Palliative care in Parkinson’s disease

Providing palliative care can help maintain patients’ independence and improve their quality of life at every stage of Parkinson’s disease – not just at the end of their lives.

In this article...
- Stages of Parkinson’s disease
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- The role of the Parkinson’s disease specialist nurse
- Ongoing palliative care for people with Parkinson’s disease

Palliative care in Parkinson’s disease

Parkinson’s disease (PD) is a progressive and chronic neurodegenerative condition with no known cure. It is associated with the degeneration of dopamine-producing nerve cells in the brain, which enable smooth, coordinated movement, and it has a range of distressing symptoms (Box 1). Its prevalence in the UK is 1.6% of the general population, rising to 2% in people aged over 80 (National Collaborating Centre for Chronic Conditions, 2006).

Falls, fractures and depression can increase the burden of the illness (Kale and Menken, 2004) and people with PD have restricted activity, decreased socialisation and increased anxiety (Wressle et al, 2007). Difficulties with speech can also lead to a withdrawal from communicating, transferring the burden of communication to carers (Miller et al, 2008).

Palliative care
Palliative care is a holistic approach to nursing, with an emphasis on quality of life, which is vital in patients for whom a cure is not possible (Box 2).

It is not restricted to end-of-life care (Clarkson, 2008; Rudkins and Aird, 2006) and includes symptom management, psychosocial support and spiritual care.

Many aspects of palliative care, such as interventions to assist with activities of daily living, apply early in the course of a life-limiting condition (Department of Health, Social Services and Public Safety, 2010). The World Health Organization (2009) recommends early referral and assessment as problems at the end of life can originate earlier in disease progression and need to be addressed as early as possible (Box 3).

Although it is most commonly applied in advanced cancer, palliative care is critical in non-malignant conditions such as PD.

Palliative care for long-term conditions
Many long-term conditions are incurable, and the importance of providing patients with adequate palliative services is now recognised (Lanoix, 2009).

The Department of Health (2005) says palliative care should be available to people with long-term neurological conditions such as PD. This can improve their health and their family’s quality of life by early identification, assessment and treatment, whether their needs are physical, psychosocial or spiritual (WHO, 2011). Evidence shows those with non-malignant conditions have similar problems to people with cancer in the last year of life (DH, 2008).

The focus of palliative care is on patients’ quality of life, enhancing open and sensitive communication and information sharing between health professionals and patients. Palliative care practitioners aim to respect patients’ choices and make sure relatives are kept involved.

Palliative care in Parkinson’s disease
People with PD have complex needs and should be cared for by a multidisciplinary team that includes nurses, GPs, neurologists and physiotherapists (National Collaborating Centre for Chronic Conditions, 2006).

The Royal College of Physicians (2008) recommends closer working links between neurology, rehabilitation and palliative care – from diagnosis to end of life – with good communication and information for patients and their families.

It also recommends that patients have an individual needs assessment, and that there is one point of contact for each stage of the condition. However, the differential...
Diagnosis and predictions of life expectancy in PD can complicate the approach to palliative care (Rudkins and Aird, 2006).

According to Thomas and McMahon (2004), palliative care services frequently do not recognise the needs of people with conditions such as PD and there is some way to go before such services are provided for all. Few people with non-malignant conditions seem to be referred for specialist palliative care, and specialist services such as hospices report little demand from patients with these conditions (Dharmasena and Forbes, 2001).

Davidson et al (2003) say this could be because some health and social care professionals lack the knowledge necessary to guide the palliative care of patients with non-malignant conditions. In addition, many people hold negative attitudes towards palliative care services, perhaps because of the close association between palliative care and advancing illness and death (Dharmasena and Forbes, 2001).

The principles of palliative care are not limited to the end of life and should be applied throughout the course of a disease by: » Offering it at an early stage to help to address the progressive nature of PD; » Providing essential symptom control and supportive care; » Taking a multidisciplinary approach to address all aspects of PD; » Considering the effects on carers, family and friends of the patient.

Four stages of care
The four stages of care in Parkinson’s disease are: diagnosis; maintenance; complex; and end-stage (Thomas and MacMahon, 2004). Palliative care can help patients at each of these stages.

Diagnosis
No nursing care is usually required at this early stage, but Parkinson’s disease nurse specialists (PDNS) offer advice and support to patients and their families. This includes providing information about the disease and drug therapy, supporting them through the diagnosis, liaising with the consultant and making referrals.

At this stage, medication and treatment generally work well and symptoms usually do not progress very far for a couple of years. Newly diagnosed patients may not want to attend PD support groups, but many find them beneficial. Knowing what support is available, and how to obtain early access to therapies can be helpful to both patients and family carers.

Where such arrangements are in place, patients should be made aware of their benefits and offered referral.

Maintenance
The maintenance stage is relatively stable with effective medication, relief of morbidity, monitoring reviews, prevention of complications, anticipatory care, and referral, and liaison between multidisciplinary team members (MacMahon and Thomas, 1998).

It is critical that people with PD receive the right medication at the right time of day, no matter where they are (Carter, 2008) (Box 4). People with PD may be admitted to hospital for a range of reasons, including falls, loss of mobility, dementia-like symptoms or infections, so health and social care professionals in all settings need to be aware of the need to adhere strictly to patients’ daily routine and their medication timetable.

Any alterations in medication regimens can affect symptom control, so patients who may be fasting in preparation for surgery, for example, still need their medication at the right time (Box 5). All members of the hospital team, from consultants to healthcare assistants, must be aware of this.

Acute care nurses also need to be aware that the symptoms of PD can change from hour to hour. As drug therapy wears off, patients may become stiff, slow or unable to move. They are often said to go “on to off”, almost like a light being switched off. For example, a patient with PD may be able to walk in the morning but not in the afternoon.

Another way of increasing the comfort of patients with PD in a hospital setting is to ensure they are close to toilet facilities because they may have bladder problems, associated with urgency and frequency.

Patients may also have communication difficulties, including slurred speech, and their thought processes can slow down (Hudson et al, 2006). Staff should be
encouraged to talk with them and help them optimise their independence.

Patients should be referred to physiotherapists, and speech and language and occupational therapists for help in maintaining movement, strength, speech and swallowing. The earlier the referral, the greater patients’ capacity to maintain function and independence.

**Complex**

As the condition advances, patients’ needs become more complex and serious symptoms and psychosocial needs have to be addressed. Supportive ongoing care and specialist input are needed, and the challenge is to bring the expertise in specialist palliative care developed for cancer patients to all people who need it (DH, 2008).

Specialist palliative care services provide advice about patients to generalist health and social care professionals, such as district nurses and GPs.

Hospices also have important roles in providing education and training, for both staff wanting to specialise in palliative care and those with significant roles in the provision of end-of-life care.

Although some palliative care specialists work alongside other staff in acute settings, a specialist palliative care workforce will not be able to meet all patients’ palliative care needs (DH, 2008). Other specialists and staff must be trained to provide palliative care in their own setting for people who do not have complex needs (National Council for Palliative Care, 2009).

The Gold Standard Framework training programmes enable general nurses to provide high-quality care for people nearing the end of life (www.goldstandardsframework.nhs.uk). The framework emphasises cross-boundary working with hospitals, hospices and care homes, focusing on reducing unnecessary admissions and length of hospital stay by close liaison and careful pre-planning to avoid crises.

**Hospice care:** Services such as a hospice at home service or day-hospice service can be used to help manage symptoms and provide respite for carers. However, patients may have negative associations of hospice care as only for cancer or “dying care”. It is important to explain to them that they can access these services for their expertise, such as in pain or bowel management, and they can use palliative care services while retaining the care of their GP and other community practitioners.

Although respite and support are available at hospices, they are not always accessible in practice. Transport can be an issue, especially in rural settings, and individual transport needs must be addressed. Age can also be a significant factor in patients’ choice of respite services. Younger people with PD may not want to access respite in settings caring primarily for older people.

**Parkinson’s disease nurse specialists:** These nurses play a crucial role in patient care. Patients in nursing homes may be concerned they will not be reviewed by their neurologist, so the PDNS can visit them and liaise with their neurologist, geriatrician or GP as necessary. This can be particularly important in terms of reviewing medication.

The PDNS can also refer patients to services provided by allied health professionals such as physiotherapists. Speech and language therapists can help with distressing symptoms such as drooling. The PDNS should be part of the patient’s multi-disciplinary care team to ensure continuity of care.

General nurses working in acute or community settings can seek advice and support from the PDNS. Although general nurses may be trained in palliative care, PD patients’ needs may vary in that certain analgesic and anti-emetic drugs cannot be used in conjunction with PD drugs. At this stage of the disease, the PDNS can guide nurses on when to decrease or discontinue PD drug therapy, and advise on managing the side-effects of these changes.

There are 290 PDNSs in the UK. Although their clinical and cost-effectiveness has been highlighted, services vary across the country and provision is uneven (Parkinson’s UK, 2008).

In many parts of the country, PDNSs provide community and outreach services and regular clinical monitoring and adjustment of medication to help avoid unnecessary hospital admissions. They also have a role in educating patients and general health and social care staff.

Details of local Parkinson’s disease nurse specialists are available on the Parkinson’s UK website.

**End stage**

As the condition advances, patients may find their medication becomes less effective. In the long term, increasing side-effects and decreasing body weight can make it necessary to reduce or change medication but this can reduce mobility. As patients age, they may develop other common illnesses that have to be treated alongside their PD, such as cardiovascular disease or diabetes.

For those living in the community, extra service provision may be needed, such as more input and condition monitoring by the PDNS and other professionals. Although patients will still need to be reviewed by their consultant at least every six months, care can be nurse led via satellite clinics with feedback from consultants.

District nurses will also be involved in these later stages. The PDNS can liaise with district nurses about patients’ care, for example regarding pain control or management of continence problems, or for advice on palliative drugs, the process of reducing or discontinuing PD medication and dealing with the possible side-effects.

**Education and training**

The National Council for Palliative Care (2009) believes that core training in palliative care should be a compulsory part of pre-registration education for all health and social care staff, and be part of continuing professional development.

Parkinson’s UK offers a range of education and training for nursing and care home staff that can be tailored to individual requirements. Study days may also

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**BOX 4. MEDICATION TIMING**

Patients with Parkinson’s disease need to take their medication on time. As part of its Get it on Time campaign, Parkinson’s UK recommends:

- **Introducing a system to alert the local Parkinson’s disease nurse specialist when people with PD are admitted to hospital**
- **Introducing a system to flag up in patients’ notes that they must receive PD medication on time**
- **Using a pill timer or alarm on the ward to alert staff when patients need medication, as this may be at different times from the standard drug rounds**
- **Introducing a self-administration policy for patients with PD**
- **Auditing the availability of PD drugs and the experiences of patients and carers in hospital**
- **Telling colleagues about the Get it on Time campaign and the importance of adhering to the medication timetable**
- **Organising training sessions on PD and medication**

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**QUICK FACT**

2% Prevalence of Parkinson’s disease in people over 80 years
be available via local organisations and agencies, while local PD support groups also volunteer to explain PD and its course to nursing home staff.

Discussion
Palliative care principles can be used by all healthcare professionals throughout each stage of PD.

Providing information about what support is available can be helpful to both patients and carers at diagnosis, and early referral to services can ensure that patients function independently for as long as possible.

Patients admitted to hospitals or nursing homes need sensitive nursing care. Health and social care professionals in these settings should tailor care to individual needs, especially adhering to patients’ daily medication timetable to manage their symptoms.

It is also important to establish the local facilities that are available for people with PD. For example, in Northern Ireland, PD social care and therapy groups invite health and social care professionals to give presentations on available services. These groups also give patients an opportunity to socialise.

Supportive ongoing care resources, such as hospice at home services or day hospices, can help with symptom management and offer respite opportunities for carers, whose caring responsibilities grow as the disease progresses, resulting in carer-giver burden (Martinez-Martin et al, 2007). Wong and Ussher (2009) point out that carers also need support in bereavement – the final task of quality palliative care.

Conclusion
Negative perceptions around hospice and palliative care must be challenged.

It is essential that those caring for people with PD can seek advice from the PDNS and specialist palliative care teams at any stage after diagnosis. This can minimise distress, prevent complications, and give patients and carers an opportunity to socialise.

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References


“Only delegate tasks that you think your team can manage” Dickon Wec- Hughes p.37

BOX 5. CASE STUDY
Dorothy Taylor is in her 70s and has advanced Parkinson’s disease. She was admitted to hospital for emergency bowel surgery and during her recovery became distressed about her medication. At home she received it every two hours but while in hospital it was only given at drug administration times. Mrs Taylor became unable to function as she was experiencing end-of-dose deterioration and an increase in symptoms of stiffness, tremor and loss of mobility. This also caused difficulty with her physiotherapy treatment. Mrs Taylor’s husband contacted her Parkinson’s disease nurse specialist, who resolved the situation by liaising with ward nursing staff and emphasising the need for Mrs Taylor to receive her drugs on time. Giving her a pill timer and alarm enabled Mrs Taylor to notify staff when she needed her medication. Staff were more compliant about giving medication on time because of the PDNS’s intervention.