Parkinson's nurses – affordable, local, accessible and expert care
A guide for planners in Wales
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreword</td>
<td>3</td>
</tr>
<tr>
<td>Executive summary</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>What is Parkinson’s?</td>
<td>5</td>
</tr>
<tr>
<td>The role of the Parkinson’s nurse</td>
<td>5</td>
</tr>
<tr>
<td>Affordable: the evidence of cost savings</td>
<td>6</td>
</tr>
<tr>
<td>Avoided consultant appointments</td>
<td>6</td>
</tr>
<tr>
<td>Parkinson’s nurses lead service redesign – how the Parkinson’s nurse role directly contributes to meeting health care standards and outcome measures</td>
<td>8</td>
</tr>
<tr>
<td>Expert: safe and clinically effective care</td>
<td>8</td>
</tr>
<tr>
<td>Expert: medicines management</td>
<td>8</td>
</tr>
<tr>
<td>Local, accessible, expert: shift of clinical care into community services</td>
<td>10</td>
</tr>
<tr>
<td>Expert: avoiding readmissions</td>
<td>11</td>
</tr>
<tr>
<td>Parkinson’s UK supporting planners and providers</td>
<td>12</td>
</tr>
<tr>
<td>More information</td>
<td>12</td>
</tr>
<tr>
<td>References</td>
<td>12</td>
</tr>
</tbody>
</table>
“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 over £12 million to pump-prime specialist Parkinson’s nurse posts across the UK. In the last five years, in partnership with health boards in Wales, we have created nurse posts in Flintshire, Gwynedd, Conwy, Anglesey, North Powys, Cwm Taf and Wrexham.

“But even with this investment, many people with Parkinson’s in Wales have still 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 Wales.

“We understand the need for financial restraint at this time and 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
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 in which 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 symptoms and medication management, care needs to be delivered by a specialist. Parkinson’s nurses provide this at a cost affordable by all health boards.

Introduction

For more than 20 years, Parkinson’s nurses have been at the heart of delivering improved services, cost savings, services that bring care closer to home, joined-up provision and a commitment to patient empowerment and satisfaction.

As a planner or provider, in this report you’ll find evidence from Parkinson’s nurses in Wales that demonstrates the significant contribution Parkinson’s nurses make to the local delivery of care for people with Parkinson’s.

Our commitment to this valuable role is mirrored in the report of the Welsh Neuroscience External Expert Review Group, All Wales Recommendations¹. This emphasises the importance of role of the specialist nurse and notes that “nurse specialists should support the medical workforce with a defined case load of no more than 300 patients each, in ... Parkinson’s and neuromuscular disease”.¹
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. 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 health board 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.

As well as having a major impact on everyday movement and control, people with Parkinson’s have to deal with a range of other symptoms, such as tiredness, pain, depression, constipation and bladder problems, affecting 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 and support needed to support people in the community will increase.

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 the person’s own home or care home. They liaise with professionals and voluntary organisations, as appropriate, to provide a comprehensive Parkinson’s service ensuring 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 health professionals who may only come across a small number of people affected by Parkinson’s. This dual approach ensures that people understand their own condition and are supported by health professionals in self management.
Affordable: the evidence of cost savings
Once Parkinson’s UK has pump primed a Parkinson’s nurse, we work with them to ensure they can collect and present evidence to show the value of their role. Much of the evidence in this report has been gathered by Parkinson’s nurses to demonstrate to their health board the impact they are having.

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. This study looked at the cost saving of offsetting consultant appointments with nurse-led clinics. This example of cost saving by substituting nurse clinics for consultant appointments has been replicated across the UK and can be seen to save on average £41,000 per year on deferred consultant outpatient appointments.

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 recommends that people with Parkinson’s are seen every six months for ongoing review and medication adjustment. The Parkinson’s nurse can carry out the majority of these reviews, therefore removing 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. Critically, this also frees up consultant time which can then be spent on initial diagnosis and complex care.

“Parkinson’s nurses can prevent a problem becoming a crisis.”
Jan Roberts, Parkinson’s nurse, Conwy
UNIVERSITY DEPARTMENT OF GERIATRIC MEDICINE, GLAN CLWYD HOSPITAL, RHYL

The nurse and research team identified that after just one year the Parkinson’s nurse saved in the region of £54,000, based upon avoidance of outpatient clinic costs at £105 per visit. At the end of one year the nurse had assessed 321 patients and made 881 interventions.

BETSI CADWALADR UNIVERSITY HEALTH BOARD, GWYNEDD, ANGLESEY

By managing her caseload of patients, the nurse in this area has reduced waiting time by a minimum of 25% for new patients.

“Our ratio of new to follow-up has also improved. Services offered by the Parkinson’s nurse have also meant that most patients in great need can now been seen in the clinic more or less the same week, thereby preventing their admission to the acute unit.”
Dr Prem Ohri, Associate Specialist

BETSI CADWALADR UNIVERSITY HEALTH BOARD, FLINTSHIRE

After two years the nurse’s caseload stood at 236. All patients were seen every six months, reducing the need for consultant appointments.

Nurse-led clinics have been established and are currently held on a monthly basis in Mold and Deeside Hospitals and Wrexham. This has removed the need for many patients to travel to the Walton Centre or the Countess of Chester Hospital, which may incur an outpatient tariff of £195.

POWYS TEACHING HEALTH BOARD

Financial savings have resulted from:
• less frequent follow up in secondary care for stable patients as they can be monitored locally
• admission prevention due to crisis management at home, with consultant advice
• early discharge home from hospital

BETSI CADWALADR UNIVERSITY HEALTH BOARD, CONWY, ANGLESEY

Interventions by a Parkinson’s nurse avoid the need for costly consultant appointments and help manage problems before they become critical. After 18 months in post the nurse in this area (pictured on left page) had a caseload of 255 patients and had carried out:
• 707 phone interventions
• 323 nurse-led clinic appointments
• 185 home visits
Parkinson’s nurses lead service redesign – how the Parkinson’s nurse role directly contributes to meeting health care standards and outcome measures.

Expert: safe and clinically effective care
Parkinson’s nurses help to meet the Standards for Health Services in Wales by meeting the NICE Guidelines.

Standard 7 of Doing Well, Doing Better – Standards for Health Service in Wales relates to safe and clinically effective care:

“Organisations and services will ensure that patients and service users are provided with safe, effective treatment and care: based on agreed best practice and guidelines including those defined by National Service Frameworks and, National Institute for Health and Clinical Excellence (NICE).”

NICE, in its Guidelines, recommends that people should be referred to a 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 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

The Guidelines stipulate 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”.

In its analysis of the cost of implementing the NICE Guidelines, the cost savings identified by the nurse’s role in reducing hospital admissions and length of stay offset the added costs of delivering these best practice guidelines.

Expert: medicines management
Standard 15 of Doing Well, Doing Better is about medicine management. It specifies:

“Organisations and services will ensure that there is timely, accessible and appropriate medicines advice and the reporting of drug-related adverse incidents.”

Reducing the length of time people with Parkinson’s spend in hospital is reliant on ward staff understanding the importance of people getting their medication on time, every time.

People with complex Parkinson’s may need medication six or seven times a day and missed medication can lead to poorly controlled symptoms. When people’s symptoms aren’t being controlled this can lead to falls, inability to eat, and, in some cases, total immobility. All of this means that patients will have a slower recovery, longer stays in hospital and feel anxious about their care in hospital.

One of the objectives for the Parkinson’s nurse in Gwynedd was to prevent unnecessarily extended hospital stays. The nurse worked with hospital ward staff to increase their understanding of the impact on patients when they did not receive their medication on time. She also aimed to improve access to medication on admission, linking with hospital pharmacists. A Get It On Time campaign was launched in November 2009 in the area to raise awareness of this issue.

Educational sessions were also given by the nurse and a hospital pharmacist with a special interest in Parkinson’s to a group of nurses responsible for the management of medicines throughout the hospital.

“[The campaign] has made me more aware of some of the difficulties faced by patients and more aware of the side effects of medication.”

“Really useful and educational. I learnt a lot.”
Feedback from ward staff at hospitals in Gwynedd

“The reassurance is knowing that there is someone locally to whom one can go for help and advice. The nurses are known to both Parkinson’s patients and carers, rather than being anonymous voices at the end of a phone line. That counts for a lot. Their being in place for the last few years has allowed a continuity and consistency of approach. The trust that has been built up in their expertise during that time is priceless.” Patient, Flintshire
WE WANT EXPERT LOCAL CARE

WE WANT EXPERT LOCAL CARE
The Parkinson’s nurse continues to oversee the management of medicines by visiting the wards on a regular basis and educating the staff on the importance of giving these specialised drugs on time.

Evaluation and monitoring of prescribed treatment in the community is an essential part of the role. The Parkinson’s nurse in Flintshire was contacted by the partner of a young person with Parkinson’s. The couple was in financial crisis because of the patient’s daily gambling. They were in danger of losing their home and the partner was going to leave.

The Parkinson’s nurse visited, reviewed the medication and found that the patient was on a medication known to have a potential side effect of compulsive behaviour. The medication was gradually withdrawn and the nurse was able to talk with the patient’s family about the possible cause of the gambling. Measures were put in place to rebuild family life and the compulsive behaviour reduced. To maintain a sense of control, the patient was encouraged to seek support from Gamblers Anonymous.

Local, accessible, expert: shift of clinical care into community services

In the NHS Annual Quality Framework for 2011-2012 the objective for delivering care closer to home is outlined: “Each Board should demonstrate a direct shift of clinical care into community services.”

Providing an accessible, flexible service is at the heart of a good Parkinson’s service. Community clinics, telephone support and home visits ensure that patients can access help earlier and avoid a problem becoming a crisis. The introduction of the nurse service in North Powys immediately led to the creation of outreach nurse-led clinics:

“Patients are now reviewed in Machynlleth, as well as Newtown community hospitals. There is provision in Llanidloes, and in Llanfair Caereinion GP surgery and there’s soon to be a service in Montgomery. All the clinics are nurse led. This is in part to address issues of rurality, as well as patient preference.” Dr Suzy Thompson, Consultant in Elderly Medicine (with special interest in Parkinson’s disease), Royal Shrewsbury Hospital
Many of the hospital admissions of people with Parkinson’s are avoidable if there are early interventions and appropriate care available in the community. The Parkinson’s nurse expertise ensures that the service is accessible and structured to meet patient needs. This includes running nurse-led clinics with flexible appointments, telephone services and home visits. Also they have the ability to manage high-need patients at home, meeting urgent needs quickly and efficiently.

In the complex stages of Parkinson’s people will 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. Nurses in Flintshire and Gwynedd reported examples of where they have been able to introduce this medication at home or in community clinics, thus avoiding the need for acute inpatient stays.

It has been calculated using figures from other nurses that such interventions can save £3,235 per patient.3

“The difference to patient care since the Parkinson’s nurse appointment to North Powys is so obvious … patients who do not have a Parkinson’s nurse’s input rely on consultant care, requiring frequent, and often, rushed appointments. In North Powys, the patients have a reliable, local, knowledgeable health professional who can resolve most clinical problems and access appropriate advice.”
Dr Suzy Thompson, Consultant in Elderly Medicine
Royal Shrewsbury Hospital

And in Gwynedd the impact on the clinical team in delivering an equitable service is huge:

“Eleri, our Parkinson’s nurse, has now been in post for two years, and she has made a tremendous difference to the provision of services to patients with Parkinson’s disease in the Gwynedd and Anglesey areas. It is not clear to me how we managed without such a post in the past. She has provided a tremendous amount of support in the management of complex patients. She has established a nurse-led clinic in Eryri hospital and Alltwen, and is developing a further one in Dolgellau. These peripheral clinics are vital for the management of patients, since many patients suffer from complex problems in remote areas, and require access to regular review.”
Dr John Hindle, Care of Elderly Consultant, Gwynedd

Expert: 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 multi-disciplinary co-ordination necessary for the complex needs of many people with Parkinson’s. This contributes to ensuring that people are not unnecessarily readmitted into hospital.

“We live in rural countryside, so the nurse, although based 40 minutes away, is always on the end of the phone and available for home visits. Both of us being Welsh speakers, it’s easier to express your thoughts and feelings. If I feel any problems have cropped up, she will get in touch with our doctor and sort it out.”
Patient of the Parkinson’s nurse in Gwynedd
Parkinson’s UK supporting planners and providers

- We can fund the initial investment in a Parkinson’s nurse, in areas where there is poor coverage, through pump priming. During this pump-priming period our local staff work with the health board to establish the objectives of the post and the criteria by which the posts are judged to have delivered these objectives.

- We can support local service redesign.

- We run a professional development programme for all Parkinson’s nurses and provide tools and materials through the Healthy Alliance partnership.

- We can offer expert trainers in Parkinson’s care and support to NHS and social care staff.

For more information

To find out more contact Lesley Carter, Head of Influence and Service Development – email lcarter@parkinsons.org.uk, call 020 7963 9346 or visit parkinsons.org.uk/walescampaigning

References

*3 Parkinson’s nurses (2011), English Nurses’ Report
*5 Doing Well, Doing Better – Standards for Health Services in Wales (2010)

“The most important thing to happen to me after being diagnosed was meeting the Parkinson’s nurse. She was fabulous. She told me from the start that it wasn’t the end for me. I just had to choose a new life journey, which I feel I’ve done.” Hywel Griffiths (cover), speaking about his Parkinson’s nurse
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 Cymru**
Maritime Offices
Woodland Terrace
Maesycoed
Pontypridd CF37 1DZ
0844 255 3784

Free* confidential helpline 0808 800 0303
Monday to Friday 9am – 8pm
Saturday 10am – 2pm. Interpreting available.
Text relay 18001 0808 800 0303

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

parkinsons.org.uk/cymru
cymru@parkinsons.org.uk