

PEOPLE.

PARKINSON'S.

SCOTLAND.

What do we know about services and support
for people with Parkinson's in Scotland?

SERVICES
February 2019

PARKINSON'S^{UK}
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Introduction

Annie Macleod, Scotland Director, Parkinson's UK



Our health and social care services are at a pivotal point. Financial pressures, lack of doctors and nurses, and long waiting times are many of the headlines we read and hear daily.

Neurological conditions like Parkinson's have not always received the focus and resources they deserve, and we are delighted that the Scottish Government and NHS Healthcare Improvement Scotland have recognised the need to take action and improve the care that people with neurological conditions receive. We want this report to inform decision makers, professionals and people with the condition alike about what is needed as Scotland's first National Action Plan for Neurological Conditions¹ and new Standards for Neurological Care and Support² are implemented.

There are more than 12,400 people with Parkinson's in Scotland, and about 30 people are diagnosed every week. Ten years from now, the number of people living with Parkinson's in Scotland will have grown by a fifth.

This report identifies the health, care and social support that people with Parkinson's need to manage this complex, progressive condition. We present the evidence supporting investment in ongoing, expert-led care for people with Parkinson's at every stage, and the critical importance of Parkinson's nurses, multi-disciplinary support and preventative care.

We also showcase some of the excellent work that is already happening in Scotland.

At Parkinson's UK in Scotland we aim to ensure that every one with Parkinson's has personalised information and support to live well. We know from what people with Parkinson's tell us that being signposted to us after their diagnosis is incredibly beneficial. We provide vital evidence-based information and mutual support throughout Scotland. We can signpost to the many support groups, services and exercise programmes available, whatever the person's age or stage of the condition.

Similarly, people affected by Parkinson's really benefit from professionals offering a multi-disciplinary approach to care. Planning for the changing, more advanced stages of Parkinson's, or what should happen during a hospital admission, is what people living with the condition want and really need, but we know that is not always what people experience.

There is much to celebrate in Scotland – many talented doctors, specialist nurses, allied health professionals and researchers, but best practice is not universal in each of our NHS Board or Health and Social Care Partnership areas. The data within this report is drawn from our UK Parkinson's Audit (parkinsons.org.uk/audit), which takes place every two years, alongside other surveys, NHS Scotland data and peer-reviewed research. We want to highlight what is possible and share good practice, as well as making an urgent call for change.

Let's join together and make sure we make life better for every single person with Parkinson's in Scotland. Every one of us has a responsibility to do so.

Annie Macleod

Dr Carl Counsell, Parkinson's Excellence Network Lead Scotland North
Dr Conor Maguire, Parkinson's Excellence Network Lead Scotland South and East
Dr Anne-Louise Cunnington, Parkinson's Excellence Network Lead Scotland West
Dr Donald Grosset, Clinical Director, UK Parkinson's Excellence Network



Parkinson's is the second most common neurodegenerative condition after Alzheimer's. It is a complex progressive disorder, predominantly affecting older age groups, which can have profound effects on many aspects of individuals' lives, both those living with it and their family members. Moreover, it is highly variable so no two people with Parkinson's are affected in the same way.

In keeping with all neurodegenerative conditions, compassionate co-ordinated multi-disciplinary care is essential but this is even more crucial in Parkinson's because so many treatment options are available including drug treatments, surgery, rehabilitation and psychological therapies. However, not all treatments are appropriate or effective for each person and some can cause harm. Therefore, best management requires care from a team of expert clinicians using a skilful blend of evidence-based, individualised, flexible therapy, which is sensitive to people's changing needs. This is not easy.

This report highlights the growing impact Parkinson's will have in Scotland as our population ages and the need to have appropriately planned and resourced

services to deal with this. We support its 13 recommendations, many of which require meaningful partnerships between Scottish Government, NHS Boards, social care providers and Parkinson's UK. Clearly the needs of people with Parkinson's must be balanced against other users of health and social care, but many of these recommendations will also benefit people with other neurodegenerative conditions, for example, increased consultant numbers and better awareness of anticipatory planning and bone health.

This report highlights that there are already many examples of excellent clinical care in Parkinson's around the country. However, the aim of the recommendations and all those involved in the Parkinson's Excellence Network is to ensure that all people affected by Parkinson's throughout Scotland receive consistently high quality care throughout the course of the condition. Challenging but achievable if we all work together.

Dr Carl Counsell
Dr Conor Maguire
Dr Anne-Louise Cunnington
Dr Donald Grosset

Our recommendations

This is a critical time for neurological care in Scotland, as the Scottish Government finalises its first ever National Action Plan for neurological conditions,³ and Healthcare Improvement Scotland launches its refreshed General Standards for Neurological Conditions.⁴ As the focus moves to implementing these plans, these are our priorities for Parkinson's care and support in Scotland.

1 Parkinson's is a complex condition affecting about 12,400 people in Scotland. Everyone with Parkinson's needs ongoing expert support from a multi-disciplinary team of health professionals. We call on Scottish Government, NHS Boards and Health and Social Care Partnerships to:

- Address the Scotland-wide shortage of consultants in neurology and older people's medicine that is leading to unacceptable waiting times for diagnosis and ongoing care.
- Ensure that everyone with Parkinson's has regular and easy contact with a Parkinson's nurse at every stage of their condition, wherever they live in Scotland.
- Enable everyone with Parkinson's to access seamless care, based on their needs, with support from a multi-disciplinary team of professionals who are experts in Parkinson's.
- Recognise that as Parkinson's progresses, people commonly develop very high care needs. Proactive and preventative care must be provided to avoid emergency hospital admissions and preventable care home admissions.

2 The number of people with Parkinson's will increase by a fifth in the next decade, and by 40% in 20 years' time. We call on Scottish Government, NHS Boards and Health and Social Care Partnerships to plan and resource Parkinson's services to meet the needs of the growing Parkinson's population.

3 More than one in every nine people with Parkinson's lives in a remote area – and they often struggle to access the support they need to live well with the condition. We call on Scottish Government, NHS Boards and Health and Social Care Partnerships to work with us to develop safe and sustainable support for people with Parkinson's in remote communities.

4 How someone receives their Parkinson's diagnosis has a long term impact on their life with the condition, but people consistently tell us that they didn't get the information they needed when they were diagnosed. We call on health professionals, Scottish Government, NHS Boards, Health and Social Care Partnerships to connect with us, so that people can access the information and support offered by Parkinson's UK in Scotland.

5 Parkinson's has over 40 recognised symptoms, including mental health issues and dementia. We call on Scottish Government, NHS Boards and Health and Social Care Partnerships to:

- Recognise the diversity of Parkinson's symptoms when planning services.
- Include mental health professionals in Parkinson's multi-disciplinary teams.
- Provide clear pathways for mental health support for people with Parkinson's, including those with Parkinson's and dementia.

6 Living well with Parkinson's can be a challenge, but social interaction, exercise, self-management and creative activities can all help. We call on health and care professionals to work with us to connect people with Parkinson's to local support to manage their condition, including information, exercise and self-management.

7 As digital leaders, at Parkinson's UK we are enthusiastic about the potential of technology to enable people to live well with Parkinson's. We call on Scottish Government, NHS Boards, Health and Social Care Partnerships and health and care professionals to work with us to develop and implement technology that can support people with Parkinson's, unpaid carers and families.

8 Unpaid carers for people with Parkinson's often deliver significant amounts of care for many years, yet receive limited support in their caring role. We call on NHS Boards, Health and Social Care Partnerships and health and care professionals to make sure that unpaid carers are identified at an early stage, listened to by professionals, and receive the support to which they are entitled under the Carers' (Scotland) Act.

9 Failing to get medication on time can be catastrophic for people with Parkinson's. Yet we know that fewer than half of people with Parkinson's always get their medication on time when they are in hospital. We call upon Scottish Government, health and care regulators, NHS Boards, Health and Social Care Partnerships and health and care professionals to make sure that people with Parkinson's get their medication on time, every time, when they are in a hospital or care home.

10 People with advanced Parkinson's must have timely access to advanced treatments like apomorphine, deep brain stimulation surgery (DBS), and Duodopa if they are the right treatment for them. We call on Scottish Government and NHS Scotland to make sure that the national DBS service has sufficient capacity to meet the need for this lifechanging treatment in Scotland. We call on Scottish Government and clinicians to work with us to develop an evidence-based pathway to enable Parkinson's specialists to make appropriate referrals for advanced treatments.

11 Parkinson's is a progressive condition. It is essential that people with Parkinson's and those close to them are given the opportunity to plan for changes - and discuss their preferences - in good time. We call on health and social care professionals to discuss anticipatory care planning with individuals and families from an early stage. People with Parkinson's and their families should be signposted to Parkinson's UK resources on advanced Parkinson's when they are ready for these discussions.

12 People with Parkinson's are at high risk of falls and fractures, but bone health has been a neglected area. We call on health and care professionals to make sure that people with Parkinson's routinely receive an assessment of their bone health and fracture risk, alongside their falls risk, so that preventative and protective measures can be introduced.

13 People with Parkinson's are very likely to need social care support as the condition progresses. We call on the Scottish Government, Care Inspectorate, Scottish Social Services Council and care providers to support the inclusion of basic information about Parkinson's in mandatory training modules for social care workers, and to promote take up of Parkinson's UK education and training among social care staff.

What do we know?

What is Parkinson's?

Parkinson's is a progressive, fluctuating neurological disorder. It affects all aspects of daily living including talking, walking, swallowing and writing. There are more than 40 recognised Parkinson's symptoms, and everyone is affected differently.

People with Parkinson's often find it hard to move freely. There are also other issues such as tiredness, pain, depression, anxiety, dementia, compulsive behaviours

and continence problems which have a huge impact.

Parkinson's symptoms get worse and become more complex over time. The severity of symptoms can fluctuate, both from day to day and even hour to hour, including sudden 'freezing' and periods when the medication wears off, leaving the person barely able to move. There is no cure, and no current treatment can slow or reverse its progression.

How is Parkinson's managed?

Parkinson's treatment is highly complex and individual. A typical GP in Scotland only sees one new case of Parkinson's every three years and so access to expert outpatient services is crucial.⁵

Everyone experiences Parkinson's differently. The complex combination of symptoms, including issues with movement and balance, speech and swallowing, everyday living and mental health means it is essential that people can access a range of services when they need them.

Parkinson's is complicated, and everyone responds differently to the medications used to manage symptoms. This means it is essential that professionals working with people with Parkinson's have knowledge about the condition.

With the right care and support, people with Parkinson's can stay well for longer, avoid unnecessary hospital admissions and remain in their own home for as long as possible.

Parkinson's symptoms are usually managed with medication, along with other support including physiotherapy, speech and language therapy and

occupational therapy. A flexible, multi-disciplinary approach is needed to support people with Parkinson's at every stage of the condition, with strong partnerships covering health and social care. Exercise, creativity and social activities also help people with Parkinson's with symptom management and improve quality of life.

Parkinson's and medication

People with Parkinson's typically take many different medications several times each day. If people with Parkinson's don't take their medicine, or it wears off, they may not be able to communicate, speak or move. They may experience painful cramps and severe mental health symptoms including anxiety, hallucinations and delusions.

Parkinson's medication regimes are complicated and are individual to each person. Symptom control must be balanced with side effects from the powerful medications that are used.

For a small number of people, conventional medication does not work, and advanced treatments delivered by injections or pumps or deep brain stimulation surgery (DBS) are needed.

How many people have Parkinson's?

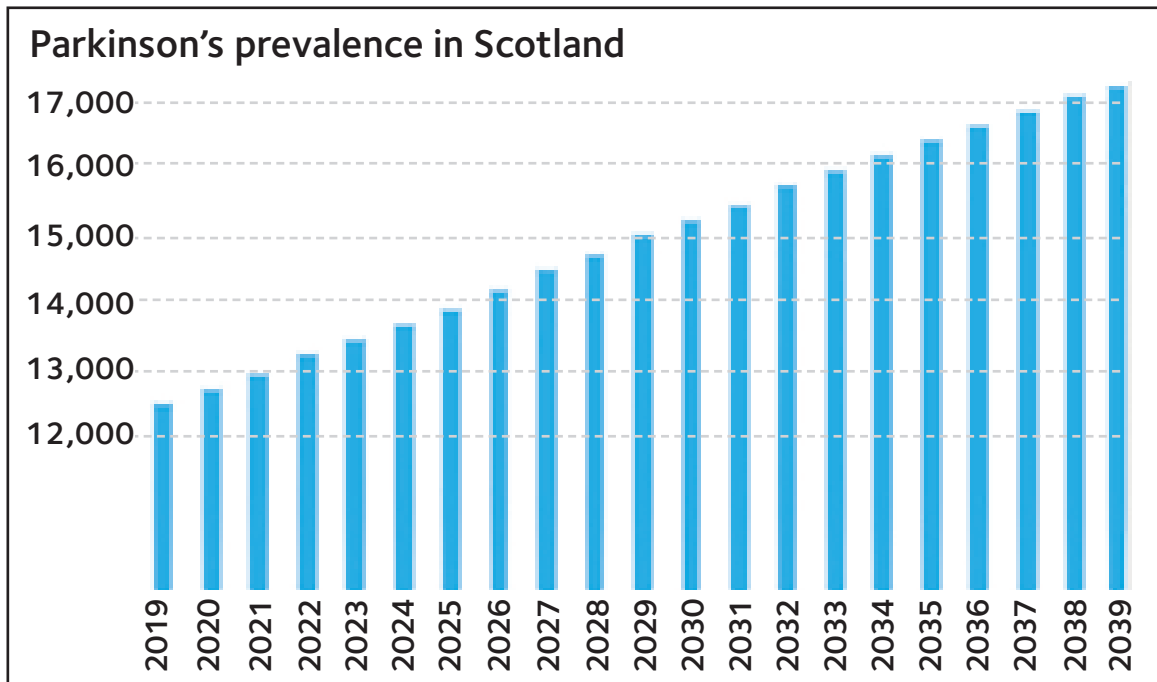
About 12,400 people are currently diagnosed with Parkinson's in Scotland.⁶ That's about one adult in every 375.⁷

We expect nearly 1,600 people to be diagnosed with Parkinson's in Scotland in 2019 - about 30 people each week.

Over the next decade, the number of people with Parkinson's in Scotland will rise by a fifth.

And in the next twenty years, we expect the number of people with Parkinson's in Scotland to increase by 40%.

These increases are because Scotland's population is growing and ageing.



What do we know?

What does the Parkinson's population look like?

Men and women

Parkinson's is more common in men than women. In Scotland, there are more than 7,000 men with Parkinson's, and more than 5,300 women.

Men aged 50-80 are 1.5 times more likely to have Parkinson's than women of the same age.

Parkinson's and age

Around 10,600 people with Parkinson's are aged over 65. That's about six in every seven people with the condition.

More than one in every three people with Parkinson's in Scotland is aged over 80 - around 4,300 people.

Older age at diagnosis is associated with worse outcomes.

What about younger people?

Parkinson's can affect people of all ages. Most people with Parkinson's are aged 65 and over, but significant numbers of younger people are also affected.

People of working age may experience difficulty in getting a diagnosis, and face issues around continuing in employment, finance and social security, sex, relationships and family issues.

- About 1,800 under 65s in Scotland have a Parkinson's diagnosis
- That's 1 in every 7 people with Parkinson's
- About 220 new people under 65 are diagnosed each year - around 18 people each month

Remote and rural communities

People with Parkinson's are overrepresented in remote communities. About 12% of all people with Parkinson's in Scotland live in remote areas, compared with less than 10% of the Scottish population as a whole.⁸

There are particular challenges for people who live in remote areas.

Accessing specialist Parkinson's care and support can be difficult and time consuming, especially when dependant on hospital transport. Social care packages are often a challenge, and even accessing

essential medication involves lengthy round trips - made even longer if your medication is not in stock at the nearest pharmacy.

We estimate that around 1,400 people with Parkinson's in Scotland live in a remote area - ie more than half an hour's drive from a settlement of over 10,000 people. Of them, about 600 people live very remotely - or over an hour's drive.

People with Parkinson's who live remotely are concentrated in the Highlands and Islands, with smaller populations in parts of the North East and South of Scotland.

Connecting from diagnosis

“Patients with suspected Parkinson’s disease should be referred untreated to a hospital clinician with sufficient expertise in movement disorders to make the diagnosis.”⁹

Parkinson’s is a complex condition, which requires specialist diagnosis and ongoing care. National Guidelines from the Scottish Intercollegiate Guidelines Network (SIGN)¹⁰ and National Institute for Health and Care Excellence (NICE),¹¹ as well as NHS Healthcare Improvement Scotland (HIS) clinical standards¹² specify that diagnosis must be made by a specialist.

In Scotland, care for the majority of people with Parkinson’s is led by a consultant in older people’s medicine with an interest in movement disorders. These doctors have expertise in supporting people with multiple conditions and complex care needs. Although they are specialists in caring for older people, they often see people with Parkinson’s of working age.

Specialist consultants

People who develop Parkinson’s at the age of 65 or under are more likely to be referred to a neurologist – a specialist in conditions of the brain and nervous system. Some older people also see a neurologist.

Nearly one in three (32%) of people with Parkinson’s in Scotland say that they do not have enough time with their consultant, or don’t have any consultant access at all.¹³

Parkinson’s UK is increasingly concerned about growing consultant caseloads and the problems that many NHS Boards appear to be having in recruiting specialist consultants, especially in more rural areas. People with Parkinson’s and their families are telling us that this is having a significant impact on their care.



Why is specialist diagnosis and monitoring needed?

There is currently no simple diagnostic test for Parkinson’s and most diagnoses are made by clinical judgement. A significant minority of people undergo a type of brain scan that measures dopamine levels in the brain, but this is not recommended for routine diagnosis.

There is sometimes considerable diagnostic uncertainty. Other conditions can look very similar to Parkinson’s but are managed very differently, and it can take a long time to confirm the diagnosis.

Clinicians with a special interest in Parkinson’s are more likely to make an accurate diagnosis than their generalist colleagues. This reduces the risk of people getting the wrong diagnosis – which could mean being prescribed unnecessary medicines with significant side effects, or debilitating symptoms going untreated.

Symptoms and treatment are complicated, and everyone with Parkinson’s has a tailored medication regime. Serious side effects of medication are common, and can include hallucinations and delusions, impulse control disorders including gambling and hypersexuality as well as uncontrolled movements.

Regular specialist reviews are needed to monitor the progress of the condition, and prescribers must balance the benefits of Parkinson’s medication against side effects to maximise quality of life. GPs simply do not see enough people with Parkinson’s to be able to diagnose and manage the condition effectively.

Connecting from diagnosis

Waiting times

About one in every ten consultant posts in neurology and medicine for older people are unfilled.¹⁴ The BMA recently reported that the official data may significantly underestimate the true consultant vacancy rate.¹⁵ The consultant workforce is under severe pressure in some parts of the country.

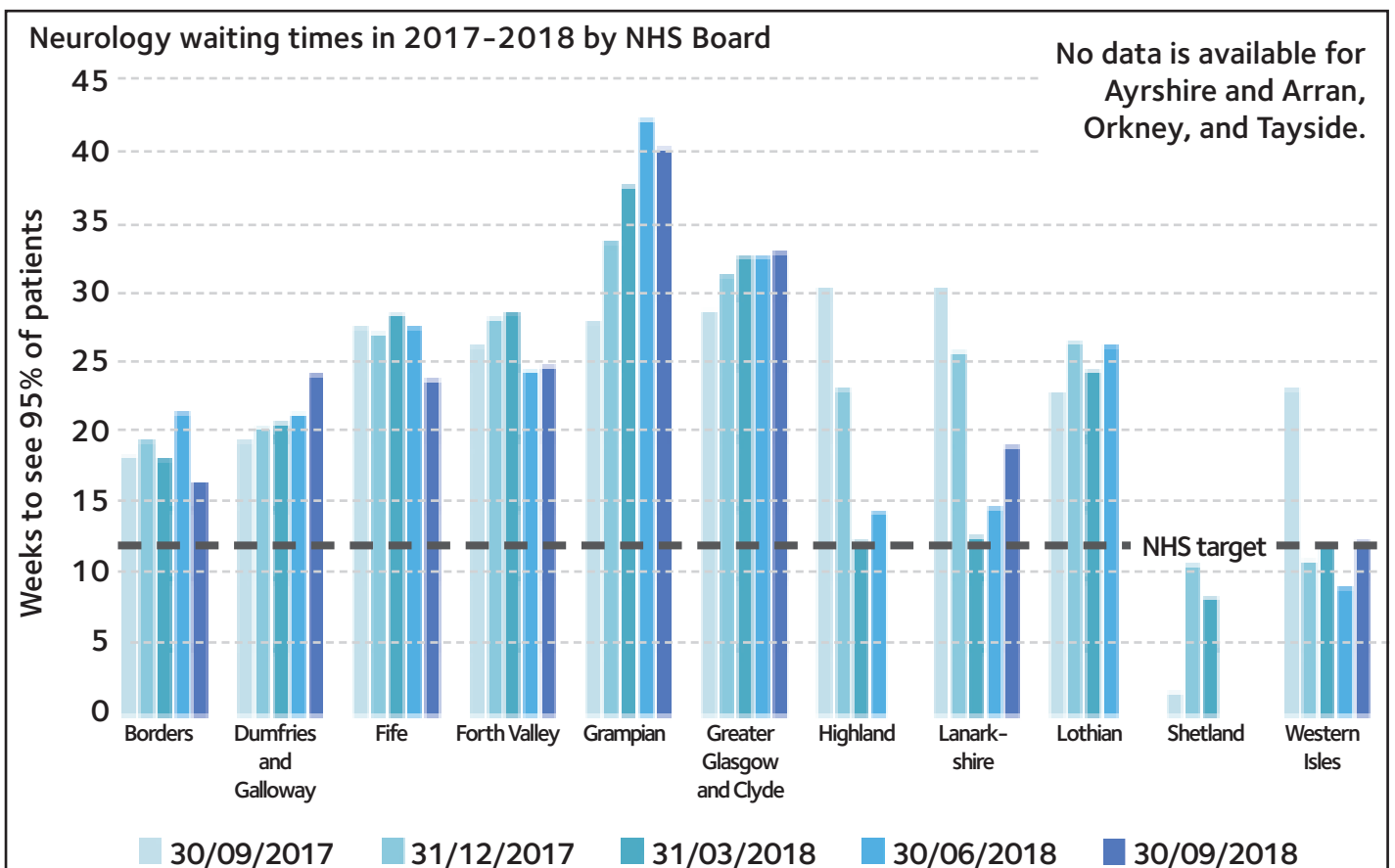
Waiting times for first appointments are growing, leaving people with suspected Parkinson's facing long periods without a diagnosis to explain worrying symptoms, or a plan to treat them. People with Parkinson's and their families tell us that this causes immense anxiety.

The Scottish Government's target for new outpatients is for 95% of people to be seen by a consultant within 12 weeks of referral.¹⁶

Between September 2017 and September 2018, 11 NHS Boards reported waiting times to see a neurologist. Only two Boards managed to meet the 12 week target at any point – and both NHS Shetland and NHS Western Isles serve very small populations.¹⁷

In July 2018, it took over 42 weeks for 95% of people to see a neurologist in NHS Grampian, and nearly 33 weeks in NHS Greater Glasgow and Clyde. Between them, these two NHS Boards serve nearly a third of Scotland's population.

The data shows that waiting times in excess of the 12 week target are typical in most NHS Boards. At the end of September 2018, the average¹⁸ waiting time to see a neurologist in NHS Greater Glasgow and Clyde was nearly 24 weeks,



Waiting times

and in NHS Grampian, nearly 23 weeks. In NHS Fife and NHS Forth Valley, the average waiting time was nearly 18 weeks. Parkinson's symptoms do not typically trigger an "urgent" referral, so people with suspected Parkinson's are less likely to be seen quickly.

We know that in many NHS Boards, consultants are under a great deal of pressure. Parkinson's consultants are needed to make an accurate initial diagnosis, but also to provide ongoing condition management. As waiting times for first appointments grow, it also becomes more difficult for people with Parkinson's to access consultants for the long-term care that they need.

In some NHS Boards, waiting times clinics using private providers have been used to bring down waiting times. Unfortunately, this has led to people receiving their Parkinson's diagnosis and being sent back to their GP with very limited information about their condition and no knowledge about local support such as Parkinson's nurses. Some of those people have found their way to us, enabling us to link them to local Parkinson's services and other support, but many more remain unsupported.

We believe that this is unacceptable, and that urgent action is needed to make sure that there are enough neurologists to support the needs of Scotland's population, including the growing population of people with Parkinson's.

We recognise that service redesign can free up consultant time, and we support initiatives that enable consultants to focus their skills and knowledge where they are most needed. However, we do not believe that safe and sustainable services for people with Parkinson's can be provided without increasing the number of consultants with expertise in the condition.

Waiting times are much shorter for people who are referred to a consultant in medicine for older people. Of the eight NHS Boards reporting data in 2017-2018, seven met the 12 week target in September 2018. NHS Lanarkshire very narrowly missed the target - by less than one day.

But one NHS Board that did not report (NHS Ayrshire and Arran) now has only one Parkinson's specialist consultant in medicine for older people where it used to have three. Waiting times for diagnosis and review are getting longer, and people with Parkinson's are telling us that it is harder to see their consultant. We are currently working with NHS Ayrshire and Arran to redesign the Parkinson's service, but in the medium to long term, more consultants will be needed to make this service sustainable and provide the care that people with Parkinson's need.

Connecting from diagnosis

Parkinson's nurses

People with Parkinson's tell us that the most important person helping them to live with their condition is their Parkinson's nurse.

"The Parkinson's nurse is the most important member of the team, I would be lost without her."¹⁹

Parkinson's nurses provide responsive, integrated care, and give people with Parkinson's and carers trusted information which helps them to self-manage their condition more effectively. They all have detailed knowledge of the complex medicines used to manage Parkinson's, and many of them are prescribers. They also save money in the long term by preventing unnecessary care home and

hospital admissions. They are a cost-effective and sustainable way for NHS Boards to meet their targets and strategic priorities.

NHS HIS Clinical Standards²⁰ state that everyone with Parkinson's needs access to a Parkinson's nurse at every stage in their condition – from diagnosis onwards.

Parkinson's UK has invested more than £12million to support the development of Parkinson's nurses across the UK, including a number of posts in Scotland. Parkinson's nurses are employed by the NHS.

There are currently 36 Parkinson's nurses in Scotland, which equates to about 29 Whole Time Equivalent (WTE) posts. While people in most parts of Scotland have access to a Parkinson's nurse, some Parkinson's nurses have extremely high caseloads.

Parkinson's UK recommends a maximum caseload of 300 people for each WTE Parkinson's nurse, and around 250 for those working in remote and rural areas.

If the existing nurse posts were evenly distributed around Scotland, each nurse would be supporting about 470 people with Parkinson's – 56% more than the recommended maximum caseload, with no allowance made for rural working. (See Appendix on p33 for a map of Parkinson's nurses in Scotland)

In reality, too many people remain without meaningful support from a Parkinson's nurse.

"I feel pretty much left alone to get on with it."²¹

The 2017 Your Life Your Services survey shows that over one in four people (27%) with Parkinson's in Scotland either have no access to a Parkinson's nurse or not enough access to their nurse. Where people have insufficient support from a Parkinson's nurse, they are less likely to be confident about self-managing their condition. They are also less likely to be referred to other professionals, such as speech therapy, physiotherapy and occupational therapy. All of this increases the risk of losing independence, requiring more support and emergency hospital admissions.

"When I was concerned about an increase in my symptoms the Parkinson's nurse acted quickly to have additional medication prescribed. This has made a world of difference to my gait and general well being."²²

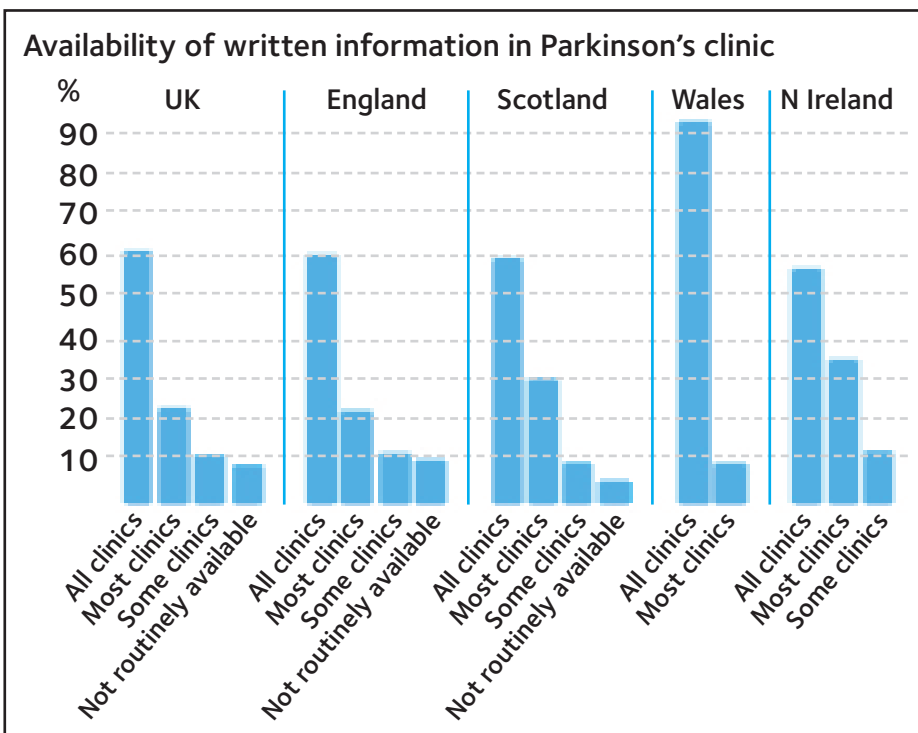


Information at diagnosis

Receiving a Parkinson's diagnosis can leave a person feeling scared, confused, or unsure about what the condition is and what it may mean for them. The National Institute for Health and Care Excellence (NICE) recently concluded that the diagnosis experience has a big impact on how people live with Parkinson's in the long term.²³ Yet we know that many people with Parkinson's in Scotland do not get the information they need at diagnosis.

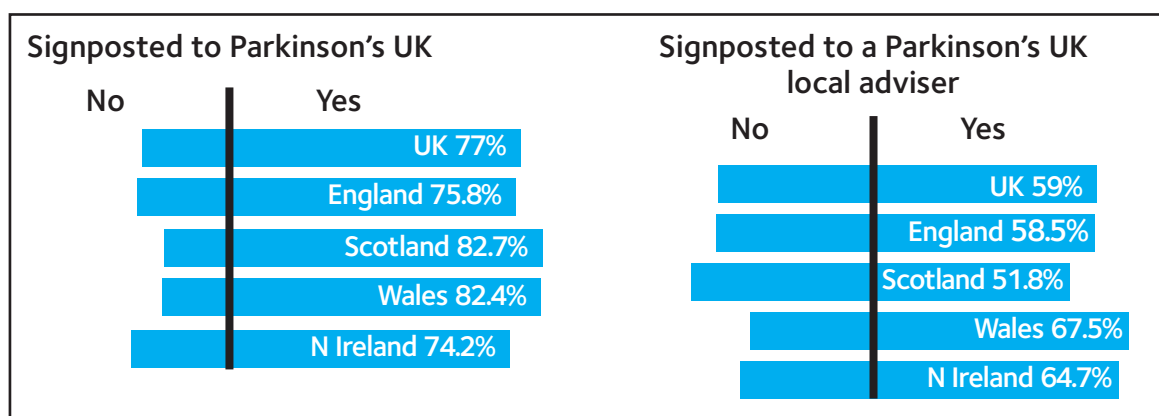
Over a fifth (21.4%) of respondents to the UK Parkinson's Audit Patient Reported Experience Measure (PREM) 2017 said that they weren't given enough information at diagnosis. But data from our 2017 Your Life Your Services survey shows an even worse picture - over half of respondents (52.3%) said that they had not been given enough information when they were diagnosed. In both surveys, more than one in ten respondents replied that they didn't know whether they had been given enough information.

However, the UK Parkinson's Audit 2017 also measured the provision of information. In Scotland, under six in ten services provided written information about Parkinson's in every clinic. This



compares with over two thirds of services in Wales.

Services were also asked if they signpost people to Parkinson's UK, and specifically to our free and confidential Parkinson's local adviser service. Here the answers were mixed - Scottish services referred people to the charity at a higher rate than the rest of the UK, and over eight in ten (83%) people were told about Parkinson's UK. But specific signposting to the Parkinson's UK Local Adviser service was much lower - only about half of people (52%) were referred to this service, the lowest total in the UK.



Connecting from diagnosis

Our Parkinson's local advisers

Our team of nine community-based Parkinson's local advisers provides free and confidential one-to-one information and support to people with Parkinson's, their families and carers. They



work with clients by email, phone and face-to-face.

The support they offer is based on the needs of the individual, but may include benefits advice, emotional support and links to local and other services.

Our Parkinson's local advisers support people at every stage of their condition, but many people find it particularly helpful to speak to them after they receive their Parkinson's diagnosis to help put things in context, and to connect them to local and national support and services.

Good practice

The UK Parkinson's Excellence Network is running a project in NHS Grampian to improve information provided at diagnosis. A consultant, a Parkinson's nurse and two people with Parkinson's selected two pieces of Parkinson's UK information that contain all the information needed at diagnosis.

This information is now sent to people as soon as possible, and preferably within a fortnight of diagnosis.

The team also records that the information has been sent.

The UK Parkinson's Excellence Network is working on a 'Signposting from Diagnosis' project. This will make sure that any Parkinson's clinician has access to resources supporting them to provide the information that people need at diagnosis.

First Steps in Aberdeen

Parkinson's UK has developed a First Steps programme to address the needs of people right from the point of diagnosis with Parkinson's.

People who have just received their diagnosis are invited to attend a two-day programme along with a partner, friend or family member. First Steps aims to help them come to terms with the condition and the change it represents. It also covers some of the practicalities of life with Parkinson's and enables people to meet others in a similar situation.

The programme is led by volunteer facilitators who themselves have Parkinson's.

The programme is currently running in Aberdeen, and we hope to roll it out more widely in Scotland in 2019.

Because Parkinson's is complex, people need access to a range of services and professionals to enable them to live as well as possible throughout their condition. Evidence-based guidelines and standards^{24 25 26} support this approach.

Professionals and services who work closely together as a multi-disciplinary team are able to provide responsive, person centred and holistic care. This approach enables care to be co-ordinated, minimises duplication, and means that people can get support from the professional or professionals who are best placed to support them at any time.

In Scotland, about three in four (75%) of services see all their patients in specialist Parkinson's or Movement Disorder clinics. This is higher than the UK as a whole, where only half of Parkinson's services work in this way.²⁷

Fewer people are seen in integrated multi-disciplinary clinics where a consultant and specialist nurse work with other health professionals such as physiotherapists, occupational therapists, speech and language therapists and sometimes other professionals.

Only 17% of Parkinson's services in Scotland provide these integrated clinics, though this is higher than for the UK as a whole (13%). In Scotland, these services are often provided in a day-hospital setting. These services receive very positive feedback from people with Parkinson's and unpaid carers who use them.

In some areas, joint clinics have been established involving professionals with overlapping expertise. For example, a multi-disciplinary Parkinson's clinic jointly led by consultants in medicine for older

Multi-disciplinary teams



people and neurologists in Aberdeen, and a joint Parkinson's clinic with old age psychiatry in North Glasgow.

Multi-disciplinary care with knowledge of Parkinson's

The best Parkinson's teams are effective because members have specialist knowledge of Parkinson's and other neurological conditions.

It is not effective to apply physiotherapy techniques designed for people with musculoskeletal problems to those whose symptoms result from neurological conditions. There are speech issues and evidence-based interventions which are specific to Parkinson's.

Occupational therapists need to understand the fluctuations in functionality and the widespread impacts of the condition to offer the right support for daily living with this complicated and highly individual condition.

Multi-disciplinary teams

Good practice

There are increasing numbers of multi-disciplinary teams and clinics in many part of the country, including in Ayrshire, Fife, Glasgow, Grampian and Tayside. Some of these teams are award-winning and have developed over many years.

In Fife there is a multi-disciplinary clinic for newly diagnosed patients so that people have the opportunity to meet the professionals that they are likely to need in future. In Dumfries and Galloway the lead Parkinson's nurse has developed a pioneering "virtual" multi-disciplinary team, enabling doctor, nurses and allied health professionals to work collaboratively and share information across the dispersed community.

NHS Highland has a specialist multi-disciplinary clinic in Inverness which reviews and treats people moving to a more complicated stage of their condition.

'Gold standard' multi-disciplinary working

In Angus there are three multi-disciplinary teams each working in a community setting. People attend an annual review and their partner or carer is also encouraged to attend.

"I receive outstanding service from my Parkinson's team and feel very involved in my care. I get an annual review with a multi-disciplinary team at which I have a 30 minute appointment each with my Parkinson's nurse, consultant, occupational therapist and physiotherapist. The whole appointment is three hours long. I complete a non-motor symptom questionnaire and get a cognitive assessment. The following week I receive a letter from the Parkinson's nurse which summarises the way forward and any medication changes and referrals made. I am free to ask any questions I like and the atmosphere is very relaxed. I think everyone would benefit from this service."²⁸



Managing all aspects of Parkinson's

Parkinson's affects far more than movement alone. For many people with Parkinson's, non-motor symptoms – including pain, bladder and bowel issues, speech problems, swallowing, drooling, fatigue, mental health symptoms – have a bigger impact on daily living.

The UK Parkinson's Audit measures whether consultants have asked people with Parkinson's about common non-motor symptoms. The 2017 audit shows that many of these important conversations are not happening.

For example, in Scotland about one in three people with Parkinson's (33%) are not asked about pain, and about four in ten (41%) are not asked about saliva.

Nearly a quarter of people (23%) are not asked about communication issues. This data is similar to the picture for the UK as a whole.

In many clinics, the effects of non-motor symptoms are neither recorded nor measured. Additionally, within speech and language, physiotherapy and occupational therapy there aren't standardised assessment measures and those in use are not always based on best practice guidance.

Asked about	Scotland (UK) %
Cognition	90 (90)
Hallucinations and delusions	89 (88)
Mood	87 (86)
Communication	77 (77)
Swallowing	86 (82)
Saliva	59 (66)
Bowel	92 (89)
Bladder	87 (86)
Pain	67 (69)
Sleep	91 (90)

People with Parkinson's commonly experience mental health and cognitive symptoms and side effects from Parkinson's medications.

About 50% of people with Parkinson's experience anxiety,²⁹ and 40% have depression.³⁰

Hallucinations and delusions are also common – around 50-60% of people will experience these at some point in the condition.^{31 32 33}

Some people develop impulse control disorders such as gambling, hypersexuality, compulsive shopping and overeating as a result of taking some Parkinson's medications. These can have a devastating impact on individuals, relationships and families.

In spite of this, access to appropriate mental health support can be difficult in much of Scotland. There are long waiting times to see psychologists and

psychiatrists. Referrals to community mental health teams and occupational therapists with an interest in mental health are very variable.

There is not a clear pathway from Parkinson's services to mental health support. Some psychiatrists and mental health nurses are reluctant to see people with Parkinson's, because it is not a primary mental health condition, or they do not have the necessary knowledge about Parkinson's. On the other hand, Parkinson's specialist consultants and nurses do not always feel that they have the training, skills or time to support someone with mental health symptoms effectively.

Mental health support

"I get anxious when going out to meet people and some days just want to cry as feel so depressed having Parkinson's." ³⁴

"My dad suffers from horrific and terrifying hallucinations and has had several episodes where we have been unable to calm him down. I have had to practically beg his community psychiatric nurse to come and visit when he is coming down from these episodes." ³⁵

Exercise

Emerging evidence³⁶ suggests that increasing exercise to 2.5 hours a week may slow the progression of Parkinson's symptoms – something that no medication can currently do. Exercise can also help people with Parkinson's to manage physical symptoms and issues such as sleep problems, fatigue, mood and mental health. Providing access to exercise is a major priority for Parkinson's UK.

Spreading Parkinson's exercise in Scotland

In October 2018, we brought together over 100 physiotherapists, sports instructors, leisure centre managers and people with Parkinson's to increase sustainable access to exercise for people with Parkinson's across Scotland.

The event enabled people to learn from Parkinson's exercise projects led by local Parkinson's UK groups, as well as initiatives led by physiotherapists and exercise providers.

We highlighted our successful collaboration with Highlife Highland and NHS Highland, which has grown from a single class in Alness to classes in Inverness, Fort William and Caithness.

We are planning similar partnerships in other parts of Scotland in 2019, including in Dundee, Aberdeenshire and Perthshire.

We know that there are some barriers for people with Parkinson's. Symptoms can make exercise more difficult. It can be difficult to travel to classes, and some people are self-conscious about the impact Parkinson's has on the way they look and how they move. It can be hard to know what type of exercise is safest and most effective.

We worked with physiotherapists to develop an evidence-based Exercise Framework, which is available on our website: parkinsons.org.uk/exercise

The Exercise Framework provides structured support for people with Parkinson's and professionals, covering suitable exercise ideas from diagnosis through to more complex Parkinson's. It's accompanied by videos showcasing how exercise can help at every stage of the condition.

Our local groups offer a range of exercise locally, including exercise classes, walking groups, hydrotherapy, Nordic walking, boxing, pilates, walking football, tai chi and many more.



Parkinson's UK is committed to supporting people with Parkinson's and those closest to them to develop the knowledge, skills and confidence to enable them to stay as well as possible for as long as possible – and to identify when they may need more support or a change in treatment.

Our local groups provide opportunities for people to come together to sustain activities that can improve health and wellbeing, and we also work with other organisations so that there is a wide range of options on offer. Social interaction, mutual support, and therapeutic activities can all enable people with Parkinson's and carers to remain connected. Activities including exercise, dance, singing groups, art classes and alternative therapies such as massage can all help. There are now more than 500 activities and opportunities for people with Parkinson's across Scotland.

We encourage health and care professionals to make referrals to our Parkinson's local advisers and local groups. We also promote activities offered by other third sector and statutory organisations. Some Parkinson's services run their own information and peer support sessions for groups of people with Parkinson's and carers, for example in Ayrshire, Lothian and Grampian.

Self-management



A Path through Parkinson's

Parkinson's UK has been delivering a self-management programme called A Path through Parkinson's since 2013. The programme was developed with people with Parkinson's, and courses are led by trained volunteer facilitators with lived experience of Parkinson's. People with Parkinson's and those who support them are welcome to attend. It offers people the opportunity to share experiences and discuss the practical and emotional impact of Parkinson's.

We are currently investigating ways to ensure that more people with Parkinson's and unpaid carers have the opportunity to develop their self-management skills.

Enabling technological innovation

Technology has a massive role to play in improving care, support and everyday life for people affected by Parkinson's.

We are enthusiastic about NHS and social care services using technology to enhance knowledge and improve people's experiences of care.

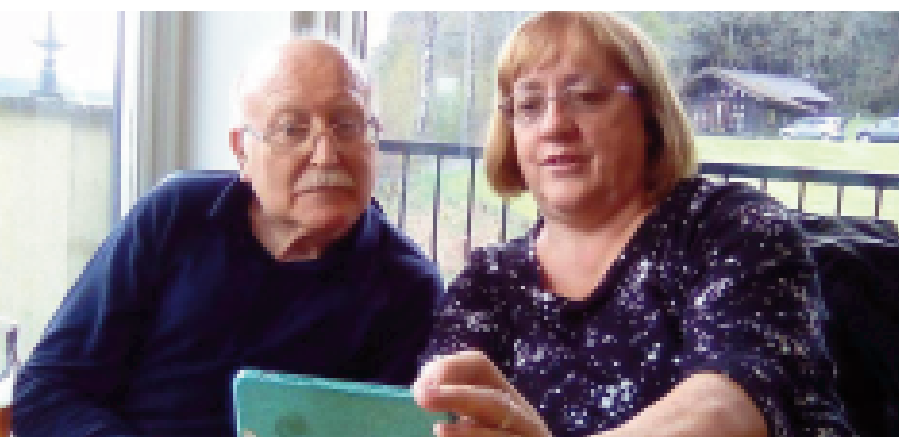
We believe that remote appointments (using Attend Anywhere software, for example) could make a huge difference to those who find it difficult to attend appointments. This includes people with

advanced Parkinson's, especially those who live in care homes who often lose contact with their specialist Parkinson's team because it is so difficult to attend clinics.

There could be big benefits too for those who live in remote and rural communities and face lengthy journeys to attend appointments. Data from fitness bands and other monitoring equipment could enrich clinicians' understanding of the person's life outside the clinic, and the impact of Parkinson's on daily life. And there is great potential for technology to enable disabled people to exercise more control over their home environment, enabling people to live independently for longer.

However, Scotland's broadband and mobile phone connectivity must be improved to enable people to use these new technologies wherever they live in Scotland. We are also mindful that while technology can help to keep people connected with professionals, family, friends and community, it can also be experienced as a replacement for much-wanted human contact. Commissioners must ensure that using technology in service provision does not cause vulnerable people to become more socially isolated.

It's also important to acknowledge that some people will need considerable support to use technology, and others may not want to use it at all. Although many older people and disabled people are confident users of digital technology, internet usage is lowest in these groups. Some types of impairment – including those common in Parkinson's – may make common technology very difficult to use.



Parkinson's UK apps and devices library

There are lots of apps and devices which claim to help people with Parkinson's to manage their symptoms. But it can be hard to know which ones are effective.

We want people with Parkinson's to know which health apps and devices are safe and really work. So we put apps and devices through a rigorous independent review process and then ask people living with Parkinson's to road test them. Apps and devices that make it through this process are then placed in our apps and device library on our website at parkinsons.org.uk/devicesandapps

Eight apps have been included so far, and more are to come. These apps help manage a range of common Parkinson's symptoms – from speech issues, to drooling and sleep problems. We want this resource to be able to guide people with Parkinson's to the most effective technology to support them.

Recognising unpaid carers

Parkinson's doesn't just affect the person who is diagnosed, but everyone close to them feels the impact too.

Many partners, family members and close friends can find it hard to identify themselves as carers, and changing circumstances put pressure on even the strongest of relationships.

As Parkinson's progresses, people often require very significant levels of care and supervision, and much of this care is provided by unpaid carers. In a study in North East England, a typical carer for someone with advanced Parkinson's was aged 70 – but the oldest was 91. On

average, carers were caring for 16 hours each day, but only about one in five accessed any formal social care provision.³⁷

Parkinson's typically progresses relatively slowly, which can make it very challenging for carers to recognise when they may need more support and ask for help.

Services should include unpaid carers in supporting the person with Parkinson's wherever possible.

“The most important thing is that professionals listen to carers!”

Jean, Fife.

Side by Side carers' support

Volunteers from our Edinburgh Branch have developed a short course for unpaid carers. It's designed to help carers to understand more about Parkinson's, and to help them to recognise and meet their own needs as well as those of the person they support. This course now also runs in West Lothian. Several of our groups also run specific activities aimed at carers.

All Parkinson's UK services are open to unpaid carers, families and friends as well as the person with Parkinson's.



When things get tough

Admissions to hospital

Around 6,000 people in Scotland live with more advanced Parkinson's, where medication does not manage Parkinson's symptoms effectively.



People with the highest levels of care need

In recent years, the NHS has recognised that a very small number of people in Scotland use a high percentage of outpatient, emergency, out of hours, community prescribing resources and inpatient bed days. Managers and planners are interested in knowing more about those with the highest level of need so that they can improve care pathways.

Scotland has over 110,000 people who between them account for the use of 50% of Scotland's total health resources. This totals over £2.9 billion per year.

According to ISD, nearly 2,300 people with Parkinson's are currently classified in this way.

This amounts to almost one in every five people with Parkinson's in Scotland. The estimated cost of care for people in this group is over £66.1 million per year.⁴⁴

Investing in preventative care to keep people with Parkinson's as well as possible for as long as possible, including support that can help people to avoid unnecessary hospital and care home admissions is a worthwhile investment for the NHS Boards and Health and Social Care Partnerships.

Most people with Parkinson's have other health conditions too.

As Parkinson's progresses, the risk of hospital admission increases.

In 2015-16, people with Parkinson's in Scotland accounted for:³⁸

- 4,295 hospital admissions
- over 75,000 bed days
- an average³⁹ hospital stay of nearly 18 days

If each hospital bed day costs £635,⁴⁰ each Parkinson's admission costs around £11,400.

This is likely to be an underestimate, as a recent UK study showed that over a quarter (27%) of inpatients with Parkinson's did not have the condition recorded in their notes.⁴¹

More than six in ten admissions for people with Parkinson's in Scotland are unplanned.⁴²

Unplanned admissions lead to longer stays in hospital.

People with Parkinson's are commonly admitted to hospital after a fall, or because they have an acute infection.

Data from NHS England shows that a person aged 65+ with Parkinson's costs the NHS 3.5 times more in unplanned hospital admissions and spends 73% longer in hospital than those of a similar age without the condition.⁴³

Inpatient medicine management

There are more than 4,000 NHS Scotland hospital admissions for people with Parkinson's per year.

People with Parkinson's are usually admitted as emergencies, because of falls and infections. People with more advanced Parkinson's are at highest risk of admission.

People with Parkinson's are prescribed complex and bespoke medication regimes to manage their symptoms, with medication taken several times a day to maximise symptom control. If people do not receive their Parkinson's medications at the correct time and dose, the results can be catastrophic. They may:

- be unable to move, speak, eat or swallow
- experience uncontrolled movements
- have distressing psychotic symptoms

It can take weeks to restore effective symptom control, and some people never recover fully. People whose Parkinson's is not managed well in hospital require more intensive support and have longer hospital stays.

The UK Parkinson's 2017 audit showed that fewer than 50% of those admitted to hospital always got their Parkinson's medication on time (within half an hour of the prescribed time). Of those who did not always receive their medication on time, 43.7% said this had a negative or significantly negative effect.

One NHS Board in Scotland now has audit data for all Parkinson's medication issued in all of its wards against prescribed times. In 2015, fewer than half of all Parkinson's medications were administered on time. We think this is likely to reflect the situation across Scotland.



“When I was in hospital my family had to constantly ask the nursing staff to give me my medication at the assigned times as the meds always arrived up to an hour or more late and on two occasions they missed a morning dose”⁴⁵

“The first thing that happened was that they took my Parkinson's medications away from me, locked them in a cabinet by the side of my bed and took away the key. I asked if I could self-medicate, but they said I couldn't because it was hospital policy.

“I was in hospital for two weeks – but if I hadn't had Parkinson's, I would have been out in four or five days! More than once, I had to miss an assessment from the hospital physiotherapist because I was “off” when they come to do my exercises with me. That's not only a problem because it was stressful and inconvenient for me (which it was!) but also because it is an entirely avoidable waste of the physio's time and already stretched NHS resources. It meant I was in hospital for far longer than I needed to be – just because I couldn't get my medication on time.”

David, Alloa

When things get tough

Inpatient medicine management

Get it on Time campaign

Parkinson's UK's Get it on Time campaign aims to make sure that people with Parkinson's get their medication on time, every time.

We have printed materials for people with Parkinson's and staff, including posters, stickers and leaflets. We have also produced a 15 minute online video for ward staff. Find out more at parkinsons.org.uk/getitontime

Good practice

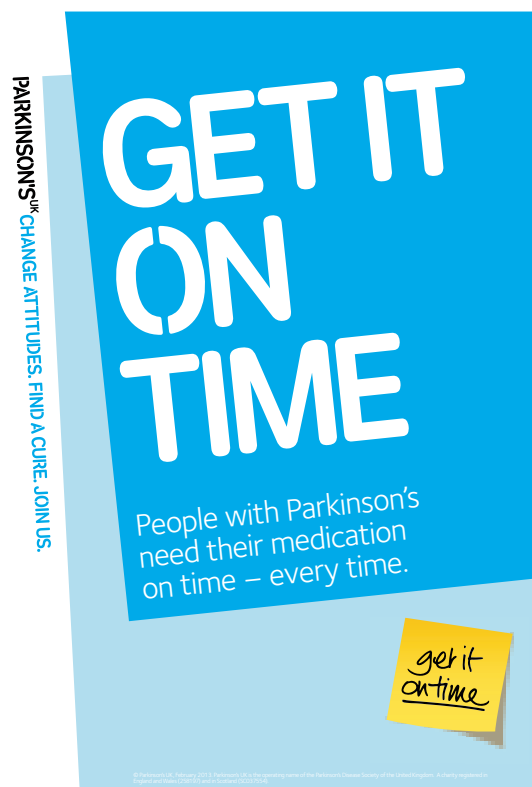
The UK Parkinson's Excellence Network has developed a Consensus Statement on Medicine Optimisation in Hospitals, which can be found at parkinsons.org.uk/professionals/resources

In NHS Tayside, there has been awareness raising and an audit to measure medication errors in several hospital sites. In 2017, nearly two thirds (64%) of people with Parkinson's got their medication on time compared with 47% the previous year.

NHS Ayrshire and Arran has had electronic prescribing for over 10 years. This has made it possible to analyse Parkinson's medications management across all its hospital wards. Data shows that the scrutiny of a regular audit improved medications management across wards, and that a ward where Get it on Time measures were implemented significantly outperformed those without these interventions.

We are working with NHS Highland staff, and on a separate project in NHS Grampian, to identify which interventions are most effective in ensuring that people with Parkinson's get their medication on time.

NHS Greater Glasgow and Clyde has introduced a dashboard, enabling all inpatients with Parkinson's to be identified. This means that Parkinson's teams are aware of where people with Parkinson's are in the hospital and can intervene to ensure that their Parkinson's is being effectively managed.



Access to advanced treatments

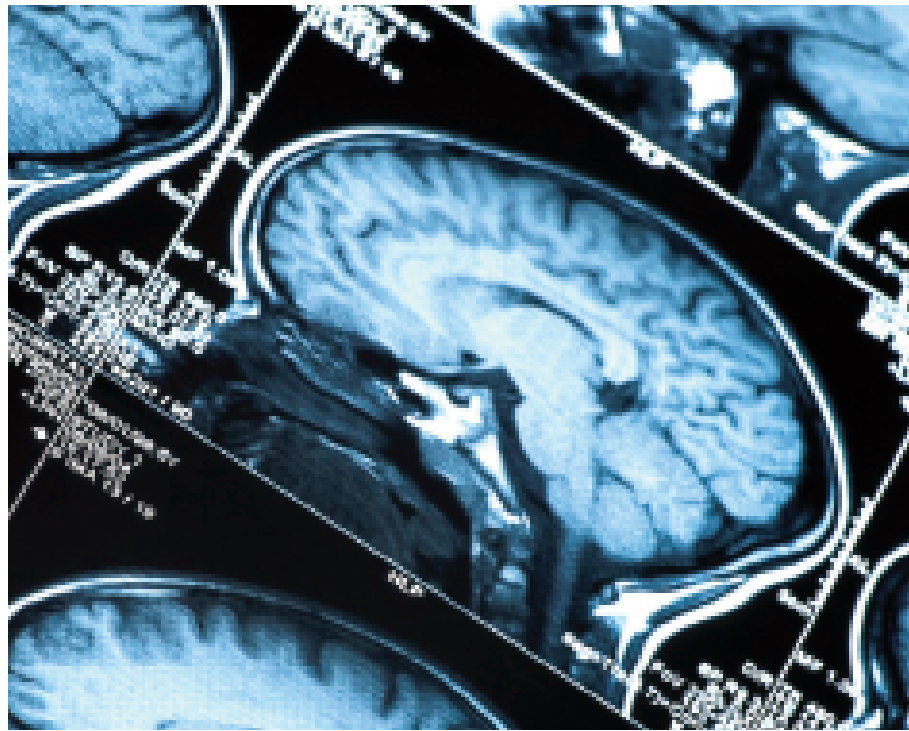
Medicines for managing advanced Parkinson's symptoms include many different preparations of oral medication and transdermal patches. These can greatly improve people's quality of life with advanced Parkinson's, and most people will respond to these treatments.

However, a minority of people with advanced Parkinson's have very severe disability, despite optimal medical treatment. These people may have significant motor fluctuations, including painful cramps, involuntary movements, freezing and unpredictable "off" periods when medication stops working, and they are unable to move. Quality of life is often extremely poor, and a lot of health and social care input is needed. The impact on unpaid carers and family members can be very high.

Everyone in this situation should be able to access advanced treatments if they are clinically appropriate, wherever they live in Scotland.

Advanced treatments	
Treatment	Delivered by
apomorphine	injections or pump
deep brain stimulation (DBS)	brain surgery
Duodopa	surgery to enable continuous infusion of levodopa-carbidopa into the intestine

Advanced treatments are not appropriate for everyone, and it is essential that people's individual situation is carefully considered before recommending a



treatment. They are not cures, but they can have a life-changing impact for individuals with Parkinson's and their families, improving symptom control and reducing dependency on others.

Parkinson's UK campaigned to establish a single national centre for DBS surgery, based at the Queen Elizabeth II Hospital in Glasgow, which opened in April 2017.

We also campaigned for Parkinson's consultants to be able to prescribe Duodopa to people who could benefit.

We are concerned that there are long waiting times for DBS surgery, and support additional investment in this national service to enable people to access this treatment in a timely fashion.

We are also concerned that there is considerable regional variation in referral to advanced treatments. We want to work with the UK Excellence Network in Scotland to reduce variation in practice, and make sure that people with Parkinson's have equity of access to advanced treatments wherever they live.

When things get tough

Anticipatory care planning

Everyone with Parkinson's is different, and it is difficult to predict how quickly the condition will progress over time for any individual. However, existing treatments cannot stop, slow or reverse the progress of the condition – and people with Parkinson's are at high risk of losing the legal capacity to make decisions through dementia and mental health symptoms.

It is important that people with Parkinson's and those closest to them are able to think about what they might want when their condition changes. Issues like

Good practice

The UK Parkinson's Excellence Network is undertaking work to support anticipatory care planning discussions. Parkinson's UK has a number of free information resources about advanced Parkinson's and decision making for people with Parkinson's and those close to them on our website at parkinsons.org.uk/advancedparkinsons.

whether homes will be suitable, planning to continue leisure activities, feeling part of the local community and interacting with family and friends are all important. People also benefit from thinking about future health and social care needs, what treatments would be considered acceptable and legal matters like Powers of Attorney and wills. When people do not have the opportunity to make plans, it can make times of crisis even more stressful and expensive.

In the Parkinson's UK 2017 audit, fewer than a third (31.6%) of people with Parkinson's in Scotland had a documented discussion about Power of Attorney.

Scotland is performing better than the other three countries of the UK, but there is still a lot of work to be done to make sure that people have had the opportunity to make their wishes known and plan for deteriorating health.

Falls and bone health

People with Parkinson's are at very high risk of falls – a recent review found that found that 60% of people with Parkinson's experience falls, and 40% fall repeatedly. These people fall an average of 21 times per year.⁴⁶

Good practice

The UK Parkinson's Excellence network has developed a free online course on managing bone health and fracture risk, and summaries of the clinical evidence on falls and Parkinson's.

The Parkinson's team at the Lightburn Hospital in East Glasgow, has shared their work on the assessment and management of falls, fracture risk and osteoporosis, with other teams in the UK Parkinson's Excellence Network. The team has audited their procedures, increased the use of fracture risk assessments and improved the falls pathway.

People with Parkinson's also have higher rates of osteoporosis than people without the condition.⁴⁷

Data from the North East of Scotland shows that people with Parkinson's are three times more likely to experience a major fracture than people of the same age.⁴⁸

The UK Parkinson's audit shows that people are commonly assessed for their risk of falls. In the Parkinson's UK 2017 Audit, more than nine in ten (93%) people with Parkinson's in Scotland had their risk for falls assessed.

However, despite the risk of osteoporosis far fewer had undergone assessment of their fracture risk – fewer than six in ten (59%).

When things get tough

Dementia

People with Parkinson's have a high risk of dementia, but people can struggle to get a formal diagnosis, or dementia support. Waiting times for dementia assessment can be long, with little or no ongoing support offered for dementia symptoms.

Parkinson's dementia can have different symptoms from more common types of dementia, like Alzheimer's or vascular dementia. Symptoms can include forgetfulness, slow thought processes and difficulty concentrating. Communication gets harder, as remembering words and names and following conversations can be a problem.

Some people find it increasingly difficult to make decisions, plan activities and solve problems. This can affect everyday activities such as dressing, cooking or cleaning. Some people have difficulty controlling their emotions. People with Parkinson's dementia often experience hallucinations and delusions, and the symptoms can fluctuate.

About 3,655 people in Scotland have Parkinson's dementia.⁴⁹

Research from the North East of Scotland shows that people with Parkinson's are six times as likely to develop dementia as people of the same age without the condition.⁵⁰

The older that someone is when they are diagnosed with Parkinson's, or the longer they live with the condition, the more likely they are to develop dementia.



When things get tough

Impact of Parkinson's on social care services

We estimate that around 6,000 people with Parkinson's in Scotland could benefit from social care support, because their Parkinson's is complex.

Research from the North East of Scotland shows that people with Parkinson's are much more likely to need some support with basic activities like washing and dressing than other people of the same age. Five years after being diagnosed, half of people with Parkinson's need this support, and after a decade almost everyone does. People diagnosed at older

ages tend to become dependent more quickly.⁵¹

The progression of Parkinson's can be gradual, which makes it difficult for people with Parkinson's and carers to identify when they need



more support. We know that many people rely on unpaid carers, and that it can be difficult to access social care packages in some parts of Scotland. Where people are using social care services, it can be challenging for social care professionals to understand the range of symptoms that people can have, and the impact of Parkinson's-specific symptoms like fluctuations, freezing, "off" periods, mental health symptoms and the dramatic impact of not receiving Parkinson's medication on time.

Data on the care home population with Parkinson's is limited. People with Parkinson's are more likely to be admitted to a care home than people of the same age without the condition.

About 10-15% of people with Parkinson's live in a care home.⁵²

That means between 1,200 to 1,800 care home residents in Scotland have Parkinson's.

Improving access to specialist care for people with advanced Parkinson's

People with Parkinson's often "drop out" of hospital-based care if they become too unwell to travel or are admitted to a care home. This increases the risk of emergency admissions to hospital.

In some NHS Boards, including Highland and Fife, consultants, specialist nurses and other professionals travel to community hospitals and clinics to deliver Parkinson's services closer to home.

In many areas, home visits are offered for people who are not well enough to get into hospital. Some Parkinson's services are linking in with care homes to make sure that residents with Parkinson's continue to receive specialist input, for example in Edinburgh and Aberdeenshire.

Good practice

Parkinson's UK has developed a learning pathway for health and social care professionals, including validated learning. We offer a range of education and training options to enable professionals to increase their knowledge of Parkinson's. Find out more at parkinsons.org.uk/professionals/learning-hub

How do we know what we know?

Parkinson's UK co-ordinates a biannual UK Parkinson's Audit which is part of a two-year improvement cycle. The clinical lead for the UK Parkinson's Audit is Dr Anne Louise Cunningham, consultant in older people's medicine in NHS Greater Glasgow and Clyde.

It is open to consultant-led services, speech and language services, physiotherapy services and occupational therapy services.

Each participating service completes an audit questionnaire based on their patient records. In addition, each service sends a Patient Report Experience Measure (PREM) survey to people with Parkinson's who use the service.

Parkinson's UK analyses the returns from both parts of the audit, develops a Service Improvement Plan for each service based on their data, and provides support to realise and evaluate changes.

Parkinson's UK also runs an annual survey called Your Life Your Services. In 2017, 172 people in Scotland took part. Some of the questions are the same as those in the Audit PREM. This enables us to capture and compare the experiences of people whose service may not have participated in the audit.

Who took part in the UK Parkinson's Audit?

In 2017, in Scotland

- 1530 people with Parkinson's represented – 931 had their records audited, and 599 participated in the PREM survey
- That's equivalent to nearly 13% of all people with Parkinson's in Scotland
- 47 services submitted complete data
- A further 6 services submitted partial data.

The 2019 Parkinson's Audit cycle will start in February 2019. Please see parkinsons.org.uk/audit for details of how services can register.

The UK Parkinson's Excellence Network

Parkinson's UK works with health and care professionals, people with Parkinson's and unpaid carers by supporting the UK Parkinson's Excellence Network. This professional-led network brings people together across the UK to develop and share skills, tools and insights, reduce unnecessary variation in practice, and improve the quality of Parkinson's care.

In Scotland, more than 300 health and care professionals are members of the Network, and there are three regional groups covering the West, East and North.



Find out more at parkinsons.org.uk/professionals or contact Mary Ellmers via scotland@parkinsons.org.uk



About Parkinson's UK

We're the Parkinson's charity that drives better care, treatments and quality of life.

Together we can bring forward the day when no one fears Parkinson's.

Our staff team is largely home-based in communities across Scotland, and we have over 40 local groups led by volunteers that provide friendship and support to people affected by Parkinson's. We also enable volunteers with experience of Parkinson's to lead self-management courses for others, to

educate health and care professionals and influence decision makers.

We have Parkinson's local advisers covering every local authority, who provide a free and confidential information and advice service to anyone affected by Parkinson's.

Parkinson's UK also funds groundbreaking Parkinson's research in Scotland, the UK and worldwide.

Find out more about us at parkinsons.org.uk/scotland

PARKINSON'S UK SCOTLAND IN 2018

Thank you to everyone who helped make this happen.

Our local advisers supported **830+** families with Parkinson's.



Including almost **300** newly diagnosed people and **200** carers.

300+ volunteers helped make everything happen.

We secured match funding from the Scottish Government to create a new Parkinson's Clinical Research Fellowship.



£670,000 raised in Scotland by our regional fundraisers

Over **800** health and social care professionals accessed Parkinson's education via study days, cascade programmes, volunteer-led sessions and online courses.

3M people have seen posts on our Facebook page.

3 support groups and cafes for people with Parkinson's and their carers were set up in 2018. We now work with more than **40** local groups.

7 of these groups are for people of working age.



We recruited Parkinson's **25** voices so that the experiences of people with Parkinson's shape our campaigns. They're influencing new National Standards for neurological care, the Scottish Neurological Action Plan, blue badge proposals and the Scottish Social Security system.



There are now **500+** activities across Scotland for people with Parkinson's. These include new exercise, singing, therapies and groups.



47 services took part in the Excellence Network audit (up 80% from 2015). Already, over 50% have submitted plans to improve their services. A new digital platform is helping more than **300** professionals to regularly share what works.



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

Find out more and contact us at parkinsons.org.uk/Scotland Follow us on Facebook at Parkinson's UK in Scotland and on Twitter at @ParkinsonsUKSco

We are supporting **3** Scottish research interest groups. More than **200** people affected by Parkinson's are members.



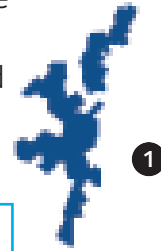
450+ media articles mentioned Parkinson's UK this year in Scotland reaching an audience of **40M**. The equivalent advertising value is **£1M+**.



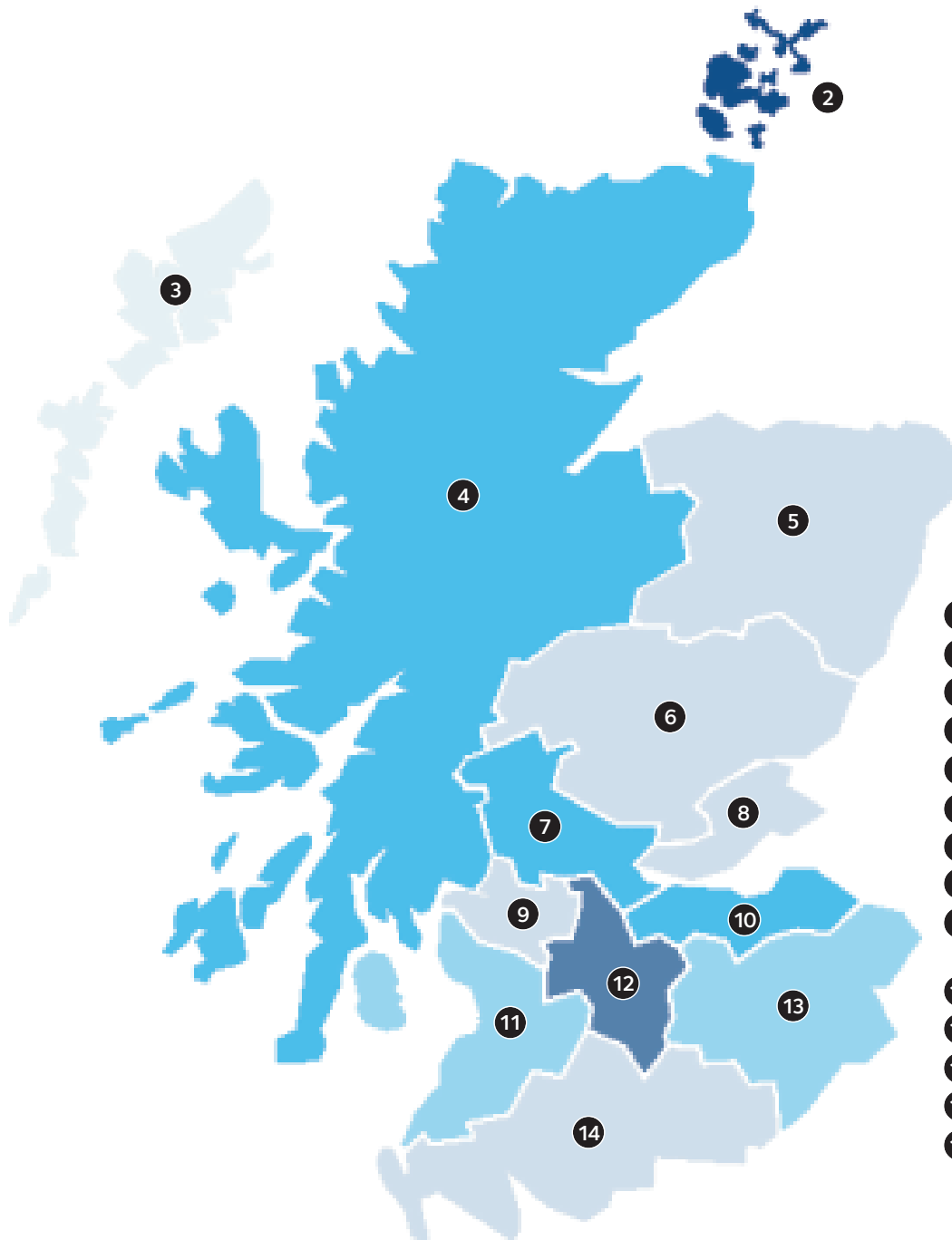
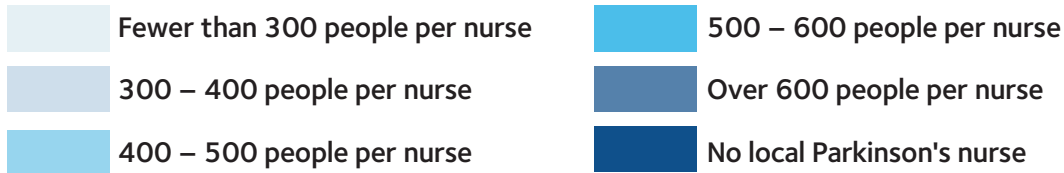
Parkinson's nurses map

In Scotland there are around 12,400 people with Parkinson's, and 29.2 whole time equivalent nurses. This means that there is one Parkinson's nurse for every 425 people in Scotland.

Parkinson's UK recommends that the maximum caseload for a full time Parkinson's nurse is 300 people, and fewer in remote and rural areas.



Number of people with Parkinson's per full time Parkinson's nurse



- 1 NHS Shetland
- 2 NHS Orkney
- 3 NHS Western Isles
- 4 NHS Highland
- 5 NHS Grampian
- 6 NHS Tayside
- 7 NHS Forth Valley
- 8 NHS Fife
- 9 NHS Greater Glasgow and Clyde
- 10 NHS Lothian
- 11 NHS Ayrshire and Arran
- 12 NHS Lanarkshire
- 13 NHS Borders
- 14 NHS Dumfries and Galloway

References

- ¹ Scottish Government, Neurological conditions national action plan 2019–2024: draft for consultation. Available at: <https://www.gov.scot/publications/national-action-plan-neurological-conditions-draft-consultation-2019-2024> [Accessed 22 January 2019]
- ² NHS Healthcare Improvement Scotland, General standards for neurological care and support. Available at: http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_care_standards.aspx [Accessed 22 January 2019]
- ³ Scottish Government, Neurological conditions national action plan 2019–2024: draft for consultation. Available at: <https://www.gov.scot/publications/national-action-plan-neurological-conditions-draft-consultation-2019-2024> [Accessed 22 January 2019]
- ⁴ NHS Healthcare Improvement Scotland, General standards for neurological care and support. Available at: http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_care_standards.aspx [Accessed 22 January 2019]
- ⁵ Scottish Intercollegiate Guidelines Network (SIGN), Diagnosis and pharmacological management of Parkinson's disease. Available at: <https://www.sign.ac.uk/sign-113-diagnosis-and-pharmacological-management-of-parkinson-s-disease.html> [Accessed 22 January 2019]
- ⁶ Parkinson's UK, The incidence and prevalence of Parkinson's in the UK Report. Available at: <https://www.parkinsons.org.uk/professionals/resources/incidence-and-prevalence-parkinsons-uk-report> [Accessed 22 January 2019]
- ⁷ This figure is calculated for adults aged over 18, based on National Records of Scotland (NRS), Mid-year population estimates for Scotland 2015. Available at <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/population-estimates-time-series-data> [Accessed 22 January 2019] and Parkinson's UK prevalence data for the same year.
- ⁸ This figure is calculated based on NRS, Population Estimates by Urban Rural Classification (2011 Data Zone based), 2016. Available at <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/2011-based-special-area-population-estimates/population-estimates-by-urban-rural-classification> [Accessed 22 January 2019] and Parkinson's UK prevalence data.
- ⁹ Scottish Intercollegiate Guidelines Network (SIGN), Diagnosis and pharmacological management of Parkinson's disease. Available at: <https://www.sign.ac.uk/sign-113-diagnosis-and-pharmacological-management-of-parkinson-s-disease.html> [Accessed 22 January 2019]
- ¹⁰ Scottish Intercollegiate Guidelines Network (SIGN), Diagnosis and pharmacological management of Parkinson's disease. Available at: <https://www.sign.ac.uk/sign-113-diagnosis-and-pharmacological-management-of-parkinson-s-disease.html> [Accessed 22 January 2019]
- ¹¹ National Institute of Health and Care Excellence (NICE), Parkinson's disease in adults, NICE guideline [NG71]. Available at: <https://www.nice.org.uk/guidance/ng71/evidence> [Accessed 22 January 2019]
- ¹² NHS Healthcare Improvement Scotland, Neurological Health Services Clinical Standards. Available at: http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_standards_2009.aspx [Accessed 22 January 2019]
- ¹³ Parkinson's UK, unpublished Scotland results from Your Life Your Services 2017.
- ¹⁴ NHS Information and Services Division (ISD), Consultant Vacancies September 2018. Available at: <https://www.opendata.nhs.scot/dataset/consultant-vacancies> [Accessed 22 January 2019]
- ¹⁵ BMA Scotland, Concern over real scale of consultant vacancies. Available at: <https://www.bma.org.uk/news/media-centre/press-releases/2018/december/concern-over-consultant-vacancies> [Accessed 22 January 2019]
- ¹⁶ Scottish Government, Local Development Plan Standards – 12 weeks referral to treatment target. Available at: <https://www2.gov.scot/About/Performance/scotPerforms/NHSScotlandperformance/12WeekFOA-LDP> [Accessed 22 January 2019]
- ¹⁷ Data from NHS ISD, in response to IR2018-01953 – To provide the median, 90th and 95th percentile waits for new outpatients for the specialties Neurology and Geriatric Medicine for people aged 18 and over. Split by NHS Board. Quarterly data for the latest 3 years (2016–2018).
- ¹⁸ Please note that this average is calculated as the median value, rather than the mean.
- ¹⁹ Parkinson's UK, unpublished response in the 2017 UK Parkinson's Audit from a Scottish participant's Patient Reported Experience Measure.
- ²⁰ NHS Healthcare Improvement Scotland, Neurological Health Services Clinical Standards. Available at: https://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_standards_2009.aspx [Accessed 22 January 2019]
- ²¹ Parkinson's UK, unpublished response in the 2017 UK Parkinson's Audit from a Scottish participant's Patient Reported Experience Measure.
- ²² Parkinson's UK, unpublished response in the 2017 UK Parkinson's Audit from a Scottish participant's Patient Reported Experience Measure.

- ²³ National Institute of Health and Care Excellence (NICE), Parkinson's disease in adults, NICE guideline [NG71]. Available at: <https://www.nice.org.uk/guidance/ng71/evidence> [Accessed 22 January 2019]
- ²⁴ NHS Healthcare Improvement Scotland, Neurological Health Services Clinical Standards. Available at: http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services_neurological_standards_2009.aspx [Accessed 22 January 2019]
- ²⁵ Scottish Intercollegiate Guidelines Network (SIGN), Diagnosis and pharmacological management of Parkinson's disease. Available at: <https://www.sign.ac.uk/sign-113-diagnosis-and-pharmacological-management-of-parkinson-s-disease.html> [Accessed 22 January 2019]
- ²⁶ National Institute of Health and Care Excellence (NICE), Parkinson's disease in adults, NICE guideline [NG71]. Available at: <https://www.nice.org.uk/guidance/ng71/evidence> [Accessed 22 January 2019]
- ²⁷ Parkinson's UK, unpublished data from the UK Parkinson's Audit 2017.
- ²⁸ Parkinson's UK, unpublished comment from a Scottish respondent to the Your Life Your Services survey 2017.
- ²⁹ Prediger R et al (2012), 'Anxiety in Parkinson's disease: A critical review of experimental and clinical studies' *Neuropharmacology*, 62: 115-124
- ³⁰ Reijnders J et al (2008), 'A systematic review of prevalence studies of depression in Parkinson's Disease' *Movement Disorders*, 23(2):183-189
- ³¹ Williams D & Lees A (2005) 'Visual hallucinations in the diagnosis of idiopathic Parkinson's disease: a retrospective autopsy study' *The Lancet Neurology*, 4(10)
- ³² Hely M (2008) 'The Sydney Multicenter Study of Parkinson's Disease: The Inevitability of Dementia at 20 years' *Movement Disorders*, 23(8).
- ³³ Forsaa E et al (2010) 'A 12-Year Population-Based Study of Psychosis in Parkinson Disease' *Archives of Neurology*, 67(8):996-1001, 67.
- ³⁴ Parkinson's UK, unpublished comment from a Scottish respondent to the Your Life Your Services survey 2017
- ³⁵ Parkinson's UK, unpublished comment from a Scottish respondent to the Your Life Your Services survey 2017
- ³⁶ Parkinson's UK, Parkinson's exercise bibliography. Available at: <https://www.parkinsons.org.uk/information-and-support/parkinsons-exercise-framework> [Accessed 20 January 2019]
- ³⁷ Hand A et al (2018) 'The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease' *Aging & Mental Health*; DOI: 10.1080/13607863.2017.1421612
- ³⁸ Parkinson's UK, Excellence Network Data Dashboards. Available at: <https://www.parkinsons.org.uk/professionals/resources/excellence-network-data-dashboards> [Accessed 20 January 2019]
- ³⁹ Please note that this average is calculated as the mean value.
- ⁴⁰ NHS ISD, Hospital Sector Running Costs: Spreadsheet RO25 board level aggregate of hospital running costs (which provides an average weekly cost per hospital inpatient stay in Scotland of £4,447 per week). Available at: <http://www.isdscotland.org/Health-Topics/Finance/Costs/ Detailed-Tables/#Hospital-Sector> [Accessed 20 January 2019]
- ⁴¹ Muzerengi S et al (2017) 'Coding accuracy for Parkinson's disease hospital admissions: implications for healthcare planning in the UK' *Public Health*, 146:4-9
- ⁴² Parkinson's UK, Excellence Network Data Dashboards. Available at: <https://www.parkinsons.org.uk/professionals/resources/excellence-network-data-dashboards> [Accessed 20 January 2019]
- ⁴³ Parkinson's UK, analysis of NHS England data from 2012-13.
- ⁴⁴ Data from NHS ISD, in response to IR2018-01995 - Number of High Resource Individuals (HRI's) with neurodegenerative long term conditions; Scotland, 2016/17
- ⁴⁵ Parkinson's UK, unpublished response in the 2017 UK Parkinson's Audit from a Scottish participant's Patient Reported Experience Measure.
- ⁴⁶ Allen NE et al (2013) 'Recurrent falls in Parkinson's disease: a systematic review' *Parkinson's Disease*; 2013:906274
- ⁴⁷ Torsney KM et al (2014) 'Bone health in Parkinson's disease: a systematic review and meta-analysis' *Journal of Neurology, Neurosurgery and Psychiatry*, 85:1159-1166
- ⁴⁸ Sleeman I et al (2016) 'Risk of fracture amongst patients with Parkinson's disease and other forms of parkinsonism' *Parkinsonism and Related Disorders*; 29:60-65
- ⁴⁹ This figure is calculated based on Aarsland D & Kurz MW (2010) 'The epidemiology of dementia associated with Parkinson disease' *Journal of the Neurological Sciences*; 289(1-2):18-22 and Parkinson's UK prevalence data.
- ⁵⁰ Giuntoli C et al (2014) 'Incidence of dementia in Parkinson's disease: the PINE Study' *Journal of Neurology, Neurosurgery and Psychiatry*, 85:e4
- ⁵¹ Macleod AD & Counsell CE (2016) 'Predictors of functional dependency in Parkinson's disease' *Movement Disorders*; 31:1482-1488
- ⁵² Hand A et al (2016) 'Medication use in people with late stage Parkinson's disease and parkinsonism living at home and in institutional care in north-east England: A balance of symptoms and side-effects?' *Parkinsonism and Related Disorders*; 32:120-123

Every week, 30 people in Scotland are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

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