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Joy

**Parkinson's nurses in Scotland: providing effective, safe, person-centred care**

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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 past five years, in partnership with health boards in Scotland, we have created nurse posts in Ayrshire and Arran, Angus, Lothian, Borders and Dumfries.

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

“We need to ensure that everyone with Parkinson’s has full access to a Parkinson’s nurse throughout

the course of their condition, wherever they live in Scotland.

“We understand the need for the NHS to deliver high-quality care that is affordable. That is why we want to celebrate the fact that Parkinson’s nurses are uniquely positioned to provide person-centred, safe and effective care and to deliver cost savings.”

**Steve Ford**  
Chief Executive, Parkinson’s UK



## Executive summary

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Parkinson's nurses are an essential element of care for people with Parkinson's and their families. Their role is recognised and supported by Scottish Government and the NHS in Scotland.

Access to Parkinson's nurses prevents fragmented care, and provides people with information and support to manage their own conditions. It embeds preventive and anticipatory care and improves outcomes. Where nurses are in place, there is more efficient use of acute and primary care resources, including expensive medical time and acute beds.

There are positive examples of how Parkinson's nurses are making a difference to individuals, families and the NHS at every stage, from diagnosis to the end of life. People with Parkinson's value the support of Parkinson's nurses and the care they are in a unique position to provide.

Scotland has relatively good Parkinson's nurse coverage, and some people in each NHS board area can access a nurse. However, there are large geographical areas within many boards where people can't access a nurse. We need more nurses, so that fair access is available to everyone throughout the country.

Parkinson's UK makes the following recommendations to maximise the effectiveness of Parkinson's nurses in Scotland:

- The Scottish Government and NHS Healthcare Improvement Scotland should ensure the continued implementation and scrutiny of the NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services.

- NHS boards should meet the NICE recommendation that each full-time Parkinson's nurse should have a maximum caseload of 300 people, or 250 in remote and rural areas. A service should be provided to all geographical locations in Scotland.
- NHS boards should encourage the use of telemedicine and virtual teams to support work in remote and rural communities.
- NHS boards should develop and publicise clear patient pathways, and encourage GPs to refer all people with suspected Parkinson's to specialist teams for diagnosis and ongoing management.
- NHS boards should allow Parkinson's nurses to work across all care settings. They should be able to respond to local needs and be available to everyone with Parkinson's.
- NHS boards should ensure that consistent nurse cover is provided, where a board employs more than one Parkinson's nurse.
- The Scottish Government, NHS Information Services Division and NHS Healthcare Improvement Scotland should work with clinicians, the Neurological Alliance of Scotland and people with neurological conditions to ensure that adequate data is collected to plan, manage and evaluate services for people with neurological conditions.



## Introduction

For more than 20 years, Parkinson's nurses have been at the heart of delivering improved services and cost savings. They have brought care closer to home, enabled joined-up provision and empowered people with Parkinson's and their families to live with their condition.

Parkinson's nurses are an essential element of a Parkinson's service in Scotland. The mandatory NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services state that every person with Parkinson's should have ongoing access to a Parkinson's nurse. They also state that Parkinson's nurses should play a leading role in the Parkinson's multidisciplinary team.<sup>1</sup>

The national Patient Pathway for Parkinson's also indicates that people with the condition should receive their care from a multidisciplinary team, including a Parkinson's nurse, from diagnosis onwards.<sup>2</sup>

**Useful for decision makers, clinicians or managers, this report contains evidence of the unique contribution Parkinson's nurses make to delivering accessible, timely, expert care for people affected by Parkinson's in Scotland.**

You will also see how Parkinson's nurses can help NHS boards to meet their strategic priorities. These include the NHS Quality Strategy, HEAT Targets, Patient Safety Programme, and waiting time guarantees. Parkinson's nurses are key to delivering the objectives of the Long Term Conditions Action Plan, and preventative and anticipatory care programmes such as Shifting the Balance of Care, and Reshaping Care for Older People.

They can also help to meet the goals of national strategies, such as those for dementia and palliative care. Please see Appendix 1 (page 20) for a full checklist showing how Parkinson's nurses can help to meet strategic priorities.

## What is Parkinson's?

Parkinson's is a progressive, fluctuating neurological condition. It affects all aspects of daily life, including talking, walking, swallowing and writing. There are also other issues, such as tiredness, pain, depression, dementia, impulsive and compulsive behaviour and continence problems, which have a huge impact on people's daily lives. The severity of symptoms can fluctuate from day to day and rapidly change during the course of the day. Some people with the condition can experience sudden 'freezing'. There is currently no cure.

One person in every 500 has Parkinson's. That's about 127,000 people in the UK, and 10,000 people in Scotland.<sup>3</sup>

**In a medium-sized health board with a population of 500,000 people, approximately 1,000 people will have Parkinson's. Up to 100 people will be diagnosed with the condition each year.**

As the Scottish population ages, the prevalence of Parkinson's will increase significantly over the next few years. It is estimated that by 2020 the number of people with Parkinson's will increase by 27%.<sup>3</sup> Scotland's age profile suggests that by 2020 there will be more than 12,000 people with Parkinson's in Scotland.

Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age people experience the onset of Parkinson's is between 50 and 60, and the incidence increases with age. Most people living with Parkinson's are over 65. However, many younger people are affected too.

The Parkinson's care pathway is extremely complex. Everyone with Parkinson's is different, but Parkinson's symptoms often include a combination of physical disability and cognitive, mental health and communication problems. Symptoms can be managed through medication and therapeutic support, but can worsen as the condition progresses.

People with Parkinson's rely on complex medication regimens to manage their symptoms, and regular adjustments are required to manage symptoms. If people do not take their medication at the right time and at the right dose this can lead to uncontrolled symptoms and extreme side effects.

People also need increasing levels of community care and support as the condition progresses.

Many people with Parkinson's also have other health issues. This can present considerable care challenges.

Without appropriate care, people with Parkinson's are at high risk of:

- expensive emergency hospital admission
- extended hospital stays
- premature care home admission

**About one in every four people with Parkinson's in Scotland is admitted to a hospital at least once in a year. More than half of these admissions are unplanned.<sup>4</sup>**

**One in every 10 people with Parkinson's in Scotland is classified as being at high risk of hospital admission in the next year.<sup>5</sup>**





## The role of the Parkinson's nurse

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The Parkinson's nurse is a specialist practitioner with expert knowledge of Parkinson's symptoms and treatment. Most are nurse prescribers. Their experience of Parkinson's is essential to providing person-centred care, enabling them to identify and respond quickly to changing symptoms. This reduces risks to individuals and families, and helps to prevent emergency admissions.

People with Parkinson's and their families value their Parkinson's nurse because she or he understands the condition. Parkinson's nurses appreciate the complex – often hidden – ways that Parkinson's affects people. This in-depth knowledge is key to the support that a Parkinson's nurse is able to provide.

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*"I'm amazed at my Parkinson's nurse's knowledge in every area of the condition – in medication, side effects, psychological effects and everything else. If you ask her one question, she'll tell you what to do. She's easy to talk to, and is really very good."*

Person with Parkinson's, NHS Ayrshire and Arran

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A Parkinson's nurse also has the following essential skills:

- clinical leadership
- case management
- education
- evaluation of care

Parkinson's nurses are leading members of the Parkinson's multidisciplinary team. They also liaise with professionals and voluntary organisations to provide a comprehensive, joined-up Parkinson's service.

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*"Having a Parkinson's nurse has significantly improved the service we are able to offer patients with Parkinson's, and their carers. Linda provides a single point of contact, so the team is able to respond quickly and appropriately, and we have better continuity of care. In particular, we have increased the support we are able to offer to people living in care homes, who are often at particular risk of complications. Linda has made a huge difference to the care and support that patients and their families receive in our area."*

Dr Ian A Gillanders, NHS Tayside

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In their working lives, most general healthcare professionals only come across a small number of people with Parkinson's. A typical Scottish GP will see a new case of Parkinson's less than once every three years.<sup>6</sup> Parkinson's nurses play an important role in educating their colleagues about the condition and how it affects people, as well as reducing risks to people with the condition. Parkinson's nurses provide education and training across Scotland, including programmes for GPs, ward staff, social care and care home workers, and nursing students.

The Parkinson's nurse is also ideally placed to provide education to people with Parkinson's, their families and carers. This approach enables people to understand their condition and treatment. It facilitates shared decision-making and self-management.

Parkinson's nurses work across a range of settings, including hospitals, clinics, health centres, care homes and people's own homes. They provide expert support and ensure continuity of care throughout the patient journey, from diagnosis to the end of life.



A woman with dark hair and glasses, wearing a blue hospital uniform, stands in a hospital hallway. She is holding a white rectangular sign with blue text. In the background, another person in a blue uniform is partially visible on the left, and a medical cart with a yellow box is on the right. The hallway has a wooden door and a green exit sign in the background.

**PEOPLE WITH  
PARKINSON'S NEED  
THEIR MEDICATION  
ON TIME**

**Mariamamma**

## Parkinson's nurses in Scotland

Parkinson's nurses work with consultants who specialise in Parkinson's. These consultants are based in the care of the elderly, and neurology services.

There are currently 25 Parkinson's nurses working across Scotland. Not all of them work full-time. Between them, they are equivalent to about 23 full-time nurses. See our snapshot of services in Appendix 2 on page 27.

NICE estimates that each Parkinson's nurse should have a maximum caseload of 300 people,<sup>7</sup> and we believe that it should be fewer than that in sparsely populated areas. There are about 10,000 people with Parkinson's in Scotland.

On this basis, we estimate that there should be at least 35 full-time equivalent Parkinson's nurses in Scotland. At present, every mainland health board in Scotland has at least one Parkinson's nurse.

However, some Parkinson's nurses have extremely large caseloads, and many people in Scotland are still unable to get access to a Parkinson's nurse.

Some island boards have established links with specialist nurses on the mainland, and we are working to develop better services for all people with Parkinson's living in remote and rural areas.

Some of Scotland's Parkinson's nurses, with Katherine Crawford, Scotland Manager, Parkinson's UK (far right)





## Parkinson's nurses are effective

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. This approach enables boards to realise, from the beginning, the benefits of investment in a nurse. Parkinson's nurses are efficient, cost-effective and sustainable.

Examples from across Scotland demonstrate that Parkinson's nurses:

- reduce waiting times
- avoid hospital admissions
- reduce delayed discharges
- bring care closer to home
- innovate to deliver efficiency savings and reduce service costs
- deliver the right care at the right time

### Reducing waiting times

Specialist nurses have been identified as an important tool in achieving targets for the time it takes from referral to treatment in neurology.<sup>9</sup>

The NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services state that people with Parkinson's should be seen at least annually for ongoing review and medication adjustment.<sup>1</sup> The Parkinson's nurse can carry out the majority of these reviews. This releases consultant time, which can then be spent on initial diagnosis and complex care.

### Increasing efficiency

Missed outpatient appointments are a major expense for the NHS. In 2010, Audit Scotland reported that missed appointments cost the NHS almost £5million in three months alone.<sup>10</sup> Parkinson's nurses often see people in local clinics, community hospitals or in people's own homes. This significantly reduces the number of missed appointments and the need for hospital transport.

### Avoiding and reducing hospital stays

People with Parkinson's are at high risk of hospital admission. Hospital stays for people with Parkinson's are more than 25% longer than those of people of a similar age without the condition.<sup>4</sup> Parkinson's nurses can identify risks and intervene early to prevent crisis admissions. 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.

Parkinson's nurses can support discharges, ensuring that patients move back home with appropriate care plans in place. They provide leadership and multidisciplinary co-ordination to meet the complex needs of many people with Parkinson's. This reduces the risk of readmission.

### Case notes

#### Angus Community Health Partnership, NHS Tayside

The Parkinson's nurse established review clinics, which significantly reduced the time between referral and treatment. Over one year, the consultant saved time equivalent to 100 new referral appointments. This enabled quicker diagnosis and improvements to other areas of the service.

#### NHS Lothian

Over two years, nurse-led review clinics have reduced waiting times to see a Parkinson's consultant by eight weeks.

After reviewing their clinic performance, the Parkinson's nurse team introduced a phone reminder system and reduced their Did Not Attend rate from 21.5% to zero.

#### NHS Ayrshire and Arran

Over 18 months, the Parkinson's nurse team estimates that they have avoided 15 hospital admissions for people with Parkinson's by intervening at an early stage. This amounts to an approximate saving of £39,000.



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"The appointment of Parkinson's nurses has significantly improved the quality of care of patients seen in my clinic. Their follow-ups may have otherwise been some months later. It has also freed up my time to deal with other clinical work.

"A nurse now does medical follow-up clinics, which, for me, has released four clinic review slots a week.

"I have to say thanks to Parkinson's UK for funding the start-up costs of the posts in Ayrshire."

Dr Andy Watt, Parkinson's Clinical Lead NHS Ayrshire and Arran

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### **NHS Dumfries and Galloway**

Creating a Parkinson's nurse post enabled the consultant to allocate more time to the hospital's rehabilitation unit. This resulted in a significantly reduced length of stay for patients. Also, there is no longer a waiting list for the rehabilitation unit and this has allowed the service to be accessed by those in acute beds in the main hospital. This will further reduce hospital stays.

### **NHS Borders**

Home visits from the Parkinson's nurse enabled two people with advanced Parkinson's to avoid hospital admission. The nurse identified that the reason why they were not coping at home was because they needed a medication adjustment. By changing the medication, their mobility improved significantly and they were able to stay at home.

### **NHS Greater Glasgow and Clyde**

In west Glasgow, the Parkinson's nurse worked with colleagues in old-age psychiatry to develop joint clinics for people with severe hallucinations, dementia and depression related to Parkinson's. Previously, people with these problems were referred to psychiatrists on a postcode basis, and there was little continuity of care. These joint clinics have led to more efficient use of mental health service time. They have also increased the Parkinson's service's capacity to manage complex mental health symptoms effectively.

## **Parkinson's nurses promote safer care**

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Preventing adverse medication events is an NHS priority, and part of the Scottish Patient Safety Programme. Parkinson's nurses have an essential role in preventing adverse events for people with Parkinson's, at home and in hospital.

People with Parkinson's may need medication six or seven times a day, at specified times. Missed medication can be very serious. It leads to poorly controlled symptoms and can make someone more likely to fall, or become unable to eat, drink or communicate. In some cases, it can lead to total immobility and psychotic symptoms. It is a major cause of extended hospital stays. The importance of medication timings is not always well understood by busy non-specialist 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
- developing systems that enable people to get their medication on time, every time

### **Case notes**

#### **NHS Dumfries and Galloway**

The Parkinson's nurse has set up a daily email alert system that highlights when a person with Parkinson's is admitted to hospital. She has developed specific audit and training initiatives around Parkinson's medication management.

#### **NHS Lothian**

Parkinson's nurses have worked with learnPro to develop an e-module called *Caring for your Parkinson's patient in hospital*. This outlines the importance of giving medication on time. In nine months, 240 NHS Lothian staff have passed the module. The team has also shared this information with their Parkinson's nurse colleagues in other boards, so that it can be rolled out across Scotland through the learnPro site.

#### **NHS Grampian**

Parkinson's nurses have worked with the Clinical Effectiveness team to develop a medication audit,



**I PROVIDE  
VITAL  
SERVICES**



**I MUST  
HAVE MY  
NURSE**

initially covering five wards at Aberdeen Royal Infirmary. They are developing a protocol for surgical patients with Parkinson's who are nil by mouth, and working to ensure that inpatients with Parkinson's are visited by the Parkinson's nurse within 48 hours of admission, or before elective surgery.

### NHS Lanarkshire

The Parkinson's nurse has developed a major education and awareness-raising programme about Parkinson's medication management. This is being implemented across all three acute hospitals. Staff in all acute settings are being offered training and information. Medication timers are being integrated into ward rounds, and Parkinson's medication will be incorporated into pre-operative assessment for all people with Parkinson's who need surgery.

## Parkinson's nurses deliver person-centred care

The NHS Quality Strategy prioritises the importance of a person-centred approach to care. Parkinson's nurses are uniquely positioned to deliver a service that focuses on individuals, their carers and families from the point of diagnosis through to end of life. They support people through referral systems in primary and secondary care, and in social care. They also provide support to people who are no longer able to attend clinics, or who have moved into care homes.

"I don't think it matters whether you're at the early or late stages of Parkinson's – you need the support for sure. If that's what you need to get through it, then support has to be given. I was so fortunate [to have access to my Parkinson's nurses] – it makes such a difference. My journey to diagnosis was hard, but it has been an awful lot easier since then."

Person with Parkinson's, NHS Ayrshire and Arran

"My Parkinson's nurse knows me so well. I have confidence in her. She changed my life from being a scared, shaking mess to a much happier person. She gives me hope."

Helene, NHS Greater Glasgow and Clyde

"My nurse has helped staff at my care home to know how best to look after me – especially when my 'power is down'. With her guidance, they are brilliant!"

Bruce, NHS Highland

Access and flexibility are at the heart of a good Parkinson's service. Community clinics, telephone support and home visits ensure that people can get help earlier and avoid a problem becoming a crisis.

People with Parkinson's can sometimes experience troubling impulsive and compulsive behaviour as a side effect of some Parkinson's medication. This can include compulsive gambling or shopping, hypersexual behaviour and binge eating. Around 17% of people taking dopamine agonists, a common class of Parkinson's medication, have one or more of these behaviours. A smaller number of people taking other types of Parkinson's medication may also be affected. Impulsive and compulsive behaviour can be difficult to talk about, and can have a devastating impact on the people affected, as well as their families and friends. Parkinson's nurses are able to discuss these issues with people, identify when a change of medication is needed, and provide emotional and practical support.

"I developed a terrible gambling problem because of my Parkinson's drugs, and I lost my home. It was awful, and it took me a long time to be able to face up to the truth and admit to myself that I had a problem. My nurse is brilliant. I know that I can contact her at any time, and she will get back to me. I trust her completely. I had already spoken to her about feeling depressed and she had helped me. So as soon as I recognised that my gambling was out of control, I felt able to phone her and tell her what was happening. She acted immediately to change my medication, and helped me get my life back together."

Person with Parkinson's, NHS Greater Glasgow and Clyde

Many hospital admissions of people with Parkinson's are avoidable with early interventions and appropriate community-based care. Parkinson's nurses have the expertise to make sure 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. Parkinson's nurses have the experience to manage high-need patients at home, meeting urgent needs quickly and efficiently.

In the advanced stages of Parkinson's, people will experience significant fluctuations in their ability to move, and may need highly specialised drug regimes, such as apomorphine injections or pumps. Without



a suitably trained Parkinson's nurse, people may not be able to access these treatments at all, and their quality of life will be severely affected.

Specialist skills are required to establish patients on these drugs, and this usually requires inpatient care. Part of this involves an apomorphine challenge test, which a Parkinson's nurse can carry out. They also teach people with the condition, and carers, about the treatment and can co-ordinate the ongoing involvement of primary care and community colleagues. This means people can start their treatment immediately after the test.

The Parkinson's nurse in NHS Tayside has reduced inpatient days for the apomorphine challenge procedure from 10 days to three. People are able to leave hospital with their new regime established, rather than waiting for a follow-up appointment. Home-based monitoring, and phone contact with the Parkinson's nurse, enables any side effects to be identified and quickly corrected.

Parkinson's nurses provide person-centred care by:

- offering expert advice and support, and building strong personal relationships throughout the patient journey
- promoting shared decision-making
- supporting self-management
- taking care to people in their communities and homes

### Person-centred care at end of life

The advanced stages of Parkinson's can be very difficult to cope with. The symptoms of advanced Parkinson's can include problems with swallowing, weight loss, falls, immobility and other symptoms that increase the risk of viral or bacterial infections and other potentially life-threatening medical crises. Mental health problems, including dementia, and communication difficulties are common. Expert support from a Parkinson's nurse can make all the difference to families.

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"When my wife Loes could no longer live independently, support from our Parkinson's nurse Sharon became even more important. Loes began to show signs of dementia and hallucinations, and her mobility was very poor. She was also losing weight.

Loes had a mixture of serious physical and mental health symptoms, which meant her care needed to be really well co-ordinated, and it was. Sharon and the consultant Dr Wilson adjusted treatment to minimise her symptoms and medication side effects. I would email Sharon with any changes that concerned me and she would let me know if these were significant, and would involve Dr Wilson if they were serious. I feel strongly that this personal contact meant that Loes received the best possible medical treatment.

"It gave me confidence to have as positive an attitude as possible. I always felt there was a way to do things. We even managed to attend her son's wedding in Salzburg the September before she died. She was also able to see both her grandsons, and we celebrated her 60th birthday with all her family.

"The end of life stage was very hard, but it was handled as well as it could have been. Thanks to Sharon, I didn't have to face difficult information and decisions on my own. I am so grateful that she was able to sit with Loes immediately after I was told that she was entering the final phase of her life. Sharon and Dr Wilson worked alongside our GP practice, so Loes was able to die peacefully at home surrounded by her family. That meant so much to all of us."

Sandy, NHS Highland

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### Case notes

#### NHS Lothian

Parkinson's nurses have worked with the Long Term Conditions Collaborative to improve the patient journey and data collection. They identified some gaps and bottlenecks in the process of referral to the Parkinson's nurse service, and have introduced new systems to tackle these.

Parkinson's nurses are also working alongside psychologists to help people to manage anxiety caused by Parkinson's. The team will pilot a series of self-management booklets through nurse-led clinics.

#### NHS Highland

The Parkinson's nurse covers an area of 10,000 square miles across North Highland. She runs clinics in three different areas, some of which use video conferencing. In rural areas with poor public transport, home visits, with follow-up by phone and email, are key.



“Sharon Sutherland is the Parkinson’s nurse working across Highland. This is a huge area. Sharon is the core of the service in Highland and without her, the service would not function. She co-ordinates care for about 350 patients. The direct access patients have to her could not be sustainably offered by consultants. This contact pre-empts problems and supports patients well. Without this, inpatient admission or long clinic waits for patients with Parkinson’s-related problems would quickly become the norm.”

Dr Martin Wilson, Consultant, NHS Highland

### **NHS Tayside**

The new Parkinson’s nurse has provided greater equity of care. People would previously have been removed from the caseload if they were too frail to attend the clinic, or moved into a care home. Now, they are able to receive home visits on a needs-assessed basis.

### **NHS Grampian**

Parkinson’s nurses have used clinic time more effectively and achieved better outcomes by providing regular review clinics in care homes. Appointments are less likely to be missed, patients are more relaxed and care home staff are better able to support residents.

### **NHS Ayrshire and Arran**

Here, the Parkinson’s nurses worked closely with a consultant to secure funding to commission a self-management course from Arthritis Care, with additional content on Parkinson’s. The eight-week course was well received, especially for the mixture of general and condition-specific issues covered. Funding has now been secured from the health board for an additional four courses.

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“When I was first diagnosed with Parkinson’s I felt very isolated. Being part of the group on the self-management course has helped me greatly. It has been especially useful to meet others and chat about our condition. Also equally important, the areas covered have made me think about my condition and how I deal with it.”

Course participant

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### **NHS Grampian**

Parkinson’s nurses have developed a course for people newly diagnosed with Parkinson’s. There has been an extremely positive response from participants, many of whom don’t feel ready to attend local support groups. Some are meeting regularly for peer support.

### **NHS Ayrshire and Arran and NHS Tayside**

Parkinson's nurses have supported the development of diagnostic protocols for GPs. This will ensure that people with suspected Parkinson's are referred untreated to a specialist for diagnosis, in line with SIGN Guidelines.<sup>6</sup>

### **NHS Dumfries and Galloway**

The NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services state that Parkinson's nurses are core members of the multidisciplinary team.<sup>1</sup> In NHS Dumfries and Galloway, the Parkinson's nurse has developed a 'virtual' multidisciplinary team. This enables people with Parkinson's to access a range of health professionals at clinics in Stranraer, Annan and Dumfries, rather than travelling to the general hospital.

### **NHS Fife**

Parkinson's nurse-led clinics operate in five locations across Fife, including three in community hospitals. This enables patients to be seen closer to home and eliminates the need to travel to an acute hospital. The Parkinson's nurses also provide a liaison service for all Fife care homes, and visit residents with Parkinson's. These initiatives have reduced Did Not Attend rates, as well as costs for patient transport and care home escort staff. People with Parkinson's and their carers prefer to avoid travelling long distances to clinics, as this can be stressful.

## **Recommendations – maximising the effectiveness of Parkinson's nurses**

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Parkinson's nurses make a real difference to people with Parkinson's in Scotland. They are highly valued by people with the condition and their families. They provide responsive, integrated and informed care.

They are also a cost-effective and sustainable way for NHS boards to meet targets and priorities.

### **NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services**

Recent improvements in support for people with Parkinson's and other neurological conditions have been driven by the NHS Clinical Standards for Neurological Health Services. The improvement programme has enabled NHS boards to begin to improve services and support, including Parkinson's nurse provision.

But Parkinson's UK has major concerns about the sustainability of this improvement, given that the programme will no longer be funded after March 2012. Without the national leadership and co-ordination currently provided by NHS Healthcare Improvement Scotland, we are concerned that local healthcare improvement groups that are implementing change within health boards may be at risk. This would have a very negative impact on frontline teams, including Parkinson's nurses.

**The Scottish Government, the NHS, the Neurological Alliance of Scotland and people living with neurological conditions should work together to ensure neurological conditions remain a clinical priority in Scotland, and that the Clinical Standards continue to be implemented.**

**NHS Healthcare Improvement Scotland (HIS) should include future scrutiny of NHS boards against the clinical standards in its ongoing work plan, so that NHS boards can resource services appropriately.**

### **Workload**

In some NHS boards, Parkinson's nurses have a caseload that vastly exceeds the maximum number recommended by NICE. They are unable to provide a comprehensive service to everyone, leading to



inequitable care. In some cases, there is a postcode lottery. In others, nurses are unable to provide care to people who aren't well enough to attend clinics, leaving those in the most challenging circumstances without the expert support that could help them stay out of hospital or residential care.

**A full-time Parkinson's nurse should not have a caseload exceeding 300 people, or 250 in remote and rural areas.**

### Remote and rural services

One in five people in Scotland lives in a remote and rural area, and many of these areas have an ageing population with higher rates of Parkinson's. Some NHS boards do not believe that they can provide a Parkinson's nurse service to people in dispersed communities. Examples from Highland, Orkney, and Dumfries and Galloway demonstrate that using initiatives such as telemedicine, 'virtual' multidisciplinary teams, and expert leadership from Parkinson's nurses in linked health boards, can provide a clinically and cost-effective Parkinson's service in remote and rural areas.

**Parkinson's nurse services should be delivered in remote and rural areas through innovative use of technology and local staff.**

### GP referral into specialist services

GPs are an essential part of the Parkinson's multidisciplinary team. The SIGN guideline on Parkinson's states that GPs should refer all suspected cases of Parkinson's untreated to a specialist Parkinson's service for diagnosis and management. Yet an estimated 15% of people with Parkinson's are managed solely by GPs in Scotland.<sup>6</sup> This means that they have no access to Parkinson's nurses or other expert advice. These people are more likely to be misdiagnosed,<sup>6</sup> to receive inappropriate treatment,<sup>11</sup> and be unable to access effective care.

**Health boards should develop clear patient pathways, which encourage GPs to refer people with suspected Parkinson's into a specialist service for diagnosis and ongoing management.**

### Structural issues

Services should be organised to enable everyone with Parkinson's to access a Parkinson's nurse, wherever they live and whoever their doctor is. In some parts of Scotland, artificial barriers can

prevent Parkinson's nurses from providing a comprehensive service, for example because they work with a particular consultant, or are based in a service that only provides care to older people.

Cross-team cover is an issue in some NHS boards, causing gaps in service if a Parkinson's nurse is absent from work for any reason.

**NHS boards should recognise that Parkinson's nurses are specialist practitioners, who should be freed to work across the whole range of care settings, responding to local needs and available to everyone with Parkinson's.**

**Where an NHS board has more than one Parkinson's nurse, they should work as a team to provide consistent cover.**

### Data

There are ongoing issues around data collection and coding around neurological conditions, including Parkinson's. NHS boards have great difficulty planning services and measuring the cost-effectiveness of current service models because this data is not consistently collected. NHS Healthcare Improvement Scotland has identified this as a national issue as part of its Clinical Standards for Neurological Health Services.<sup>1</sup> But more work is needed to ensure that accurate data is available to meet the needs of people with Parkinson's and other neurological conditions.

**The Scottish Government, Information Services Division Scotland and NHS Healthcare Improvement Scotland should work with clinicians, the Neurological Alliance of Scotland and people with neurological conditions to ensure that adequate data is collected to plan, manage and evaluate services for people with neurological conditions.**

## Parkinson's UK supporting clinicians and managers

- 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 Scotland team will work with the health board to establish the objectives of the post and the criteria by which a Parkinson's nurse is 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 offer expert trainers in Parkinson's care and support to NHS and social care staff.
- We offer locally based information and support workers in every mainland health board area. They deliver free, confidential, one-to-one information and support to people with Parkinson's and their families and carers. This may include benefits advice, emotional support and links to other services.
- We support people living with Parkinson's throughout Scotland to participate effectively in local service development and Patient Focus Public Involvement groups, representing the interests of people with Parkinson's.
- We provide clear, accurate, up-to-date information for everyone affected by Parkinson's, including information for professionals. Our patient information is certified under the Information Standard scheme.

## More information

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- 8 This assumes a ratio of one Parkinson's nurse to 300 people with Parkinson's over 80% of the population (27 FTE nurse posts), and one Parkinson's nurse to 250 people for 20% of the population living in remote and rural areas (eight FTE nurse posts).
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## Appendix 1: Achieving NHS targets at a glance

Strategic goal	Target	How Parkinson's nurses help
Current HEAT Targets	Deliver 18 weeks referral to treatment from 31 December 2011.	Nurse-led care and review clinics free consultants' time.
	Reduced emergency inpatient bed days for people aged 75 and over through improved partnership working between the acute, primary and community care sectors.	Nurses create better planned and co-ordinated care among older people with Parkinson's. Nurse-led medication reviews prevent emergency admissions.
	Reduction in the rates of attendance at A&E between 2009/10 and 2013/14.	There are fewer emergency admissions due to uncontrolled Parkinson's symptoms. Advanced care planning and medication reviews led by nurses prevent emergency admissions.
NHS Quality Strategy	Person-centred – mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making.	Nurses create effective long-term relationships with patients and families. They provide support to enable people to share decisions about their care.
	Safe – there will be no avoidable injury or harm to people from healthcare, advice or support they receive, and an appropriate, clean and safe environment will be provided for the delivery of healthcare services at all times.	Having Parkinson's nurses prevents adverse medication incidents when people with Parkinson's are in hospital. Advice, support and monitoring enables proper support for complicated medication regimens.
	Effective – the most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit. Wasteful or harmful variation will be eradicated.	Parkinson's nurses identify when people need additional support and co-ordinate care accordingly. Nurses network regularly to share good practice across Scotland.



Scottish Patient Safety Programme	Prevent adverse drug events.	This is a key element of Parkinson's nurses' education work.
	Drive a change in the safety culture in NHS organisations.	Nurses support this by providing non-Parkinson's specialists with expert education and support on medication.
HIS Clinical Standards for Neurological Health Services	1.1 The NHS board provides accurate and current information to patients and their carers about their condition.	Nurses signpost, deliver the right information at the right time, build good relationships with Parkinson's UK and are aware of current issues. They're able to provide NHS boards with accurate information about services.
	2.1 The NHS board demonstrates that a minimum of 90% of outpatient demand for all neurological health services can be met by substantive resources without resorting to waiting time initiatives, reliance on temporary staffing or other short-term measures.	Nurses provide sustainable staffing, which frees up consultants' time for diagnosis and complex cases.
	2.6 Individuals affected by a chronic neurological disease are provided with a contact point within the relevant neurology service to allow for re-entry into the service.	Nurses are a main point of contact and provide continuity of care for people with Parkinson's and their carers.
	4.7 There are multidisciplinary systems in place, with input from a specialist clinical pharmacist, for: <ul style="list-style-type: none"> <li>• safe use of medicines</li> <li>• access to formulary medicines</li> <li>• use of non formulary and unlicensed medicines</li> <li>• education of non-medical and medical prescribers</li> <li>• regular medicines reconciliation and review</li> </ul>	Parkinson's nurses have developed close relationships with colleagues involved in Parkinson's medication management, including hospital and community pharmacists. Many are nurse prescribers.
	4.8 The neurology service has channels of communication with the individual responsible for long term conditions in the local community health partnerships or equivalent, to co-ordinate the provision of services, equipment and medication, by the NHS and social services.	Nurses provide co-ordinated care and continuity of care, including liaison with colleagues in primary, community and social care.

	<p>4.9 People affected by neurological conditions have ongoing access to self management options.</p>	<p>Nurses support self-management, including courses for the newly diagnosed and those who have lived with the condition longer. They provide ongoing support, education and information for people with Parkinson's and their families.</p>
	<p>4.10 Patients with advanced conditions or complex needs have access to assessment and treatment in their place of residence by a member of the neurology multidisciplinary team where they are unable to access services at hospitals or clinics.</p> <p>4.12a Palliative care is provided for patients with neurological conditions, their family and carers, as required throughout the course of their illness, and in accordance with the wishes of the patient.</p> <p>4.12b Specialist palliative care is provided for patients with complex needs.</p> <p>4.12c Patients with neurological conditions are encouraged to discuss advanced care planning, when clinically appropriate.</p>	<p>Nurses make home visits, including regular visits to care home residents and others with complex care needs.</p> <p>Continuity of care and specialist knowledge enables Parkinson's nurses to identify when to introduce information and start advanced care planning in good time. Ongoing relationships build trust with patients and families. Expert knowledge of the condition is needed to identify when end of life care is needed. Parkinson's nurses work with palliative care specialists and others to provide appropriate care.</p>
	<p>17.1 Patients with suspected Parkinson's disease and related conditions are referred to a defined Parkinson's disease service delivered through a multidisciplinary team.</p>	<p>Nurses are central to the multidisciplinary Parkinson's service.</p>
	<p>17.2 The Parkinson's disease multidisciplinary team consists of, as a minimum: a doctor who specialises in PD, a Parkinson's nurse, the patient and carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from the following services: physiotherapy, occupational therapy, speech and language therapy, dietetics, pharmacy and mental health services.</p>	<p><b>Mandatory to meet this standard.</b> Access to a Parkinson's nurse is needed as part of a multidisciplinary team.</p>

	18.2 Patients with Parkinson's disease and their carers are provided with ongoing access to a Parkinson's disease nurse specialist.	<b>Mandatory to meet this standard.</b> Access to a Parkinson's nurse is needed from the point of diagnosis onwards.
	18.3 The diagnosis of Parkinson's disease is reviewed and reconsidered if atypical clinical features develop.	Nurse-led review clinics help with this, with nurses referring non-complex cases on to the consultant.
	19.1a The timing and dosage of medication for Parkinson's disease is specified and adhered to when the patient is in hospital.	Nurses educate colleagues on the importance of Parkinson's medication. They provide support, assessment and education for people with Parkinson's to enable them to self-administer their medication.
	19.2 Reconciliation of the record of medicines and dosages is undertaken at each patient visit to ensure that the patient, GP, consultant, pharmacist and Parkinson's disease nurse specialist determine accurately what anti-Parkinson's disease drugs the patient is taking.	Nurses play a key role in medicine reconciliation.
	19.3 Patients with Parkinson's disease are offered a regular review of their condition and medication, according to their clinical need, but at least annually.	Nurse-led review clinics free up consultant time to meet this standard.
Long term Conditions Action Plan	Change 1 – Improve the experience of care by empowering people with long term conditions to be full partners.	Ongoing work with people with Parkinson's and their families enables nurses to become partners in care.
	Change 2 – Support people with long term conditions to be involved in care planning.	Nurses engage people with Parkinson's and enable them to plan care.
	Change 3 – Build capacity to support self management.	Nurses promote access to self-management courses, and develop resources.
	Change 4 – Provide staff with access to the training that ensures that they have the right knowledge, skills and approach to long term conditions care.	Nurses train and educate colleagues to support people with Parkinson's and provide better care.



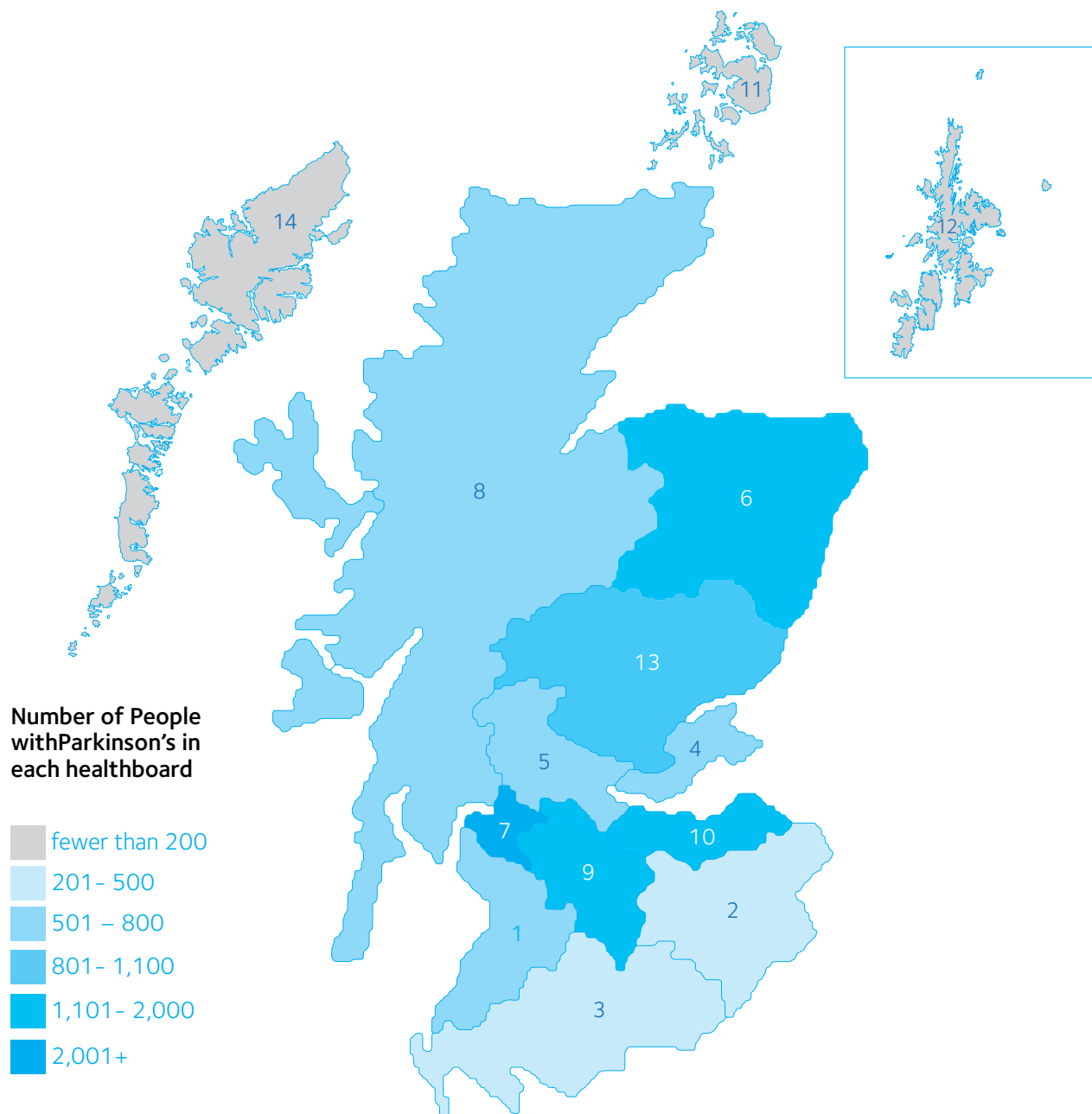
Self Management Strategy	Support for people with long term conditions to manage their condition at every stage in the journey from diagnosis to end of life, with particular emphasis on transitions.	Nurses have the expertise to provide evidence-based information at every stage, enabling people with Parkinson's to take control. In ongoing relationships, they promote a self-management approach. They also provide sustainable staffing, which frees up consultants' time for diagnosis and complex cases.
	Ensure all relevant NHS services, including telehealth, understand the particular needs and their role in contributing to successful self management for people living with long term conditions.	Nurses' specialist knowledge of Parkinson's symptoms and medication enables issues to be identified. Nurses also work with people and their families, enabling them to manage symptoms and medications effectively.
	Encourage a culture within the NHS of effective communication between professionals and with people living with long term conditions and their unpaid carers.	They strongly support self-management principles, and are supported by Parkinson's nurse networking and continuing professional development (CPD).
Shifting the Balance of Care Action Plan – Improvement Areas	1. Maximise flexible and responsive care at home, with support for carers.	Nurses help by making home visits and promoting self-management. They take a leading role in care co-ordination, working with families as well as individuals.
	2. Integrate health and social care and support for people in need and at risk.	Nurses are leading members of the team, identifying the need for social care involvement, signposting and referrals.
	3. Reduce avoidable unscheduled attendances and admissions to acute hospitals.	Better co-ordinated and planned care helps to prevent emergency admissions. Nurse-led medication reviews and advanced care planning prevent emergency admissions. Nurse reviews of vulnerable people at home prevent emergency admissions.

	4. Improve capacity and flow for scheduled care.	Nurses facilitate the use of community hospitals as alternatives to acute beds where hospital admission is required.
	5. Extend the range of services provided by non-medical practitioners outside acute hospital.	Nurses play a central role in community and home settings, and a key role in co-ordinating care from professional colleagues in health and social care.
	6. Improve access to care for remote and rural populations.	Nurse-led care is sustainable and feasible in rural areas, with nurses using telehealth, virtual teams, peripatetic clinics and home visits to cover remote and rural areas.
	7. Improve palliative and end of life care.	Continuity of care and specialist knowledge enables Parkinson's nurses to identify when to introduce information and start advanced care planning in good time. Ongoing relationships build trust with patients and families. Expert knowledge of the condition is needed to identify when end of life care is needed. Parkinson's nurses work with palliative care specialists and others to provide appropriate care.
Reshaping Care for Older People	Support a shift in expectation away from institutional care settings towards community and home-based care; services focused on prevention, maintenance of independence, recovery, rehabilitation and re-ablement, with a corresponding reduction in the need for emergency admission to hospital or a care home.	Expert support for individuals and families enables people to stay at home for longer. Appropriate review and medication can keep people out of institutional settings and prevent emergency admission to hospitals and care homes.
	Clear and agreed care pathways for all older people, particularly those with complex care and support needs, to enable them to move smoothly through the care system, accessing timely and effective community and hospital care as necessary.	Nurses have a central role and information overview, enabling care pathways to be developed for older people with Parkinson's who require high levels of care and have complex support needs.

	Support carers and communities to advance supported self-care. Develop information, advice and assistance to help older people make key decisions and navigate the care system.	Nurses play a key role in supporting individuals and families.
	Put in place a community capacity building programme in collaboration with third sector partners.	Nurses create positive links with local Parkinson's UK information and support workers and other third sector support networks.
Dementia Strategy	Continuing to increase the number of people with dementia who have a diagnosis, to enable them to have better access to information and support.	Many people with Parkinson's dementia do not receive a diagnosis because expert knowledge is needed to identify cognitive decline in Parkinson's. Parkinson's nurses are able to provide this and expedite referrals to specialist mental health services for support.
	Improving staff skills and knowledge in both health and social care settings.	Nurses educate non-specialist colleagues about Parkinson's dementia, which is often unidentified and untreated.
	Ensuring that people receiving care in all settings get access to treatment and support that is appropriate, with a particular focus on reducing the inappropriate use of psychoactive medication.	Nurses play a key role in supporting people with Parkinson's to receive appropriate treatment for Parkinson's dementia, care co-ordination and referrals. They can monitor people for medication issues where side effects can be very dangerous for people with Parkinson's. Some psychoactive medications are strongly contraindicated in Parkinson's.
Living and Dying Well	NHS boards, through palliative care networks and community health partnerships, should ensure that recognised tools/ triggers to support the identification of the palliative and end of life care needs of patients diagnosed with a progressive, life-limiting or incurable condition, and the needs of their carers are used across all care settings by 2010.	Nurses can use specialist knowledge to identify when people with Parkinson's are nearing the end of life, through the use of recognised care pathways and frameworks. These may be missed by non-specialist colleagues.



## Appendix 2: Snapshot of Parkinson's nurses in Scotland



### Number of Parkinson's nurses in each NHS health board

- |   |  |
|---|--|
| 1 NHS Ayrshire and Arran – 1.8 nurse posts              | 9 NHS Lanarkshire – 2 nurse posts  |
| 2 NHS Borders – 0.7 nurse posts                         | 10 NHS Lothian – 3 nurse posts   |
| 3 NHS Dumfries and Galloway – 1 nurse post              | 11 NHS Orkney – no nurse posts (NHS Grampian provides a limited service)   |
| 4 NHS Fife – 2 nurse posts                              | 12 NHS Shetland – no nurse posts (NHS Grampian provides a limited service) |
| 5 NHS Forth Valley – 1 nurse post (and 1 support nurse) | 13 NHS Tayside – 2.5 nurse posts   |
| 6 NHS Grampian – 0.9 nurse posts                        | 14 NHS Western Isles – no nurse posts                                      |
| 7 NHS Greater Glasgow and Clyde – 8 nurse posts         |  |
| 8 NHS Highland – 1 nurse post                           |  |

Information applies as of April 2012.

# 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.

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

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