

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



**I DELIVER
EXPERT CARE**

Deirdre

**Parkinson's nurses – affordable, local,
accessible and expert care**

The contribution of Parkinson's nurses in Northern
Ireland: a guide to equitable services

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“People with Parkinson’s tell us the most important person helping them manage their condition is their Parkinson’s nurse. We feel passionately that everyone affected by Parkinson’s should benefit from this support.

“That’s why we’ve invested more than £12million to pump-prime specialist Parkinson’s nurse posts across the UK. In the last five years, in partnership with health and social care trusts in Northern Ireland and Northern Ireland Hospice, we have created nurse posts in the Southern, Western and Northern Health and Social Care Trusts.

“But, even with this investment, many people with Parkinson’s in Northern Ireland have never seen a Parkinson’s nurse or are unable to access one.

We need more Parkinson’s nurses to ensure that everyone with Parkinson’s has full access to a Parkinson’s nurse, wherever they live in Northern Ireland.

“We understand the need for financial restraint at this time. That is why we want to celebrate the fact that Parkinson’s nurses provide cost-effective, best practice care that is vital to patients’ wellbeing.”

Steve Ford
Chief Executive, Parkinson’s UK



Eimer

Executive summary

- Parkinson's nurses are essential to delivering expert, accessible care for people with Parkinson's at all stages of the condition.
- By providing care in local settings, whether at home or in nurse-led clinics, Parkinson's nurses keep care closer to home and support both carers and patients.
- Provision of this expert care is recognised by NICE as delivering cost savings. This report identifies some of the key areas where these savings are generated.
- Patient satisfaction is high among those with access to specialist nurses. People report feeling confident knowing that expert advice is available locally.
- Given the complexity of Parkinson's symptoms and medication management, care needs to be delivered by a specialist. Parkinson's nurses provide this at a cost that is affordable for all health and social care trusts.

Introduction

For more than 20 years, Parkinson's nurses have been at the heart of delivering improved services and cost savings. These nurses bring care closer to home for people affected by Parkinson's, enable joined-up provision and are committed to patient empowerment and satisfaction.

Parkinson's nurses make a significant contribution to the local delivery of care for people with Parkinson's. In this report, you'll find evidence of this from Parkinson's nurses in Northern Ireland.

This report coincides with the publication of the recently published Compton Review 'Transforming Your Care'. If The Compton Review is fully implemented, it will have a profound influence on health policy and practice within the health service. The priorities for high quality interventions outlined in the Compton Review mirror our commitment to the valuable role of the Parkinson's nurse.

What is Parkinson's?

Parkinson's is a progressive neurological condition that involves gradual deterioration in areas of the brain affecting muscle control, movement and balance. Around one person in every 500 has Parkinson's. That's more than 3,000 people in Northern Ireland. Most people who get Parkinson's are aged 50 or over, but it also affects younger people.

In a health and social care trust with a population of 500,000 people, there may be approximately 1,000 patients with Parkinson's. Each year, between 20 and 100 people will be diagnosed.

Parkinson's can have a major impact on everyday movements, such as walking and swallowing, but a range of other symptoms can significantly affect the day-to-day lives of people who have the condition. These include problems with communication, tiredness, pain, depression, constipation and bladder problems. This means the Parkinson's care pathway is complex.

Symptoms can fluctuate, both from day to day and more rapidly, from hour to hour. Because each person with Parkinson's has different needs, they require regular reviews.

As Parkinson's progresses, medication issues become more critical. Regular adjustments and additions are usually required. Correspondingly, the amount of care needed to support people in the community increases.



The role of the Parkinson's nurse

The Parkinson's nurse is a specialist practitioner whose essential skills are clinical leadership, case management, education and the evaluation of care. They may provide this in hospitals, clinics, health centres or in a patient's own home or care home. They liaise with professionals and voluntary organisations, as appropriate, to provide a comprehensive Parkinson's service. This ensures ongoing, joined-up care.

The Parkinson's nurse is ideally placed to provide education, not only to patients, their families and carers, but also to a range of healthcare professionals. These professionals may only have had experience of seeing a small number of people affected by Parkinson's. This dual approach ensures that people understand their own condition, and that self-management is supported by healthcare professionals.

We believe that Parkinson's nurses would be well placed to enable health and social care trusts to deliver a high quality service for people with Parkinson's, under the priority areas set out in The Department of Health, Social Services and Public Safety publication, Priority for Action 2010–2011. These priority areas are highlighted in blue boxes throughout this document.

Affordable: the evidence of cost savings

PRIORITY AREA 7: ENSURE FINANCIAL STABILITY AND THE EFFECTIVE USE OF RESOURCES

Aim: to ensure that all of the resources available to the Northern Ireland Health and Social Care Service are used appropriately and effectively to improve the health and wellbeing of the Northern Ireland population and to provide better treatment and care, and that the service lives within available resources.

We understand that trusts have a duty to protect and improve front-line services. At the same time, there is a need to ensure effective interventions and key reforms are incorporated to make best use of available resources.

The introduction of a specialist Parkinson's nurse secures value for money, delivers effective interventions and reduces errors and waste. It also helps to keep people healthy and independent for as long as possible.

We are committed to developing and promoting innovative practice in Parkinson's services. Once Parkinson's UK has pump-primed a Parkinson's nurse, we work with them to ensure they can collect and present evidence of the value of their role. Much of the evidence in this report has been gathered by Parkinson's nurses to demonstrate the impact of their service to their own trusts.

However, one of the first studies to identify the cost-effectiveness of Parkinson's nurses was conducted in North Wales in 2003 by Sally Roberts and Peter Hodson.¹ This study looked at the cost saving of substituting consultant appointments with nurse-led clinics. This example has been replicated across the UK. It can save, on average, **£41,000** per year on deferred consultant outpatient appointments.²

A nurse with short brown hair, wearing a dark patterned top with pink accents and a lanyard with an ID badge, stands in a hospital room. She is holding a large blue sign with white text. In the background, a sign on the wall reads "BED 1".

**I PROVIDE
VITAL
SERVICES**

An elderly woman with short grey hair and glasses, wearing a white hospital gown, is sitting in a hospital bed. She is holding a large blue sign with white text. The room has orange walls and medical equipment visible in the background.

**I MUST
HAVE MY
NURSE**

Lisa and Sheena

Affordable: avoided consultant appointments

The National Institute for Health and Clinical Evidence (NICE) Guideline for the diagnosis and management of Parkinson's disease in primary and secondary care was adopted for use in Northern Ireland in 2007.³ The guideline recommends that people with Parkinson's are seen by a specialist every six months for ongoing review and medication adjustment.

A Parkinson's nurse can carry out the majority of these reviews, which reduces the need for consultant appointments. Often, these reviews can be held in local clinics, community hospitals or in the person's home. This can reduce the need for hospital transport and costly outpatient appointments.

In Northern Ireland, the cost per consultant appointment ranges between **£200** and **£490**, depending on specialism.

The specialist nursing tariff is less than half that of the lower consultant rate. A nurse with a caseload of 300 would save, at the very least, **£30,000** per year. This is just by seeing patients who would otherwise attend an outpatient appointment with a consultant.

In the Northern Health and Social Care Trust, there are an estimated 900 people with Parkinson's. If all of these patients were seen just once a year by a consultant (less than the six to 12 months recommended by NICE) it could potentially cost in the region of **£180,000** at the lowest consultant rate. Alternatively, nurses could deliver these reviews for **£90,000** (based on figures for specialist nurse review costs).

Critically, this also frees consultant time, which can then be spent on initial diagnosis and complex care. This cost-effective approach to follow-up appointments would allow capacity to deliver the targets that: "all outpatients will be seen within nine weeks following GP referral" and that "maximum treatment waiting times are maintained at March 2010 levels".

Affordable and expert: reducing hospital admissions

PRIORITY AREA 3: INTEGRATE PRIMARY, COMMUNITY AND SECONDARY CARE SERVICES

Aim: to ensure greater engagement between secondary and primary care clinicians and practitioners to agree clinical pathways which reduce the use of hospital services and increase the capability of primary care to manage patients more locally.

More than one-third of people with Parkinson's go into hospital each year. Emergency admissions count for 75% of these. The majority of people with Parkinson's admitted into hospital will be older people. Many of these will be frail and with co-morbidities.

Analysis of hospital admission data for England in 2006/7 showed that there were 82,493 individual admissions of people with Parkinson's. The average length of stay was five days longer than the general population of a comparable age.⁴

Admissions can be avoided if a Parkinson's nurse is able to make a timely intervention while the patient is in the community. Managing people in the community relieves the ever increasing demands placed on hospitals. Patients can be seen, diagnosed and treated in the right setting, by the right person and at the right time. In other parts of the UK, nurses have reduced hospital admissions from 172 to 154. This means a 10% reduction in admissions after a Parkinson's nurse takes up their post. This reduction offers a fixed annual cost saving of **£81,522**.

As an example, early recognition and treatment of urinary tract infections or medication-induced hallucinations removes the need for hospital admission. This saves money and causes less disruption and distress for the patient.

"A patient rang in a distressed state, worried that his medication was suddenly not working. His mobility was very poor and he thought this must mean his Parkinson's was deteriorating rapidly.



“Through gentle questioning, I was able to establish that the problems were related to a urinary tract infection. This was exacerbating his Parkinson’s symptoms and having an adverse effect on his response to Parkinson’s medication. I reassured him these problems would settle, once the infection was treated.

“I liaised with the community nursing team and the patient’s GP to explain the situation. I reassured them that a hospital admission was not required. In fact, this could have had an adverse effect on the patient.

“The patient was relieved that it wasn’t a rapid deterioration in Parkinson’s and that he did not need to be admitted to hospital.”

Parkinson’s nurse, Belfast

During 2010–11, commissioners and trusts were encouraged to: “build a continuum of responsive, integrated primary and community care that promotes good health, prevents ill health and focuses on people at risk, supporting them to live independent lives and reducing unnecessary and inappropriate reliance on hospitals and other institutional care.” A core element of the Parkinson’s nurse’s role is to deliver education to colleagues, which meets this requirement.

Parkinson’s nurses provide education and training across Northern Ireland, including programmes for GPs, ward staff, social care and care home workers, and nursing students.

“I’m beginning to receive more telephone calls for patient advice from care of older person wards. I am delighted about this.”

Parkinson’s nurse, Western Health and Social Care Trust

Parkinson’s nurses can identify risks and intervene early to prevent crisis situations. By working with ward staff, they can ensure that people with Parkinson’s receive their medication on time, avoiding complications that lead to longer hospital stays.

Medication management is a particular concern for people with Parkinson’s going into hospital. Each patient has a very specific timetable of when they need their medication. Missed medication can be very serious, as symptoms will be poorly controlled. This can result in a person with Parkinson’s being unable to eat, drink, or communicate. In some cases, it can lead to total immobility and psychotic symptoms. This is a major cause of extended hospital stays. The importance of this element of Parkinson’s care is not always well understood by busy ward staff.



Parkinson's nurses prevent adverse medication incidents by:

- liaising with ward staff when someone with Parkinson's is admitted to hospital, to ensure that medication requirements are understood
- providing education and training for colleagues
- educating and supporting patients and carers to feel confident about asking for their medication when they go into hospital

One Parkinson's nurse in the Western Health and Social Care Trust is developing a communication sheet for patients on the orthopaedics ward. Patients and their families can use this to record information about their specific experience of Parkinson's, which may affect care. Information includes 'wearing off' and 'off' time (when the effects of medication wear off before the next dose is due) and variation in symptoms at different times of day. This resource is being developed in conjunction with patients, who know what is particularly relevant for them.

Parkinson's nurses can also support discharge, ensuring patients return home with an appropriate care plan in place. By providing a multidisciplinary approach to co-ordinating care plans, nurses are able to meet the complex needs

of many people with Parkinson's. This can reduce the risk of re-admission.

A Parkinson's nurse is also ideally placed to provide education to people with Parkinson's, their families and carers. They may run an education programme, for example once a week for six weeks, which introduces people to sources of help and support. This approach enables people to come to terms with their diagnosis and make informed choices about their treatment. It encourages shared decision-making and self-management.

Parkinson's nurses support people through referral systems in primary and secondary care. They also ensure support for people who are no longer able to attend clinics or who have moved into care homes. This approach means that the specialist advice mentioned by NICE is available from the point of diagnosis through to end of life care.

A healthcare worker, likely a nurse, is standing in a hospital hallway. She is wearing blue scrubs with white piping and glasses. She is holding a white rectangular sign with blue text that reads "PEOPLE NEED THEIR MEDICATION ON TIME". In the background, another person in blue scrubs is partially visible on the left, and a medication cart with a yellow box is on the right. The hallway has a wooden door and a green exit sign in the background.

**PEOPLE NEED
THEIR MEDICATION
ON TIME**

Affordable and expert: helping people with Parkinson's to live independently

PRIORITY AREA 4: HELP OLDER PEOPLE TO LIVE INDEPENDENTLY

Aim: to ensure that older people are able to remain independent in their own homes and communities with a good quality of life for as long as possible.

Parkinson's is a condition that mainly affects older people. The rates of incidence increase as people age. In people aged over 80, one in 50 may be affected by Parkinson's. As the number of people living for longer increases, it will become even more critical to get the management of Parkinson's right.

People with Parkinson's want to remain independent for as long as possible. Access to appropriate services will help to deliver this outcome.

Parkinson's nurses deliver support, not only for the person with Parkinson's, but their families and carers.

Many carers would find it difficult to continue without the responsive, inclusive approach of a Parkinson's nurse. Almost two-thirds of carers of people with Parkinson's in Northern Ireland care for more than 50 hours each week. The health of more than half of these people deteriorated after beginning their caring responsibilities.

"You are so very alone when you are the sole carer. To have someone who has the knowledge of Parkinson's ... that you can discuss problems with, is very reassuring."

A carer of someone with Parkinson's

Accessible and expert: fair access to high-quality local care

PRIORITY AREA 2: ENSURE SERVICES ARE SAFE AND SUSTAINABLE, ACCESSIBLE AND PATIENT-CENTRED

Aim: to ensure that patients and clients have timely access to high-quality services responsive to their particular needs and delivered locally, where this can be done safely, sustainably and cost-effectively.

Commissioners and trusts must ensure that services are delivered to agreed common standards. There should be no inappropriate variation in the care and treatment that people are receiving. Clinicians and practitioners are expected to look closely at their own practice and ensure that it meets current best practice. The NICE guideline³ recommends that people should be referred to a Parkinson's specialist, which may be a Parkinson's nurse, for the following services:

- 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 guidelines make clear that: "people with long-term neurological conditions have improved outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated expertise."

The NICE guidelines include analysis of the cost of implementing its recommendations. This demonstrates that the added costs of delivering best practice are offset by cost savings that come from the role the Parkinson's nurse plays in reducing hospital admissions and length of stay.

Timeliness and ease of access remain important issues for service planners. Accessibility and flexibility are at the heart of a good Parkinson's service, especially for the most vulnerable and disadvantaged service users.

Parkinson's nurses are able to deliver community clinics, telephone support and home visits. This ensures that people can access help earlier, and may avoid a problem becoming a crisis.

"The day before I was due to see my neurologist, I received a cancellation notice in the post. I was very disappointed, as I felt my medication needed to be reviewed. I rang my Parkinson's nurse, and as a result, I had my medication altered. If there had been no Parkinson's nurse there to help me, I would have been left to suffer alone."

A person with Parkinson's

When the Parkinson's nurse post was created in the Southern Health and Social Care Trust, the nurse developed clinics in Lurgan, Banbridge, Dungannon and Newry. Patients unable to get to local clinics were offered a home visit. In 2010, the nurse saw 125 people in nurse-led clinics, made 128 home visits and 263 telephone consultations. These often avoided the need for a GP visit or clinic appointment. For January to September 2011, the figures rose to 220 people seen in clinic, 201 home visits and 360 telephone consultations.

"Following the appointment of a Parkinson's nurse, there has undoubtedly been a vast improvement in the care offered. The feedback from patients is entirely positive. The Parkinson's nurse has a huge impact on the quality of life of people with Parkinson's. By targeting the service to those in greatest need, the benefits are tangible and visible."

Dr Raeburn Forbes, Consultant Neurologist

The two Parkinson's nurses in the Western Health and Social Care Trust have been able to establish clinics in Strabane, Omagh and Waterside, as well as supporting clinics in Enniskillen. The posts also support hospital staff, with education sessions and ward visits. This link with hospital services leads to better understanding of the condition and better management of Parkinson's medication in hospital. By advising on discharge, Parkinson's nurses can also facilitate a successful transition back into the community.

Parkinson's nurses and Parkinson's UK staff can deliver education sessions to care home staff. This can increase the level of confidence staff have to manage the complications of advanced Parkinson's.

A middle-aged man with a receding hairline, wearing a dark blue pinstriped suit, a light blue shirt, and a purple striped tie, is seated in a chair with red and gold striped upholstery. He is holding a bright blue rectangular sign in front of his chest. The sign has the text "I WANT TO STAY INDEPENDENT" written in white, bold, sans-serif capital letters. The background consists of wood-paneled walls with decorative carvings.

**I WANT
TO STAY
INDEPENDENT**

Jack

Parkinson's UK: supporting planners and providers

- We can fund the initial investment in a Parkinson's nurse in areas where there is little or no coverage. Once the post has demonstrated cost savings, funding is then picked up by the local health and social care trust.
- We have local service development officers who can support and advise on service redesign across the whole Parkinson's pathway. They can also help trusts and commissioners develop a business case for establishing a Parkinson's nurse post.
- We are the primary provider of Parkinson's patient information and support through our publications, website and free confidential helpline.
- Neurological Commissioning Support is a joint initiative between Parkinson's UK, the Multiple Sclerosis Society and Motor Neurone Disease Association. We have developed a range of commissioning tools, including 'Neuronavigator', designed to support local commissioning decisions.
- We run a professional development programme for all Parkinson's nurses and provide tools and materials through the Healthy Alliance partnership.
- Our local teams can offer expert education for health and social care staff working with people with Parkinson's.
- We also have teams of information and support workers who can offer confidential, one-to-one information, signposting to local services and benefits advice.

More information

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1 Hodson P et al (2003) 'The economic utility of introducing a Parkinson's Disease Nurse Specialist service', Health & Ageing 3, *The Clinician*

2 Parkinson's UK (2011), England nurses' report

3 National Institute for Health and Clinical Excellence (2006) Guideline 35. Parkinson's disease: national clinical guideline for diagnosis and management in primary and secondary care

4 Hospital Episode Statistics (2006-2007) NHS

We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK

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Free* confidential helpline **0808 800 0303**.

Monday to Friday 9am–8pm,

Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

*calls are free from UK landlines and most mobile networks.

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