

**PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.**



Lorraine

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

A guide for commissioners in England

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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, via our pump-priming programme, setting up specialist Parkinson's nurse posts. Even with this investment, thousands of people have still never seen a Parkinson's nurse.

Currently only 80% of primary care trusts in England have full access to a nurse. And there's a risk that current financial pressures in the NHS may limit access even further. However, the evidence collected here shows how Parkinson's nurses provide cost-effective, quality care that is vital to patients.

**Steve Ford**  
Chief Executive

## Executive summary

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This report has been written for commissioners and managers within the NHS and social care in England. It focuses on the contribution that Parkinson's nurses play in delivering quality patient outcomes and cost-effective care.

The evidence shows:

- Parkinson's nurses are essential to deliver expert, accessible care for people with Parkinson's at all stages of the condition
- how this kind of expert care delivers cost savings to the local health economy. On average a nurse can save each year:
  - £43,812 in avoided consultant appointments
  - £80,000 in unplanned admissions to hospital
  - £147,021 in days spent in hospital
- 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
- the Parkinson's nurse service contributes to meeting QIPP targets, NICE standards and indicators within the new Outcomes Framework
- patient satisfaction is high among those with access to specialist nurses. People report feeling confident knowing that expert advice is available locally
- that given the complexity of symptoms and medication management, care needs to be delivered by a specialist. Parkinson's nurses provide this at a cost affordable by all care providers





## Introduction

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For more than 20 years, Parkinson's nurses have been at the heart of delivering cost savings for the NHS, providing care closer to home, joined-up service provision, and ensuring patient empowerment and satisfaction. In this report we use new evidence to demonstrate the significant contribution Parkinson's specialist nurses make to the local delivery of care for people with Parkinson's.

## What is Parkinson's?

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Parkinson's is a progressive neurological condition. One person in every 500 has Parkinson's. That's about 120,000 people in the UK. Most people who get Parkinson's are aged 50 or over but one in 20 is under the age of 40.

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 diagnosed each year.

Parkinson's has a major impact on movement and control. People with Parkinson's also have to deal with a range of other symptoms, such as tiredness, pain, depression, constipation and bladder problems, which affect their day-to-day lives.

The Parkinson's care pathway is complex. Regular reviews are required as each person's needs will vary greatly. As the condition progresses, medication issues become more critical, with regular adjustments and additions being required. Correspondingly, the amount of care needed to support people in the community will increase.

## The role of Parkinson's nurses

Parkinson's nurses are specialist practitioners whose essential skills are clinical leadership, case management, education and the evaluation of care. This may be in hospitals, clinics, health centres, the person's own home or care home, and might be on a routine or emergency basis. They liaise with professional and voluntary organisations, as appropriate, to provide a comprehensive Parkinson's service ensuring ongoing, joined-up care.

Parkinson's nurses are ideally placed to provide education not only to patients, their families and carers, but also to a range of health professionals, who may only come across a small number of people affected by Parkinson's. This will ensure everyone involved properly understands the condition and people with Parkinson's are supported in self management.

A Royal College of Nursing accredited competency framework<sup>1</sup> for the role of the Parkinson's nurse is available.

## How Parkinson's nurses contribute to QIPP



## The evidence of cost savings

Once Parkinson's UK has pump primed a Parkinson's nurse, we work with them to make sure they can collect and present evidence to show the value of their role in monetary and practical terms. Much of the evidence in this report has been gathered by Parkinson's nurses working in their trusts to demonstrate the impact they are having.

### Avoided consultant appointments

The NICE guideline for Parkinson's recommends that people with Parkinson's are seen every six months for ongoing review and medication adjustment. The Parkinson's nurse can carry out much of this ongoing follow-up and review, by running nurse-led clinics and through telephone services and home visits. As part of an integrated Parkinson's service this can replace consultant appointments and free up consultation time for diagnosis or complex care issues.

Taking the annual savings from the nurse posts below we can see that a single Parkinson's nurse can save, on average, **£43,812** in consultant appointments each year.

#### WESTERN CHESHIRE PRIMARY CARE TRUST

For an average 12-month period between January 2009 and February 2010, 504 patients were seen in a nurse-led clinic, or at home, rather than by the consultant. At a local tariff of £194, the Parkinson's nurse saved on average £97,776 in avoided consultant appointments for this trust each year.

#### DONCASTER PRIMARY CARE TRUST

On average, in a four-week month, 56 patients are reviewed in secondary care clinics, and 20 patients in nurse-led clinics, by two-and-a-half whole-time equivalent Parkinson's nurses.

Based on Department of Health national tariff (2006) the cost of an out-patient follow-up appointment is £126. Therefore, there is a cost saving of £7,056 per month on secondary clinics and £2,520 on nurse-led clinics. Over a 12-month period the cost saving would be a total of £114,912 or £45,965 per nurse each year.

#### BURY PRIMARY CARE TRUST

Consultant follow-up appointments have been reduced by six appointment slots per week since the Parkinson's nurse started in post. This trust calculated that this amounts to an annual cost reduction of £32,568 each year.

#### DERBYSHIRE PRIMARY CARE TRUST

For an average 12-month period, 206 patients were seen in a nurse-led clinic rather than by the consultant. This trust calculated that this saved £25,421 in avoided consultant appointments each year.

#### SUFFOLK PRIMARY CARE TRUST

For an average 12-month period between March 2006 and July 2007, 159 patients were seen in a nurse-led clinic rather than by the consultant. At a local tariff of £109, the Parkinson's nurse saved on average £17,331 in avoided consultant appointments for this trust each year.

"Clear channels of communication have been set up, with the nurse providing the first contact for the GP and patients, and then the more serious issues being escalated to me. Additionally there is a palpable increase in the understanding of neurology in the community ... overall it has been a great advance in the community, in a relatively short time."

Consultant neurologist working with the Bassettlaw nurse

## Reducing unplanned admission to hospital

Analysis of hospital admission data for England in 2006/07 showed that there were 82,493 individual admissions of people with Parkinson's. 75% of these were non-elective emergency admissions<sup>2</sup>.

Many of the admissions of people with Parkinson's are avoidable if there are early interventions and appropriate care is available in the community. The Parkinson's nurse provides key elements of this care that is accessible and structured to meet patient needs. This includes running nurse-led clinics with flexible appointments, telephone services and home visits.

Working as a case manager, their preventative approach will ensure that the right therapies and interventions are co-ordinated to support people in the community. They also have the ability to manage high-need patients at home, meeting urgent needs quickly and efficiently.

The data from the nurses in Harlow and Pennine Acute Trust shows that community-based Parkinson's nurses can save more than **£80,000** per year in avoided admissions.

### PENNINE ACUTE TRUST

Admission figures for patients with Parkinson's from Bury Primary Care Trust to Fairfield Hospital from 2008-2009 compared to 2009-2010, have reduced from 172 to 154. This is an admissions reduction of 10% since the Parkinson's nurse started in post. The trust calculated the fixed annual cost saving of this reduction is £81,522 each year.

### HARLOW HOSPITAL

In 2004, prior to the appointment of the Parkinson's nurse, there were 55 admissions of people with Parkinson's to this hospital. The Parkinson's nurse was able to reduce this to 18 admissions in 2005. This is a reduction of 67% in admissions since the nurse started in post. The trust estimated that it saved £80,000 in unnecessary admissions in that first year alone.

## Reducing admissions for specialised care

In the complex stages of Parkinson's care, people may need highly specialised drug regimes such as apomorphine injections or pumps. Specialist skills are required to establish patients on these drugs and this usually requires inpatient care. Suitably trained Parkinson's nurses are able to carry out apomorphine challenge tests and start people on apomorphine injections and pumps in the community. This avoids a hospital stay – saving money and the disruption to the individual that an inpatient stay brings.

### WEST CHESHIRE PRIMARY CARE TRUST

In West Cheshire in 2009 the Parkinson's nurse prevented three day-case admissions for people starting apomorphine injections. And two people with Parkinson's were started on their apomorphine pumps in the community, avoiding the need for a hospital stay of up to five days each in a specialist unit.

### EAST BERKSHIRE PRIMARY CARE TRUST

In East Berkshire the nurse was able to carry out apomorphine challenges in the day hospital and GP practice, rather than with people as inpatients. Undertaking the challenge in an acute setting would cost a minimum of £2,000 per patient. The cost savings provided by the nurse post in this trust was calculated as £10,000 over 18 months.

### BURY PRIMARY CARE TRUST

In Bury, the trust calculated that providing the apomorphine service in the community saved £3,235 per patient.

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"You always went that extra mile for him and helped him to stay at home as long as he possibly could. You helped put practical lifelines in place, like suggesting carers come in and give dad his medication and explaining to them that dad wasn't being difficult, it was the Parkinson's that prevented him from responding to their requests." Letter to the East Berkshire Nurse

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**I PROVIDE  
VITAL  
SERVICES**

**BED 1**

**I MUST  
HAVE MY  
NURSE**



## Reducing the number of days spent in hospital

Parkinson's nurses also have a key role in ensuring that people with Parkinson's do not spend more time in hospital than is necessary. They provide education to ward staff and people with Parkinson's so that when people go into hospital they get their medication on time. This is vital to avoid complications and to stop Parkinson's symptoms getting out of control, which can lead to much longer time spent in hospital than necessary. By working with the discharge team Parkinson's nurses can make sure the necessary support is ready for the patient and their family when they go back home or move to a care home.

The data from the nurses in the three trusts below shows that Parkinson's nurses can save on average **£147,021** per year in bed days.

### PENNINE ACUTE TRUST

The Parkinson's nurse appointed in 2009 saved Pennine Acute Trust £190,218 each year by reducing the number of bed days for people with Parkinson's. Between 2008/09 and 2009/10 there were 294 fewer bed days used for Parkinson's patients at a cost of £647 per day.

### HARLOW PRIMARY CARE TRUST

In 2004, before the appointment of the Parkinson's nurse, people with Parkinson's totalled 337 bed days in this hospital. The Parkinson's nurse was able to demonstrate a reduction to 69 bed days in 2005. At a cost of £647 per day for a Parkinson's patient, this is a saving of £173,396 each year.

### DERBYSHIRE COUNTY PRIMARY CARE TRUST

In an average 12-month period before the Parkinson's nurse came into post the trust calculated the cost data for bed days for people with Parkinson's was £340,979. This cost had dropped to £263,531 on average in the 12-month period after the nurse was in post, saving £77,448 each year.

"I support people with Parkinson's as inpatients who are generally admitted with other co-morbidities. Similarly, I support medical staff and therapists by advising on treatment options and by providing teaching and update sessions." Parkinson's nurse

## Avoiding readmissions

Avoiding readmissions is a major outcome for NHS staff and we have found that Parkinson's nurses can support discharge and ensure that patients are moving back home with an appropriate care plan in place. They can provide the leadership and multidisciplinary co-ordination necessary for the complex needs people with Parkinson's. This means that people are less likely to be unnecessarily readmitted to hospital.

### BURY PRIMARY CARE TRUST

Readmission figures for patients with Parkinson's have been reduced as a result of the appointment of the Parkinson's nurse. In 2008/09, when there was no nurse post, there were 40 readmissions, whereas in 2009/10, when the nurse started, there were 28 readmissions.

"We carry out domiciliary visits to those patients who are housebound and make sure we see individuals at home annually at least to assess their condition and medication but also to see if they are able to manage at home independently." Parkinson's nurse



“Parkinson’s nurses can support patients to take control.”

Jacqueline Young,  
Parkinson’s nurse,  
Huntingdon

## Parkinson’s nurses leading innovation and service redesign

In Huntingdon and Cambridge, Parkinson’s nurses were at the heart of service redesign, along with the local GPs, transforming Parkinson’s services across the area.

- **Increasing accessibility**

Before the investment in Parkinson’s nurses, clinics were only held in the acute hospital. People had problems accessing this service, especially with poor local transport. Since 2009, ten clinics are now held in six locations across Huntingdonshire, bringing care closer to people’s homes.

- **Meeting needs at different stages of Parkinson’s**  
Huntingdon and Cambridge Parkinson’s nurses also started a rolling programme of information/education courses involving the Parkinson’s multidisciplinary team. They also run courses for people with Parkinson’s and their partners or carers. There are now three separate courses running to meet the needs of people at different stages of the condition.

- **Taking Parkinsons services into care homes**

All care home residents with Parkinson’s or a Parkinsonism have been reviewed and are seen every six or 12 months and more frequently if necessary.

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“One gentleman now can walk to my clinic using his four-wheeled walker as he lives next door to the medical centre and another man is able to come on his mobility scooter. Coming to clinic under their own steam means a lot to people who can become more and more isolated by their condition.”

Jacqueline Young, Parkinson’s nurse, Huntingdon

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## The Parkinson's nurse contribution to meeting health care standards and outcome measures.

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### NICE guidelines for Parkinson's

The National Institute for Health and Clinical Excellence (NICE) Guideline for the diagnosis and management of Parkinson's disease in primary and secondary care recommends that people should have referral to a specialist, which may be a Parkinson's nurse for:

- monitoring and altering medication appropriately
- providing a continuing point of contact for support, which include 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

### NHS and Social Care Outcomes Frameworks

The new Department of Health Outcomes Frameworks for the NHS<sup>3</sup> and social care<sup>4</sup> have set out the priorities that must be delivering across the health and social care system in the future. The Parkinson's nurse service will directly contribute to achieving a number of the indicators in the 'enhancing quality of life' domain and the 'ensuring people have a positive experience of care and support' domain.

#### Domain: Enhancing quality of life

##### Indicator: Ensuring people are supported to manage their condition

The Parkinson's nurse is very commonly described by people with Parkinson's as the most important professional who supports them to understand and manage their Parkinson's.

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"The specialist nurse being in place for the last few years has allowed a continuity and consistency of approach and the trust that has been built up in their expertise during that time is priceless."

A patient in Huntingdon

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The education sessions run by a Parkinson's nurse were described very positively:

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"The contents and scope of each session were well-balanced, professionally delivered and easy to assimilate. The information imparted has been invaluable and is already helping us both in many ways." Comment from our website

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##### Indicator: Reducing time spent in hospital by people with long-term conditions

A big factor in reducing the time people spend in hospital is to provide good quality care. In Parkinson's this comes through ensuring ward staff understand the importance of people getting their medication on time, every time. The Parkinson's nurses in Colchester have devised a range of resources including a ward pack and an e-learning intranet programme that all staff can access. The nurses across East Anglia produced a traffic light poster to alert staff to the dangers of taking people off their medication.

Parkinson's UK have produced a range of materials as part of our Get It On Time campaign that Parkinson's nurses can use to help educate their colleagues about the importance of getting medication on time.

##### Indicator: Enhancing quality of life for carers

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"Thanks to the Get It On Time campaign, staff at my local hospital now understand that I need my medication on time and have improved the way they manage patients with Parkinson's."

Tina Walker, Kettering

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In North Devon, the Parkinson's nurse provided support to an elderly carer who was locking herself and her husband in the house to avoid her increasingly confused husband from wandering. The wife was constantly being woken during the night. With changes to her husband's medication, and by arranging regular respite, the wife was able to achieve some rest, have a better quality of life and was able to continue to care for her husband at home.

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

Comment from our website

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**I WANT  
TO STAY  
INDEPENDENT**

Ken

## Domain: Ensuring people have a positive experience of care and support

### Indicator: Improving hospital responsiveness to personal needs

Training courses are run on a regular basis for ward staff, so that the principles of nursing someone with Parkinson's are reviewed in a busy ward environment. Parkinson's nurses are able to educate ward staff about particular symptoms associated with Parkinson's, such as freezing (this is when someone is suddenly unable to move or complete a movement) and 'off periods' (this is when someone's symptoms start to become a problem as their Parkinson's medication is 'wearing off').

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"Super session – basic, recognisable and very useful, especially the impact on rest of family."

"More aware of the importance of medication, more understanding that when nursing patients with Parkinson's for other conditions their Parkinson's may be making things worse."

Feedback from ward staff about training

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### Indicator: Improving the experience of care for people at the end of their lives

In Huntingdon, specialist nurses care for people in local care homes on a regular basis. They are able to offer expert support and care for people when they are nearing the end of their lives. By supporting the staff, there are real opportunities to avoid unnecessary hospital admissions.

A nurse from Huntingdon visited one patient who had become hard to wake at times and unable

to take oral medication. This meant that her Parkinson's symptoms became much worse, with her limbs becoming stiff and the care staff finding it increasingly difficult to move her without causing discomfort. The Parkinson's nurse was able to advise the GP on alternative Parkinson's medication, in the form of a transdermal preparation, to manage her Parkinson's. This successful treatment allowed the home staff to continue to care for her within the home and ease the lady's discomfort, improving her quality of life in the last few weeks of her life.

### Indicator: People know what choices are available to them locally, what they are entitled to and who to contact when they need help

Parkinson's nurses provide a continuous point of contact throughout the patient's journey and offer advice and signposting to other sources of help. They are available at clinic, over the phone and by email.

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"The specialist nursing team provided by Cambridgeshire Community Services NHS Trust has been invaluable. The regular contact that we have with a specialist nurse gives an understanding of how the body changes in response to medication, as well as appreciation of personal needs."

"We are exceptionally lucky to have such a provision of care by the nursing team. It means we can remain in our own home with specialist nurses providing the medical and personal care."

"Peace of mind with the knowledge that I am being attended by an experienced professional."

Comments from our website

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## How Parkinson's UK can support local services

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- 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 commissioning organisation.
- 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 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 and signposting to local services and benefits advice.

## For more information

To find out more contact Lesley Carter,  
Head of Influence and Service Development,  
by emailing [professionals@parkinsons.org.uk](mailto:professionals@parkinsons.org.uk),  
calling **020 7963 9346** or visiting  
[parkinsons.org.uk/professionals](http://parkinsons.org.uk/professionals)

## References

- 1 Royal College of Nursing, Parkinson's Disease Society and Parkinson's Disease Nurse Specialist Association (2008) A competency framework for nurses working in Parkinson's disease management 2nd edition
- 2 Hospital Episode Statistics (2006-2007) NHS
- 3 Department of Health (2011) The NHS Outcomes Framework 2011/12
- 4 Department of Health (2011) 'Transparency in outcomes: a framework for quality in adult social care' The 2011/12 Adult Social Care Outcomes Framework

# 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**

215 Vauxhall Bridge Road,  
London SW1V 1EJ

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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