For people with Parkinson’s, the effective management of symptoms is essential to maintain their quality of life. Key to achieving this is a co-ordinated and efficient care package. Individuals whose care is unplanned and unco-ordinated are more likely to be high users of health services, including emergency care.

Parkinson’s Disease Nurse Specialists (PDNS) offer great potential for NHS providers and commissioners to improve quality of care while, at the same time, contributing to the achievement of healthcare targets and reducing costs. By providing expert advice and support to patients, they promote self care and ensure patients are able to manage their symptoms effectively. This leads to more appropriate use of health and social care services.

The Parkinson’s Disease Society (PDS) is firmly committed to ensuring that all people with Parkinson’s have access to a specialist Parkinson’s nurse. The PDS will fund a new post for two years, providing that the local health organisation confirms it will pick up the funding after this point. This gives local health organisations time to prove for themselves the clinical and financial value of having a specialist nurse.

**Benefits of a PDNS**

- Contributes significantly to improved symptom control and the general health of people with Parkinson’s
- Conducts clinical reviews and carries out medication adjustments
- Maintains people in the community and contributes to a reduction in hospital admissions
- Diverts appointments away from consultants, helping them to meet outpatient waiting times for diagnosis and complex cases
- Co-ordinates health and social service support for people with Parkinson’s
- Helps support self care and preserves patients’ sense of wellbeing
- Assists unpaid carers to care effectively
- Delivers education to all health and social care professionals involved along the patient care pathway
Prevalence of Parkinson’s

Parkinson’s disease is a progressive, disabling neurological condition. It is the second most prevalent degenerative neurological condition in the UK. Approximately 120,000 people have Parkinson’s in the UK – that is one in every 500 people. One in every 20 people is under the age of 40 when first diagnosed. The principle signs of the condition are rest tremor, rigidity and slowness of movement. However, although Parkinson’s is predominantly a movement disorder, non-motor symptoms, such as cognitive damage and dementia, bladder and bowel problems and sleep disturbance, are also widely associated with the condition. The number and severity of these symptoms increase as the condition progresses, as do the health needs and costs of the care of people with Parkinson’s.

In a healthcare organisation with a population of 500,000 people, there may be approximately 1,000 patients with Parkinson’s and between 20 and 100 people will be newly diagnosed each year.

Costs of managing Parkinson’s

Parkinson’s disease is costly to health and social services. In 1998, the direct costs of care in the UK were evaluated in a sample of people with Parkinson’s. Although drug costs and inflation mean that these figures are now an underestimate of the current costs, the figures do reveal important information about how money is spent on Parkinson’s patients.

The total mean annual cost of care per patient for all patients in 1998 was £5,993.

- Social services costs accounted for 34% of total costs and tended to rise with increasing age.
- NHS costs accounted for 38% of total costs
- Total annual direct costs were £4,189 for each patient living at home; £15,355 for patients whose care was divided between home and residential or nursing home care; and £19,338 for patients in full-time care.

Providing support to people with Parkinson’s disease in care homes costs much more than other forms of care. Although most patients want to stay at home, the reality is that in many areas community services have not been available to make this happen.

However, it has been estimated that by developing and funding community-based services for people with Parkinson’s, the savings in health costs would be around £36 million, or 30% of the money spent on supporting people in care homes.

Making cost savings at a local level through Parkinson’s Disease Nurse Specialists

Research published in 2004 by Professor Brian Jarman indicated that PDNSs are cost neutral. However, where PDNSs have measured the impact of their services in more detail, they have been able to demonstrate significant cost savings for their local health economy at the same time as improving quality of life for people with Parkinson’s.

Harlow

For two years before the PDNS came into post, Harlow PCT had established robust data on hospital admissions for primary and secondary diagnosis of Parkinson’s. When the nurse came into post, she was able to identify trigger factors for hospital admissions. She worked with the multidisciplinary team to ensure early therapy interventions and established herself with patients as the first port of call in a crisis. She was also able to use daily admissions reports and PAIR reports (patients at risk of readmissions) to allocate her resources to where they were most needed. Ten months after the post was created, recorded data clearly showed the upward trend in admissions and length of stay was reversed, with a saving to the PCT of £80,000.

Conwy and Denbighshire

The PDNS in Conwy and Denbighshire NHS Trust undertook 541 patient consultations in a nurse-led clinic over a six-month period. By doing so, the PDNS freed up consultant appointments for other patients. This had a positive impact on waiting list targets and led to a cost saving of consultant time of £50,550.

Mansfield

The PDNS in Mansfield PCT has been crucial in reducing hospital admissions. Data collected surrounding inpatient admissions with Parkinson’s disease as the primary cause of admission before the nurse was in post show 91 admissions for 2004/2005. Data for 2005/2006 shows this is reduced to 43 (57% reduction) when the PDNS is in post. This has been achieved through a multi-disciplinary Parkinson’s disease clinic, therapy-led education group, apomorphine therapy service and telephone support.

How PDNSs contribute to meeting healthcare targets and standards

England

The Department of Health has set a number of tough targets for NHS organisations to meet in order to improve health outcomes for people with long-term conditions. Supporting people with long-term conditions: an NHS and social care model to support local innovation and integration provides the framework for improving care of patients with conditions like Parkinson’s. It describes how the NHS and social care should aim to:

- reduce emergency bed days by 5% by March 2008
- improve care in primary and community settings
- ensure that health communities will offer personalised care plans for vulnerable people most at risk from 2005 onwards
- increase the number of people over 65 supported to live at home by 1% a year in 2007 and 2008

In addition, the 18-week target for the patient pathway from GP referral to the start of treatment by the end of 2008 is a key objective for the NHS in England. Specialist nurses can play a vital role in ensuring this target is met for all people with Parkinson’s.

The National Institute for Health and Clinical Excellence (NICE) in its Guideline for the diagnosis and management of Parkinson’s disease in primary and secondary care acknowledged the role of PDNSs.

NICE recommends that all people with Parkinson’s disease should have referral to a specialist, which may be a Parkinson’s Disease Nurse Specialist (PDNS) for:

- monitoring and altering medication appropriately
- providing a continuing point of contact for support, which includes home visits
- acting as a reliable source of information about clinical and social issues that are of concern to people with Parkinson’s and their carers

The National Service Framework (NSF) for Long-term (Neurological) Conditions, Quality Requirement 1: a person-centred service

Wales

The NICE Guideline for Parkinson’s was commissioned jointly by the Welsh Assembly Government and therefore also applies to health services in Wales.

Designed for Life outlines a future vision for Chronic Disease Management Services in Wales, with an emphasis on early assessment, accurate and timely diagnosis, appropriate specialist service provision by a multidisciplinary team and support for self-management. PDNSs will clearly be key in delivering this vision for people with Parkinson’s.

In addition, support for the role of specialist nurses has been endorsed by the Welsh Assembly Government in policy documents for other conditions, such as the National Service Framework for diabetes, and this support is likely to be expanded as care pathways for other conditions are developed as part of the implementation of Designed for Life.

Scotland

Systematic support for people with long-term conditions is a key pillar of Delivering for Health, the Scottish Executive’s vision for the NHS. The overall direction of policy is moving towards early interventional, community-based health services with multidisciplinary teams delivering patient-centred care. This contrasts with the traditional model of doctor-led, hospital-focused services, with high levels of unplanned admissions. PDNSs can help make this vision a reality for people with Parkinson’s through preventing unplanned admissions and supporting self care.

*People with long-term neurological conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses*...
7 key PDNS interventions

By managing Parkinson’s patients throughout the course of the condition and by acting as a regular point of contact, they can pick up potential problems before they occur. They can:

1. reduce unplanned admissions
2. prevent unnecessarily extended hospital stays
3. reduce the need for outpatient care
4. help achieve outpatient waiting times
5. empower and educate patients to become expert in their condition
6. help integrate health and social care
7. educate health and social care professionals about Parkinson’s along the patient’s care pathway

Seven key PDNS interventions

1 Reducing unplanned admissions

“One day, my husband’s mobility deteriorated rapidly and I was so concerned that I was considering taking him to A&E. I contacted the specialist Parkinson’s nurse and she asked me a number of questions. She combined her expert knowledge of Parkinson’s with my responses and was able to deduce that the problems were medication-related and would probably settle down within a few days. The nurse was right. Her advice put our minds at rest and saved us from using up hospital resources unnecessarily.”

Expert opinion from the NICE cost impact report\(^4\) (2006) estimates that PDNS care, as part of a multidisciplinary team, can reduce admission for Parkinson’s disease by 50%.

Hospital inpatient and outpatient figures obtained from Hospital Episode Statistics data (HES) showed 6,313 admissions for Parkinson’s in 2004/5 in England. The tariff cost data of £1,220 per admission (2006/7 PbR tariff) would indicate that having a PDNS as part of multidisciplinary care teams could save the NHS over £3.8 million in hospital admissions every year.

A PDNS at East and North Hertfordshire PCT has contributed to a projected 25% reduction in the cost of Parkinson’s admissions each month. The development of the Trust’s multidisciplinary neurology team is projected to save £12,792 in Parkinson’s bed days per month alone (based on a tariff of £2132 per admission).

2 Preventing unnecessarily extended hospital stays

“We remind staff on the relevant wards about how important it is going to be for these patients to get their medication on time.”

PDNS Sue Freeman at Southend Hospital

Hospital stays can be stressful for patients with Parkinson’s. Often they will be on a number of drugs, each of which must be taken throughout the day at specific times. If a person is unable to take their prescribed medication at the right time, the balance of chemicals in their bodies can be severely disrupted – and this will lead to their Parkinson’s symptoms becoming uncontrolled with possibly lengthy recovery time to stability. Inflexible drug rounds, low levels of support for self-administration processes and lack of understanding among ward staff can all lead to problems for patients.

Nine out of ten PDNSs surveyed by the PDS\(^5\) felt that patients with Parkinson’s may experience clinical problems or an extended hospital stay as a result of missed or late administration of their medication.

Disruption of an individual’s medication regimen can have serious consequences for ward management and the treatment for which the person was originally admitted. There is an increased risk of accidents and falls and, in some cases, the originally planned treatment may be no longer possible. The person with Parkinson’s may also feel a loss of dignity and independence, as well as the ability to communicate and exercise choice in their care.

For patients with Parkinson’s and their families, the management of medication in hospital is a major issue, and one which they see specialist nurses as being key to improving. Their concerns lead to the PDS launching the ‘Get it on time’ campaign.

PDNSs play a crucial role in educating other hospital staff about Parkinson’s and the need for medication to be administered on time.

The PDNS and a pharmacist at Greasby Clinic in the Wirral have been running a series of workshops on Parkinson’s and medicines management for staff. Teaching and information packs have also been distributed to all wards.

3 Reducing the need for outpatient care

“I know if I have a problem with my medication I can ring the PDNS for help. Her availability saved me having to go back to hospital to see my consultant.”

Expert opinion\(^1\) suggests that access to specialist Parkinson’s nursing care and therapy services may potentially reduce outpatient attendance by 40%. A large part of outpatient attendance for people with Parkinson’s is for clinical monitoring and medication adjustment. The NICE Guideline recommends that these services may be provided by specialist nurses.

The potential impact a PDNS can have on reducing the need for outpatient care is significant, given that outpatient attendance for Parkinson’s patients in England is estimated at 62,569 attendances per annum, which is 14% of neurology follow-up appointments. At a cost of £103 per attendance, this could lead to an estimated saving of £6 million\(^6\).

Greater Peterborough Primary Care Partnership has predicted 500 elderly care follow-up appointments could be saved annually by revision of a patient care pathway for Parkinson’s disease and a specialist nurse, saving £47,000\(^7\). Generic competencies have been used to define skill mix and an administrator assists clinical staff.

4 Helping achieve outpatient waiting times

Although NICE recommends that all people with suspected Parkinson’s should consult a specialist within six weeks of the initial GP referral, waiting times at the end of 2005, according to a PDS survey of 200 GPs\(^2\), were 17 weeks for a neurologist and ten weeks for a geriatrician. As Parkinson’s can take more than one consultation to diagnose, waiting times of this length will make the target of 18 weeks from referral to diagnosis in England challenging in many areas.

By managing outpatient follow-ups, PDNSs are having a positive impact on waiting times, relieving the burden on consultants.

“We now have full coverage with Parkinson’s Disease Nurse Specialists across the whole of Birmingham. This means that review appointments in outpatients can be less frequent, with the nurses seeing patients in between visits to the consultant. The nurses are able to titrate patient’s medication and monitor their progress, if necessary in their own homes. Since consultants are seeing fewer follow-up patients, we can fit in more new referrals to the movement disorders clinics. This allows us to keep below the six-week referral limit set by the Government.”

Dr Carl Clarke, Clinical Neurologist, University of Birmingham and City Hospital

Parkinson’s Disease Nurse Specialists can triage patients through the system, thereby reducing waits. The PDNS in Northumbria does an initial assessment on new referrals, speeding up the assessment process and diagnosis.
5 Empowering patients and families to become experts

“I have received more information about my condition from my PDNS than any other health professional I have encountered. Information is empowering – it has helped me to manage my condition more positively.”

“When I first went on the medication, I had really bad side effects. It was the PDNS who explained the side effects were caused by the drugs and helped to come up with a medication regimen that worked for me. She supported me and made me feel like I was involved in my treatment and that I could play a part in my own care – it didn’t have to be my way or the medical way, we could work together on it.”

There is evidence to suggest that people with long-term neurological conditions such as Parkinson’s have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as a specialist nurse21.

PCTs and health boards can work with PDNSs to ensure patients and families are given the support and information they need to manage their symptoms throughout the course of the condition. When patients and informal carers have the ability to self care, they make fewer and more appropriate demands on primary and secondary care services22.

In Cornwall there is a Parkinson’s-specific Expert Patients Programme led by patient trainers who themselves have the condition.

The PDS, in partnership with Northumbria Healthcare NHS Foundation Trust, is part of a Department of Health project piloting Information Prescriptions for Parkinson’s patients and their carers. The project is focused on giving relevant information about symptoms and treatment options at all stages of the condition, from diagnosis to the advanced stages, including end of life care.

6 Helping integrate health and social care

PDNSs can provide a single point of contact for patients and ensure that they can access the services they need to manage their condition effectively. This role as a co-ordinator of services ensures an holistic approach and that patients get appropriate care and support when they need it.

Local implementation teams can bring together primary and secondary healthcare organisations with social services, voluntary sector and patient/service user representation. These networks cross organisational boundaries and focus on improving outcomes for people with Parkinson’s, by educating staff and making explicit patient care pathways.

The Northern Ireland Hospice Board has developed a specialist palliative care PDNS post. This nurse is responsible for promoting the concept of patients, carers and professionals accessing specialist palliative care services. The nurse identifies specialist palliative care needs for patients with Parkinson’s and works in collaboration with the Hospice Nurse Specialists.

7 Educating health and social care professionals about Parkinson’s along the patient’s care pathway

A large number of health and social care professionals are involved in the management of Parkinson’s:

- GPs
- Neurologists
- Care of the elderly physicians
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Practice nurses
- Nurses with a special interest in neurology
- Old age psychiatrists
- Community matrons
- Community and hospital pharmacists
- Ward staff
- Dieticians
- Continence advisors
- Social services
- PDNS Community Support Workers

Solid understanding of the nature and complexity of Parkinson’s is key to these professionals making effective health or social care interventions. Specialist Parkinson’s nurses play a central role in the education of these professionals and contribute significantly to overall improved standards of care.

6 Investing in a PDNS

With NHS reforms pointing the way to more healthcare activity in the community, now is an excellent time for commissioners to create specialist Parkinson’s nursing posts.

Local cost pressures need not prevent the creation of these posts. Commissioners do not need to invest upfront in a specialist nursing service. The PDS will fund a new PDNS post for two years, providing that the local health organisation confirms it will pick up the funding afterwards. This gives local health organisations time to evaluate for themselves the clinical and financial value of having a specialist nurse.

The Society has helped many local health organisations scope their nurse services, and will help local teams find a model of specialist Parkinson’s nursing that works for them and works for the needs of people with Parkinson’s in their area.

If you would like to set up a specialist Parkinson’s nursing post with the support of the PDS, contact: Lesley Carter, Head of Influence and Service Development Email: lcarter@parkinsons.org.uk Tel: 07876 455 936

Continued professional development

Employers of PDNSs can be confident their nurses will be supported throughout their career. Both formal and informal PDNS networks exist across the UK, which promote best practice and provide mentorship.

The PDS is committed to developing the skills of the PDNS once he or she is in post. Healthy Alliance is a unique collaboration between the PDS and GlaxoSmithKline, to provide a dedicated package of support and training for PDNSs across the UK. Healthy Alliance carries out nurse inductions, runs conferences for nurses and provides training materials.

The PDS, Parkinson’s Disease Nurse Specialist Association (PDNSA) and the Royal College of Nursing (RCN) have collaborated as one body to produce an integrated career and competency framework for nurses working in Parkinson’s disease management23. These competencies have been produced to maintain the highest level of standard, competence and professional integrity within the Parkinson’s disease specialty. The PDS also produces a wide range of information resources, covering all aspects of the condition, for healthcare professionals and for patients and carers.

The Parkinson’s Disease Society of the United Kingdom

The Parkinson’s Disease Society (PDS) is the UK’s leading authority on the condition. The charity campaigns for a better quality of life for people with Parkinson’s and spent almost £4m in 2006 funding research. The PDS also provides information and a local support network for people with Parkinson’s, their families, friends and carers.

For further information please contact: Free Helpline: 0808 800 0303 www.parkinsons.org.uk
Parkinson's Disease Society estimate.


14Scottish Executive (2005) Delivering for Health


19NHS Employers (2006) Improving services for people with long-term conditions through large-scale workforce change


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