

# SCOTLAND

**CAN'T WAIT**



Priorities for better services for people with Parkinson's



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# Introduction

About 13,000 people in Scotland have Parkinson's, and more than 30 are newly diagnosed each week. They are **a large and growing group who can't wait for better care and support.**

Neither can the partners, family members and friends supporting someone to live as well as they can with Parkinson's in Scotland.

Parkinson's is the fastest growing neurological condition in the world. Ignoring the projected increase in people living with Parkinson's in Scotland is not an option. Without access to expert Parkinson's teams, people with Parkinson's and those close to them face an increasingly uphill battle to stay as well as they can. To be confident about how to manage their own condition. To maintain independence and avoid hospital admissions or crisis care interventions.

**People with Parkinson's can't wait for the Scottish Government, our NHS Boards and other statutory services to build the workforce and services that they need.** In too many parts of Scotland, services are already overstretched - and as the number of people with Parkinson's continues to grow, the pressure on hard-pushed professionals will increase. Perhaps to breaking point.

And without leadership, joint working, and concerted action now, there is a risk that services will crumble. This report identifies 3 areas for action, and makes recommendations for each.

These recommendations can't wait. We must deliver the Parkinson's workforce we need in Scotland. We must make sure that people with Parkinson's get their medication on time, every time, when they are in hospital. We must recognise and provide support for the significant

mental health impacts of Parkinson's, including Parkinson's dementia.

The evidence of need is presented here. We have used data from NHS Scotland Parkinson's services collected as part of our comprehensive UK Parkinson's Audit programme. This innovative improvement project has been examining clinical records and patient and carer feedback from Parkinson's services across the UK for over a decade. It enables us to provide targeted support to help participating services to get better, and drive large scale changes too.

We have also looked at NHS Scotland data and peer reviewed research to inform our findings. We know where things are going well and there are improvements to celebrate, share and spread. And we know where people are simply not getting the support that they need.

Parkinson's UK Scotland can't wait. We are impatient for change. So is our community of people with Parkinson's, their families and friends, health and care professionals, researchers, campaigners, committed volunteers and other supporters. Please work with us to lead, plan and deliver the care that people with Parkinson's need in Scotland.



**James Jopling**  
Scotland Director  
Parkinson's UK

# Introduction

Parkinson's is the fastest growing neurological condition in the world and the second most common neurodegenerative disease after Alzheimer's. It is typically a slowly progressive and complex disorder. Parkinson's can have profound effects on the lives of the person affected and their loved ones.

Parkinson's is a very individual and variable condition with each person with Parkinson's experiencing different symptoms and response to treatment. The nature and severity of symptoms and rate at which the condition progresses is also individual.

It is therefore essential that a Parkinson's service has a responsive and flexible specialist multidisciplinary team. The team should be proactive as well as reactive, working around the person's wishes and goals to keep them and their family at the centre of care. Seamless communication between all the professionals that a person needs is crucial.

The [first Parkinson's UK Scotland report on health and services](#) was published early in 2019. It listed 13 recommendations and priorities for Parkinson's care and support in Scotland. Since then, we have contended with a global pandemic and the negative physical, mental and social impacts on people living with Parkinson's. In addition, NHS Scotland has undergone reorganisation and ongoing workforce issues during covid recovery. All of this could affect the the quality of care people with Parkinson's receive - and equity of access to services.

This report highlights the current landscape and the growing impact Parkinson's will have

in Scotland as our population ages. It explores the need to have appropriately planned and resourced NHS services to support people with Parkinson's in Scotland.

As the UK Parkinson's Excellence Network leads in Scotland, we support this comprehensive report's priorities. They cover 3 important domains: workforce, time critical medications management and improved care for the mental health symptoms of Parkinson's and Parkinson's dementia.

This report is not all bad news: it also uses data from the latest UK Parkinson's Audit to highlight achievements from services across NHS Scotland which provide excellent and innovative clinical care. As clinicians, we want to make sure that everyone affected by Parkinson's receives high quality care at all stages of their condition, wherever they live.

Meeting this report's recommendations will require meaningful partnerships between policy makers including the Scottish Government, NHS Boards, social care providers and Parkinson's UK. Challenging though this may be, we believe this work is needed to future-proof Parkinson's care in Scotland.



**Parkinson's Excellence Network Leads, Scotland**  
Dr Anne Louise Cunnington, Dr Zoe Muir,  
Dr Julie Jones, Dr Gordon Duncan

# Recommendations

## Can't wait ... for NHS Scotland Parkinson's services

- All NHS Boards should develop multidisciplinary Parkinson's services, in line with the UK Parkinson's Excellence Network [Vision for Integrated Multidisciplinary Care](#).<sup>1</sup>
- NHS Boards and Parkinson's teams should adopt a person-centred approach to decide which consultant or team should lead an individual's care. Decisions should not be made on the basis of age alone. People should be supported through any transition between care teams.
- More neurologists and older people's medicine consultants with an interest in movement disorders are needed across Scotland. Each NHS Board must make sure it has enough consultants to cover the needs of its Parkinson's population.
- Particular action is needed on persistent consultant vacancies in NHS Highland, NHS Lanarkshire and NHS Dumfries and Galloway.
- NHS Ayrshire and Arran should continue to review its consultant support for people with Parkinson's.
- NHS Boards with remote populations and those that provide specialist services must meet the care needs of people with complex conditions like Parkinson's, no matter their age. They should minimise travel for patients who find this difficult, for example, through consultants providing local clinics.

- Parkinson's nurses should have a maximum caseload of 300 people, and fewer in remote and rural areas.
- All NHS boards should review their Parkinson's nurse caseloads, and plan for future increases in the number of people with Parkinson's.
- All NHS Boards should have robust succession plans as Parkinson's nurses approach retirement age.

## Can't wait ... for time critical medications

- NHS Boards must prioritise Parkinson's medication management. Time critical medicines must be on the agenda for education, clinical governance and patient safety teams.
- Parkinson's medications should be explicitly considered as a national priority for NHS Scotland, It should be part of the NHS HIS -i-Hub improvement work and added to the Scottish Patient Safety Programme's High Risk Medications Framework.<sup>2</sup>
- NHS Boards must promote opportunities for all ward staff and hospital pharmacists to access the UK Parkinson's Excellence Network's free learning about Parkinson's medication.
- All NHS Boards must implement a medicines self-administration policy that enables people with Parkinson's to take their own Parkinson's medication if they are able and willing to do so. This should apply in all inpatient settings.

- All NHS Boards should use their electronic prescribing systems to enable ongoing monitoring of Parkinson's medicines in hospital, sharing learning from NHS Ayrshire and Arran.
- All NHS Boards must introduce an electronic alert system to inform local specialist Parkinson's service whenever someone with Parkinson's is admitted to hospital or changes ward.
- All NHS Boards should encourage their Emergency Departments to take part in the Royal College of Emergency Medicine Quality Improvement Programme on time critical medicines.<sup>3</sup>
- NHS Scotland Parkinson's teams should build on recent progress. They must make time to discuss memory and thinking issues with people with Parkinson's and their families, and encourage future planning including Powers of Attorney. These conversations should not wait until a person is already showing signs of dementia.
- Parkinson's services should have links to dementia services and vice versa. Joint clinics and other forms of partnership working should be the norm for people with Parkinson's dementia.

### **Can't wait ... for mental health and dementia needs to be recognised**

- NHS Education Scotland should work with Parkinson's UK to develop and deliver information and training about Parkinson's for generic mental health professionals to support them to tailor their approach.
- NHS Scotland should increase its neuropsychology and neuropsychiatry workforce to meet the needs of people with neurological conditions.
- NHS Boards should enable and encourage joint working between Parkinson's services and mental health teams - including dedicated mental health capacity in Parkinson's teams and joint clinics.
- NHS Boards should work with Parkinson's clinicians to ensure they can prescribe clozapine to people with Parkinson's who could benefit.
- NHS Boards should ensure that Parkinson's professionals can use protected time to undertake education and training on Parkinson's dementia.
- The Scottish Government, NHS Education for Scotland and the Scottish Social Services Council should make sure that standard dementia training modules for health and social care workers include information on the specific issues faced by people with Parkinson's dementia.
- NHS Scotland should collect and publish information on how many people have a dementia diagnosis and the type that they have, including Parkinson's dementia.
- Data on those who access post-diagnostic support should include take up by dementia subtype, to identify and address inequalities in access to post-diagnostic support for people with different types of dementia.

# What is Parkinson's?

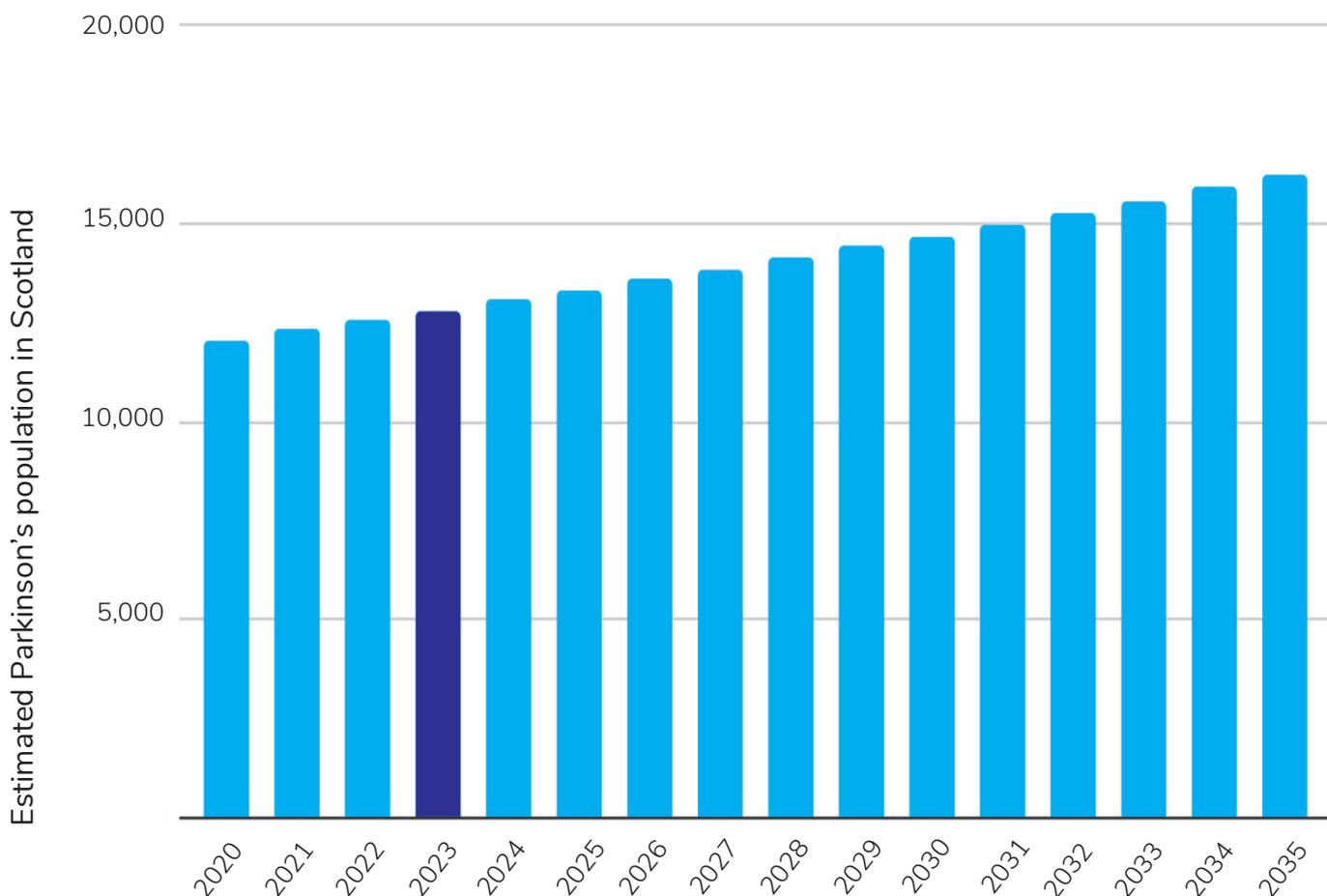
Parkinson's is the fastest growing neurological condition in the world. There are nearly 13,000 people with Parkinson's in Scotland, and each week more than 30 more are diagnosed. By 2030, we estimate that the number of people with Parkinson's in Scotland will increase to around 15,000.<sup>4</sup>

NHS Scotland does not routinely collect or analyse data about the Parkinson's

population. Parkinson's UK is working with academic partners to update our prevalence estimates, based on the best evidence. This may increase our projections. We expect to complete this work during 2024.

Parkinson's affects all aspects of daily living including talking, walking, swallowing and writing. There are more than 40 recognised Parkinson's symptoms, and everyone is

## Increasing population of people with Parkinson's (2020-2035)



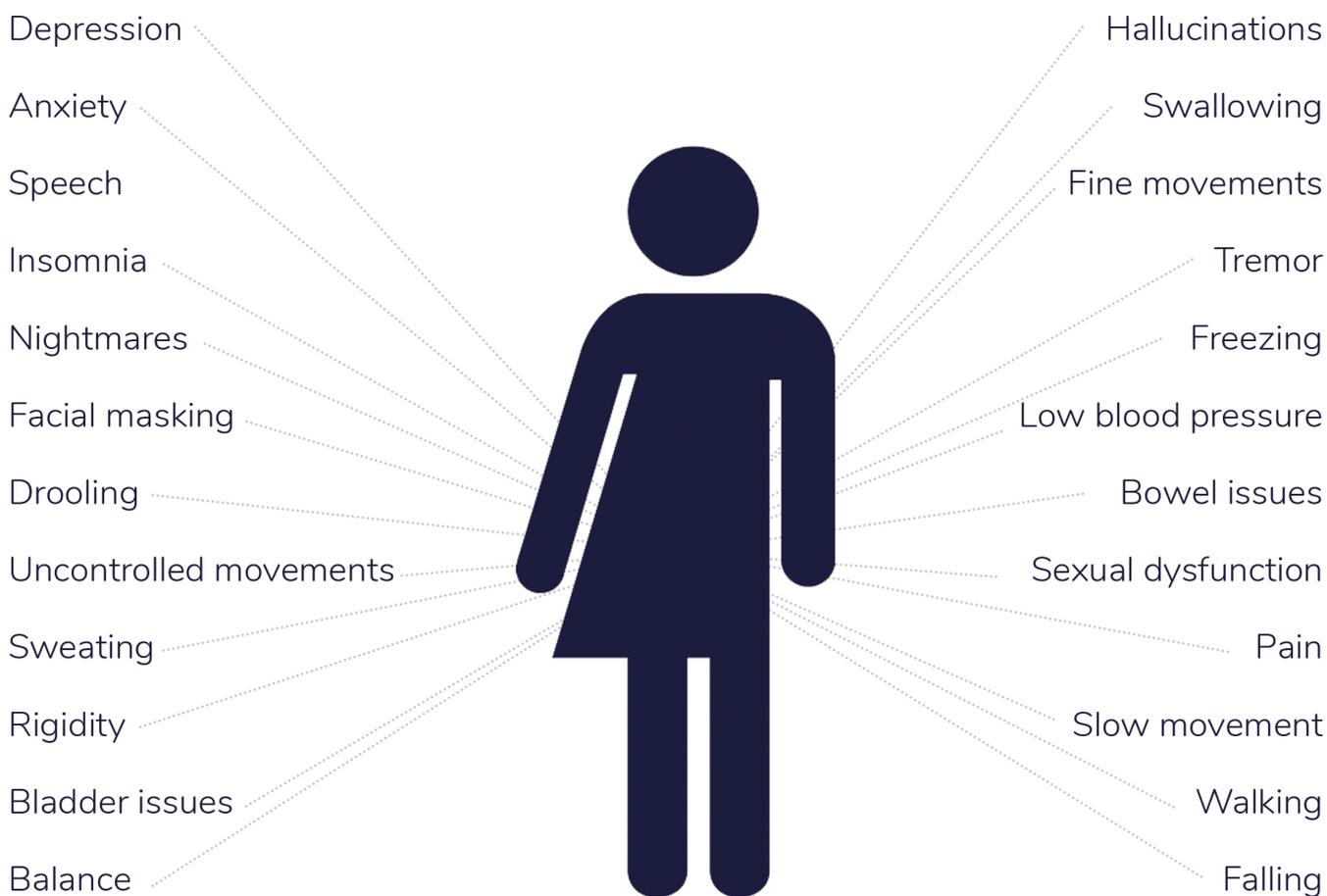
affected differently. People with Parkinson's often find it hard to move freely. Issues such as fatigue, pain, depression, anxiety, dementia, compulsive behaviours and continence problems are common and have a huge impact.

Although Parkinson's is a brain condition, it is experienced throughout the body. Many systems are affected.

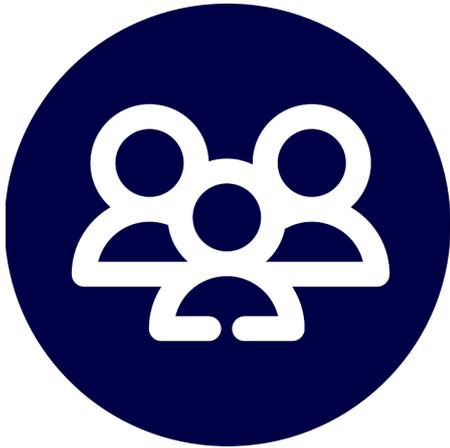
Parkinson's symptoms get worse and become more complex over time. The severity of symptoms can fluctuate, both from day to day and even hour to hour, including sudden 'freezing' and periods when the medication wears off, leaving the person barely able to move.

There is no cure, and no current treatment can slow or reverse the progression of Parkinson's.

## Common Parkinson's symptoms



# Parkinson's in Scotland



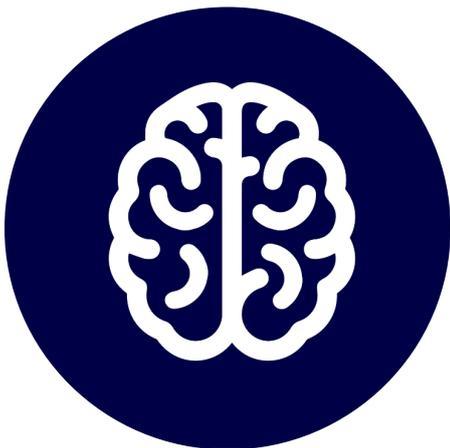
**12,900** people have Parkinson's and 30 are newly diagnosed every week in Scotland



**57%** of people with Parkinson's are male, **43%** are female  
**15%** are of working age, **85%** are over 60 and **1 in 3 (34%)** are aged over 80



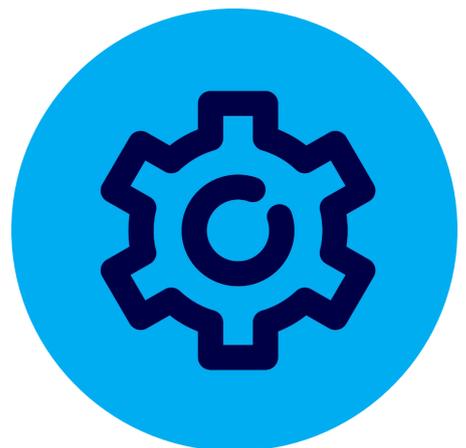
**24%** now live alone and **1 in 3** will at some point  
**10-15%** live in a care home and about **1 in 6** are among the highest users of healthcare in Scotland



**30%** have dementia and an estimated **50%** need support with daily activities



**66%** of people with Parkinson's live in an urban area  
**21%** in 'accessible rural' regions and **12%** in areas defined as 'remote'



**17%** live in areas defined as 'most deprived'  
**20%** are in 'more deprived', **20%** in 'mixed', **21%** in 'less deprived' and **21%** in 'least deprived'

Section 1

PEOPLE WITH  
PARKINSON'S

**CAN'T WAIT**

...FOR THE  
HEALTHCARE  
THEY NEED

## What care do people with Parkinson's need?

Parkinson's is very complex. A GP in Scotland will only see one new case of Parkinson's every 3-4 years.<sup>5</sup> Because everyone with Parkinson's experiences it differently, diagnosis can be difficult and everyone needs a personal treatment regime. Symptoms and treatments need to change as the

condition progresses. Access to specialist multidisciplinary care is crucial.

Parkinson's symptoms are usually managed with medication, along with treatment and therapy from a range of doctors, nurses and allied health professionals. A flexible, multidisciplinary approach is needed to support people with Parkinson's at every stage of the condition, with strong partnerships covering health and social care.

## Parkinson's medication and other treatment

People with Parkinson's typically take many different medications several times each day to manage their symptoms.

As Parkinson's progresses, people start to experience their medication "wearing off" between doses, leaving them unable to move or communicate. Some people have extreme and unpredictable fluctuations in their ability to move.

Parkinson's medication regimes are individual to each person. Symptom control must be balanced with side effects from powerful medications. And everyone responds differently to Parkinson's medicines. This is why many Parkinson's treatments can only be prescribed by a consultant, and why it is important that medications are regularly reviewed.

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

## What does multidisciplinary care look like?

Parkinson's UK has brought together Parkinson's experts in the UK Parkinson's Excellence Network to develop an evidence-based [Vision for Integrated Multidisciplinary Care](#).<sup>6</sup>

People with Parkinson's need access to a core team of professionals with expertise to assess and support movement, mental health, cognition, speech, swallowing, continence, work-related issues, social care needs and more.

**This core team includes those listed opposite.**

People with Parkinson's also need access to other professionals including: neurosurgery, gastroenterology, dietetics, continence services, pain services, mental health services, sleep services, pharmacy, palliative care, community services and social services.

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.

Exercise, creativity and social activities also help people with Parkinson's to manage their symptoms and improve their quality of life.

- consultant specialising in movement disorders
- specialist Parkinson's nurse
- physiotherapist with expertise in Parkinson's
- occupational therapist with expertise in Parkinson's
- speech and language therapist with expertise in Parkinson's
- specialist mental health professional

### Recommendation

All NHS Boards should develop multidisciplinary Parkinson's services, in line with the UK Parkinson's Excellence Network [Vision for Integrated Multidisciplinary Care](#).<sup>7</sup>



## People with Parkinson's can't wait ... for specialist doctors

**There is currently no simple diagnostic test for Parkinson's, and lots of other conditions can cause similar symptoms.**

GPs do not see enough people with Parkinson's to diagnose it accurately and manage it effectively.

Evidence-based clinical guidelines on Parkinson's from the National Institute for Health and Care Excellence (NICE)<sup>8</sup> specify that only consultants with an interest in

movement disorders should make the diagnosis, and that people need their condition to be reviewed every 6 to 12 months to confirm that both the diagnosis and treatment are correct.

The medicines used to treat Parkinson's can have significant side effects. A number of commonly-used medications can only be initiated by a specialist, so access to a consultant is essential for people to achieve the best possible quality of life.

## Which consultant?

In Scotland, the majority of people with Parkinson's see a consultant in older people's medicine with an interest in movement disorders. These doctors have expertise in supporting people with multiple health conditions and complex care needs. Although they are specialists in caring for older people, they also see people with Parkinson's of working age, especially when their Parkinson's becomes more advanced.

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.

There's no clinically agreed age cut off for which type of doctor people see, and NHS Boards have different policies. While some Boards refer everyone aged over 65 to older people's medicine for a diagnosis, many have no defined age, and at least one board in Scotland will not refer new patients to older people's medicine until they are aged 75+.

Neurology and medicine for older people departments are configured and managed

differently, so the type of support that people with Parkinson's can access can vary because of the department that their consultant works in.

Parkinson's UK Scotland often hears from people who feel that they are too young to be referred to a consultant in older people's medicine and feel out of place in that setting. We also hear from people of working age who would prefer their care to be managed by a team based in older people's medicine.

Some people are transferred from one department to another without a clear explanation, which they often find unsettling and upsetting. It takes time to build a relationship with a new Parkinson's team, and the impact of service transition on the individual and their partner or other unpaid carer does not seem to be considered.

We believe that decisions about which consultant a person sees should be based on their individual circumstances, and not on age alone. Factors like other medical conditions, the person's general level of fitness and "biological age" are also important factors. People need confidence that they are being treated by the right person in the right place for them.

### Recommendation

NHS Boards and Parkinson's teams should adopt a person-centred approach to decide which consultant or team should lead an individual's care. Decisions should not be made on the basis of age alone. People should be supported through any transition between care teams.

## Access to consultants

In the 2022 Parkinson's Audit,<sup>9</sup> more than 1 in 10 (11%) of people in Scotland said that they do not have enough time with their consultant to meet their needs or had no access at all. While this is much better than the UK as a whole (1 in 5, 20%) there is still more work to be done.

We are hearing about more and more people who have sought a diagnosis in the private sector because of excessively long waiting times to see a consultant in Scotland. Some are also using private providers to provide ongoing treatment because they can't see their NHS consultant in a reasonable time frame.

The Association for British Neurologists (ABN) reports that the UK is ranked 44 out of 45 countries in Europe for access to a neurologist. It calculates that there is one consultant for every 91,575 people. Both France and Germany have about 1 consultant for every 25,000 people.<sup>10</sup> This means that even if NHS Boards are not reporting vacancies, neurologists are overstretched.

According to NHS Education for Scotland, NHS Scotland has 11.5 full time consultant vacancies in older people's medicine with 2 Boards reporting vacancy rates above 21%, and another 2 between 12 and 14%.<sup>11</sup> Recent research covering 12 out of 14 NHS Boards in Scotland showed huge variation in consultant and team provision for older people's medicine across Scotland, and concluded that workforce and services were not matched to population need.<sup>12</sup> The number of consultants for older people in NHS Scotland ranges from zero to 2.3 per 100,000 people aged over 65 in NHS Boards.<sup>13</sup>

The British Medical Association (BMA) Scotland has recently warned that the true rate of consultant vacancies may be more than double that reflected in NHS Scotland data because certain types of vacancy are excluded.<sup>14</sup>

Parkinson's UK Scotland was disappointed that the Scottish Government's 2022 Health and Social Care Workforce Strategy<sup>15</sup> did not mention the growing need for care and support for people with neurological conditions.

**“As the population gets older, the shift towards longterm, complex and multi-layered conditions will continue as will demands on our Health and Social Care services and workforce.”<sup>16</sup>**

While the strategy did identify the growth in complex lifelong conditions as Scotland's population ages, the emphasis was placed on generalist community-based support and expanding complex nursing care provision in care homes. The national strategy remained silent on the provision of the specialist support that people with complicated conditions like Parkinson's need to stay well and independent for longer. Neither has this been articulated in local NHS Board Workforce Plans.

NHS Ayrshire and Arran has over 1,000 residents with Parkinson's, and a long-standing issue with recruiting sufficient consultants in medicine for older people. Those who develop Parkinson's at a younger age are typically seen

by neurologists based in NHS Greater Glasgow and Clyde. The latest NHS data (September 2023) suggests that 2 consultant vacancies have recently been filled.

We hope that the new recruitment will help to reduce very long waiting times for diagnosis and review for people in NHS Ayrshire and Arran, as we have been extremely concerned about the medium to long term sustainability of medical staffing of the Parkinson's service for older people in NHS Ayrshire and Arran.

The impact of consultant pressures is immense. It has a huge impact on people's ability to live well with Parkinson's - from getting a timely diagnosis to ongoing medical treatment and support.

**“ We appreciate how busy the specialist doctor is, but sometimes we would welcome a shorter break between appointments, which themselves often feel rushed.”<sup>17</sup>**

Person with Parkinson's

### **Recommendation**

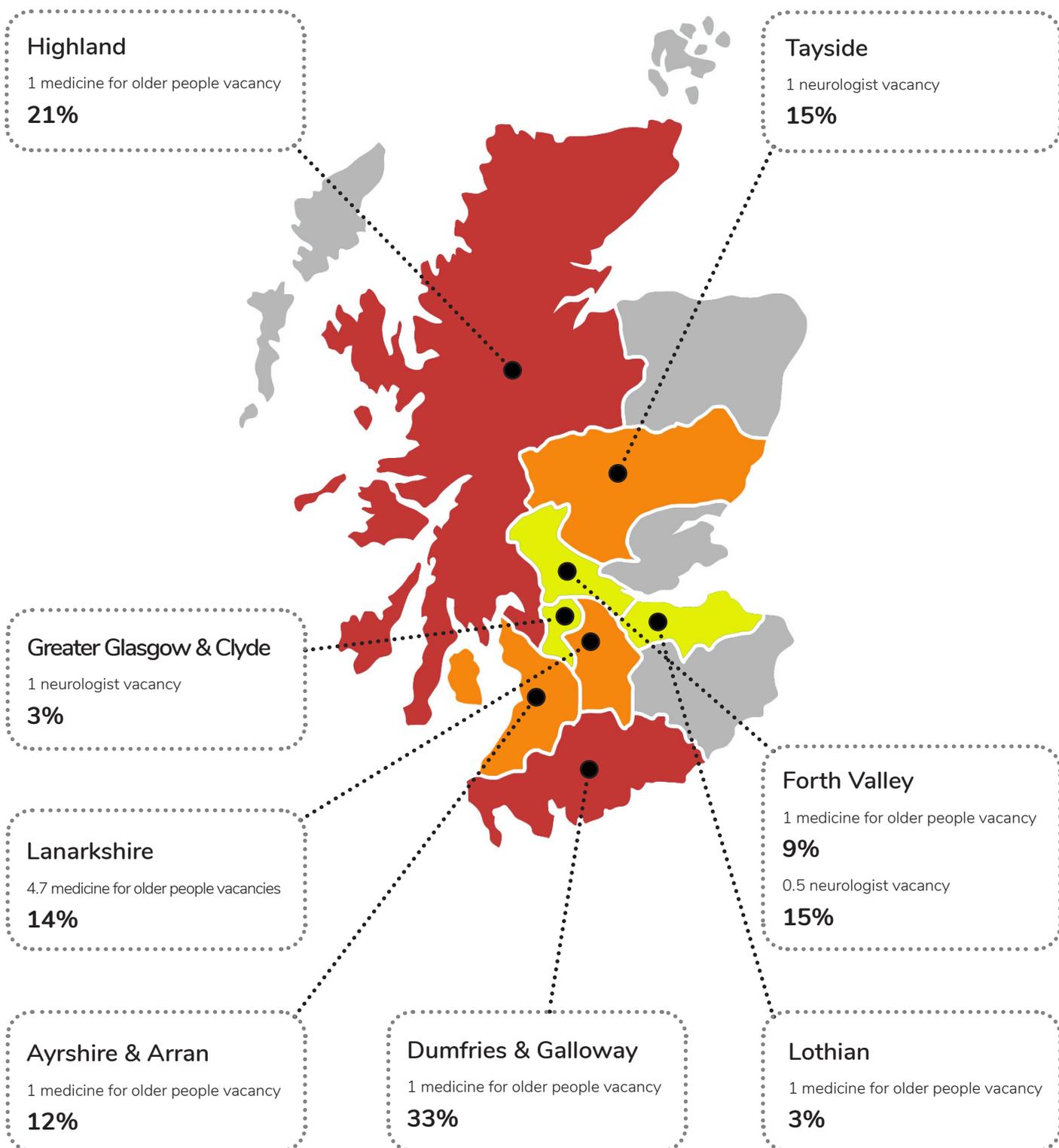
More neurologists and older people's medicine consultants with an interest in movement disorders are needed across Scotland. Each NHS Board must make sure that it has enough consultants to cover the needs of its Parkinson's population.

Particular action is needed on persistent consultant vacancies in NHS Highland, NHS Lanarkshire and NHS Dumfries and Galloway.

NHS Ayrshire and Arran should continue to review its consultant support for people with Parkinson's.

## Consultant access areas of concern in Scotland

Vacancy rates: ■ 1-10% ■ 11-20% ■ 21% +





## People with Parkinson's can't wait ... in rural communities

People with Parkinson's are over-represented in Scotland's remote communities. We estimate that 12% of people with Parkinson's in Scotland - more than 1,500 people - live more than half an hour's drive from a town with a population of 10,000 people or more. That compares with just 8% of the whole population of Scotland.<sup>18</sup>

Many people living with Parkinson's in the Northern Isles, more remote parts of North Highland, Grampian, Dumfries and Galloway

and Borders can access local medical support. In these areas, consultants travel to local clinics to provide care as well as offering virtual consultations. There are locally-based Parkinson's nurses or a Parkinson's practitioner, too. These arrangements seem to work well.

Those in the Western Isles and parts of Argyll and Bute currently have to travel to Glasgow for diagnosis or a face-to-face appointment. All other medical appointments take place online. If someone is unable to travel, they may not

receive a diagnosis or have new symptoms reviewed and treated.

The difference in access to specialist Parkinson's services is driven by the policies of the NHS Board providing consultant cover. While people with Parkinson's in Orkney and Shetland receive neurologist support from NHS Grampian, those in the Western Isles and Argyll and Bute are referred to neurology services provided by NHS Greater Glasgow and Clyde. There is a lack of transparency in the cross-border arrangements between Boards which can make it difficult to assess who is ultimately responsible for decisions about services. There is currently no medicine for older people consultant in the Western Isles, despite the aging population in the Western Isles.

Most people with Parkinson's tell us that they find it challenging, expensive and difficult to travel long distances to see their consultant. They would like to receive their in-person medical care locally.

Access to Parkinson's services for older people in some remote and rural areas of Scotland is becoming more difficult, especially for those who are no longer able to travel. We need to make sure that everyone in remote and rural

areas can get access to the expert medical support that they need, whatever their age or ability to travel.



**It makes life really difficult to have to go to Glasgow every time you need an expert opinion. The NHS has to approve patient travel, and they won't make it easy to take someone with you. It's expensive to fly to Glasgow - you're lucky to get a return flight for £300 so it is a big deal if the Board won't reimburse the cost of someone going with you. I can't believe it is cost-effective for the NHS to have to pay for people to leave the island every time they need to see someone."**

Anne, Stornoway

## **Recommendation**

NHS Boards with remote populations and those that provide specialist services must meet the care needs of people with complex conditions like Parkinson's, no matter their age. They should minimise travel for patients who find this difficult, for example, through consultants providing local clinics.

## Waiting times

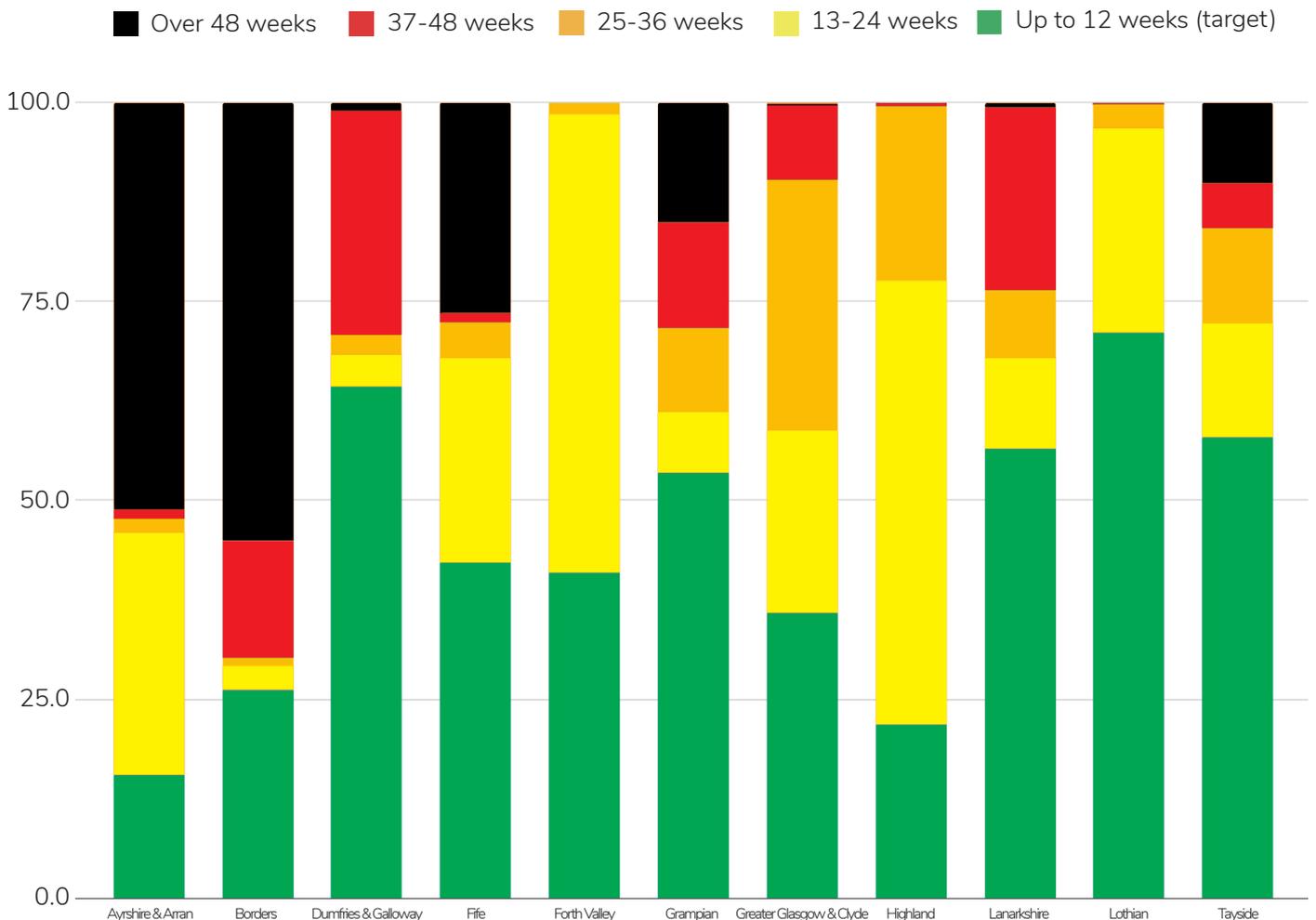
People with Parkinson’s can’t wait for diagnosis and ongoing care. We analysed NHS waiting times data for older people’s medicine and neurology.<sup>19</sup>

The neurology data is extremely concerning. It shows huge variation across Scotland. The NHS referral to treatment target is 12 weeks. The best performing NHS Board is Dumfries

& Galloway - but even then, fewer than 2 in 3 people (64%) are seen within the 12 week target. In NHS Ayrshire and Arran, only 15% of people receive an appointment within 12 weeks.

At the other end of the scale, almost two thirds (63%) of all people referred to neurology wait more than 48 weeks in NHS Borders and more than half (51%) in NHS Ayrshire & Arran. More than 1 in 4 (27%) of people wait over 48 weeks in NHS Fife and more than 1 in 5 (22%) in NHS Grampian.

### Neurology waiting times in Scotland (mainland NHS Boards)



The data for medicine for older people consultants shows much less variation. In 6 out of the 11 mainland NHS Boards, more than 9 out of 10 people are seen within 12 weeks. In the worst performing Board, NHS Borders, over half of people (55%) are seen within 12 weeks and 99% are seen within 24 weeks.

This variation is unacceptable. And where new referrals are showing such variation, it is likely that people needing to see their consultant about their ongoing Parkinson's care are also facing long waits:

**“ Longer between appointments. Used to be seen more regularly, but [it is] not [the] staff's fault.”<sup>20</sup>**

Person 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. But people with Parkinson's need safe and sustainable services - and that means increasing the number of consultants with expertise in the condition.



**In 6 out of the 11 mainland NHS boards, more than 9 out of 10 people were seen within 12 weeks.**

### Recommendation

NHS Boards must reduce unacceptably long waiting times to see a neurologist for a first appointment. All NHS Boards should also make sure that there is sufficient consultant capacity to manage review appointments for a growing population of people with Parkinson's.

## Access to advanced treatments

For most people, Parkinson's is managed via oral medication and patches.

However some people need advanced treatments to help them manage very severe motor symptoms despite optimal Parkinson's medication. These symptoms can include painful cramps, extreme tremor, involuntary movements and freezing and can fluctuate rapidly. For some people, Parkinson's medicines "wear off" unpredictably leaving them unable to move. This can happen even

when taking tablets every couple of hours. For people in this situation, quality of life is extremely poor. They have very high support needs, and there is a significant impact on partners, family members and others providing unpaid care.

Access to advanced treatments can be life-changing. They are not suitable for everyone, and do not provide a cure for Parkinson's, but can significantly improve symptoms and increase independence. But in order to be considered for these treatments, people need to be assessed and referred by an experienced consultant - and that means they need access.

## Advanced (non-oral) therapies approved for use in NHS Scotland

<b>Apomorphine</b>	Under the skin by injections or pump
<b>Deep Brain Stimulation</b>	Brain surgery to implant electrodes and a pulse generator to control stimulation levels
<b>Duodopa</b>	Surgery to enable continuous infusion of levodopa/carbidopa into the small intestine via a pump

The Scottish Medicines Consortium (SMC) currently has decisions pending on two other advanced treatments for use in NHS Scotland.

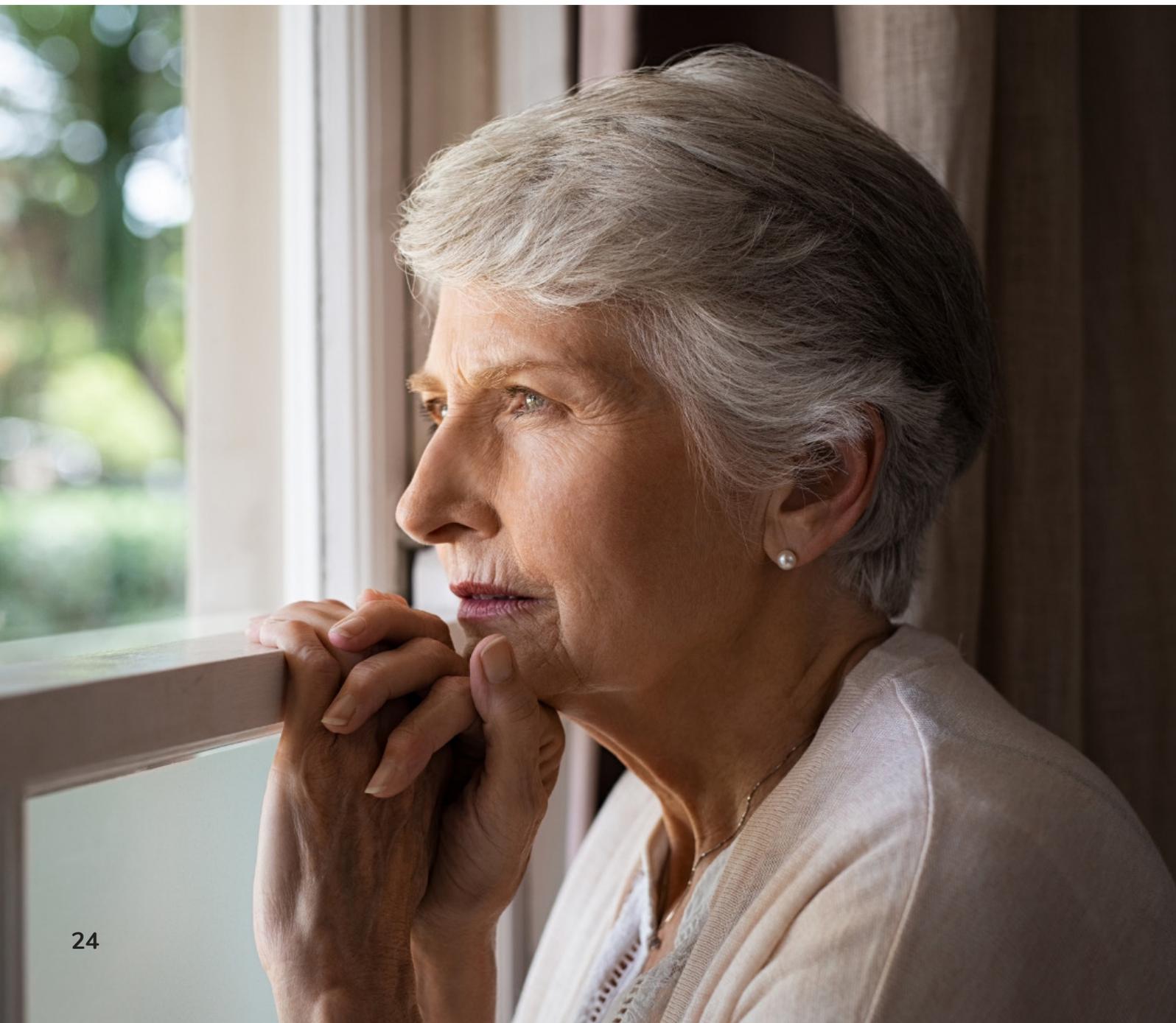
## Impact of Covid-19

Research from Lancaster University shows that people with Parkinson's deteriorated during the pandemic.<sup>21</sup> Symptoms affecting movement and mental health got worse.

At the same time, there was reduced access to healthcare and face to face community support

like social and physical activity sessions that can help people with Parkinson's to stay well.

The pandemic made it much harder to access a GP to be referred for a new diagnosis, adding to delays in many NHS Boards for routine care. Neither neurology nor medicine for older people were identified as priorities in the Scottish Government's NHS Recovery Plan.<sup>22</sup>





## Can't wait ... for 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. In the 2022 Parkinson's Audit, nearly three quarters (73%) of people with Parkinson's described the support they got from their Parkinson's nurse as "excellent".<sup>23</sup>

Parkinson's nurses have specific training and skills in Parkinson's. They are senior nurses, classified as clinical nurse specialists.

Most people with Parkinson's in Scotland say they have access to a Parkinson's nurse. But

nearly 1 in 7 (15%) report that they are unable to contact their nurse between scheduled appointments.<sup>24</sup> We're concerned that as the number of people with Parkinson's grows, the pressure on Parkinson's nurses will increase.

Parkinson's UK recommends a maximum caseload of 300 people with Parkinson's for each full time specialist nurse, with fewer in remote areas, to account for additional travel. That means that Scotland needs a minimum of 44 full time Parkinson's specialist nurses covering routine patient-facing work. NHS Scotland has fewer than 33 full time equivalent

Parkinson's nurses in this role. We are at least 11 full-time specialist nurses short in Scotland.<sup>25</sup>

If the existing specialist nurse posts were evenly distributed around Scotland, each nurse would be supporting about 400 people with Parkinson's - equivalent to each nurse carrying about 33% more than their minimum recommended caseload. There is no allowance for people who live in remote areas and no flexibility to meet the needs of a growing population of people with Parkinson's.

In reality, there is wide variation across Scotland. And while there are Parkinson's specialist nurses in each NHS Board, some nurses have extremely high caseloads.



**Although I am quite independent, I would like to have more support from the nursing service to speak about my illness and concerns I have. Appointments are too rushed. I get tongue tied. I get quite a lot of anxiety and find the fast pace of review clinics very pressured and feel that if I could speak with the nurse more regularly I would understand how my diagnosis affects me.”<sup>26</sup>**

Person with Parkinson's

## More about Parkinson's nurses

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

- enabling consultants to focus their scarce time on those that most need expert medical input
- proactively identifying when someone's Parkinson's is changing, suggesting changes in medication or when other professionals

such as physiotherapists, speech therapists, occupational therapists, mental health professionals and social care are needed

- preventing unnecessary care home and hospital admissions

Parkinson's nurses are a cost-effective and sustainable way for NHS Boards to meet their targets and strategic priorities.

Between 1996 and 2022, Parkinson's UK invested more than £12m into pump priming 323 Parkinson's nurse posts across the UK, including 22 posts in Scotland. In some areas, Parkinson's specialist nurses have other names such as movement disorder specialist nurses or neurology specialist nurses. In NHS Orkney, there is a Parkinson's practitioner - a senior physiotherapist who works in a similar

way to a nurse specialist, and who we have included in our Parkinson's nurse count.

In Shetland, an existing clinical nurse specialist was given additional hours (2.5 hours a week) to support people with Parkinson's alongside an existing caseload of people with multiple sclerosis (MS), stroke and motor neurone disease (MND). All four conditions are complex, with very different needs, and altogether she supports around 250 people.

In addition to our figures, there is an additional half time specialist nurse attached

to the national Deep Brain Stimulation Centre in Glasgow.

A small number of nurses are part of Parkinson's teams but are not graded as clinical nurse specialists. These are in place in NHS Ayrshire and Arran, NHS Forth Valley and NHS Greater Glasgow and Clyde. NHS Western Isles has similar in their neurology nurse team. These add up to about 3 full time equivalent posts across Scotland.

We used intelligence from local Parkinson's teams to map the Parkinson's nurse workforce in Scotland.

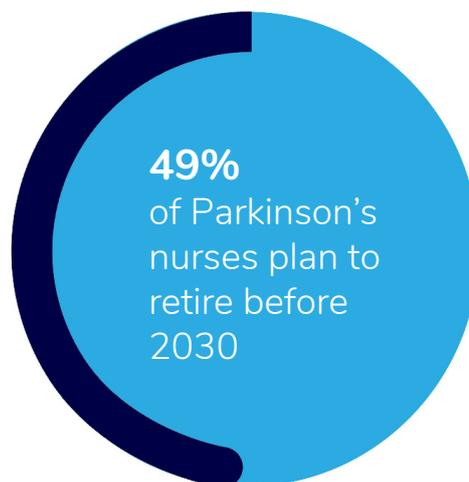
## In reality, too many people remain without meaningful support from a Parkinson's nurse

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.

Recent UK-wide research shows that half (49%) of Parkinson's nurses plan to retire before 2030.<sup>27</sup> We're taking action before the current cohort of experienced Parkinson's nurses in Scotland reach retirement. We're working with NHS Boards to plan sustainable Parkinson's nurse provision to meet the needs of the growing population of people with Parkinson's.

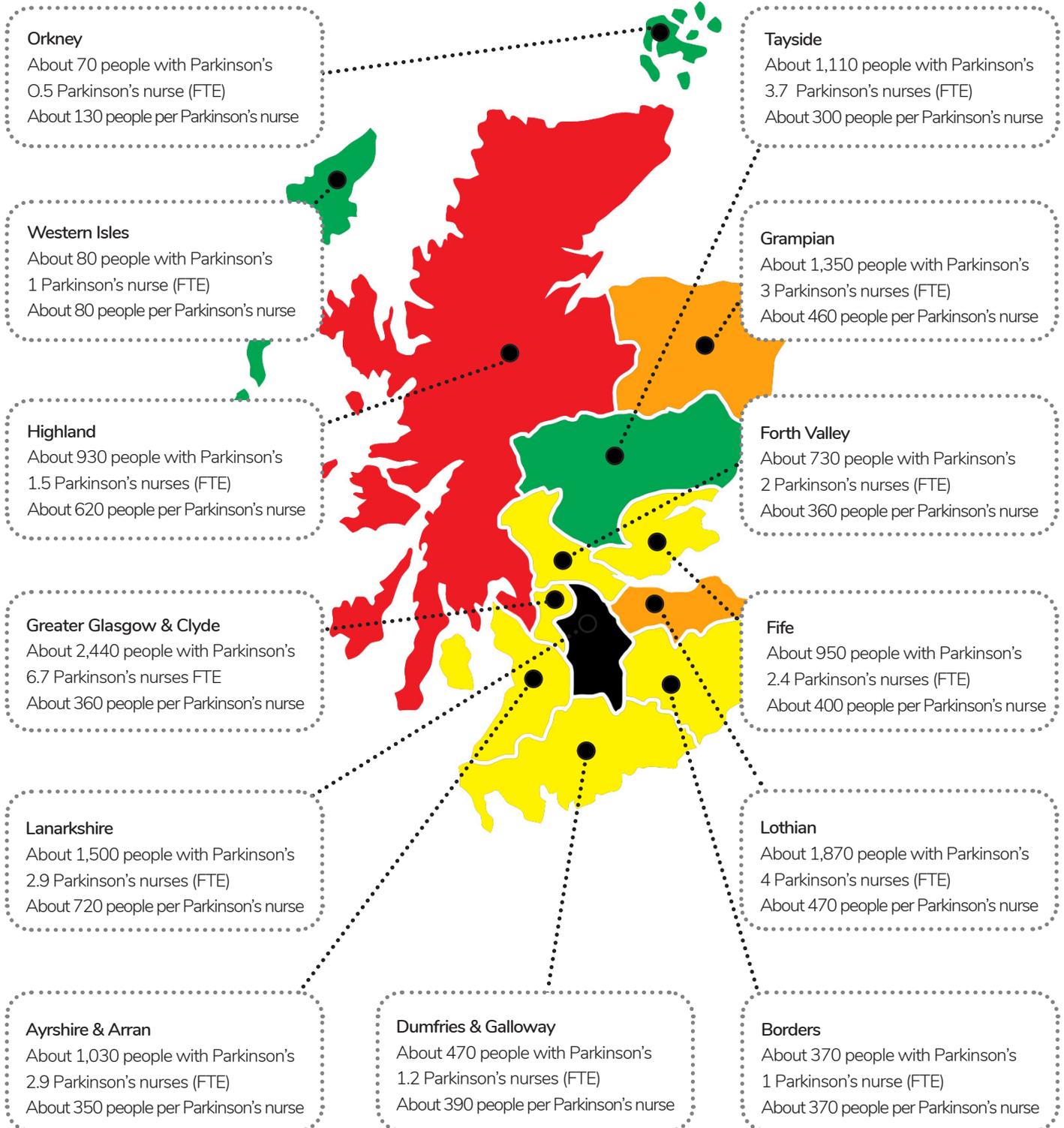
“Those working are great they just need more staff...nurse is retiring and I am anxious about that as she is great.”<sup>28</sup>

Person with Parkinson's



## Parkinson's nurses in Scotland

People with Parkinson's : Parkinson's nurse



## Recommendation

Parkinson's nurses should have a maximum caseload of 300 people, and fewer in remote and rural areas.

All NHS boards should review their Parkinson's nurse caseloads, and plan for future increases in the number of people with Parkinson's. Priority NHS Boards are NHS Highland, NHS Lanarkshire and NHS Shetland.

All NHS Boards should have robust succession plans as Parkinson's nurses approach retirement age.

## Keeping people with Parkinson's out of hospital

Parkinson's is a complicated, progressive condition. And most people with Parkinson's also have other health conditions. People with Parkinson's are more likely to be admitted to hospital. A typical hospital stay is 73% longer than people of the same age without Parkinson's.<sup>29</sup>

In 2022-3:

- people with Parkinson's were admitted to hospital in Scotland at least 4,415 times
- 9 in every 10 admissions (86%) were unplanned<sup>30</sup>

These figures are likely to be underestimates. UK data shows that more than 1 in 4 (27%) of

people with Parkinson's who are admitted to hospital do not have their Parkinson's recorded in their notes.<sup>31</sup>

As Parkinson's progresses, care needs increase. And that has a budgetary impact for NHS Boards and health and social care partnerships. About 2,035 people with Parkinson's are among the people who need the highest levels of healthcare spend in Scotland. According to Public Health Scotland, the 1 in 6 people with Parkinson's with the highest health-based care needs cost nearly £73m per year in Scotland.<sup>32</sup>

The longer that people live with Parkinson's, the higher the risk of hospital admission. People with Parkinson's are commonly admitted to hospital after a fall, or because they have an acute infection. Having access to proper Parkinson's support can anticipate issues before they develop and prevent hospital admissions. They can also delay or prevent care home admissions.



## People with Parkinson's can't wait ... for allied health professionals

The headline data for the 2022 Parkinson's Audit shows that Scotland is outperforming the UK in terms of access to essential professionals like physiotherapists, occupational therapist and speech and language therapists, with around 9 in 10 patients being able to access these when needed.<sup>33</sup>

However, feedback from health professionals across Scotland is that it is becoming much more difficult to refer patients to allied health

professional colleagues. Being able to refer to a service is not the same thing as working together to help a person holistically, and it does not mean that the service is delivered in a timely way. Professionals have told us that this is their main concern about Parkinson's services.

Feedback collected as part of the UK Parkinson's Audit 2022 confirms that when multidisciplinary care works well, it is really appreciated by people with Parkinson's:

**“ They are excellent, all round, and I hope they continue to be ready and able and and adequately resourced to continue.”<sup>34</sup>**

Person with Parkinson’s

### Access to essential professionals

Physiotherapy to help maintain movement, balance and prevent falls

Scotland 93%

UK 88%

Occupational therapy to help maintain independence, daily tasks and work

Scotland 87%

UK 82%

Speech and language therapy to help with communication and swallowing

Scotland 87%

UK 83%

However, the free text comments in the audit also reveal major concerns, such as atomised service provision:

**“ The service can appear to be disjointed - each individual service has been good, especially physio, but there doesn’t appear to be a team around the person.”<sup>35</sup>**

Person with Parkinson’s

Some people have no idea about what support is available or how to engage with services on offer. Others say that there are real issues with lack of access to professionals:

**“ Long waiting lists for support services such as occupational therapist and physiotherapist are a problem when help is needed quickly.”<sup>36</sup>**

Person with Parkinson’s

### Recommendation

NHS Boards should support Parkinson’s services to work in multidisciplinary teams, in line with the Parkinson’s UK vision for integrated multidisciplinary care.<sup>37</sup>



## Parkinson's professionals can't wait ... for action on burnout and stress

**We work closely with Parkinson's specialist professionals. Parkinson's UK Scotland is increasingly concerned to hear about growing workloads and stress that many professionals are reporting.**

Parkinson's teams have always worked hard, but as the NHS struggles to recover post-Covid-19 they are stretched like never before and staff burnout is a major risk.

Disruption to Parkinson's services and diagnostic

pathways during the Covid-19 pandemic means that people are presenting at clinics with more complex issues and physical deconditioning. Professionals - particularly doctors and allied health professionals - are also frequently deployed to cover duties other than their Parkinson's specialist roles, leaving much less capacity for their Parkinson's work.

As the Institute for Healthcare Improvement (IHI) points out, there is a catastrophic impact on staff wellbeing - and that this has a

significant knock-on effect to the quality and safety of care:

**“ Burnout, moral distress, moral injury, and compassion fatigue in the healthcare workforce continue to undercut wellbeing and mental health for healthcare workers, significantly contributing to retention challenges and staffing shortages, as well as leading to negative impacts on healthcare quality, workforce safety, patient safety, and patient experience.”<sup>38</sup>**

is little sense that these are being implemented widely and prioritised within NHS Boards. People with Parkinson’s and their families need professionals who feel safe and well at work.

Initiatives such as the IHI Framework for Improving Joy in Work, and Scotland’s National Wellbeing Hub<sup>39</sup> are positive, but siloed. There

### Recommendation

Scottish Government and NHS Boards must prioritise staff wellbeing (including work-life balance, career progression, leadership, training and fair pay and conditions) across the NHS, including in Parkinson’s teams.

Section 2

# PEOPLE WITH PARKINSON'S

**CAN'T WAIT**

...FOR TIME  
CRITICAL  
MEDICATION



## People with Parkinson's can't wait ... for time critical medication

**People with Parkinson's are at high risk of hospital admission.**

In 2022-3, there were 4,450 admissions for people with Parkinson's in Scotland - of which nearly 9 in 10 (86%) were unplanned.<sup>40</sup> This is equivalent to 1 in every 3 people with Parkinson's experiencing a hospital admission each year, although hundreds of people with Parkinson's go into hospital more than once.

Unplanned admissions are often caused by

falls and infections. People with more advanced Parkinson's or Parkinson's dementia are at the highest risk.

But although hospital-based care is often needed to heal fractures and manage infections, it can also put people with Parkinson's in harm's way. Hospitals can be dangerous places if people with Parkinson's do not get their medicines on time.

Parkinson's medication is time critical. It is dangerous if medicine is taken early, late or

missed. NICE guidance states that levodopa-based medicines must be given within 30 minutes of their prescribed time.<sup>41</sup>

Every individual with Parkinson's has their own bespoke medication regime to manage their symptoms, and tablets are taken several times a day. If they don't take their medicines at the right time and dose, they may become extremely unwell. People can:

- become unable to speak, move, swallow or pass urine
- have uncontrolled movements or pain
- experience distressing hallucinations or severe anxiety

It can take weeks to stabilise their condition, and some people never recover.

We have heard from people who were scared that they were going to die because they had not been given their medication on time. And missed doses can be fatal. In extreme cases, Parkinsonism-hyperpyrexia syndrome can be caused by missed medication. This has a mortality rate of 4% and causes long term harm to about 1 in 3 of those who develop it.<sup>42</sup> Data from NHS Scotland shows that on an

average ward, fewer than half of all Parkinson's medicines are administered within 30 minutes of their prescribed time.<sup>43</sup> The 2022 Parkinson's Audit reports that only 42% of people in Scotland's hospitals always received their medication on time.<sup>44</sup> This is inline with the rest of the UK, and has not improved over many years.

We estimate that more than 100,000 Parkinson's medications are given more than 30 minutes outside their prescribed time or missed altogether each year in Scotland's hospitals.<sup>45</sup>

Yet only a handful of adverse incidents and complaints are reported. People with Parkinson's and their families tell us that it is hard to complain - or feed back - about poor care. This is because:

- they do not want to relive a traumatic experience
- they are worried that complaining may impact on future care

We've been raising Parkinson's medication management with the Scottish Government, in Holyrood, and with key health and care bodies for many years - but progress has been slow.

**“ Fewer than half of all Parkinson's medicines are administered on time in Scotland's hospitals.”**

UK Parkinson's Audit 2022

## People with Parkinson's and their families really can't wait

They need Scottish Government, NHS Boards and leaders in professional education, clinical governance and patient safety to prioritise Parkinson's medicine administration in hospital. Delivering simple system improvements can make it much easier for

## Can't wait ... for NHS Boards to act

We're disappointed that NHS boards have not been able to prioritise Parkinson's medication management, largely because of pressures during the pandemic and recovery. We believe that mainstream NHS leadership is crucial to transforming the experiences of people with Parkinson's when they are in hospital.

Parkinson's UK has curated a range of education materials to support NHS professionals here: [www.parkinsons.org.uk/time-critical-medication-resources](http://www.parkinsons.org.uk/time-critical-medication-resources)

These include [10 Recommendations: A Guide for Your Hospital in Scotland](#).<sup>46</sup>

frontline staff to provide safe and effective care for inpatients with Parkinson's, and for others who need time critical medicines.

In 2019, we published a comprehensive set of recommendations in our [Get it on Time Scotland report](#).

We have updated our recommendations below.



### Recommendation

NHS Boards must prioritise Parkinson's medication management. Time critical medicines must be on the agenda for education, clinical governance and patient safety teams.

## Can't wait ... for inclusion in national safety initiatives

The issues around Parkinson's medicines are clear, but have yet to be centred in national clinical safety and improvement initiatives. These issues are complex and national leadership is needed.

The Scottish Patient Safety Programme has been up and running for over 15 years. It's delivered major reductions in harms - including hospital acquired infections, sepsis and falls, It has never specifically addressed Parkinson's medication, and there is no time critical medicine element in other national programmes that are part of NHS Healthcare Improvement Scotland (HIS) i-Hub improvement work.

### Recommendation

Parkinson's medications should be explicitly considered as a national priority for NHS Scotland, It should be part of the NHS HIS -i-Hub improvement work and added to the Scottish Patient Safety Programme's High Risk Medications Framework.<sup>47</sup>

## Can't wait ... for staff education

Despite some excellent initiatives by local Parkinson's specialist teams, the uptake of learning about Parkinson's medication by general ward staff is still very low in Scotland. Parkinson's

UK has curated a range of free education materials to support health and care staff. These include a [15 minute session for ward staff](#).<sup>48</sup>

All of our time critical medication resources can be found here: [www.parkinsons.org.uk/time-critical-medication-resources](http://www.parkinsons.org.uk/time-critical-medication-resources)

### Recommendation

NHS Boards must promote opportunities for all ward staff and hospital pharmacists to access the UK Parkinson's Excellence Network's free learning about Parkinson's medication.

## Can't wait ... to be able to self-administer Parkinson's medication

People with Parkinson's and unpaid carers often become experts in managing Parkinson's medicines. Yet it remains common for people with Parkinson's to arrive in hospital, or on a ward, and to have their essential medicines confiscated.

Although some people may be too unwell to self-administer their medication, many people are very able to manage. Because

many Boards do not have a supported self administration policy in place, people who are able to manage their own medication can be denied the opportunity to do so. Practice can also vary between wards and even between shifts.

People tell us that relying on busy nurses to find time to administer their Parkinson's medication at the time that they need it is disempowering and can cause great anxiety. It increases the risk that medications will be early, late or missed and that people will be put at risk.

### Recommendation

All NHS Boards must implement a medicines self-administration policy that enables people with Parkinson's to take their own Parkinson's medication if they are able and willing to do so. This should apply in all inpatient settings.

## Can't wait ... for electronic prescribing

We've been highlighting the potential of electronic prescribing - also known as Hospital Electronic Prescribing and Medicines Administration (HEPMA) - as a tool to improve time critical medicines delivery in hospitals.

NHS Ayrshire and Arran has used its HEPMA data to continuously audit Parkinson's medicine administration times for many years. Parkinson's nurses and pharmacists have

used this data to deliver targeted and general improvements throughout the NHS Board. The use of a visual alert on wards linked to HEPMA records has increased the timeliness of Parkinson's medication. This project recently won a Parkinson's Excellence Network award for Innovation in Practice<sup>49</sup> and was shortlisted for a Nursing Times award for Technology and Data in Nursing.<sup>50</sup>

A recent review found that across NHS Ayrshire and Arran, timely medication of Parkinson's medicines increased significantly after the visual alert was introduced. Before this was implemented in 2018, timely

medication administration rates were consistently below 50%. Afterwards they were consistently over 60% and in some cases over 80%.<sup>51</sup>

We are keen to see this intervention used in other NHS Scotland hospitals, but the rollout of HEPMA in other NHS Boards has been extremely slow. By mid 2023,

12 of Scotland's NHS Boards have rolled out HEPMA. The remaining two, NHS Fife and NHS Borders are not expected to have HEPMA in place until 2024 - 19 years after Audit Scotland requested a timetable for implementation in NHS Scotland.<sup>52</sup> We'll now encourage NHS Boards to prioritise Parkinson's medicines safety programmes in their HEPMA implementation.

### Recommendation

All NHS Boards should use their electronic prescribing systems to enable ongoing monitoring of Parkinson's medicines in hospital, sharing learning from NHS Ayrshire and Arran.

## Can't wait ... for an alert system

Although the majority of NHS Boards in Scotland have an alert system that informs the specialist Parkinson's team when someone with

the condition is admitted to hospital, this is not the case across the country. We'll continue to press NHS Borders, NHS Highland and NHS Lanarkshire to introduce effective alert systems that bring them into line with the rest of NHS Scotland.

### Recommendation

All NHS Boards must introduce an electronic alert system to inform local specialist Parkinson's service whenever someone with Parkinson's is admitted to hospital or changes ward.

## Can't wait ... for Emergency Departments to act

People with Parkinson's are at high risk of emergency hospital admission - and their arrival in hospital can be the point at which their medication administration starts to go wrong. Getting it right in the Emergency Department can improve people's chances of getting their medication on time during the rest of their admission.

The Royal College of Emergency Medicine is implementing a 3-year improvement programme, to make sure that people arriving in emergency departments receive time critical medication on time, every time.

In the first year it will focus on Parkinson's medicines and insulin for people with diabetes. 26 Emergency Departments in Scotland are eligible to take part and we encourage them to do so.

It also complements a resource we created with the Scottish Ambulance Service. [Our resource for ambulance crews](#)<sup>53</sup> is designed to enable them to support people with Parkinson's to get their medication on time when they're going to hospital and during transfer. This has been even more important in the light of recent pressures on ambulance response times and lengthy waiting times to admit people to A&E on arrival at hospital.

### Recommendation

All NHS Boards should encourage their Emergency Departments to take part in the Royal College of Emergency Medicine Quality Improvement Programme on time critical medicines.<sup>54</sup>

## Future initiatives

A team in NHS Grampian has been running a Quality Improvement project on Parkinson's medications management at Aberdeen Royal Infirmary. This was paused during the pandemic but has resumed and the team has been extending the project to further wards. The team have helped to develop a new guide for Charge Nurses and Ward staff to help them

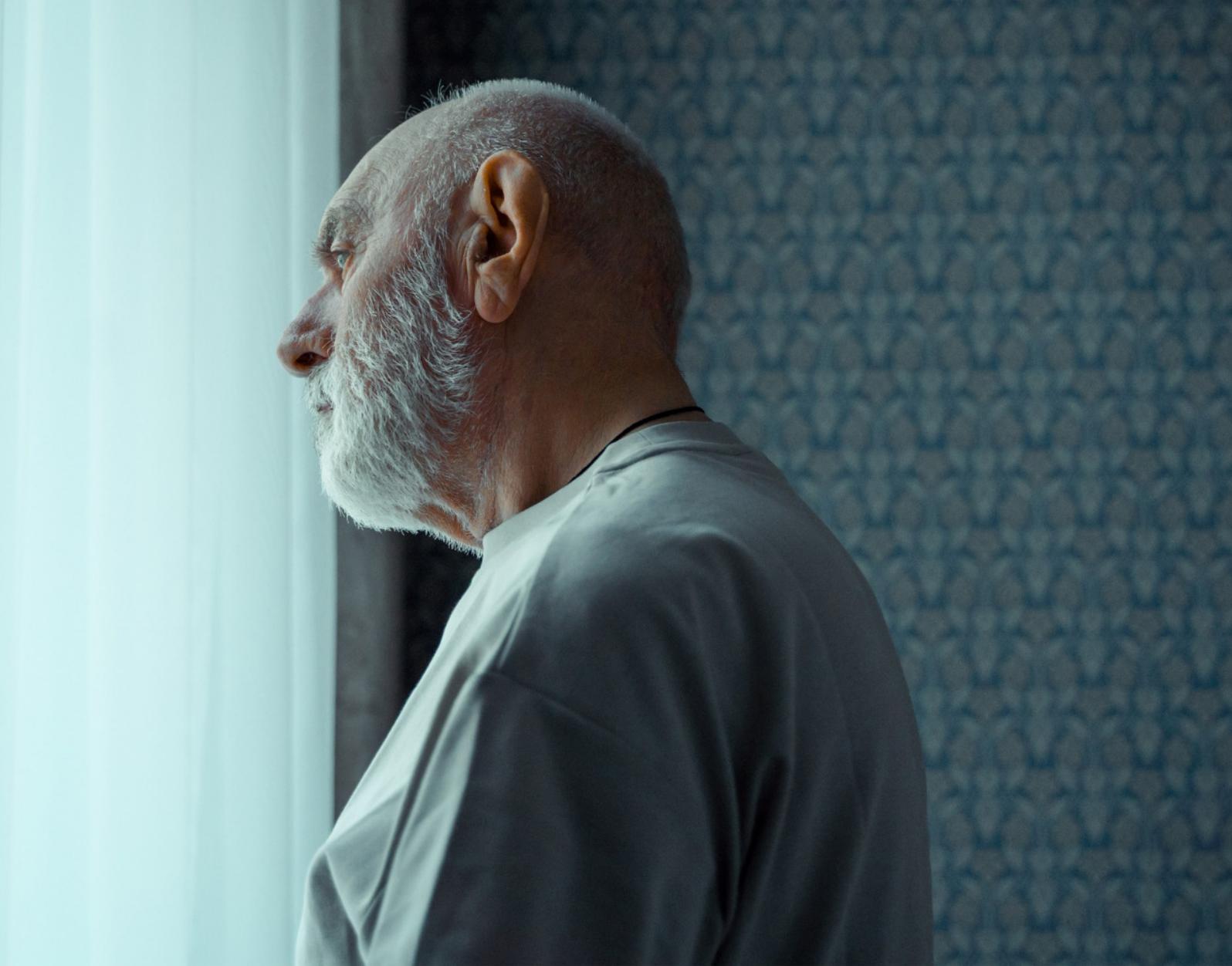
to understand what they can do to improve medications management for people with Parkinson's while they are in hospital.

We are also developing a new area of analysis as part of the UK Parkinson's Audit. This new tool will enable hospital pharmacists to audit medicines administration for inpatients with Parkinson's, and we'll use the data to suggest changes and drive improvement.

# PEOPLE WITH PARKINSON'S

**CAN'T WAIT**

...FOR MENTAL  
HEALTH  
SUPPORT



## People with Parkinson's can't wait ... for better emotional support

**Living with Parkinson's can have a negative impact on mental wellbeing. Adjusting to an uncertain future, stigmatised symptoms, changed relationships, deteriorating health, employment and financial concerns can all contribute to poor mental health.**

People with Parkinson's consistently tell us that they received little information when they were diagnosed. In the 2022 UK Parkinson's Audit<sup>55</sup>, only 7 in 10 (69.4%) of people in Scotland believed that they were given enough information at diagnosis.

This may be because appointment times are very short - some Parkinson's consultants only have 10 - 15 minutes for each appointment. Being told you have Parkinson's can be overwhelming and it is hard to take information in at that point. Having an appointment with a Parkinson's nurse within a few days of diagnosis can really help - but not all areas have this.

But some people are told that they have Parkinson's by letter or over the phone, and are left to process this information without support. We

know that the support people get when they are diagnosed has a direct impact on how well people can manage their Parkinson's in the future.<sup>56</sup> In some parts of Scotland, newly diagnosed events are offered, but it is increasingly difficult for hard-pushed Parkinson's health teams to provide these:

**“ The two-day course which my partner and I attended when first diagnosed was informative and helped me come to terms with the illness.”<sup>57</sup>**

Person with Parkinson's

Many people tell us that they needed much more emotional support at diagnosis and afterwards. NHS services for neurological conditions like Parkinson's are a long way from the kind of support in place for people with other life-changing conditions, such as cancer.

**“ When [I was] diagnosed it was over the phone, then I heard nothing for a month. I understand now why that was, but it would have been better to be told I would be contacted in a month by the Parkinson's nurse at diagnosis so I didn't feel so alone.”<sup>58</sup>**

Person with Parkinson's

### **Support for people newly diagnosed with Parkinson's**

Parkinson's UK is developing our support for people who are newly diagnosed with Parkinson's and their family, friends and carers.

Our First Steps programme is led by volunteers who live with Parkinson's. It aims to help people take the first steps in making sense of their diagnosis, and empower them to start living well with Parkinson's. It takes place over 3 sessions. We are developing plans to offer this in person as well as online. Find out more <https://www.parkinsons.org.uk/information-and-support/first-steps-programme>

Parkinson's Connect is our pioneering programme to connect with people with Parkinson's, and their families, right at the point of diagnosis. We have been piloting this work in several sites in the UK, including in Glasgow and are looking forward to rolling out the programme more widely in 2024 and beyond. Find out more: <https://www.parkinsons.org.uk/information-and-support/what-parkinsons-connect>

## Can't wait ... for mental health to be addressed

Mental health in Parkinson's is complicated. In addition to the personal issues above, mental health symptoms are part of Parkinson's. Processes inside the brain affect mental health and thinking. The side effects of Parkinson's medication can also have an impact.

Many people develop depression or anxiety before they are diagnosed with Parkinson's. As the condition progresses, medicines designed to treat motor symptoms can have a negative impact on mental health, so they need to be reduced or stopped.

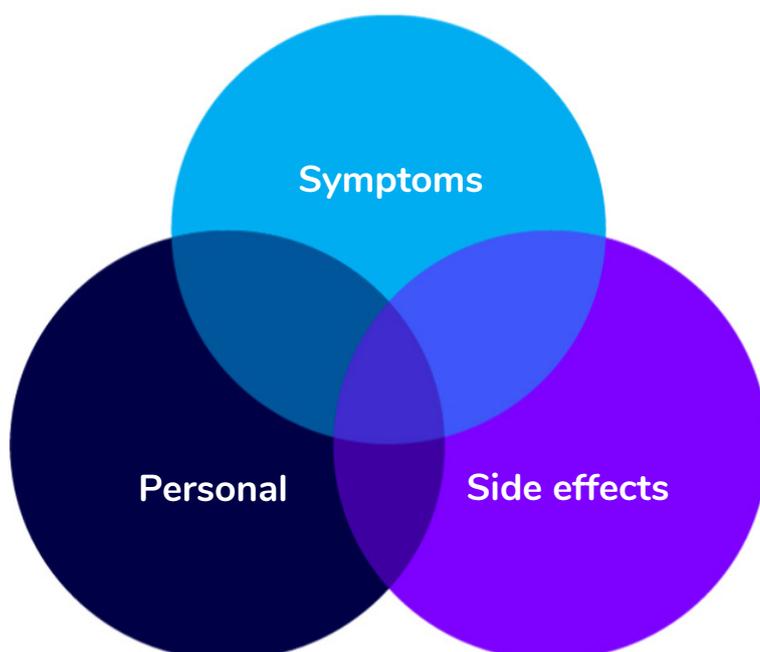
For many people with Parkinson's, and those

close to them, the impact on mental health is harder to live with than the physical symptoms of Parkinson's.

Parkinson's is classified as a "movement disorder". Treatment is typically focussed on assessing and managing motor symptoms that affect movement, posture and balance. More recently, the profound impact of Parkinson's on mental health has begun to be recognised, but symptoms are often under-identified and under-treated.

NHS Scotland services for "physical health" conditions and "mental health" conditions are often separate, with limited joint working. This is extremely unhelpful for people whose condition affects both. It is often difficult for people with Parkinson's to get their mental health symptoms assessed, identified and treated.

## Mental health and Parkinson's



### Symptoms

Anxiety, depression, hallucinations, delusions, dementia

### Side effects

Impulse control disorders, hallucinations, delusions, confusion

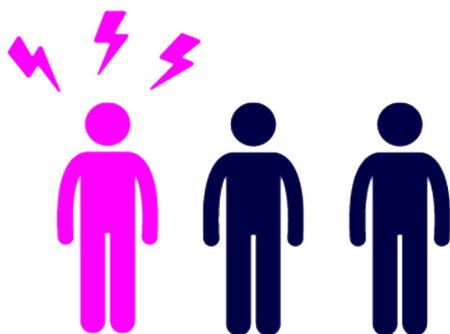
### Personal

Grief, loss, adjustment, worry, relationships, finances, work, other health conditions

## Parkinson's and mood

About three in 10 (30%) of people with Parkinson's experience anxiety,<sup>59</sup> and 4 in 10 (40%) have depression.<sup>60 61</sup>

Apathy is when someone loses their motivation to do things. It is not always associated with low mood or depression. People with apathy lose interest in activities they used to enjoy. They may have difficulties planning tasks or thinking of what to do. Between 3 and 4 in 10 (30-40%) people with Parkinson's experience apathy.<sup>62</sup>



Nearly a third of people with Parkinson's have anxiety



40% of people with Parkinson's have depression



I get anxious when I think too far ahead and create scenarios in my head of what my future might look like as my Parkinson's progresses. Then I start to question the very active lifestyle I lead and that I was convinced is helping to slow down progression of my symptoms. Is this really the case?

So now I am anxious about what the future holds, have lost my drive to do something about it, and depression sets in.

Turning up and being me has been getting more and more challenging each day although deep down I think I know this is the right thing to do while I try and get some help. Thankfully I was able to recognise this dip and have spoken with close friends and family, who have been phenomenally supportive. I now understand that this is not a sign of weakness but a sign of strength in being able to admit I need help.”

Brian, Glasgow

## Hallucinations and delusions

Hallucinations are also common – around 50-60% of people with Parkinson's will experience them at some point.<sup>63 64</sup> Many hallucinations are visual, but people may also smell, hear, feel, taste or sense something that isn't really there.<sup>65</sup>

Hallucinations can happen at any stage of Parkinson's, but are more common among people who have had Parkinson's for a while. After 20 years with Parkinson's, about 3 in 4 people (74%) will have experienced hallucinations.

Hallucinations can sometimes be triggered by Parkinson's medication, or by infections. It's important for people to tell their Parkinson's

team if they experience hallucinations. It may affect current and future treatment options.

If people are aware that their hallucinations aren't real and can co-exist with them, treatment may not be needed.

Complex hallucinations can be terrifying. People lack insight, and life becomes very difficult both for them and the people around them.

People with Parkinson's sometimes also experience delusions - thoughts or beliefs that aren't based on evidence. These can be very disturbing. Common delusions feature paranoia, jealousy or special powers. Sometimes people become convinced that their partner is being unfaithful.

## Parkinson's and impulsive and compulsive behaviours

Some people develop impulsive and compulsive behaviours as a result of Parkinson's medicines or surgery. Those affected can't resist the temptation to behave in a certain way. They will carry out an activity repetitively without thinking, even when it is no longer enjoyable.

Common impulsive and compulsive behaviours include gambling, hypersexuality, shopping and overeating, but lots of others have been reported. They can have a devastating impact on individuals, relationships and families because the person can't stop - even when the activity is harming the person or people around them.

Research about how many people with Parkinson's are affected is mixed, One recent review shows that over 4 in 10 (43%) of people taking medication for Parkinson's experience impulsive and compulsive behaviours.<sup>66</sup>

Impulsive and compulsive behaviours are particularly associated with a class of Parkinson's drugs called dopamine agonists, but can be triggered by other types of treatment too.

Anyone can experience changes in behaviour, but those diagnosed at younger ages and men in particular are thought to be at higher risk.<sup>67</sup> In one study of people diagnosed with Parkinson's under 50, nearly 6 in 10 (58.3%) experienced impulsive and compulsive behaviours.<sup>68</sup>

## How are NHS services doing in Scotland?

Clinical notes show that over 9 in 10 (91.8%) people with Parkinson's in our audited services have been asked about their mood, and a similar number (92.5%) about hallucinations.<sup>69</sup> However, these questions may be too brief to make an impact on people with Parkinson's in the context of a busy consultation. Fewer than 4 in 10 (37.4%) of people reported that they had discussed mood with their clinician<sup>70</sup> - which is worrying when so many people with Parkinson's experience anxiety and depression.

There is also some concerning evidence that people with mental health symptoms may be missed:

- Fewer than 2 in 5 (37%) of Parkinson's services use a standardised tool to assess mood
- Over 1 in 5 (22.7%) of people at risk of impulse control disorders are not routinely monitored for these side effects

The 2022 Parkinson's Audit found concerning gaps in mental health support in Scotland:

- Nearly 1 in 5 (18.5%) of Parkinson's services say they cannot refer to psychiatry or mental health services with experience in Parkinson's
- More than 3 in 10 (31.6%) of people who had tried to access mental health support could not access it

Where people with Parkinson's can access mental health support, they express very high levels of satisfaction. Half (50.8%) report that the support they receive is excellent.<sup>71</sup>

But waiting lists can be very long:

**“It took way too long to access psychiatry.”<sup>72</sup>**

Person with Parkinson's

Too often there is not a clear pathway from Parkinson's services to mental health support. Some psychiatrists, psychologists and mental

## Different perceptions of discussions of mood



**92%**  
clinical notes  
reporting  
that mood  
has been  
discussed



**37%**  
people with  
Parkinson's  
reporting  
mood has  
been discussed

health nurses are reluctant to see people with Parkinson's, because it is not a primary mental health condition. They may feel that they do not have the necessary knowledge about Parkinson's.

On the other hand, Parkinson's specialist consultants and nurses do not always have the training, skills or time to support someone with mental health symptoms effectively.

The mental health needs that arise from living with a complex neurological condition like Parkinson's are not on the agenda for mental health services in Scotland.

Mental health care is under-resourced, and as Audit Scotland has recently reported, data collection about the workforce and outcomes of services is very poor.<sup>73</sup> And the landscape is complicated. There is very limited joint working

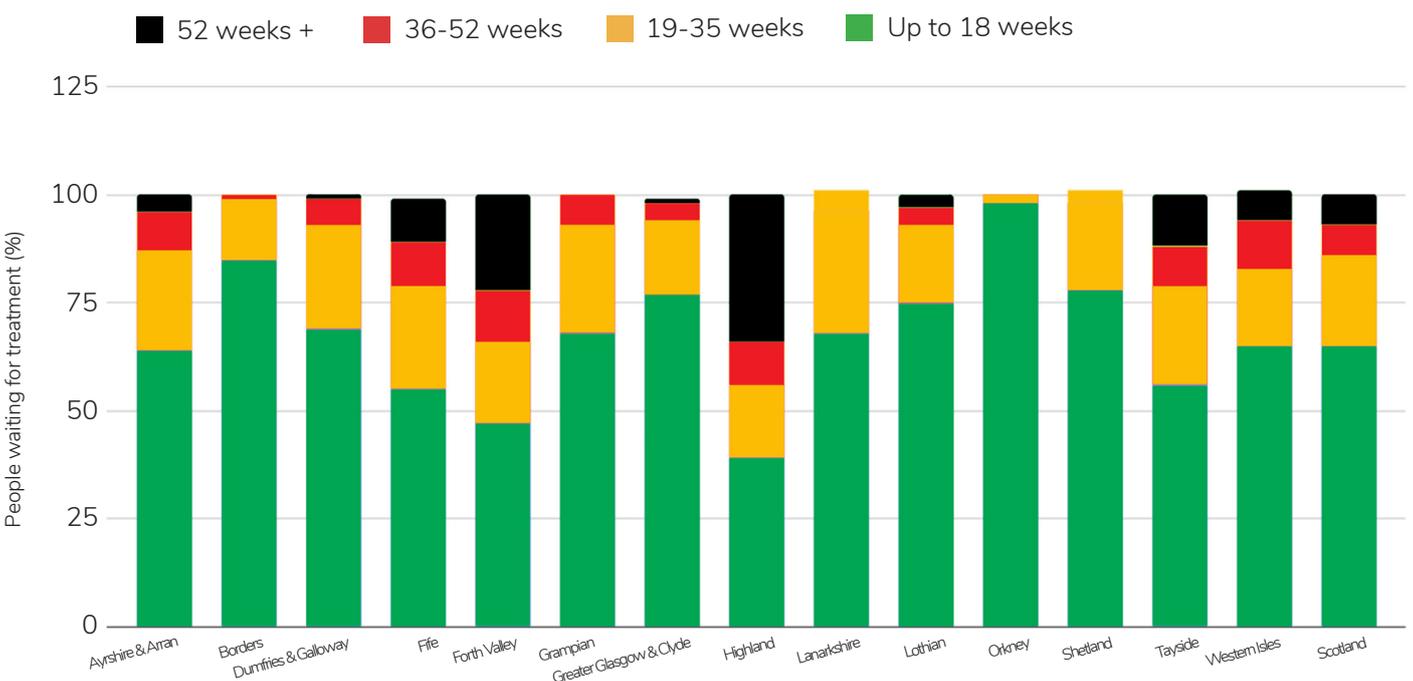
between Parkinson's services and mental health teams, although where this is in place it works well.

Most people with Parkinson's who see a psychiatrist will see a general psychiatrist or old age psychiatrist. It is very unusual to see a neuropsychiatrist - a doctor who specialises in the psychiatry of brain disorders - because there are very few of them in Scotland.

Neuropsychologists are clinical psychologists who have undertaken additional training in brain conditions and the biological factors that affect mental health. Part of their role is supporting people with neurological conditions to cope with how their condition affects their mental health, behaviour and cognition.

In June 2023, there were just 55.1 FTE neuropsychologists in Scotland, accounting for 3.4% of the overall psychology workforce.<sup>74</sup>

## Psychological treatment waiting times by NHS Board (June 2023)



People with Parkinson's are affected by long waiting times for psychological support. Data from June 2023 showed that people in many NHS Boards are waiting far longer than the Scottish Government's 18 week target. Across Scotland, over 1,500 people had waited longer than a year. In NHS Highland over a third (34%) of people had waited over 12 months. That is 383 people. In NHS Forth Valley, a similar number of people have waited over a year - accounting for over 1 in 5 (22%) of the total number of people waiting for support.<sup>75</sup>

Many people with Parkinson's who need mental health support are referred to generic services, such as cognitive behavioural therapy (CBT). But this is not tailored to the specific needs of people with Parkinson's, and practitioners are not trained to understand the complex interplays between long-term physical health conditions and mental health. These are particularly important in Parkinson's.

People with Parkinson's do not always benefit from generic support. Common issues include:

- practitioners' lack of knowledge about - and flexibility to respond to - the more complex issues that people with Parkinson's may face
- activities that are difficult for some people with Parkinson's, such as writing a mood or thought diary, speaking or concentrating for long periods of time
- misinterpreting common Parkinson's symptoms like slowness or quietness of speech, slow movement, and facial masking as mental health symptoms
- people with parkinson's being penalised for non-attendance at sessions if they are unwell or their medication is not working well

### Community-level support for mental health

At Parkinson's UK Scotland, we're keen to increase community level support for people experiencing anxiety, apathy and depression because of their Parkinson's. We're working with partners SAMH (Scottish Association for Mental Health), Glasgow Life and the online mental health service provider Silvercloud to pilot a personalised programme specifically for people with Parkinson's and those closest to them who are experiencing low mood, depression or anxiety.

The pilot is based in NHS Greater Glasgow and Clyde, with referral from local NHS Parkinson's teams and people will also be able to self refer. We hope to show that this approach can help people find strategies to cope, including tools that can improve mental health over the longer term.

In Borders, we've been working with local people to launch a men's group to help men who are living with Parkinson's to get support from each other.

Across Scotland, we offer over 45 local groups and activities, which many people report help to improve their mental health. Staying social, remaining physically active, being creative and other opportunities all help people to manage the mental health aspects of Parkinson's.

## Recommendation

NHS Education Scotland should work with Parkinson's UK to develop and deliver information and training about Parkinson's for generic mental health professionals to support them to tailor their approach.

NHS Scotland should increase its neuropsychology and neuropsychiatry workforce to meet the needs of people with neurological conditions

NHS Boards should enable and encourage joint working between Parkinson's services and mental health teams - including dedicated mental health capacity in Parkinson's teams and joint clinics

## Can't wait ... for better treatments for Parkinson's psychosis

About three quarters (75%) of people with Parkinson's will experience hallucinations or delusions if they live for more than 20 years after diagnosis.<sup>76</sup> Severe and distressing hallucinations and delusions make it incredibly challenging for individuals and those around them to manage at home. They often result in care home admissions.<sup>77</sup>

Many medicines used to treat psychosis make the motor symptoms of Parkinson's worse. There is a drug called clozapine which can treat Parkinson's psychosis without exacerbating other symptoms,

NICE recommends that all Parkinson's services should prescribe clozapine for hallucinations or delusions.<sup>78 79</sup> But clozapine is more commonly used in much higher doses to

### Hope for new treatment

Parkinson's UK is funding a groundbreaking trial into repurposing an existing low-cost medication to treat Parkinson's hallucinations. Ondansetron is already used to treat nausea in people receiving treatment for cancer. The UK-wide trial has sites in 6 NHS Boards: Forth Valley, Grampian, Greater Glasgow and Clyde, Lanarkshire, Lothian and Tayside.

treat schizophrenia. People who take it need regular blood tests to check for dangerous side effects. NHS Boards restrict prescribing to psychiatrists, and Parkinson's clinics are not set up to provide ongoing monitoring,

Only about 3 in 10 (29.6%) of NHS Parkinson's services in Scotland say that they have a

pathway to prescribe and monitor the use of clozapine.<sup>80</sup> This means that the majority of people with distressing hallucinations and delusions are unable to access a treatment that could help them.

The Parkinson's Excellence Network is working with clinicians across the UK to support local clozapine policy development.

### Recommendation

NHS Boards should work with Parkinson's clinicians to make sure that they can prescribe clozapine to people with Parkinson's who could benefit.

## Can't wait ... for better dementia support

Parkinson's dementia is not well-known or understood by many health and care professionals or services. Individuals and those close to them often miss out on well-informed support and care.

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.

About 3 in 10 (30%) of people with Parkinson's have dementia.<sup>81</sup> We estimate that more than 3,800 people in Scotland have Parkinson's dementia.<sup>82</sup>

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

### Parkinson's dementia and dementia with Lewy bodies

Parkinson's dementia is diagnosed when someone develops dementia symptoms after they have been diagnosed with Parkinson's. Dementia with Lewy bodies is diagnosed when someone develops the symptoms of dementia before or at the same time as they develop other Parkinson's symptoms. Some people with dementia with Lewy bodies, never experience motor symptoms.

In general, people with Parkinson's dementia will continue to be seen by Parkinson's teams whereas people with dementia with Lewy bodies are more likely to be managed by dementia services.

without the condition.<sup>83</sup> 15 years after diagnosis, nearly 8 in 10 people (79%) have dementia.<sup>84</sup>

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.<sup>85 86</sup>

Parkinson's dementia can have different symptoms from more common types of dementia, like Alzheimer's or vascular dementia. It is very similar to dementia with Lewy bodies, and there can be some diagnostic overlap between them.

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.

Living with Parkinson's dementia can also be particularly challenging when it develops after people have lived with Parkinson's for some time. People commonly have physical impairments, communication issues and already need help with activities of daily living before Parkinson's dementia develops.

Yet there is low awareness, even amongst people with Parkinson's and those closest to them. In our UK-wide survey of carers, fewer than half (48%) knew that people with Parkinson's were at increased risk of dementia. The majority (58%) said that earlier conversations with professionals would have helped them.<sup>87</sup>

In the 2022 UK Parkinson's Audit, almost all patients' clinical notes (94%) recorded that cognition had been asked about or



**Euan has slowly lost his fitness, his strength, his dexterity, his ability to work and run a business, his ability to sea kayak and to climb mountains, his ability to really enjoy social gatherings, his ability to drive his beloved car, his ability to plan and make fantastic things with wood. He still takes amazing photographs, but processing them is increasingly impossible.**

**And now we find we have to face the biggest theft of all... Parkinson's dementia has arrived and is here to stay, and so the stealing away becomes ever more poignant and problematic. Euan is losing his ability to concentrate, to choose words, to decide, to organise, to read, to understand, to remember how to do things or what has been said, to follow a discussion or argument, to find his way.**

**But we are lucky, we are a great team and we will face it together..."**

Katie, Ayrshire

### **Working with people with Parkinson's to develop better information on dementia.**

Dementia is hard to talk about: both for people with Parkinson's and for the professionals that support them. We want to make it easier for people to have important conversations.

We worked with University College London academics, artists, people with Parkinson's and the families to co-design information resources to enable people to talk about this taboo topic more easily. Read the materials at [www.parkinsons.org.uk/thinkingandmemory](http://www.parkinsons.org.uk/thinkingandmemory). There is also a guide for health professionals.<sup>88</sup>

assessed. Yet as with broader mental health issues, these brief interactions were not registered as significant by people with Parkinson's and unpaid carers. Fewer than a third (30.5%) said that they had discussed memory or cognition - including dementia

- in their Parkinson's appointments. This was even lower than the UK average of 33%.<sup>89</sup> Many families have told us that they felt dismissed when they tried to raise concerns about dementia with health professionals.

In the 2022 Audit, Scotland outperformed the rest of the UK in terms of future care planning. However, nearly two thirds (63%) of NHS Scotland notes did not record any discussion about Powers of Attorney (PoA). This is much better than in the rest of the UK (75%) and has increased since previous audits.<sup>90</sup> This may reflect increased focus on future care planning from the Scottish Government and NHS Scotland in recent years. However, the data shows that there is still a long way to go for Parkinson's services.

PoA is needed to enable a named person to make important decisions about finances, health and welfare on someone else's behalf if they can no longer do so. If someone can't make decisions and a PoA is not in place, it can become very complicated and expensive to take action on someone's behalf or influence decisions about their care and treatment.

### **Recommendation**

NHS Scotland Parkinson's teams should build on recent progress. They must make time to discuss memory and thinking issues with people with Parkinson's and their families, and encourage future planning including Powers of Attorney. These conversations should not wait until a person is already showing signs of dementia.

## Cant wait ... for professionals to get training on Parkinson's dementia

Health and care professionals need more training to provide effective and safe care for people with Parkinson's dementia. In a survey of UK Parkinson's health professionals, over

two thirds (68%) said they needed more training on Parkinson's dementia.<sup>91</sup> This need is reflected in families' experiences of Parkinson's care. Only 1 in 4 (25%) of unpaid carers reported that Parkinson's specialists took full account of the person's dementia - and the same proportion said that dementia was not considered at all.<sup>92</sup>

## What do carers say about Parkinson's services?

The 2023 Scottish Intercollegiate Guidelines Network (SIGN) Guideline on Assessment, diagnosis, care and support for people with dementia and their carers recommends that "All

healthcare professionals involved in a diagnosis of dementia should be competent in discussing a diagnosis of dementia and be knowledgeable about dementia."<sup>93</sup> To meet this recommendation and make sure that people with Parkinson's dementia get the informed care that they deserve, Parkinson's health professionals must have these skills and knowledge.



**25%**  
Parkinson's dementia  
fully taken into account



**25%**  
Parkinson's dementia  
mostly taken into account



**25%**  
Parkinson's dementia  
sometimes taken into account



**25%**  
Parkinson's dementia  
never taken into account

### Recommendation

Parkinson's services should have links to dementia services and vice versa. Joint clinics and other forms of partnership working should be the norm for people with Parkinson's dementia.

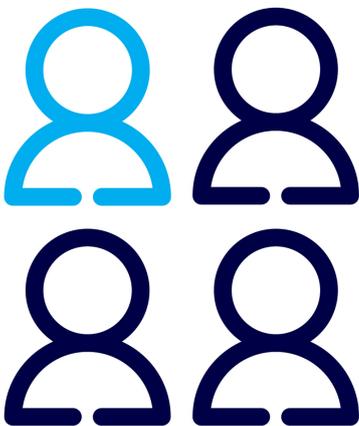
NHS Boards should ensure that Parkinson's professionals can use protected time to undertake education and training on Parkinson's dementia.

## Can't wait ... for better NHS and social care support

People with Parkinson's dementia often require high levels of care - including admissions to hospital.

Families of people with Parkinson's dementia tell us that hospital staff typically struggle to meet the specific needs of inpatients with Parkinson's dementia. Nearly half of carers (48%) said that hospital staff did not have enough knowledge to provide the care that someone with Parkinson's dementia needs in hospital.

Unpaid carers had even less confidence in social care staff. Only 1 in 4 unpaid carers (25%) said that they believed that workers providing care in the person's own home understood Parkinson's dementia.<sup>94</sup>



**1 in 4 unpaid carers said they believed that workers providing care in the person's own home understood Parkinson's dementia**

Researchers looking at care home staff in Scotland and England, found that workers reported high confidence in knowing about dementia generally, but had low confidence about Parkinson's



**While my husband was at home he had his name down for day care, but places at centres that could cope with his disabilities were few so he did not access day care before his admission to a home. To give me some respite visiting carers were assigned to come to our home, with limited success, due to the lack of understanding of Parkinson's dementia.”<sup>95</sup>**

Person with Parkinson's

**...communication can become very limited, physical contact, acts of caring become the essence of the relationship, which makes handing over your loved one to a care home very hard.”<sup>96</sup>**

Person with Parkinson's

dementia issues, especially hallucinations, medication and sleep disturbance.<sup>97</sup> This can make it difficult to find a care home place or a short

break setting. Unpaid carers may be unwilling to take a place that does not meet the needs of the person that they support.

### Recommendation

The Scottish Government, NHS Education for Scotland and the Scottish Social Services Council should make sure that standard dementia training modules for health and social care workers include information on the specific issues faced by people with Parkinson's dementia.

## Can't wait ... for better data on Parkinson's dementia

People with Parkinson's and their families need a health and care system that knows how many people have Parkinson's dementia, and can provide the services that they need.

NHS Scotland holds very limited data on dementia. The data it publishes about the number of people with dementia does not

include those who do not have a formal diagnosis. Neither does it break down different types of dementia, which makes it impossible to identify whether there are gaps in diagnosis for different types of dementia or to plan the right services.

The Scottish Government's 2023 Dementia Strategy made a commitment to finding out how many people are living with dementia in Scotland, including the type or types of dementia they have.<sup>98</sup> But it remains to be seen whether this will be delivered.

### Recommendation

NHS Scotland should collect and publish information on how many people have a dementia diagnosis and the type that they have, including Parkinson's dementia.

Since 2017, everyone with a dementia diagnosis in Scotland is entitled to a year of post-diagnostic support. Yet in 2020-21, only about 1 in 3 (33.7%) of eligible people accessed it.<sup>99</sup>

Families of people with Parkinson's dementia often tell us that they were not told about this support. Those who do not access mainstream dementia services may be more likely to miss out. Our local advisers can signpost people to local post diagnostic support if people with dementia come to us. People may feel that services branded for Alzheimer's are not relevant for them if they have Parkinson's dementia.

### **Parkinson's carers can't wait for support**

Parkinson's does not only affect the person with the diagnosis. Everyone close to them feels the impact too.

As Parkinson's progresses, people require high levels of personal care. Much of this care is provided by partners, relatives or close friends - so called informal or unpaid care. This can include help with getting up, eating, drinking, dressing, washing and toileting as well as support with communication, changes to behaviour, mental health or cognitive symptoms.

Typically unpaid carers of people with Parkinson's dementia provide care for 12 hours a day, 7 days a week, and over 1 in 3 (36%) provide care for 20-24 hours each day.<sup>100</sup> The night-time issues for people with Parkinson's dementia cause particular issues in terms of care provision. The lack of night-time care can drive exhausted carers to the brink.

It can be relentless. No wonder that unpaid carers of people with Parkinson's experience higher rates of mental and physical ill health.

### **Recommendation**

Data on those who access post-diagnostic support should include take up by dementia subtype, to identify and address inequalities in access to post-diagnostic support for people with different types of dementia.

## Parkinson's UK Scotland

We're the Scotland team of the largest European charitable funder of Parkinson's research. We know we're close to major breakthroughs. By funding the right research into the most promising treatments, we get closer to a cure every day.

Until then, we're here for everyone affected by Parkinson's. Fighting for fair treatment and better services. Making everyone see its real impact.

Our Scotland team is home-based in communities across the country. We have over 45 volunteer-led local groups providing friendship and support to people living with Parkinson's. We're helping to support hundreds of people with Parkinson's to be more physically active, as well as supporting creative and social opportunities across Scotland.

We're working with the Parkinson's community to deliver support for unpaid carers, improve mental health, and provide services for people of working age, and those in Scotland's remote and rural communities.

Our 4 local Research Interest Groups keep people in touch with Parkinson's research.

Our team of Parkinson's local advisers provide free and confidential information, advice and emotional support to people with Parkinson's, their families and friends.

We also work with health and care professionals, decision makers, researchers, funders and supporters to change things for the better,

For more information, please visit our website, [www.parkinsons.org.uk/scotland](http://www.parkinsons.org.uk/scotland) or contact us at [scotland@parkinsons.org.uk](mailto:scotland@parkinsons.org.uk)



## Parkinson's Excellence Network

The Parkinson's Excellence Network brings together health and social care professionals, people with Parkinson's and unpaid carers to transform Parkinson's care. It enables people across Scotland and the UK to develop and share skills, training and tools and reduce unnecessary variation in practice.

In Scotland, more than 300 health and care professionals are members of the network, and

there are 3 regional groups, covering the West, South and East and North.

For more information, please visit our website, [www.parkinsons.org.uk/professionals](http://www.parkinsons.org.uk/professionals)

Our work with the Excellence Network in Scotland is led by Mary Ellmers and Sam Matson. Please contact us at [scotland@parkinsons.org.uk](mailto:scotland@parkinsons.org.uk)

## UK Parkinson's Audit

Since 2009, Parkinson's UK has coordinated a UK-wide audit to measure the quality of NHS care for people with Parkinson's. The audit now runs every 2 - 3 years.

The clinical lead for the UK Parkinson's Audit is Dr Anne Louise Cunnington, Consultant in medicine for older people in NHS Greater Glasgow and Clyde.

Services led by consultants, Parkinson's nurses, occupational therapists, physiotherapists and speech and language therapists who care for people with Parkinson's are able to take part.

Each service uses patient record data to measure the quality of the service against international best practice. And people with Parkinson's who use the service are invited to complete a Patient Reported Experience Measure (PREM) survey.

Parkinson's UK works with each service to develop and deliver a Service Improvement Plan based on their data, and the overall data enables us to agree national priorities for service improvement.

In 2022, in Scotland:

- 47 services took part from 11 NHS Boards
- Information from 859 patient records was considered
- 666 people completed the PREM survey

You can see reports, data and visual display dashboards from the 2022 Parkinson's Audit at [www.parkinsons.org.uk/audit](http://www.parkinsons.org.uk/audit)

The next UK Parkinson's Audit will take place in 2025.

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**We are Parkinson's UK in Scotland.  
Powered by people.  
Improving life for everyone affected  
by Parkinson's.  
Together we'll find a cure.**

**PARKINSON'S<sup>UK</sup>**  
SCOTLAND

Free confidential helpline 0808 800 0303  
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Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom, a charity registered in England and Wales (258197) and in Scotland (SCO37554).