
 1. What principles did you expect?
 2. What principles were presented to you?
 3. Did they meet your needs?
- What features of Parkinson's disease will give nursing and care staff the greatest challenges?
- What resources might help carers and their clients?

Figure 2.

CHECKLIST FOR CARERS

- Listen and give clients time to respond
- Avoid assumptions, look beyond the poor facial expression
- Talk to the person, include them – do not talk about them
- Refer to a speech and language therapist for advice on communication and swallowing
- Give drugs at the times suited to the individual, not the drug round
- Regularly review the timing and dosage of drugs
- Be aware of the possible side-effects of drugs
- Refer back to the specialist or GP if you are concerned
- Treat each person with dignity, respect and as an individual
- Value the family and try to involve them in care
- Refer to the Parkinson's Disease Society if you are unsure of any aspect of care
- Encourage independence
- Refer to the therapists for advice and treatment options
- Be aware of possible movement and fluctuations
- Sometimes music, rhythm or just telling someone that you understand and have time for them can make all the difference.

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KEY POINTS

- **Parkinson's disease is a common neurological condition.**
- **It is progressive and fluctuating and affects each person differently.**
- **Parkinson's disease and its treatment has a dramatic impact upon the quality of life of those living with it.**
- **Understanding the symptoms of the disease and treatment side-effects is a major challenge for care home staff.**