



appg
on Parkinson's



Mental health matters too

Improving mental health services for people with Parkinson's who experience anxiety and depression

May 2018

Executive summary and recommendations

While the physical symptoms of Parkinson's such as tremor, slowness of movement and rigidity are familiar, less attention has been paid to associated mental health and cognitive symptoms such as psychosis, impulsive and compulsive behaviours, hallucinations, mild cognitive impairment, dementia, anxiety and depression.

The All-Party Parliamentary Group (APPG) on Parkinson's has chosen to focus this inquiry on access to psychological support for people with Parkinson's who experience anxiety and depression, due to the commonality of the symptoms and the impact on quality of life.

People with Parkinson's often report anxiety or depression as the most distressing aspect of their condition. At any given time, up to 40% of people with Parkinson's will have significant symptoms of depression¹ and up to 31% of people with Parkinson's will experience significant symptoms of anxiety². Therefore the mental health needs of people with Parkinson's cannot continue to go unheard.

This inquiry heard from people with Parkinson's and health professionals who are united in their dissatisfaction with the current state of mental health services for people with the condition.

We found people with Parkinson's have waited months and in some cases years before seeing a mental health professional after the problem was identified. And difficulties with diagnosis are compounded by a lack of guidance for health professionals.

We know early intervention is key to treating anxiety and depression, yet complexities in the referral process, including having to refer people back to their GP, has created further unnecessary delays.

A historical and false divide between physical and mental health services has led to people with Parkinson's experiencing disconnected care. We heard from professionals describing communication barriers between departments, difficulties accessing patient notes, and a shortage of mental health professionals with the knowledge and skills to meet the specific needs of people with Parkinson's. However, there are pockets of best practice, where physical and mental health professionals are working together to deliver person-centred holistic care.

When people have accessed mental health services, they often experienced inadequate care not tailored to their needs as a person with Parkinson's. Under-resourcing of mental health care, combined with a move away from centralised specialist care to community services focused on recovery, has led to specialists such as neuropsychologists and neuropsychiatrists being few and far between. This has left many people with Parkinson's accessing generic Improved Access to Psychological Therapies (IAPT) not tailored to their needs.

To tackle the challenges presented in this inquiry, the APPG on Parkinson's makes the following recommendations:

NHS England and Public Health England should:

- commit to establishing a working group involving strategic partners to investigate new datasets (including access to mental health services, workforce, treatments offered and waiting times) for people with Parkinson's experiencing mental health problems, such as anxiety or depression
- work with local health bodies to implement agreed new datasets

This improved data collection will assist with designing and delivering better services, which will lead to better outcomes for people with Parkinson's.

The National Institute of Health Research should:

- fund more research on mental health interventions for people with Parkinson's, to understand what the most effective treatment options are for anxiety and depression

NICE guidance on Parkinson's should:

- be updated to reflect effective evidence-based interventions for the treatment of depression and anxiety in people with Parkinson's

More research on effective treatments for anxiety and depression and better guidance for health and care professionals will improve practice and support for people with Parkinson's.

Clinical Commissioning Groups (CCGs) should:

- work with current Parkinson's services to integrate multidisciplinary teams to include mental health professionals (dedicated sessional time from both psychology and psychiatry) to upskill and work with the rest of the team

NHS England should:

- expand the current 'early implementer' projects that integrate Improving Access to Psychological Therapies (IAPT) with physical healthcare to include projects including people with Parkinson's

Taking a holistic, person-centred approach to care with joined-up services will better meet the mental health needs of people with Parkinson's.

Employers of staff treating people with Parkinson's using cognitive behavioural therapy (CBT) should:

- ensure that appropriate Parkinson's learning is available and has been undertaken. An example of this learning could be *Understanding Parkinson's for health and social care staff* – available free of charge from the UK Parkinson's Excellence Network

Health Education England (HEE) should:

- further develop *Training for long term conditions for Improving Access to Psychological Therapies (IAPT) therapists* to include information on how to support people with Parkinson's experiencing anxiety and depression

The UK Parkinson's Excellence Network should:

- set up a mental health hub to support these recommendations and improve and share best practice within the Parkinson's community, including examples of integrated physical and mental healthcare pathways

Building understanding of the specific needs of people with Parkinson's, sharing best practice and fostering collaboration between physical and mental health professionals will ensure mental health services meet their needs.

Carers and family members should:

- be supported in addressing their own mental health concerns by professionals, and should be signposted to Parkinson's UK support services

Recognising and addressing the mental health concerns of carers and family members, and signposting them to Parkinson's UK, will ensure they receive support to live with the condition.

Written by Parkinson's UK on behalf of the APPG on Parkinson's.

Foreword

As someone whose father had Parkinson's, I know the importance of having the right support at the right time, as well as the impact this can have on the person with the condition and their family.

This inquiry considered the access to services and support, primarily in England, for people with Parkinson's who experience anxiety and depression.

As Co-Chair of the All-Party Parliamentary Group on Parkinson's, and Chair of the oral evidence sessions, I was alarmed to hear how little mental health support people with the condition receive. And I was saddened to hear the effect this has on them and their families and carers.

It was interesting to hear from professionals about the challenges they face when trying to treat their patients with Parkinson's and address their mental health needs too.

I was, however, encouraged that there are pockets of good practice. But it is now vital that the NHS and decision-makers take the recommendations in this report forward to improve the mental health services provided to people with Parkinson's.

This report outlines the evidence the inquiry received and makes robust recommendations to government departments with responsibility for health services, the NHS and commissioners of local health services.

I would like to thank all of those who submitted written evidence to the inquiry, and all the witnesses who came to Parliament to speak in front of the inquiry panel.

In particular, I thank the people who gave personal accounts of trying to access mental health support and the difficulties that they faced.

I trust this report will help Parkinson's UK in its work campaigning for improvements to mental health support received by people with Parkinson's.

And I hope that the various systems in the UK will act to ensure people get the support they need, when they need it.

Baroness Gale

Co-Chair, All-Party Parliamentary Group on Parkinson's



Up to 40% of people
with Parkinson's will experience
significant symptoms of depression

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About Parkinson's

Parkinson's is a progressive, fluctuating neurological disorder that affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely.

There are also other issues such as tiredness, pain, anxiety, depression, dementia, hallucinations and continence problems, which can have a huge impact.

The severity of symptoms can fluctuate rapidly during the day, including sudden 'freezing'. There is no cure.

Parkinson's affects about 145,000 people in the UK. While the majority of people develop symptoms after the age of 65, thousands of working-age people are also affected³.

About the All-Party Parliamentary Group on Parkinson's (APPG)

The All-Party Parliamentary Group (APPG) on Parkinson's was established in June 2008. It is a cross-party group of MPs and peers with an interest in Parkinson's.

The aim of the APPG is to raise awareness of the condition among parliamentarians, and to influence legislation and policy makers, to improve the lives of people affected by Parkinson's.

The APPG is chaired by Madeleine Moon MP and Baroness Gale. It meets several times each year, and focuses on specific issues of importance to people with Parkinson's and their families and carers. Parkinson's UK acts as the secretariat to the APPG.

Background to the inquiry and assessment of current policy context

Mental health and Parkinson's

Mental health problems are common in people with Parkinson's and can have a huge impact on their quality of life. Currently, mental health is often overlooked and neglected, with treatment and support focusing on the movement related symptoms of Parkinson's.

Good care for people with Parkinson's means addressing a range of different needs, including mental health, without which people may struggle to take control, impacting on all aspects of their life.

Research suggests that, at any given time, up to 40% of people with Parkinson's will have depression⁴ and up to 31% will experience anxiety⁵. This is high compared with the general population, where one in six (17%) experience a common mental health problem such as anxiety or depression⁶.

There are many factors that may contribute to anxiety or depression in Parkinson's. Firstly, either condition can be caused by the reaction to an initial diagnosis, as well as the changes people experience as the condition progresses.

However, research suggests that anxiety and depression can also be clinical symptoms of Parkinson's, just as tremor or slowness of movement are caused by changes to chemicals in the brain.

Although the exact causes of depression in Parkinson's are not known, it is believed changes in brain structure, signalling by

neurotransmitters and levels of inflammatory and neurotrophic factors contribute to its development⁷.

Some people with Parkinson's may also experience heightened anxiety when they are 'off'. When a person takes their medication, their symptoms can improve.

But these symptoms can sometimes recur before the next dose is due, causing a person's condition to fluctuate – which is known as 'wearing off'.

If people go 'off' and have difficulties moving, it can make them feel anxious or result in a panic attack.

People with Parkinson's may not know why they have become depressed or anxious.

They may look back over the years and realise they developed these symptoms prior to the onset of movement related symptoms, such as tremor, which then led to a diagnosis of Parkinson's.

Depression is a common symptom of other conditions, including long-term conditions.

However, evidence suggests that depression is more frequent in people with Parkinson's⁸. Despite this, there have been no attempts at a policy level to address the mental health needs of people with Parkinson's.

It is also these neurobehavioral problems that may prevent someone with Parkinson's, as well as friends, family and carers, from coping effectively with the condition. In fact, people often report depression or anxiety as the most disabling aspects of Parkinson's⁹.

"I get very anxious about anything new – meeting new people, travelling to a new place – the stress then impacts on my Parkinson's symptoms. I also can get depressed – the physical impact of Parkinson's makes it difficult for me to go out on my own, or to complete tasks in the house that I used to be able to do – sometimes leading to frustration, loneliness and depression. My wife still works full time, and has to make most of the financial decisions as I can have difficulties with passwords/technology etc."¹⁰

Person with Parkinson's

Parkinson's UK undertook a survey of people affected by Parkinson's across the UK, which ran between March and May 2017. A total of 745 people responded to the survey, sharing their experiences of how mental health problems have had an impact on their quality of life and movement related symptoms, as well as what support they have received.

The survey showed that 70% of respondents with Parkinson's felt their mental health impacts on their quality of life¹¹. Further findings show how mental health problems impact on people's quality of life:

- Over 70% of respondents stated their mental health has affected their ability to socialise with others.
- Nearly 50% reported finding it harder to leave the house because of their mental health.
- Over 50% believed their mental health has negatively affected their relationships with friends and family.
- 27% shared that they have felt suicidal.
- 39% felt they were dependent on others to make decisions for them.
- Nearly 30% reported that they have stopped exercising.

Research suggests that people experiencing Parkinson's and depression or anxiety have poorer health outcomes, with reduced quality of life, poor functional status and worsened cognition¹².

Depression and anxiety are key determinations of quality of life for the person with Parkinson's, as well as friends and family.

About the inquiry

The inquiry focused on access to psychological support for people with Parkinson's who experience anxiety and depression.

While acknowledging people with Parkinson's may experience several mental health and cognitive symptoms as part of their condition (including psychosis, impulsive and compulsive behaviours, hallucinations, mild cognitive impairment and dementia), anxiety and depression are some of the most common mental health symptoms that significantly impact on a person's quality of life.

Parkinson's UK launched the inquiry by seeking evidence through:

- a survey for people affected by the condition – it was live from 22 June to 25 August 2017 and 311 people with Parkinson's completed it
- a survey for professionals – it was live from 22 June to 25 August 2017, and 17 professionals completed it
- an open call for written evidence from professionals, people affected by Parkinson's and professional organisations – 26 submissions were received
- oral evidence sessions in Parliament with a person with Parkinson's, professionals and professional organisations – six sessions took place in October 2017

Mental health services and support for people with Parkinson's in Northern Ireland, Scotland and Wales

The evidence, analysis and recommendations in this report refer to England. To set the report within the wider context of the UK, this section explores the policy landscape around mental health services in Northern Ireland, Scotland and Wales.

Northern Ireland

Northern Ireland has high levels of mental ill health, which are estimated to be 25% higher than those in the rest of the UK¹³. The country has the highest incidence of self-harm and suicide in the UK¹⁴ and has significantly higher antidepressant prescribing costs per capita than any other area in the UK¹⁵.

The *Bamford Review*¹⁶ aimed to address Northern Ireland's wide range of mental health needs and for many signalled a new era for the provision of services. However, since its publication in 2007, there has been very limited research on the impact of policy, the costs involved and service users' experiences of services.

Also, there has been little research on mental health professionals' perspectives on the effectiveness of the services they provide.

A progress review of the *Bamford Review* in 2015¹⁷ highlighted several significant gaps and limitations. These included problems arising from the fragmentation of services that have created difficulty for both service users and carers to access appropriate services to meet their needs.

It also identified a vacuum in leadership post-Bamford, and there had been a loss of focus, drive and ambition for service improvement.

Up to 31% of people
with Parkinson's
will experience significant
symptoms of anxiety



In 2016, the Bengoa panel (an expert panel behind the review of Northern Ireland's health service chaired by Professor Rafael Bengoa) published a report called *Systems, not structures – changing health and social care*¹⁸.

In response to this, another report was published called *Health and Wellbeing 2026: Delivering Together*¹⁹ – with a commitment by the Department of Health to achieve parity of esteem between physical and mental health.

In 2017, an additional £50million funding for mental health services in Northern Ireland was announced by the UK government, although this has not yet been put in place.

However, with a lack of funding and government, currently none of Northern Ireland's health trusts are meeting their waiting-time targets for people with mental health problems, according to the Health and Social Care Board. Without additional investment, there is a high risk of continuing breaches of the 13-week target²⁰.

A shortage of neuropsychologists and neuropsychiatrists in Northern Ireland, with long waiting lists for any specialised services available, means people with Parkinson's accessing mental health professionals are seen by generalist practitioners who may not have any knowledge of Parkinson's²¹.

This can also lead to issues around contraindications of medication for mental health issues and how they interact with Parkinson's medication.

Anecdotally, people with Parkinson's in Northern Ireland have reported living with low mood but not knowing how to access professional help.

A lack of statistical information or gathering of robust data means it is hard to quantify how far reaching the issue is.

There is also no clear care pathway for Parkinson's in Northern Ireland. Discussion with healthcare professionals highlights the clear need for psychological input on multidisciplinary teams working with people living with the condition.

Scotland

NHS Healthcare Improvement Scotland (HIS) – the special health board responsible for delivering better quality health and social care for everyone in Scotland – has developed a set of Clinical Standards for Neurological Health Services.

These specify that neurology services should have access to integrated neuropsychology and neuropsychiatry services and specialist neuropsychological assessment and rehabilitation, and that mental health professionals should input into the Parkinson's multidisciplinary team.

NHS HIS is currently working to revise these standards.

Anecdotally, access to mental health support for people with Parkinson's is limited in most parts of Scotland. It is very rare for psychiatry and psychology to work together in an integrated team in secondary care, which is where Parkinson's services are based.

General access to psychological therapies is challenging in Scotland. Currently, only 77%²² of people can access psychological therapies within 18 weeks, against a national target of 90% being seen within 18 weeks.

People with Parkinson's may not be counted within this target, as Parkinson's is not defined as a mental illness or disorder.

This is likely to contribute to longer waiting times for people with Parkinson's, as managers will prioritise resources to services that contribute to performance against targets.

In most areas, there is no clear pathway from Parkinson's services to mental health support, so a general referral is made.

Some psychiatrists and mental health nurses are reluctant to see people with Parkinson's because they do not have the necessary knowledge about the condition and medication.

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

A recent report released by Scottish Care²³ about the mental health of social care users highlights older service users are often affected by mental health concerns not picked up by the NHS.

The report indicates that care plans address physical issues like washing, dressing or eating but don't generally address a person's mental wellbeing.

Those supporting individuals who access social care say older people's mental health problems should be better recognised, and resources allocated to address them should improve.

They also acknowledge gaps in the current social care workforce's skills, and in ensuring staff have the correct level of support, greater emphasis on multidisciplinary working, and maximising the potential of self-directed support.

Wales

Policy frameworks in Wales offer ample opportunities to address the mental health and wellbeing of the population through the Well-being of Future Generations (Wales) Act 2015²⁴ and the Together for Mental Health Delivery Plan 2016-2019²⁵.

More specifically, the Neurological Conditions Delivery Plan 2017-2020²⁶ highlights the importance of psychological and psychiatric support services for people living with a neurological condition and their families.

The plan outlines investments that have been made in neurorehabilitation. However, it also acknowledges that these have not solved the significant gaps in psychological and neuropsychiatric support available.

While the plan notes the need for these services, including opportunities for self-referral, importantly, it does not present clear actions to outline how the Welsh Government will address the significant gaps in neuropsychology and neuropsychiatry services that are present across Wales.

In recognising this, it is also important to acknowledge good practice. For example, at the time of writing this report, Aneurin Bevan University Health Board, is recruiting a specialist nurse post to cover Parkinson's and dementia (which will be pump-primed by Parkinson's UK).

This will be the first post of its kind in Wales and one that will enable greater focus on the mental health needs of people using the service, including the management of anxiety and depression.

Rates of Parkinson's are growing and are projected to increase in Wales as the population ages²⁷. At present, a quarter to a half of people with Parkinson's in Wales also experience serious psychiatric disorders²⁸.

A key concern is that Wales NHS does not operate a Parkinson's specific pathway. At policy level, Parkinson's is addressed as one of the many neurocognitions, as per the Neurological Conditions Delivery plan.

At operational level, Parkinson's services are split between Neurology and Care of Older People.

While there is an acceptance that transdiagnostic services in neuropsychology and neuropsychiatry may be the most efficient arrangement²⁹, this lack of service integration, coupled with a shortage in specialist clinical staff, significantly dilutes the possibilities of accessing holistic mental health services to meet the specific needs of people living with Parkinson's in Wales.

Current policy context in England

The NHS Constitution in England includes a commitment to achieving "parity of esteem" to ensure the system can "improve, prevent, diagnose and treat both physical and mental health problems with equal regard"³⁰.

The *Five year forward view for mental health* highlights that people with long-term physical illnesses suffer more complications if they also develop mental health problems.

This increases the cost of care by an average of 45%³¹. Conversely, by treating a person's mental health concerns, this saves an estimated £1,760 in annual expenditure on physical healthcare costs³².

In a patient experience survey conducted by the Neurological Alliance in 2016, only 19% of respondents rated mental health services as 'good' or 'excellent' compared to 45% for physical health services³³. To date, this has been unaddressed and there has been no consideration of how 'parity of esteem' applies to people with Parkinson's.

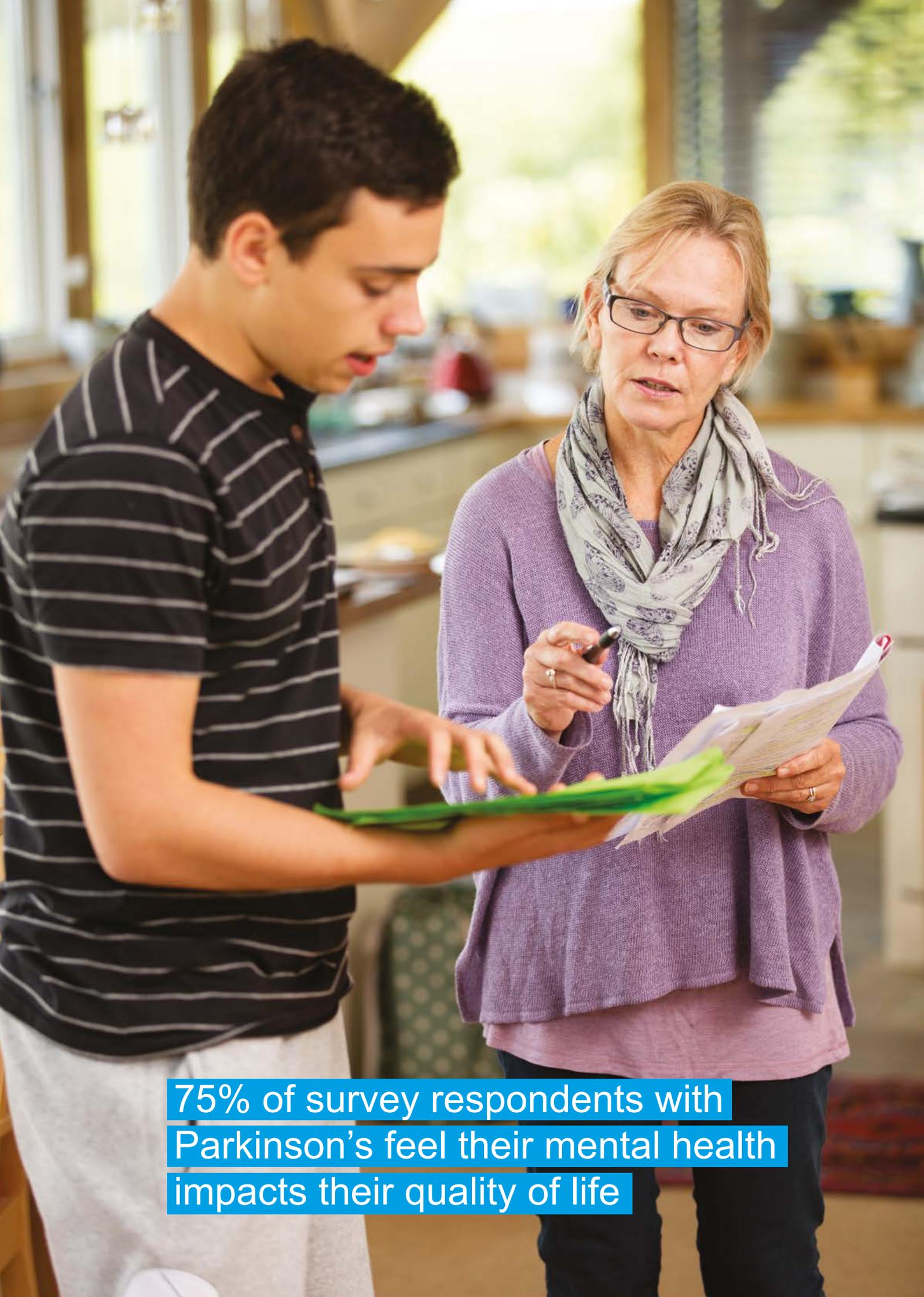
The recently updated Parkinson's NICE guideline was a missed opportunity with no specific recommendation around how to treat people living with Parkinson's and mental health problems³⁴.

Instead, they simply refer to existing NICE guidelines on depression in adults with a chronic physical health problem.

A recent NHS England and NHS Improvement publication recognises the limitation of guidance for anxiety and depression comorbid with a long-term condition³⁵.

This isn't acceptable when other guidelines for neurological conditions include recommendations to provide annual or regular screening for cognitive, emotional or mental health problems.

For example, the NICE guidance for multiple sclerosis includes anxiety and depression as symptoms to be assessed as part of an annual comprehensive review³⁶.



75% of survey respondents with Parkinson's feel their mental health impacts their quality of life

Inquiry findings

What mental health services are like for people with Parkinson's

“Anxiety is the single worst thing that I suffer and exacerbates all other symptoms exponentially.”³⁷

Person with Parkinson's

People often report depression or anxiety as the most disabling aspect of Parkinson's³⁸. The evidence gathered through this inquiry has exposed the difficulty people with Parkinson's face in accessing quality mental health care tailored to their specific needs.

People with Parkinson's and healthcare professionals are united in their dissatisfaction with the current state of mental health services in England. 'Poor', 'limited' and 'postcode lottery' were just some of the words used in the submissions from people with Parkinson's³⁹. 'Patchy at best'⁴⁰, 'huge gaps in service provision'⁴¹ and 'far from what it needs to be'⁴² emerged from health professionals' evidence.

The inquiry heard examples of people with Parkinson's receiving care from professionals operating as part of a multidisciplinary team, as well as cases of people receiving support from individual departments operating in isolation.

It was felt by many that providing holistic, person-centred care – which we know is crucial for people with Parkinson's – is most effectively delivered through a multidisciplinary team approach⁴³.

At present, many multidisciplinary services don't have access to mental health services⁴⁴. A Neurological Alliance report found that across many neurological conditions, specialist neuropsychological and neuropsychiatric support is not available as part of a

multidisciplinary team, despite the high prevalence of mental health problems among people with neurological conditions⁴⁵.

This is reflective of a similar aspiration in the *Five year forward view for mental health* for people with severe mental health conditions who are not having their physical care needs met. The aim is that: “Mental health services will be delivered by multidisciplinary integrated teams, with named, accountable clinicians, across primary, secondary and social care.”⁴⁶

In the absence of a team-led approach, people living with Parkinson's have reported experiencing a disjointed and fragmented approach to their care. They are often required to attend multiple appointments and retell their story several times due to poor communication between staff and across individual hospitals. This leads to further distress for the person with Parkinson's, their family and carers.

“Parkinson's patients have fed back to me that there is no single care co-ordinator who looks after their mental healthcare, social care and physical care. It is just up to them and their GP, who might be a locum, or who they don't really know, and they are struggling.”⁴⁷

James Sparkes, Long-term Conditions Lead at North East Essex Improving Access to Psychological Therapy (IAPT)

A Parkinson's Disease Nurse Specialist Association survey of 95 of their members in 2017 from across the UK found that where services are available, episodes of care are often short and aimed at crisis intervention being reactive rather than proactive⁴⁸.

There is a systemic lack of integration between physical health and mental health services meaning people with Parkinson's often find themselves 'lost in the system'. This is further complicated by variation in inclusion and exclusion criteria between the different mental health and physical health services⁴⁹.

Existing good practice

There are some examples of good, even excellent, practice. Some health professionals indicated that they could draw a colleague from another specialism into a clinic at short notice. The multidisciplinary team from the Specialist Assessment and Rehabilitation Centre in Derby can be credited with offering straightforward access to appropriate mental health care⁵⁰.

People with Parkinson's are given a direct referral by their consultant or Parkinson's nurse, rather than being referred back to their GP, as is often the case elsewhere in the country⁵¹.

At the Parkinson's Advanced Symptoms Unit in Teesside, there is a community-based, rapid access multidisciplinary service for people with Parkinson's. There are flexible appointments, a clinic every Wednesday and short response times. Slots are deliberately left each week for people who ring the helpline and need to spend more time on a certain issue⁵².

Unfortunately, this service which integrates a mental health practitioner into a multidisciplinary Parkinson's team is the exception rather than the rule. Dr Neil Archibald, Consultant Neurologist in Teesside, said: "We are unusual in the personnel we have for our team and a little unusual in how we set the service up."⁵³

The relative of a person with Parkinson's, and a user of his service, said to Dr Archibald: "We have had more advice and support in two hours than we had in the previous two years. Dad was confused, depressed and having many hallucinations. We felt the care he received was disjointed and there was no continuity. There was a lack of knowledge about Parkinson's."⁵⁴

The Derby team suggests that their example of holistic, stepped care and integration between services be expanded and standardised. This service was driven by the professionals within

it rather than being directly commissioned to work in this way.

The inquiry also heard evidence from the multidisciplinary team in Derby on how they approach meeting the needs of people with Parkinson's experiencing anxiety and/or depression.

They had identified gaps in the mental health provision for people with Parkinson's, noting communication difficulties with mental health services, long waits for patients accessing support, and a lack of knowledge about Parkinson's among mental health professionals.

To address this gap, the team integrated a mental health professional into the team. This began with psychiatrist Dr Christine Taylor, who joined the team as part of her special interest training, and then later through specialist clinical psychologist Dr Jessica Marsh, who provides one day a week to the Parkinson's service.

Adopting a stepped care approach has enabled upskilling of other team members on psychological care and mental health concerns such as anxiety and depression.

Their joined-up approach has meant people are able to access support for their mental health problems quicker and their physical and mental health needs are addressed together. For example, patients engaging in exercise and motivation linked to a person's mental health, as Dr Marsh described:

"[...]a particular patient who might be having some difficulty engaging with the physio exercises that we want them to do, help their mobility, what is it that is stopping them from being able to access and make use of those exercises? Is it their mood? Is their mood and sense of hopelessness, sense of loss, sense of change in their identity stopping them being

able to access and make best use of the services we can provide in that more physical way?⁵⁵

The specialist occupational therapist sees the person with Parkinson's soon after diagnosis, and at this point screens the person for anxiety or depression.

They can refer the person to the mental health professional in the team, thereby creating a focus on the person's mental wellbeing on a par with their physical wellbeing from the outset.

The Derby team concludes that a successful multidisciplinary team should contain occupational therapists, physiotherapists, specialist nurses, speech and language therapists, psychiatrists and psychologists⁵⁶.

"A team of multiple disciplines would be best placed to do such work, with involvement from organisations such as Parkinson's UK and any other relevant mental health and neurological rehabilitation services/organisations. Such work would be best led by mental health professionals with experience and expertise in Parkinson's.⁵⁷"

Dr Jessica Marsh, Specialist Clinical Psychologist

This service was not commissioned to work in this way by the NHS and has drawn on the observations of professionals working in the field identifying a clear gap where patients were being failed by the system as it stood.

This example shows clearly the benefits of an integrated approach to meeting both the physical and mental health needs of people with Parkinson's. There is recognition that this is a developing service and additional input from mental health professionals is still required. It is, however, one example of how integrated care can work.

Access to services

Diagnosis

Difficulties in diagnosing anxiety and depression in people with Parkinson's are compounded by an absence of Parkinson's specific guidance available to health professionals and commissioners.

Anxiety and depression can be part of, or contribute to, Parkinson's movement and non-movement related symptoms. They are complicated and intertwining, making recognising and diagnosing Parkinson's symptoms difficult for health professionals, as well as for the person with Parkinson's themselves.

Family members may miss, or misinterpret, the signs too⁵⁸. A physical symptom, such as loss of facial expression, may appear as depression in someone who isn't depressed.

Conversely, a person with Parkinson's experiencing verbal communication issues may have this attributed to a physical symptom because of their Parkinson's, as opposed to being caused by anxiety or depression⁵⁹.

"It would be good if medical professionals could acknowledge that anxiety is a large part of the condition as it can make physical symptoms appear worse than they are.⁶⁰"

Person with Parkinson's

There is also difficulty in identifying the cause of the anxiety or depression, as this may result from coming to terms with the diagnosis of Parkinson's itself or chemical changes in the brain, or through the difficulties of living with Parkinson's such as 'freezing' (not being able to move) causing anxiety⁶¹.

Whatever the reason, non-diagnosis, late diagnosis or misdiagnosis poses a significant problem for accessing mental health services in Parkinson's.

“Parkinson’s is a neuropsychiatric condition and, with the biochemical changes that can happen, we need input from psychiatry.”⁶²

Dr Jessica Marsh, Specialist Clinical Psychologist

The need for better, Parkinson’s specific training was raised by people with Parkinson’s responding to our survey⁶³. Some also suggested that the Parkinson’s multidisciplinary teams all include a mental health professional who specialises in Parkinson’s⁶⁴.

Another person with Parkinson’s wants to see all medical professionals asking people with Parkinson’s about their mental health:

“If it becomes clear the person is living with anxiety or depression, I would want to see action taken quickly to support that person – with a range of treatment options including medication and talking therapies.”⁶⁵

“There was no support, which was very distressing for my father and the family. There was a total lack of understanding of the link between Parkinson’s and mental health concerns from both healthcare professionals and social services.”⁶⁶

Person with Parkinson’s

Early diagnosis and intervention for anxiety and depression can make a big difference to a person’s ability to manage these symptoms.

This view was supported by a Parkinson’s nurse who suggested patients should be offered cognitive behavioural therapy (CBT) or talking therapies as early as possible to prevent worsening of symptoms⁶⁷.

Stigma

Despite improvements in the general public’s perception, stigma around mental health still exists. And in Parkinson’s, as in other health conditions, this stigma can prevent people

from accessing the treatment they need. Reluctant to seek support, many people with Parkinson’s misconstrue the symptoms as ‘just getting old’.

“We still have the stigma to deal with, particularly for older male patients. They often struggle to talk about how they are feeling. We very specifically ask about sleep, mood, appetite, anxiety, hallucinations and cognition. This is not routine practice and there is not a standardised way of approaching the consultation that would allow you to record that information every time.”⁶⁸

Dr Neil Archibald, Consultant Neurologist

“There doesn’t seem to be an understanding of the mental health difficulties of Parkinson’s disease. The focus seems to be on movement and motor symptoms and a reluctance by professionals in general to talk about the mental side, which is more difficult and challenging than the physical aspects.”⁶⁹

Person with Parkinson’s

The attitude of many health professionals and patients that mental health problems are ‘just part of Parkinson’s’ also prevents people from accessing proper support. Sometimes a referral won’t be accepted for this reason⁷⁰.

This is despite the fact people often report anxiety or depression as the condition’s most disabling aspect⁷¹.

“The healthcare professionals in the psychiatric unit and social services had little or no understanding of the link between Parkinson’s and mental health.”⁷²

Person with Parkinson’s

“Rarely discussed by professionals and still taboo at Parkinson’s support group. I wasn’t offered anything, other than antidepressants, until my wife confronted my GP.”⁷³

Person with Parkinson’s

The person with Parkinson's may not want to 'trouble the doctor' with these issues, especially if they have limited consultation time with their specialist. Inevitably, they may judge other symptoms to be higher priority.

"It tends to be taken up with a discussion of physical symptoms. I also tend to concentrate on that aspect of things."⁷⁴

Person with Parkinson's

The Royal College of Psychiatrists said that: "As professionals, we should 'normalise' the notion of mental health problems being part of Parkinson's and be sufficiently knowledgeable of the physical and mental health concerns the person may experience to give them confidence in the services."⁷⁵

Referral

Many people with Parkinson's report excessive waiting times for treatment after referral to mental health services by their GP.

We heard in many cases people waiting months rather than weeks, and in some cases over a year. One person waited 18 months to see a neuropsychologist and another was told the waiting list for a psychologist was over two years:

"...the waiting list is over two years to see a psychologist. I saw a CBT therapist. Unfortunately, she thought she was helping me. I didn't feel helped and was told [I] cannot access any help for six months."⁷⁶

Person with Parkinson's

In responses to the inquiry survey, many people with Parkinson's reported difficulty in receiving a referral to mental health services from their Parkinson's nurse or other members of their multidisciplinary team. Some people were also passed back to their GP to make the referral to the mental health professional, and as a result the person with Parkinson's gets 'lost in the system'⁷⁷.

"The process of referral is frustrating and hard when you have Parkinson's. Many medical staff treat you as senile."⁷⁸

Person with Parkinson's

The separate commissioning of the majority of Parkinson's services from mental health services impedes the ability to deliver integrated physical and mental health care. Professor Richard Brown shared that he felt there is an artificial separation across trusts between the two sets of healthcare professionals and several other witnesses to the inquiry agreed with this assessment. There is a divide between those working in physical health and those in mental health, which he believes needs to change⁷⁹.

"As a neuroscience centre, a neurologist, I have a catchment area of 1.5 million. We deal with six different CCGs that our patients come to us from. Six different sets of commissioners and potentially six different psychiatry departments dotted about in the different regions. It becomes incredibly difficult to have an integrated service when you are trying to figure out that variability and means you cannot build professional relationships with other services very easily."⁸⁰

Dr Neil Archibald, Consultant Neurologist

Another factor when looking at the problem of referring is the patient's physical access to mental health services. It is important that their mobility is considered when looking at the distance away and regularity of their treatment for mental health symptoms⁸¹. While some people are fortunate to have their Parkinson's specialist nearby, others will need to travel a significant distance to see them once or twice a year. But when it comes to psychological support, those appointments are weekly or fortnightly, with services finding it hard to deliver to a wide geographic area⁸². Patients often have to travel 50 or 60 miles there and then the same back again⁸³.

27% of survey
respondents have
felt suicidal



“There is simply virtually nothing available. Even to attend support groups, I have to travel miles and I have limited mobility.”⁸⁴”

Person with Parkinson’s

Parkinson’s Disease Nurse Specialist Hannah Martin explained how self-referral had the possibility of self-empowerment and could inspire self-management of the condition, but warned that there were barriers that could affect this: *“...If you are anxious and struggling to talk about something or if you just have a quiet voice as part of the Parkinson’s, or a stutter, for example, or just a delayed thought process.”⁸⁵”*

Delays in treating anxiety and depression does cause damage – the Royal College of Psychiatrists reported that it results in reduced quality of life for the person with Parkinson’s and their carer or companion⁸⁶.

Quality of services

Neuropsychology

It is clear from the evidence submitted to this inquiry that a skills shortage exists, and neuropsychologists, who can offer people with Parkinson’s the tailored support they need, are too few and far between.

Professor Richard Brown, Professor of Neuropsychology and Clinical Neuroscience, warned that there aren’t enough psychiatrists and clinical psychologists to meet the demand for Parkinson’s, let alone all long-term health conditions. Currently there is only one neuropsychologist for a population of 600,000 people on average, and this can vary from one in 150,000 people in the population to one in 1.5 million⁸⁷. He also raised concerns about skill shortages, and notes the move away from specialist training more generally:

“We need to think about how we address that skills shortage through training places, which is obviously something Health Education England and other funders will be thinking

about. Although the direction of travel seems to be moving away from specialist training unfortunately.”⁸⁸”

There was an acknowledgement of a training gap in non-specialist mental health professionals supporting people with Parkinson’s. They are not receiving the training they need to provide quality care tailored to the person’s needs. Although we are seeing more psychiatrists, fewer qualifying are continuing on to higher specialist training⁸⁹.

“We need more specialist training. We have amazing CBT therapists – they just need more specialisms, with more co-located and joint working with Parkinson’s and other departments.”⁹⁰”

James Sparkes

Steve Ford, Chief Executive of Parkinson’s UK, highlighted the real challenges for younger people with Parkinson’s gaining access to mental health services with any experience or understanding of the condition⁹¹.

We heard that neuropsychologists are in an excellent position to develop links between mental health and neurology or geriatrics. Already bridging the gap between the physical and psychological in their roles, they have specialist training and accreditation in mental health and psychological interventions⁹².

Unfortunately, there are too few neuropsychologists and they are thinly spread across the country, further adding to the postcode lottery of care for people with Parkinson’s. For instance, Dr Amanda Mobley is the only neuropsychologist in Worcestershire, a county of 600,000 people, and works three days a week. It isn’t possible for her to see everyone with Parkinson’s. She says her role is about making sure people receive the appropriate support, being able to link up the pathways and having oversight of the whole process⁹³.

A recent King's Fund report on staffing and funding of NHS mental health providers noted the trend of moving away from specialists in community settings, and specialists being more sparsely deployed within community teams. These issues are compounded by the shortage of specialist mental health professionals, with 10% of specialist posts in England currently left vacant⁹⁴.

Disconnected care

People with Parkinson's are feeling 'lost in the system'. Poor communication between services and a lack of integration between physical and mental health services is negatively impacting continuity of care and the ability to deliver a person-centred approach.

"You are almost pushed from pillar to post. You find yourself repeating the same story over and over again."⁹⁵

Gary Berry, person with Parkinson's

A life-changing diagnosis such as this requires stability and easy-to-access advice and support. It can be a distressing experience for the person with Parkinson's to tell their story, so having to do this repeatedly to different professionals is far from ideal. We also heard examples of a disconnect between healthcare professionals. One survey respondent highlighted that their community psychiatrist without Parkinson's specialised training didn't agree with their Parkinson's specialist about their treatment. This resulted in the feeling of being 'overdosed in medication', as well as being taken to two different hospitals⁹⁶.

Difficulties in sharing patient information between physical health and mental health services adds further complications. This puts the onus on the patient to pass on this information in a consultation. This can be helped if letters are copied to the health professional on either side⁹⁷ – however this does not routinely happen⁹⁸.

"Even when I specifically write to a psychiatrist saying: 'You are about to see one of my patients, I would really like some feedback about what you think and what we should do together to help them', 50% of the time I get nothing back. I am flying utterly blind and, unfortunately, what that means is mistakes are made and care is disjointed."⁹⁹

Dr Neil Archibald, Consultant Neurologist

Many Parkinson's nurses responding to the Parkinson Disease Specialist Nurse Association survey cited their frustration with being unable to access patients' psychiatric notes¹⁰⁰.

"My mental health trust site is across the road, but we just do not have access to mental health service notes."¹⁰¹

Hannah Martin, Parkinson's Nurse

A Parkinson's nurse responding to the survey highlighted communication as being vital in ensuring "psychological care is everyone's business". She listed learning from each other, being able to share experiences and discuss difficult cases with colleagues, and training as being particularly significant.

"There was a big push a few years ago for management of medication on time being important for everybody. I think a similar push on mental health problems might be a really good thing."¹⁰²

Lisa Brown, Parkinson's Nurse

The overwhelming feeling is the way forward for all would be implementing joined-up working by creating integrated services¹⁰³.

Quality of care is also impacted by the overstretching of mental health services as people with Parkinson's compete for their mental health care. *The Guardian* newspaper revealed ambulance call-outs for people with mental health concerns had soared by 23% in 2016-17, compared to 2014-15¹⁰⁴.

Early intervention and access to mental health services would help prevent people reaching crisis point and reduce the number of avoidable admissions to hospital. A mental health system under strain and with limited resources means there is pressure to discharge people early. Unfortunately, this approach is inappropriate for an incurable lifelong condition such as Parkinson's.

In the experience of Dr Christine Taylor, a consultant in old-age psychiatry, patients are kept on short term in mental health services compared with Parkinson's services that follow the person for life¹⁰⁵. This is compounded by a view that mental health is not a high priority:

“Mental health is arguably not regarded as a high priority in the NHS and society.”¹⁰⁶

Pete Smith, Parkinson's Nurse

In a joint written submission to this inquiry, the Royal College of Psychiatrists advocate for multidisciplinary teams that include neurology, psychiatry and allied health professionals, citing examples of best practice from Oxford and Newcastle.

Improving Access to Psychological Therapies (IAPT) service

IAPT services provide evidence-based treatments for anxiety and depression. Written and oral evidence suggest IAPTs do not meet the needs of people with Parkinson's, as many mental health professionals have insufficient training in the condition.

Concerns included an inability to respond flexibly to the more complex needs of people with Parkinson's when addressing problems with anxiety and depression, leaving people with Parkinson's with their needs unmet.

An example was given of someone with Parkinson's who was unable to physically write being asked to fill out 'thought diaries' in between CBT sessions¹⁰⁷.

A long-term conditions lead for IAPT explained that at present CBT therapists are trained to treat common mental health problems but not for people who also have a physical long-term condition¹⁰⁸. An IAPT practitioner who is unfamiliar with the complexity of Parkinson's may recommend inappropriate activities for the person with the condition, therefore compromising the quality of treatment the person with Parkinson's receives¹⁰⁹.

“A patient really deserves to see someone who knows about anxiety and depression in Parkinson's, not anxiety and depression as it may affect someone who does not have a brain disease.”¹¹⁰

Professor Tom Foltynie, Consultant Neurologist

NHS England's *Implementing the five year forward view for mental health* recommends an expansion of IAPT services into looking at people with long-term conditions, with an immediate focus on diabetes, cardiac and respiratory. Health Education England has begun a programme of top-up training available to IAPT therapists in management of anxiety and depression in long-term physical conditions.

In considering a person's mental health and physical health needs together this represents a welcome step forward. However, there is a need to expand this work to include Parkinson's and neurological conditions more broadly, especially given the high prevalence of mental health symptoms within these populations¹¹¹. We have also heard of penalties enforced for non-attendance – which is a particularly punitive approach for a person with Parkinson's:

“Our waiting lists are booming, so we have a cut-throat policy – if you do not turn up for just one session, or you cancel two sessions, you will be discharged. How easy is it for someone with Parkinson's to miss a couple of

appointments or forget an appointment?¹¹²

James Sparkes, Long-term Conditions Lead for IAPT

Dr Amanda Mobley highlighted that recently published NICE guidelines on Parkinson's do not adequately deal with the issues that people with Parkinson's face in relation to receiving high-quality mental health care. The guidance simply refers people to generic NICE guidelines for anxiety and depression in chronic long-term health conditions¹¹³.

"All chronic conditions are different and the clinical features of Parkinson's, which are part of the disease process, may lead to under diagnosis because of Parkinson's-related issues like loss of facial expression, slowness of movement and apathy.¹¹⁴"

Neurology Academy, written evidence

There is a pressing need to develop NICE guidance on diagnosis of mental health symptoms, treatment and support for people with Parkinson's tailored to their specific needs. This would enable the spread of best practice across the NHS to areas where it is sorely needed. As we learnt earlier, some areas of the country have a specialist neuropsychology service accepting referrals for people with Parkinson's. However, this is an exceptionally limited resource with few areas having access to this specialist support¹¹⁵.

Impact on carers and families

Carers provide a substantial amount of the care people with Parkinson's receive. There was the feeling among submissions by professionals that huge amounts of carer strain are seen in local services.

"The processes are so long winded, the focus is always on the here and now with little advice for the future. There is little or no support for my wife who is my full-time carer. It's a very lonely journey.¹¹⁶"

Person with Parkinson's

One of the main reasons people with Parkinson's are admitted to care homes for definite or indefinite periods is carer breakdown. Their carer – whether significant other, child or other family member – stops being able to manage¹¹⁷. Often this is driven by neuropsychiatric problems in Parkinson's – people hallucinating or experiencing extreme sleeplessness or other behavioural issues¹¹⁸.

"If we are not alert to the warning signs of the strain, in the care environment, in general neurology services, in other movement disorder clinics, unplanned care is the inevitable consequence.¹¹⁹"

Nina Williams, Mental Health Nurse

Unsurprisingly, the person with Parkinson's does better if the carer is supported too. Clearly, the mental health of both matters. Professor Tom Foltynie, Consultant Neurologist and representative of the Association of British Neurologists, said: *"There should be provision for not only pharmacological therapies but counselling and support groups for patients and carers.¹²⁰"*

"There are a lot of carer issues for somebody who has anxiety and depression. It affects everybody, not just the person with Parkinson's – it affects their family and support network around them too.¹²¹"

Clare Johnson, Specialist Occupational Therapist

A recent study on the role of informal carers in caring for people in the advanced stages of Parkinson's found that they were experiencing a number of health problems, with 6% experiencing mental health concerns such as anxiety and depression¹²².

Evidence and data

Evidence about the problem

A Freedom of Information request by Parkinson's UK found none of the CCGs in England have been gathering data about

Parkinson's affects
about 145,000
people in the UK



the mental health needs of people with Parkinson's¹²³.

“The data question – this is something that we really struggle with. We asked all of the Clinical Commissioning Groups in England whether they had done any work to gather data on the mental health needs of people living with Parkinson's. We can find no access to that. We have asked questions and MPs in the APPG have been asking questions of the Department of Health and have really struggled to get any information.”¹²⁴”

Steve Ford, Chief Executive, Parkinson's UK

Parkinson's UK and MPs from the APPG have asked the Department of Health for this information and are yet to receive any evidence to indicate that these data are being collected¹²⁵.

There is a clear need for these data to be collected and analysed so the unmet need can be understood and relevant services commissioned to meet these needs.

It was highlighted in the *Five year forward view for mental health* that although CCGs collected condition-specific data on physical health, this was not the case for mental health¹²⁶.

The implementation plan includes the development of a five-year data plan to consider providing better data “...on prevalence and incidence, access, quality, outcomes, prevention and spend across mental health services”¹²⁷. It is encouraging to see the current lack of data acknowledged.

However, it is not clear whether this plan will involve linking this data with people with long-term physical conditions such as Parkinson's. Evidence from submissions to this inquiry indicates that while depression in Parkinson's has been studied for 40 years, research into anxiety in Parkinson's has been

minimal. Professor Richard Brown said recent evidence suggests we put the two together, instead of looking at one or the other in isolation¹²⁸.

Research that demonstrates interventions work

It is clear from the evidence submitted that there is agreement among healthcare professionals for the need to generate more evidence on the type of mental health interventions that are most effective for people with Parkinson's, emphasising the need to move beyond the one-size-fits-all approach¹²⁹.

“One of the reasons we're not getting into NICE guidance is because there is not enough evidence. NICE looks at evidence and, if there is none, they will not look at it.”¹³⁰”

Professor Iracema Leroi, Royal College of Psychiatrists – Faculty of Older Age

Therefore, research is needed to enhance best practice in the treatment of people with Parkinson's experiencing mental health concerns, and for this best practice to be spread across the country through inclusion in NICE guidelines.

Professor Leroi said we need to understand how these therapies can be adapted to people with Parkinson's. Do they need to be shorter? Do they need to involve carers or change the therapy structure? How do they deal with multiple concerns and focuses within a therapy session?

Conclusion and recommendations

From the evidence submitted to the inquiry, it is clear people with Parkinson's don't receive the same level of care for anxiety and depression as they do for their physical symptoms.

From people with Parkinson's, carers and families, to professionals and professional organisations, the message was overwhelming. Virtually every respondent felt that mental health services need to be drastically improved to enable people with Parkinson's to take control of the condition.

The recognition of the importance of addressing people's mental health needs across all levels of government is welcome. However, there is much to do to ensure these services meet the specific mental health needs of people with Parkinson's.

Evidence received by the inquiry shows clear recommendations about the actions needed to improve mental health services for people with Parkinson's who experience anxiety and depression.

Not enough is known about the mental health services that people with Parkinson's access. More data is needed for commissioners to deliver mental health services that meet the needs of people with Parkinson's.

We recommend:

NHS England and Public Health England should:

- commit to establishing a working group involving strategic partners to investigate new datasets (including access to mental health services, workforce, treatments offered and waiting times) for people with Parkinson's experiencing mental health problems, such as anxiety or depression
- work with local health bodies to implement agreed new datasets

Many of the professionals and people with Parkinson's who provided evidence to the inquiry shared concerns about whether the mental health interventions delivered were effective for people with Parkinson's.

A lack of specific guidance on how to support and treat people with Parkinson's who experience anxiety and depression is preventing effective practice from spreading across the health system.

We recommend:

The National Institute of Health Research should:

- fund more research on mental health interventions for people with Parkinson's, to understand what the most effective treatment options are for anxiety and depression

NICE guidance on Parkinson's should:

- be updated to reflect effective evidence based interventions for the treatment of depression and anxiety in people with Parkinson's

Access to mental health services across the UK is patchy and can take a long time – this is the same for many long-term conditions including Parkinson's.

People with Parkinson's taking part in the inquiry experienced a variety of waiting times – from a few weeks to over a year.

This should be set against the context of the national standard in England for waiting times for generic IAPT services – 75% of people to be seen within six weeks and 95% of people to be seen within 18 weeks.

We heard many examples and ways that physical and mental health services have operated in isolation, leading to people with Parkinson's receiving disconnected fragmented care.

Conversely, we also highlighted some examples of best practice such as the multidisciplinary team set up in Derby that looks at a person's mental health needs as well as the physical aspects of the condition.

We recommend:

Clinical Commissioning Groups (CCGs) should:

- work with current Parkinson's services to integrate multidisciplinary teams to include mental health professionals (dedicated sessional time from both psychology and psychiatry) to upskill and work with the rest of the team

NHS England should:

- expand the current 'early implementer' projects that integrate Improving Access to Psychological Therapies (IAPT) with physical healthcare to include projects including people with Parkinson's

Overwhelming evidence emerged from the inquiry that people with Parkinson's are not getting the same level of treatment for their mental health as their physical health.

We also learned that one contributing factor could be professionals' lack of confidence in this area.

We recommend:

Employers of staff treating people with Parkinson's using cognitive behavioural therapy (CBT) should:

- ensure that appropriate Parkinson's learning is available and has been undertaken. An example of this learning could be *Understanding Parkinson's for health and social care staff* – available free of charge from the UK Parkinson's Excellence

Health Education England (HEE) should:

- further develop *Training for long term conditions for Improving Access to Psychological Therapies (IAPT) therapists* to include information on how to support people with Parkinson's experiencing anxiety and depression

The UK Parkinson's Excellence Network should:

- set up a mental health hub/forum to support these recommendations and improve and share best practice within the Parkinson's community, including examples of integrated physical and mental health care pathways

We also heard of the knock-on impact that poor mental health can have on the carers and family members of people with Parkinson's, who often have their own mental health needs ignored.

We recommend:

Carers and family members should:

- be supported in addressing their own mental health concerns by professionals, and should be signposted to Parkinson's UK support services



Nearly 50% of survey respondents find it harder to leave the house because of their mental health

Glossary

All-Party Parliamentary Group – an informal cross-party group of MPs and lords set up around specific issues. The All Party Parliamentary Group on Parkinson’s was set up in 2008 with the aim of raising awareness of Parkinson’s in Parliament.

Cognitive behavioural therapy (CBT)

– talking therapy that can help someone manage their problems by changing the way they think and behave. Most commonly used to treat anxiety and depression, it can also be useful for other mental and physical health problems.

Clinical Commissioning Group (CCG) – local organisations set up to commission local health services in England. They took over this role from primary care trusts with the introduction of the Health and Social Care Act 2012. At the time of writing, 209 clinical commissioning groups are authorised to operate by NHS England.

Improving Access to Psychological Therapies (IAPT) – the IAPT programme began in 2008 and has transformed treatment of adult anxiety disorders and depression in England. IAPT services provide evidence-based treatments for people with anxiety and depression, in line with NICE guidelines.

Multidisciplinary team – a group of health and social care workers who are members of different disciplines, each providing specific services to the service user.

For people with Parkinson’s, a full multidisciplinary team should include medical specialists, nurse specialists, physiotherapists, occupational therapists, speech and language therapists, dietitians, clinical psychology professionals, palliative care professionals and social workers.

NICE guidelines – the National Institute for Health and Care Excellence (NICE) is an independent public body that provides national guidance and advice to improve health and social care in England. NICE guidelines make evidence based recommendations on a wide range of topics.

Guideline recommendations set out:

- the care and services suitable for most people with a specific condition or need
- the care and services suitable for particular populations, groups or people in particular circumstances or settings, for example when being discharged from hospital
- ways to promote and protect good health, or prevent ill health
- the configuration and provision of health and social care services
- how national and local public sector organisations and partnerships can improve the quality of care and services, for example how the NHS and social care services work together

Parkinson’s nurse – a nurse practitioner with specialist knowledge and experience in caring for people with Parkinson’s. Key responsibilities include: making and receiving referrals to other healthcare professionals, managing caseloads, providing information, education and support to people in their own homes, clinics and in hospitals, and prescribing medicines and treatments to people with Parkinson’s and monitoring these.

Social care – services that provide help for people in performing daily living tasks to ensure they remain safe and independent. This can be anything from assistance with personal tasks such as washing and dressing, assistive equipment such as grab rails, or respite for the individual’s carer through breaks or access to a day centre. This can be provided at home or in residential care.

Acronyms

APPG	All-Party Parliamentary Group
CBT	Cognitive behavioural therapy
CCG	Clinical Commissioning Group
IAPT	Improving Access to Psychological Therapies
NICE	The National Institute for Health and Care Excellence

Participants in written and oral evidence

The inquiry received a total of 350 submissions, including 311 survey responses from people affected by Parkinson's.

Written evidence was provided by the following organisations:

- British Geriatrics Society
- British Psychological Society
- Cornwall Partnership Trust
- King's College NHS Foundation Trust
- Neurology Academy
- Norfolk Community Health and Care NHS Trust
- North Tees and Hartlepool NHS Trust
- Northern Health and Social Care Trust
- Parkinson's Disease Nurse Specialist Association
- Parkinson's UK
- Royal College of Occupational Therapists
- Royal College of Psychiatrists
- Royal College of Speech and Language Therapists
- Sherwood Forest Hospitals NHS Foundation Trust
- Wilmington Healthcare Ltd

Oral evidence session on 14 October:

- Professor Thomas Foltynie, Association of British Neurologists
- Professor Richard Walker, British Geriatrics Society
- Dr Simon Prangnell, British Psychological Society
- Professor Iracema Leroi, Royal College of Psychiatrists (Faculty of Old Age)

Oral evidence session on 24 October:

- Gary Berry, living with Parkinson's
- Steve Ford, Chief Executive, Parkinson's UK
- Professor Richard Brown, Professor of Neuropsychology and Clinical Neuroscience, King's College
- Derby Multidisciplinary team:
 - Dr Rob Skelly, Consultant Geriatrician
 - Dr Christine Taylor, Consultant in Old Age Psychiatry

- Dr Jessica Marsh, Specialist Clinical Psychologist
- Clare Johnson, Specialist Occupational Therapist
- Lisa Brown, Specialist Parkinson's Nurse

Oral evidence session on 31 October:

- Jane Price and Hannah Martin, Parkinson's Disease Nurse Specialist Association
- James Sparkes, Long-term Conditions Lead for Improving Access to Psychological Therapies
- Dr Neil Archibald, Consultant Neurologist
- Nina Williams, Mental Health Nurse
- Dr David Okai, Royal College of Psychiatrists, Faculty of Neuropsychiatry
- Dr Amanda Mobley, Consultant Clinical Neuropsychologist

Panel members

Parkinson's UK is grateful to the following members of the APPG on Parkinson's who took part in the oral evidence sessions:

- Baroness Gale (Chair)
- Baroness Masham
- Nick Thomas-Symonds MP
- Mary Glendon MP

One person was told the waiting list for a psychologist was over two years



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“Anxiety is the single worst thing that I suffer and exacerbates all other symptoms exponentially.”

Person with Parkinson’s

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