

An elderly couple is seen from behind, looking out a large window at a lush green landscape with trees and a house in the distance. The woman on the left has short grey hair and wears a teal top and a pearl necklace. The man on the right has grey hair and wears a blue and white striped shirt. The scene is brightly lit, suggesting daytime.

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The state of health and social care for
people with Parkinson's-related dementia

Written by Sam Freeman Carney. November 2021

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Executive summary

Around three in 10 people with Parkinson's have Parkinson's related dementia at any one time. Despite this, the health and social care system is failing to meet the needs of people with the condition and their friends, family and carers.

This report, based on interviews with people with Parkinson's-related dementia and their carers, and surveys of carers and healthcare professionals, shows people face challenges right from the beginning of their journey. Our survey found that diagnosis took an average of six months, and we have seen dementia diagnosis rates worsen in England during the pandemic for people aged over 65, dropping by 6% in a year.¹ Yet people with Parkinson's-related dementia need a diagnosis to access vital support for their complex and multiple needs.

Most health professionals we surveyed said they did adapt their appointments when they saw a person with dementia. However, only 14% said their education and training had prepared them well to provide high quality care for people with Parkinson's-related dementia.

Around a quarter of carers surveyed reported that health professionals responsible for Parkinson's care did not understand and take account of the person they cared for having dementia.

It is deeply concerning that when someone was admitted to hospital for a reason unconnected to their Parkinson's-related dementia, 48% of carers thought that hospital staff did not have sufficient knowledge to care for the person. And in only 33% of cases did the person receive their Parkinson's medication on time, every time – which is key to keeping Parkinson's symptoms under control.

Over half of the carers we surveyed are providing more than 70 hours of direct care each week. Yet only 15% had accessed respite care. This has severely impacted carers' mental health, with 65% experiencing anxiety and 62% depression.

There is a lack of support and guidance for carers on how to support the person they are caring for when they experience distressing hallucinations and delusions. 75% of carers had witnessed hallucinations and 51% delusions. 55% of people with Parkinson's-related dementia found these symptoms distressing. Yet only 5% were offered training on how to manage in these situations.

The social care crisis has hit people with Parkinson's-related dementia hard. They face difficulties in accessing social care services, catastrophic care costs, paid carers with little or no knowledge of the condition, and challenges in accessing the healthcare services they need when in a care home or if they are housebound.

Far-reaching changes are needed so the health and social care system can deliver high quality, person-centred care for people with Parkinson's-related dementia and provide better support for carers.

Our recommendations

- **The government** must make sure that the recently announced £500 million of funding for training the social care workforce includes training on Parkinson's and Parkinson's-related dementia for social care staff directly providing care.
- **Health Education England** should roll out basic training for non-specialist health professionals about caring for people with Parkinson's-related dementia.
- **Integrated care systems** (all the organisations that meet health and care needs in an area) must work with NHS Trusts to ensure people with Parkinson's-related dementia have access to a Parkinson's multidisciplinary team, with a clear referral pathway into neuropsychiatry and/or old age psychiatry.
- **Integrated care systems** must provide the resource required to ensure there is capacity within the Parkinson's workforce and appropriate contracting arrangements to:
 - deliver models of care that enable multidisciplinary team working
 - provide appointments of suitable length to meet the needs of people with Parkinson's-related dementia.
- **All NHS acute hospital trusts in England** must adopt the principles set out in the revised Dementia-Friendly Hospital Charter and implement the changes needed.
- **Integrated care systems** should fund and ensure training/education is available for unpaid carers on the neuropsychological and neuropsychiatric symptoms of Parkinson's-related dementia. This should include how to support the person with Parkinson's-related dementia if they are experiencing distressing delusions or hallucinations.
- **The government** must work with local authorities to ensure there is adequate funding to provide unpaid carers of people with Parkinson's-related dementia with the breaks they need.
- The **Department of Health and Social Care** must assess provision of respite care for people with Parkinson's-related dementia, and publish its findings. This should include an audit of the training day centre staff receive, including on Parkinson's and dementia.
- **NHS Digital** should publish diagnosis rates of dementia subtypes (including Parkinson's dementia and dementia with Lewy bodies – the two types of Parkinson's-related dementia) as part of its 'Recorded Dementia Diagnoses' monthly data set.
- Parkinson's UK is a member of the Care and Support Alliance and supports its seven principles for social care reform. The principles seek to ensure funding of social care is put on a sustainable footing, and access to care and quality of care are improved (see appendix 1 for the full list of principles).
- For NHS continuing healthcare to improve, the **Department of Health and Social Care, NHS England, local commissioners and local authorities** must implement the recommendations set out in the Continuing Healthcare Alliance report *Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?* This calls for changes to NHS continuing healthcare assessment and decision-making processes to make the system fairer for individuals in need of care (see appendix 2 for the full list of recommendations).

Introduction

This report explores people's experiences of today's health and social care system. It is based on a survey of 209 carers of people with Parkinson's-related dementia and 74 healthcare professionals across the UK. We also interviewed five people with Parkinson's-related dementia and nine carers.

The report focuses mainly on the health and social care system in England (though we do discuss dementia care in Northern Ireland, Scotland and Wales later in this section). So the survey statistics used throughout refer to the 166 carers and 64 professionals based in England. We have changed people's names to protect their anonymity.

About Parkinson's-related dementia

Historically, Parkinson's has been understood primarily as a movement disorder. In some cases, the organisation of services to support people with Parkinson's still reflects this view. However, people with Parkinson's can also experience several non-motor symptoms, including depression, apathy, anxiety and dementia.

Dementia is a decline in mental ability, which can affect thinking, problem-solving, concentration and memory. There are many subtypes of dementia. Parkinson's-related dementia takes two forms:

- **Dementia with Lewy bodies** is diagnosed when someone has the symptoms of dementia either before or at the same time as they develop Parkinson's. In some cases of dementia with Lewy bodies, no motor symptoms may develop at all.

- **Parkinson's dementia** is diagnosed when someone already has the motor symptoms of Parkinson's and dementia symptoms appear a year or more after the motor symptoms.

We use the term Parkinson's-related dementia in this report when referring to both subtypes of dementia collectively.



People with Parkinson's are up to six times more likely to develop dementia than unaffected people in the population.² At any one time, between 24% and 31%³ of people with Parkinson's are likely to have dementia.⁴ People develop Parkinson's at different ages, so some live with the condition longer than others. However, research suggests that at least 75% of those living more than 10 years with Parkinson's will develop dementia.⁵

Despite a growing focus on improving dementia care and support across the UK, there are still crucial challenges that must be addressed for people affected by Parkinson's-related dementia.

Parkinson's-related dementia typically slows down a person's speed of thinking and creates problems with understanding, planning, judgement, language and memory. However, unlike in Alzheimer's, it may not affect memory early on.⁶ Not everyone with Parkinson's-related dementia shows every symptom. Common experiences linked to thinking, personality and behaviour include:

- **Extreme swings from alert to confused or sleepy.** This may happen without warning, change from hour to hour or day to day, and last different lengths of time. Referred to as 'fluctuating cognition', this means that someone is able to make important decisions at some times, but not at others.
- **Recurrent, complex visual hallucinations** – especially seeing people or animals that are not there, often in great detail.
- **Disturbed vision** – problems with how the brain makes sense of what it sees.
- **Sleep disturbance** – very vivid dreams that the person acts out.
- **Mood changes** such as anxiety and depression.
- **Changes in personality** – such as becoming more withdrawn or apathetic.



Around
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Less commonly, people with Parkinson's-related dementia can develop delusions. These are fixed beliefs about the world, such as paranoid ideas, or believing they are not at home when they are.

It's critical to note that people with Parkinson's-related dementia are living with both motor and cognitive symptoms, unlike most other subtypes of dementia. Living with dementia can make it more challenging to manage the physical symptoms of Parkinson's. For example, medications that improve movement can make dementia symptoms worse, and having dementia can mean that deep brain stimulation is not a suitable treatment option for a person with Parkinson's-related dementia.⁷

Symptoms affecting other body systems can also become more troublesome in Parkinson's-related dementia, including needing to get up at night to pass urine frequently, feeling dizzy on standing, greater unsteadiness and more frequent falls.

Living with Parkinson's-related dementia

People we interviewed explained the impact of some of the cognitive difficulties they experience on their day to day living, and tasks they find challenging. These include planning activities, processing conversations, memory problems and doing paperwork.

“I find it very difficult to understand and compute what is being said to me, and I need to have it repeated, often several times. I forget things very quickly and I find it difficult to plan. I'm very slow doing paperwork.”

Sam, who has Parkinson's dementia

Communication

People with dementia can find it difficult to communicate their needs. This means those around them may not know what to do to help and support them.

“...I think when someone has dementia, they can't report how they feel. They can't report symptoms, that's the problem, then it's guesswork from the point of view of the carer [who] has to try and guess what's going on. It's a matter of luck whether you get it right or not really.”

Daisy, carer of a person with Parkinson's dementia

Adjusting to living with Parkinson's-related dementia

Several of the people with dementia we interviewed said they don't like to dwell or think about living with dementia, and find it upsetting to reflect on how they 'used to be'. Unlike other dementias, people with Parkinson's-related dementia often have insight into their own condition and find it a source of frustration or sadness.

“It upsets me in a lot of ways. When I think what I used to be, to what I am now, what I have to do now, it is quite upsetting if I delve down into it deeply. I try not to let it get me down.”

John, who has Parkinson's dementia

Many carers reported changes in the person with dementia and how this could be challenging to adapt to.

“...He was changing from the Malcolm who used to be very, very capable, always helped, always able to do anything, was changing to somebody who actually couldn't, was finding some of the simpler things really difficult to do, and I was finding that hard, really.”

Alice, carer of a person with Parkinson's dementia



Community involvement

We found people had mixed experiences of being able to play an active role in their local communities.

“I don't really belong to any community projects or anything like that. I have a circle of friends that I deal with. They're sympathetic to my needs, which I'm quite happy to go along with.”

John, who has Parkinson's dementia

“Can't do what I used to do. I used to play sports, I don't now, I don't do anything. It's slowly sort of fizzled out.”

Malcolm, who has Parkinson's dementia

Some found it hard to continue doing social and recreational activities, while others were supported to take part in these activities and maintain social stimulation.

“...We have a very vibrant branch committee at Parkinson's UK. They're terrific how they have built on those support methods, often in a practical way. Sometimes, I do dance, and I do, well, Mondays it's a walk, Nordic walking. I do that twice a week, Mondays and Thursdays. Wednesdays, I...meet other people there, and do, you know, a bible study group that I go to.”

Sam, who has Parkinson's dementia

“Socialising became an all important stress reliever and came in the form of our involvement with Dance for Parkinson's and a PD support group which we attended for several years.”

Stevie, carer of a person with Parkinson's dementia



The policy context in England

Over the last decade dementia has risen as an issue in the public consciousness and it has come to prominence as a health issue on the government's agenda.

Government strategy on dementia

The first National Dementia Strategy in 2009⁸ focused on raising awareness, combating stigma, improving diagnosis rates and broadening the range of services available for people with dementia and their families.

This was followed by David Cameron's Prime Minister's Challenge on Dementia 2012.⁹ This aimed to raise awareness and tackle stigma by creating Dementia Friendly Communities led by the Alzheimer's Society. It also sought to deliver improved dementia health and social care across different care settings and increased funding for dementia research.

The Prime Minister's Challenge on Dementia 2020¹⁰ is the current iteration of the government's strategy for dementia, launched in 2015. Its objectives built on the previous strategy. They include measures on raising awareness and understanding risk factors for developing dementia, diagnosis, training for NHS staff, making hospitals and care homes dementia-friendly, expanding the Dementia Friendly Communities and Dementia Friends programmes, and increasing dementia research funding and participation in research.

The Challenge on Dementia 2020 also contains a commitment to establish an international dementia institute to become a global leader in dementia research. The Medical Research Council, Alzheimer's Society and Alzheimer's Research UK joined forces to invest £290 million to set up the UK Dementia Research Institute, which launched in 2017.

In its 2019 manifesto¹¹ the Conservative Party committed to doubling dementia research funding and increasing the pace of trials for new treatments – referred to as the 'Dementia Moonshot'. The All-Party Parliamentary Group on Dementia recently published a report, *Fuelling the moonshot: Unleashing the UK's potential through dementia research*,¹² which sets out the key tenets of how this commitment should be delivered.

In answer to a parliamentary question¹³ in March 2021, the government said proposals for a new strategy, including their plans for dementia care, support, awareness and research in England, will be announced later in the year.

Clinical guidance on dementia

The National Institute for Health and Care Excellence (NICE) guideline on dementia – *Dementia: assessment, management and support for people living with dementia and their carers*¹⁴ – contains limited guidance for health professionals on Parkinson's-related dementia. It includes content on diagnostic criteria, some information on pharmacological management of non-Alzheimer's dementia and a caution on the use of antipsychotic drugs in people with Parkinson's-related dementia. However, there is no guidance on non-pharmacological treatment and management of Parkinson's-related dementia.

The NICE guideline on dementia does refer to the NICE guideline on Parkinson's for management of Parkinson's symptoms,¹⁵ and notes that this guidance should be adapted for people with dementia. However, similarly to the guideline on dementia, the Parkinson's guideline has limited guidance for health professionals – just information on dementia drugs, and a cross-reference to the NICE dementia guideline for guidance on hallucinations and delusions in dementia. Again, there is no guidance on non-pharmacological treatment and management of Parkinson's-related dementia.

Social care

Social care is in urgent need of reform. An ageing population, including a growing number of people living with multimorbidities, has led to increasing demand for social care services. At the same time, local authorities' budgets have been tightened, making it ever more difficult to keep up with this growing demand. According to 2019/20 statistics from NHS Digital, 1.9 million people in England asked their local authorities for support. This is over 100,000 more than in 2015/16.¹⁶ Of these, only 43% received support from a service, 28% were given advice or signposted and 29% received no support.

Lack of sustainable funding for social care has impacted access to care and quality of care. It has left many people and families with the significant financial burden of paying for their own or their loved ones' care.

There have been numerous commissions and reviews into how to reform the social care system. However, inaction on this issue has meant little progress has been made.

In September 2021, the government announced¹⁷ changes to the way social care is funded and how financial contributions that individuals make towards their own care are calculated.

A 1.25% levy will be applied to national insurance contributions, projected to raise £36 billion for health and social care over the next three years. From 2022/23 and 2024/25, adult social care will receive an extra £5.4 billion of funding.

From October 2023, the amount anyone has to personally pay for their care will be capped at £86,000. Other changes on this date will include:

- Those with less than £20,000 in assets will not have to contribute to their care costs from their assets.
- People with assets up to £100,000 will be eligible for some government support (up from the current limit of £23,250).
- Steps will be taken so those paying for their own care (self-funders) are charged at the same rates as the local authority pays. Currently self-funders often pay a higher rate for their care.
- The Minimum Income Guarantee and Personal Expense Allowance will be unfrozen in April 2022, and will rise in line with inflation.
- A White Paper on NHS integration with social care is expected this year (2021).

The plan pledges £500 million for social care workforce training, and extra money for local authorities to help deliver social care and integration. While increased funding is welcome, there is scepticism about how far it will go to 'fixing' social care.^{18,19} The King's Fund suggests almost half the funding will cover the cost of introducing the cap on care costs, leaving little to address the major issues of workforce and access to and quality of care.²⁰ Changes to the means test threshold are an improvement on the current system and will result in more people receiving state-funded care.





Dementia care in Northern Ireland

Over 20,000 people in Northern Ireland have dementia. People with dementia in Northern Ireland are more likely to get a diagnosis than anywhere else in the UK.²¹ However, there is still room to improve care and support and to create dementia-friendly communities.

In Northern Ireland, care home residents accounted for 51%²² of all coronavirus-related deaths, compared to 50% in Scotland, 39% in England and 34% in Wales. The Northern Ireland Statistics and Research Agency has confirmed that over a third of all deaths in Northern Ireland relating to the virus were people with dementia.

Pressing for full implementation of the Mental Capacity (Northern Ireland) Act 2016

It is essential people with dementia are supported to make their own decisions for as long as possible, and, when they no longer can, that their rights are protected in decisions made on their behalf.

The Mental Capacity (Northern Ireland) Act passed into law in May 2016²³ and the Department of Health is now developing the Code of Practice. The Act will support people with dementia to make decisions about their own health, welfare and finances when they have capacity to do so. It will require those responsible for their care to respect those decisions in practice.

Regional Dementia Care Pathway

By 2051 it is estimated that there could be 60,000 people living with dementia in Northern Ireland. It is therefore important that arrangements are in place that provide equitable, efficient and effective services that promote independence and wellbeing.

The Regional Dementia Care Pathway²⁴ sets out the Department of Health's vision for high quality dementia services in Northern Ireland.

The pathway describes the care that a person with dementia may receive from the moment they consult their GP with concerns about symptoms, through to diagnosis and the end of their life. It has been developed using the expertise of people working in dementia care and sought the views of people with dementia and their families and carers. It includes provision for younger people with dementia and people with learning disabilities.

Improving Dementia Services in Northern Ireland – regional strategy

The Health and Social Care Board and Public Health Agency work in partnership with the Alzheimer's Society and local Health and Social Care Trusts to implement Improving Dementia Services in Northern Ireland²⁵. Published in 2011, this regional strategy aims to promote a culture that ensures people with dementia are supported to live with dignity and without stigma.

The strategy contains 44 recommendations categorised under seven themes, including raising awareness, promoting early assessment and diagnosis, and supporting people with dementia and their caregivers.

The Dementia Learning and Development Framework

Launched in September 2016 by Northern Ireland's Health Minister, the Dementia Learning and Development Framework²⁶ has been developed to enable health and social care staff to deliver the best quality of care to people living with dementia, their families and carers.

Who pays for dementia care in Northern Ireland?

There are national rules about who has to pay for care and support, although these can vary locally. It mainly depends on the type of care and support that a person needs, where they live and what is available. Usually, Health and Social Care Trusts do not charge for services provided in a person's home, but there are some exceptions. Whether or not a person has to pay depends on what services are needed, income and assets (such as any savings or shares).

If living in a care home, a person might pay for all of their care and support costs, which means they are a 'self-funder'. Or, they may make a contribution, with the Trust also contributing, or the Trust may pay the full cost. Again, this depends on income and assets, and on a person's needs. Some people are eligible to receive financial support to help with nursing care.

Dementia care in Wales

The Welsh government published its Dementia action plan for Wales²⁷ in 2018 and it will be reviewed and refreshed in 2022. Progress against the plan is informed and monitored by the Dementia Oversight of Implementation and Impact Group, which includes people accessing dementia services across Wales.

The coronavirus pandemic has hit the most vulnerable in society the hardest, including those living with dementia and their families. Throughout the pandemic the action plan has remained prominent. However, there has been an inevitable impact on its delivery due to the additional pressures on health and social care systems since March 2020. Key areas of impact are:

- **disruption of access to GP and routine hospital appointments** for people with dementia, impacting people's general health and wellbeing
- **disruption of access to memory assessment and diagnosis services** – there is now an inevitable and significant backlog and waiting list to be addressed
- **increased pressure on unpaid carers**, due to suspension of respite and carer's assessments, plus challenges in parts of Wales in recruiting and retaining social care staff
- **the opening up of services suspended due to coronavirus** – it's not yet fully clear how services will open up and how the confidence of practitioners and service users to access services can be rebuilt
- concern that the move to a **digital service offer** to sustain services during the pandemic **may be the default position for the future**.

The All Wales Dementia Care Pathway of Standards,²⁸ published in March 2021, aims to improve dementia care for people with the condition and their carers by providing a clear pathway towards implementing effective standards within dementia care over the next two years.

Dementia care in Scotland

In Scotland, about 90,000 people have dementia. It's estimated that about a third of those – some 30,000 people – are in hospital or in a care home at any time. The majority of Scotland's care home residents – around two thirds of them – have dementia.²⁹

Parkinson's UK Scotland estimates that more than 3,600 people in Scotland have Parkinson's dementia.³⁰ Research from the north-east of Scotland shows that people with Parkinson's are about six times more likely to develop dementia as people of the same age without the condition.³¹

Dementia has been one of the Scottish government's policy priorities since 2007. There is a Charter of Rights for People with Dementia and their Carers in Scotland³² and the NHS and Standards of Care for Dementia in Scotland.³³ Everyone receiving NHS and social care services in Scotland should receive care in line with the Health and Social Care Standards.³⁴ There have been three dementia strategies published: the first in 2010,³⁵ the second in 2013,³⁶ and the third in 2017.³⁷ Work on the fourth strategy was delayed because of the coronavirus pandemic, and a National COVID-19 Dementia Transition and Resilience Plan is being developed, which will build on the 2017–2020 strategy.



The main issues for people with dementia and their partners and families during the coronavirus pandemic in Scotland included:

- **high death rates among people with dementia** – one in four (24%) of people who died of coronavirus between March 2020 and August 2021 had a diagnosis of dementia³⁸
- **increased frailty, reduced mobility, and increased mental health issues** – and more rapid symptom progression and increased complexity in people's needs
- **considerable disruption to daily routines, social interactions, health and social care support** – including diagnosis – and community-based therapeutic activities
- **carers with little or no support**, and no access to respite while caring for people with increasingly complex needs.³⁹

Since 2013, everyone with dementia in Scotland has been entitled to at least a year of support after their diagnosis, and this right was further developed in 2017. Post-diagnostic support is provided by third sector or NHS employees, but should include support to:

- understand dementia and manage symptoms
- keep up community connections and make new ones
- meet other people with dementia and their partners and families
- plan for future decision-making
- plan for future support needs.

However, recent data suggests that about six in 10 (58%) of people diagnosed with dementia in Scotland are not referred for post-diagnostic support.⁴⁰ One of the issues is that dementia can only be diagnosed in secondary care, and someone can only be referred for support after their diagnosis is confirmed – often after a long waiting time. Many people do not receive their diagnosis until their dementia is quite advanced, which can reduce the benefit of post-diagnostic support. NHS Scotland is finding out whether providing dementia expertise within GP practices can make it easier for people to access dementia support.⁴¹

Wider policy developments in Scotland

There have been major changes in laws and policy over the last decade in Scotland. NHS and local authorities were brought together to provide integrated health and social care in 2016. Legislation to make sure that everyone who uses social care is able to choose self-directed support was passed in 2013, and the Carers Act (Scotland) 2016 created new legal rights for unpaid carers to be recognised, supported and involved in decisions about the care of the person who they support.

In 2019, free personal care was extended to people aged under 65 for the first time. Not all home care services are classified as personal care, and people may be charged for these. Fees vary by local authority area. The current Scottish government has pledged to abolish all non-residential social care charges. In Scotland, self-funding care home residents have to pay accommodation costs. These vary by care home. In Scotland, the average self-funding care home resident pays £894 per week in a care home without nursing care and £995 per week with nursing care.⁴²

When powers over some disability benefits were devolved to Scotland, the Scottish government introduced a Carers Allowance Supplement in 2018. This is paid twice yearly, and means that the rate that eligible carers receive is in line with Jobseeker's Allowance. A new Scottish Carer's Assistance benefit will be introduced. And new social security benefits for disabled people of working age and pension age will start to be introduced from 2022.

New legislation is promised in 2022 to create a National Care Service in Scotland⁴³ and this is expected to transform the landscape around social and community care at every level. Changes will cover all areas – from how social care is accessed, how it is paid for, the types of professionals and organisations that can provide individuals and families with the support they need, and the ways in which care providers are regulated.

An independent review of incapacity law in Scotland will also be published shortly, with new legislation expected to follow.

Healthcare

In this section, we look at the journey people with Parkinson's-related dementia go through, starting with experiences of being diagnosed.

People with Parkinson's-related dementia have complex needs and are likely to encounter a wide range of health professionals. We explore these professionals' understanding of the different aspects of the condition, as well as how joined-up people's experience of their health service is.

Because people with Parkinson's-related dementia are often admitted to hospital for reasons other than their Parkinson's or dementia, we look at the suitability of the care they receive while in hospital.

Finally, we take a look at planning for people's future care needs.

Experience of diagnosis

It's important that people with Parkinson's who develop dementia are diagnosed by a specialist (e.g. a neurologist or psychiatrist) as soon as possible, as medication regimes and programmes including physiotherapy and speech therapy may need to be adjusted. Parkinson's specialists should proactively ask patients about changes in their thinking and planning.

It is difficult to get a diagnosis of dementia. It's even more difficult to find out the subtype, such as dementia with Lewy bodies or Parkinson's dementia, as Georgina's experience below shows. Our survey of carers of people with Parkinson's-related dementia found that it took on average six months to get a diagnosis, and 45% said the process was difficult. This is at a time where the diagnosis rate for all dementias in England for people aged over 65 has dropped by 6% over the course of a year during the pandemic.⁴⁴



On average it took 6 months to get a diagnosis, 45% of carers said the process was difficult

“I'd been going to neurology since 1996, and every time I saw a different neurologist I got a different diagnosis. It was 2014 before I was told by a neurologist that I definitely hadn't got Parkinson's, so I was sent for a lot more scans. That had been going on for nearly 20 years. In April 2015 I saw yet another neurologist, and he thought I'd got Wilson's disease, so he tested for that, and he sent me for a DAT scan, which happened in December of that year. It took until March 2016 for the results to come back, and he gave me a diagnosis of suspicion of Lewy body disease, so he referred me to another neurologist.”

Georgina, who has Parkinson's dementia

From our survey of health professionals, the top three barriers to getting an earlier diagnosis of Parkinson's-related dementia in England were:

- **short length of appointments** and not enough time to discuss both motor and non-motor symptoms (64% of professionals said this was a problem for people with Parkinson's dementia, while 56% said it was a problem for people with dementia with Lewy bodies)
- **lack of a pathway to professional colleagues** who can make a diagnosis of dementia (Parkinson's dementia 52%, dementia with Lewy bodies 63%)
- **lack of awareness of dementia symptoms among people with Parkinson's** (52% for both subtypes of dementia).

It is no surprise that appointment times are seen as one of the main barriers to early diagnosis. We hear from many consultants who have just 10- to 20-minute appointments. There are up to 40 symptoms associated with Parkinson's and it is a progressive condition. With such short appointment times, it is easy to see how symptoms of dementia could be missed.

Another barrier that featured high on the list for health professionals was lack of a clear pathway to help professionals diagnose Parkinson's-related dementia. From our carers' survey, we found that most people with Parkinson's-related dementia were diagnosed by either a neurologist (37%) or a psychiatrist (11%), with a further 13% without an official

diagnosis. This somewhat reflects the balance of people with Parkinson's dementia and people with dementia with Lewy bodies cared for by those who took part. Since dementia symptoms in people with dementia with Lewy bodies appear before other Parkinson's symptoms, they are more likely to be diagnosed by a psychiatrist, rather than a neurologist or geriatrician.

Health professionals cited lack of awareness of dementia symptoms among people with Parkinson's as another barrier to more timely diagnosis. Findings from our carers' survey support this – fewer than half (48%) of respondents knew people with Parkinson's were at increased risk of developing dementia.

There is evidence to suggest that Parkinson's-related dementia is being underdiagnosed.^{45,46} It is also worth noting that the UK Parkinson's Audit found that: “Standardised assessment tools are routinely available in only 74.1% of all or most clinics to assess and monitor cognitive function.”⁴⁷

Parkinson's UK recommends that Parkinson's-related dementia is diagnosed by a specialist. Yet only 56% of respondents to our carers' survey said the person they care for was diagnosed by either a neurologist, geriatrician, 'specialist' or psychiatrist.

Difficulty in getting a diagnosis means delays in accessing the appropriate support, care and treatment for people living with the challenges and complexities of Parkinson's-related dementia.



Quality of care – taking time to understand dementia

“When I had the neurologist, Dr Jones, absolutely brilliant. He was wonderful. Then he left and went back to Spain not long ago, beginning of last year if I remember rightly. He was really good, he took time and he explained why the shaking happens and the walking. When you freeze, he explained how to, you know, hold somebody’s hand, look at their feet, it bypasses that bit so it gets you walking. He was absolutely wonderful, he explained everything. He was really good, and he took time. As my medication started wearing off and he’d have to put me on something new, he’d explain how that medication would work. The new consultant, who I’ve seen once, who last year altered my appointments seven times within two months, I had been warned that he was very abrupt, you only get 10 minutes, he won’t give you any longer than 10 minutes. I was told that he’s more interested in the disease than you. Does that make sense?”

Georgina, who has Parkinson’s dementia

“You know, it seems to be a difficulty in explaining things to everybody involved with him really, and I do think it would be good if there was support for family members, but as I say, we have relied in the past on the Parkinson’s nurse when we’ve been in a terrible mess, but I know she hasn’t got the time now, and there are people more in need of support.”

Vivian, carer of a person with Parkinson’s dementia

Cheryl, a carer of a person with Parkinson’s dementia, shared that the consultant doesn’t understand the dementia element of the condition: “No. Not as well as the mobility element for the Parkinson’s.”

Clearly, people with Parkinson’s-related dementia can have a mixed experience with healthcare professionals. In the example of Georgina, you can see a sharp contrast between her previous and current neurologists within the same service.

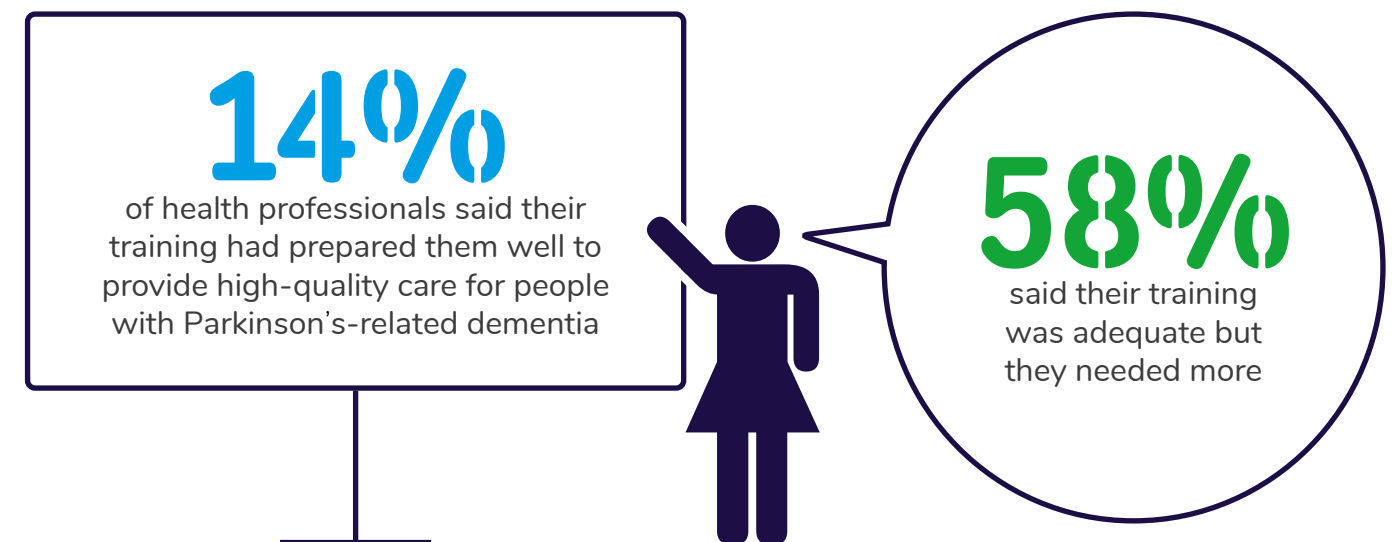
From our carers’ survey we found only 25% agreed that the health professionals responsible for Parkinson’s care took account of the dementia aspect of the person’s condition, while 25% said it was not considered at all. A further 25% said dementia was taken into account on most occasions, while the final quarter said dementia was only occasionally taken into account.

Adapting appointments

There is a clear need to adapt how healthcare appointments are conducted. People with Parkinson’s-related dementia who are cognitively impaired and may experience communication difficulties must be able to understand and fully engage with their healthcare professionals about their health, care and treatment.

We asked healthcare professionals how they adapted their appointments for people with Parkinson’s-related dementia. We found 78% adapt their communication style, which is encouraging and important to make a meaningful consultation possible. Strikingly, only 22% of the health professionals who responded provide written information in a more accessible format. The vast majority – 89% – said they communicate both with the carer and the person with Parkinson’s-related dementia. Interestingly, only 42% offer longer appointments.

Lack of time in appointments was cited as a key cause of a person’s needs related to their dementia not being adequately addressed. In fact, our survey of health professionals found geriatricians and neurologists typically only have around 20 minutes for a follow-up appointment, making it challenging to prioritise what to address. Interestingly, there was a wide variation in time for assessment appointments, ranging from 30 to 90 minutes.



Training and education in Parkinson’s-related dementia

When asked in our survey if they felt they had the tools and knowledge to provide high quality healthcare for people with Parkinson’s-related dementia, health professionals responded as follows:

- **14% said they felt well prepared through their training and education** to provide high quality care for people with Parkinson’s-related dementia.
- **17% felt they had received adequate training and education** in Parkinson’s-related dementia.
- **59% said they had received adequate training and education to some extent**, but needed more training.
- **9% did not feel they had sufficient training or education** on Parkinson’s-related dementia.

More needs to be done to ensure healthcare professionals can access and receive the training and education opportunities they need to better meet the needs of people with Parkinson’s-related dementia.

When asked what the gaps in training and education are on Parkinson’s-related dementia, health professionals cited:

- **diagnosis making** – information on the different types of dementia, tools to diagnose and how to use these tools
- **behavioural management** – how to manage hallucinations and delusions, and more challenging behaviours
- **service organisation** – how to organise a cognitive screening for people with Parkinson’s, living well with dementia courses or psychoeducation
- **modes of delivery** – having online, remote and face to face options available.

Some health professionals suggested targeting non-specialist and ward staff who may have contact with people with Parkinson’s-related dementia, but have little or no knowledge of the condition. This would cover management of the condition, especially medication, as some anticholinergic medications are harmful to people with Parkinson’s-related dementia.



Working in a generalist team – dementia diagnoses can sometimes be classed as just dementia – training specifically on effects of Lewy body and diagnosis process would be relevant.”

Healthcare professional survey respondent



...more on hallucinations/delusions and how to help manage them, non-pharmacologically and pharmacologically, and more awareness of local services.”

Healthcare professional survey respondent

Post-diagnosis support

Lack of quality post-diagnosis support for people with dementia is a well-known, long-standing issue. With 61% of health professionals in our survey saying there are gaps in post-diagnosis support locally, it appears this is also the case for people with Parkinson’s-related dementia.

Most people are referred to memory clinics and psychiatry services. However, these services are often overstretched. It is felt that these interventions are often brief and don’t provide ongoing support. There are some instances of community mental health teams not accepting referrals for people with Parkinson’s-related dementia, as they have a physical condition or they don’t see dementia as a ‘mental health’ issue.

Many professionals commented on the patchy provision of support groups, day centres and cognitive stimulation activities, as well as many day centres having to close during the pandemic.

The impact of the pandemic

To a large extent, healthcare professionals reported that, compared to before the pandemic, length of appointments hasn’t changed (73% said this) and nor has the number of appointments per year (77% said this).

Health professionals’ observations of the numbers of people with Parkinson’s-related dementia being diagnosed compared to pre-pandemic levels were mixed:

	Parkinson’s dementia	Dementia with Lewy bodies
No change	31%	39%
An increase	20%	13%
A decrease	5%	2%
Unsure	44%	47%

However, it was striking that 61% of healthcare professionals had noticed an increased rate of cognitive decline in people with Parkinson’s-related dementia compared to pre-pandemic norms.

Changes to our way of life under the pandemic may have resulted in people with Parkinson’s-related dementia having less cognitive stimulation – for example having less contact with others – leading to a decline in cognitive abilities. This decline may also be reflected in a survey by Lancaster University and Parkinson’s UK at the height of the pandemic where 26.7% of people with Parkinson’s-related dementia reported they were not coping well with the pandemic.⁴⁸

Care coordination within the NHS

“The consultants seem to have prescribed appropriately, although there have been no consultations on alternatives. When we moved to Bristol in 2014, I was seen by a physiotherapist, an occupational therapist and a speech therapist. I do not see the same consultant on each visit that I go there, and that’s rather concerning to be having to go through the whole process again. I understand that the system operates appointments being made in response to need rather than on a regular basis. This leaves one somewhat isolated.”

Daisy, carer of a person with Parkinson’s dementia

In the interviews and through our carers’ survey we heard of many cases of people with Parkinson’s-related dementia not receiving a joined-up approach to care. Lack of communication between different elements of their care, and having to retell their story over and over again, were common. People with Parkinson’s-related dementia are often under the care of professionals from a range of disciplines, often disconnected from each other. This can negatively impact quality of care.⁴⁹

“...I think we feel nobody really knows us apart from – I mean, his GP knows him a bit, but we don’t see him very often. Because Parkinson’s is a progressive condition, it’s important that somebody can see how it’s progressed in the last six months, a year. So, instead of keeping seeing different people, it would be helpful to have a key person, yes...”

Daisy, carer of a person with Parkinson’s dementia

We found that in many areas people with Parkinson’s-related dementia have no single point of contact in the event of a medical crisis. Only 14% of professionals were aware of a single point of contact, 45% were unsure and 41% said there was no one. This indicates a lack of care coordination for people living with Parkinson’s-related dementia, which stops people with multiple and complex needs getting holistic, person-centred care.

Different parts of the health and social care system use various patient record systems, and can leave one service without access to the records of another. From our survey of healthcare professionals, only 11% had access to a person’s social care records, 17% had access to mental health notes, and 54% had access to patient notes from people seen in community settings.

“We can see her in intervals between the consultants, the Parkinson’s nurse, but I can contact her by email at other times and sometimes she is quite helpful, but one of the big issues is that my husband’s on a particular antipsychotic to try and control the hallucinations and she’s not allowed to make any changes in that at all. That can only be done via the consultant. So if anything goes wrong on that score, and I do have serious worries about it, then I can only wait until we see the consultant.”

Cheryl, carer of a person with Parkinson’s dementia



After two months in hospital, leaving was difficult... During those days, I was visited by physios, OTs, social workers, palliative care, counsellors and many other medical professionals; had I not been there throughout each day, I'd have missed meeting with these very important people who were crucial to Tim's care and who also provided amazing support for me."

Stevie, carer of a person with Parkinson's dementia

Of the healthcare professionals who took part in the survey, 66% worked as part of a multidisciplinary team (MDT) and 33% did not. Of these, most MDTs included a geriatrician or neurologist, Parkinson's nurse, physiotherapist, occupational therapist and speech and language therapist. Around a quarter included a psychologist or psychiatrist. Interestingly, when asked which professions should make up an MDT for a person with Parkinson's-related dementia, 72% thought that a psychologist should be included and 81% thought a psychiatrist was needed. Other specialities seen as key components of an MDT for a person with Parkinson's-related dementia included a GP, pharmacist and community psychiatric nurse.

Although it can be challenging to establish a joined-up, multidisciplinary approach to care, it is thought to deliver the most therapeutic benefit.⁵⁰

Care in hospital

We heard of several people with Parkinson's-related dementia having poor experiences in hospital after being admitted for reasons other than their dementia. Staff were unaware of Parkinson's-related dementia and how to meet their specific needs.

"I got taken into hospital last year by ambulance because they thought I was having a heart attack... 'What are your mum's problems?' 'She has got Parkinson's, she has got Lewy body dementia.' 'Never heard of that. Is that a thing?' he went. 'Yes, this is her medication that she's taking for it,' this, that and the other. 'Never heard of it, we'll put down she has got Alzheimer's.' ...I just thought that was quite bad really."

Georgina, who has Parkinson's dementia

Our carers' survey showed:

- **Only 21% of carers felt supported by hospital staff to look after their loved one.** 44% said it could be improved. 31% said they did not feel supported.
- **48% of carers thought that hospital staff did not have sufficient knowledge to provide the care their loved one required.** 34% said hospital staff did have the knowledge needed but that this could be improved.
- It is of great concern that **only 33% of people with Parkinson's-related dementia got their Parkinson's medication on time, every time while in hospital.** 48% did not get their medication on time, every time and 20% were not sure.
- **59% of carers provided care (such as feeding or explaining procedures) during their loved one's stay in hospital.** 33% did not provide this, and 8% said it was not needed.

Case study: 25 hours in A&E

"He was in A&E for 25 hours. He went in at tea time one day and didn't get moved to a ward until gone tea time the next day. Nobody came and offered him food, apart from when I asked. He's been in here all this time, and he didn't have his lunch because he was so gone that day, didn't open his eyes all day. He hasn't eaten in the care home, he's been sat here all this time, he has no food, I'm frightened to go out and find something. We were there all night long. There was only a crisp machine and a coffee machine that was accessible at that point because all the cafes were shut. Nobody came to see if he was hungry or not or to offer him drinks. I had to keep asking. Now, if I hadn't followed that ambulance and I hadn't been there, what would have become of him in that 25 hours?"

"I slipped out for six hours just to get a little bit of sleep because he was fast asleep at 2.30 in the morning. I thought 'right, I'll get some sleep because I know the doctors are coming around in the morning and I need to be awake enough to hear what they're saying.'"

"By the time I got back, he'd had another fall in A&E. So, they'd wedged him in a chair with a table in front of him, to stop him from standing up, but the lady in the bed next to him said to me, 'They've been shouting at him. Every time he tries to stand up, they're shouting at him to 'Sit still, we told you to sit still.' She said, 'It's not very kind', and that was an old lady next to him telling me. I said, 'Well, there's no good them shouting at him because he won't understand why he has to sit still.' If his legs feel stiff, he will try to stand up or take the pressure off his bottom because he's been sitting still too long, and then he'll sit back. But if he does one step even, he will fall over. But obviously, they're running around and it's going ballistic in there, there were two beds to each bay and there was another stack of beds in front of that. So they didn't have time to watch him."

"It was only on the fifth day that he'd been in the hospital that two people came to him in bed and said, 'We're the hospital dementia people, we've come to see how we can help.' I thought 'he's been here five days, maybe you need to be in A&E where people are actually hurting themselves if they're not getting that care.' So, what do people do that are on their own? That haven't got a wife that's able to support them? Or children, or anything. If he'd been in there by himself all that time, what would have happened to him? That frightens me."

"Barry kept trying to get out of bed. Once they found him a bed from A&E, he was fairly calm in A&E even though it was absolutely crazy all around us, a woman with norovirus next to us, a man throwing up every 10 minutes that side. He seemed a bit oblivious to it all, it was quite weird. It was me that was more distressed. But once he'd got to a bed, after the 25 hours, it was then that he started getting really distressed because he couldn't understand yet another environment, where there were five men, three and two. Acute observation ward, he would not keep still in the bed."

"Every few minutes he kept trying to put his feet down to get away, and every time I said, 'Just keep still, you'll be safe if you keep still, you don't want to fall again.' And he was convinced that he needed to get away from there. 'If I don't get out of here, I'm never going to get out of here. Something bad's going to happen if I don't get away from here.' And then he threw a packet of biscuits that the nurse had given him across the room, and I thought 'oh, he's getting aggressive. I've not seen that side of him ever before.' 'Why did you do that?' He said, 'I needed to get them away because I need to get ready to be able to make a quick getaway.'"

Clare, carer of a person with Parkinson's dementia

It is clear that many people with Parkinson's-related dementia being admitted to hospital for reasons other than their dementia or Parkinson's are experiencing poor quality care, often in a chaotic environment not suited to their needs.



When I got the diagnosis we arranged powers of attorney, will was already made, we sorted everything out, get it over and done with at the time.”

Georgina, a person with Parkinson's dementia

Thinking about future care needs

“Yes, we definitely have. I mean, at the moment, we're having someone just to keep him company, and also his organisational skills aren't very good. His study looks a tip, so they're going to come and help him organise all his files. So, they're the two things at the moment that we need help with, but obviously, when it gets to the stage where it is disrupting my sleep a lot and, you know, he does need more care then yes, we will up that. Yes, I realise that that's going to happen, but at the moment we're alright.”

Harriet, carer of a person with Parkinson's dementia

Through our interviews and results from the carers' survey, we found that more than half of people (52%) were unaware that having Parkinson's leads to an increased risk of developing dementia.

According to our survey of health professionals, the majority (70%) provide information on the risk of developing dementia when someone starts to develop mild cognitive impairment, or after they experience delirium or other mental health issues. Only 8% provide this information at diagnosis, 13% in the early stage of Parkinson's and 14% at a person's annual review of care and treatment. This increases to 27% in the 'maintenance' stage of Parkinson's and 31% in the advanced stage.

Many carers we interviewed wanted to know earlier about the possibility of their loved one developing dementia, so they could plan for their future care needs. In our carers' survey 58% said they would have found it useful to have known about the risk of developing dementia so they could prepare for changes in their loved one's care needs in advance.



Recommendations

- **NHS Digital** should publish diagnosis rates of dementia subtypes (including Parkinson's dementia and dementia with Lewy bodies – the two types of Parkinson's-related dementia) as part of its 'Recorded Dementia Diagnoses' monthly data set.
- **Health Education England** should roll out basic training for non-specialist health professionals about caring for people with Parkinson's-related dementia.
- **Integrated care systems** (all the organisations that meet health and care needs in an area) must work with **NHS Trusts** to ensure people with Parkinson's-related dementia have access to a Parkinson's multidisciplinary team, with a clear referral pathway into neuropsychiatry and/or old age psychiatry.
- **Integrated care systems** must provide the resource required to ensure there is capacity within the Parkinson's workforce and appropriate contracting arrangements to:
 - deliver models of care that enable multidisciplinary team working
 - provide appointments of suitable length to meet the needs of people with Parkinson's-related dementia.
- All **NHS acute hospital trusts** in England must adopt the principles set out in the revised Dementia-Friendly Hospital Charter and implement the changes needed.

Support for carers' needs

Living with Parkinson's and dementia

“It's just that the person who's caring for a person with Parkinson's is actually living with it as well because they're having to live around it. We have to stimulate them and take them to physio because, of course, he can't drive anymore. So, I'm his driver, I'm his carer. I have to think for two of us because, although he's mentally okay, he would never be able to cope with remembering when to order his tablets, or taking his tablets, or, 'Which tablets am I taking and which aren't I?'

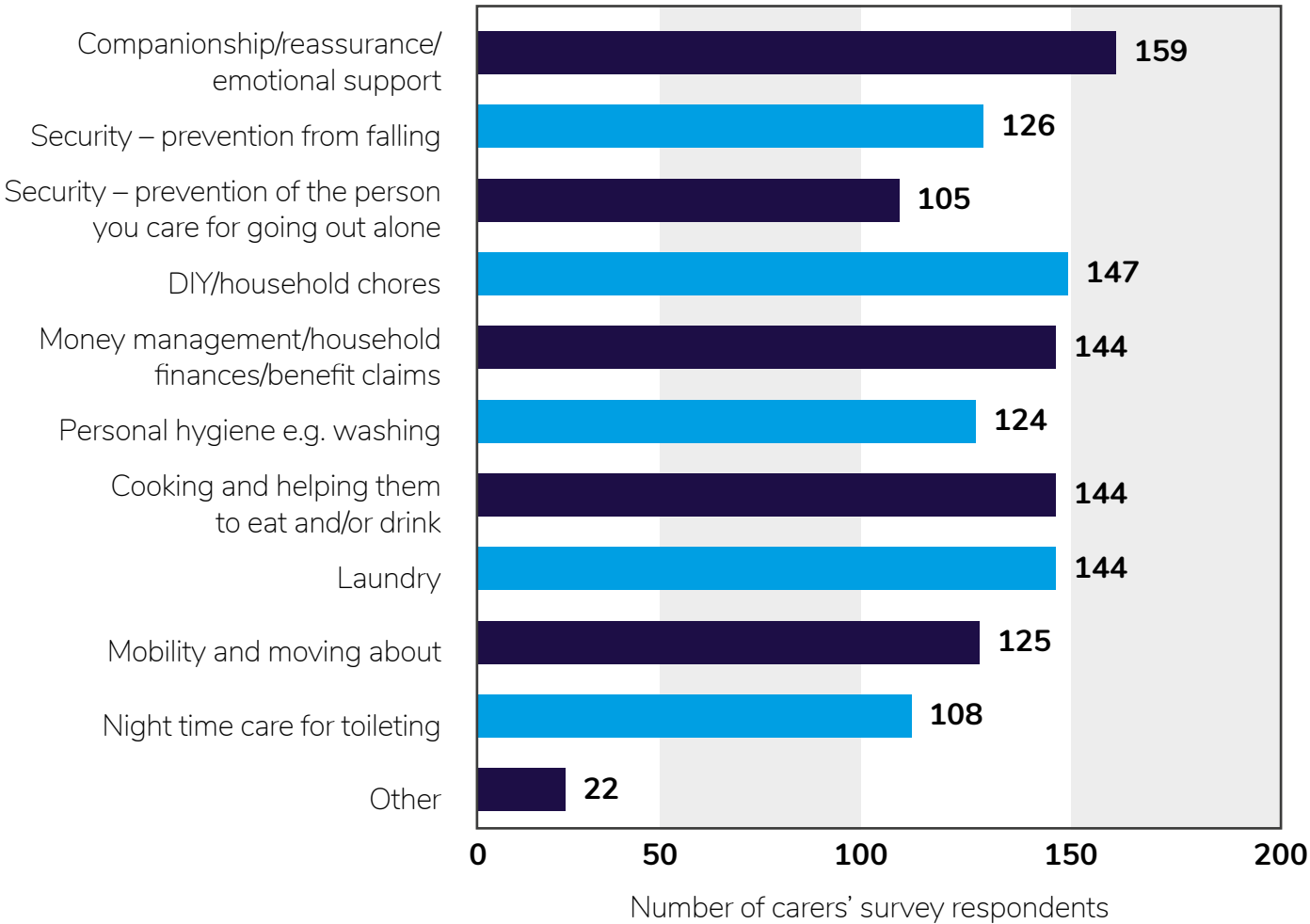
“So, I'm thinking for two of us all of the time, of what he needs to be doing and how I need to be stimulating him as well as looking after myself and our home and garden. So, yes, it is hard work and you do need a couple of days when you can go and be normal really, that's all. It is a full-time job.”

Angela, carer of a person with Parkinson's dementia

Family, friends and unpaid carers of people with Parkinson's-related dementia play a crucial role in supporting their loved ones with day to day living and helping meet their health and care needs. As this quote suggests, caring for someone with Parkinson's-related dementia is all-encompassing, and involves providing support for most aspects of daily living.

This chart gives examples of the wide range of tasks and types of care unpaid carers are providing for people with Parkinson's-related dementia.

What type of care do you provide?



Our carers' survey shows 36% of carers are providing 20-24 hours of care per day, with the majority (53%) providing 10 or more hours of care per day. Carers responding to the survey were predominantly female (73%) and mainly between the ages of 60 and 79 years old (69%). These findings are supported by a recent study looking at the care burden of spouses of people with Parkinson's-related dementia, which found they provide on average 84 hours of care per week.⁵¹ In many cases (60%) they are the sole carer of the person they are caring for – meaning they are receiving no paid care and are unable to access regular care support from friends and family.

We found carers do have support networks they can 'lean on', including family (56%), friends (30%) and community groups (10%). However, a worrying 29% said they did not have any support networks. Only 13% of respondents found support groups for people with both Parkinson's and dementia available locally – most were for either condition, not both.

Understandably, their caring responsibilities have taken their toll on carers' mental health, with 65% experiencing anxiety, 62% depression, 77% insufficient sleep, 64% loneliness and 59% isolation. We know that carers of people with Parkinson's more broadly have been impacted by the coronavirus pandemic, with 68% taking on more caring responsibilities and 42% saying it has had a negative impact on their mental health.⁵²

Our carers' survey suggests 41% of carers have had a carer's assessment, 31% have not, and a further 28% have not been offered or even heard of a carer's assessment. Despite the right to a carer's assessment being in law due to the Care Act 2014, in reality, people are not being made aware of this or are not being offered an assessment.

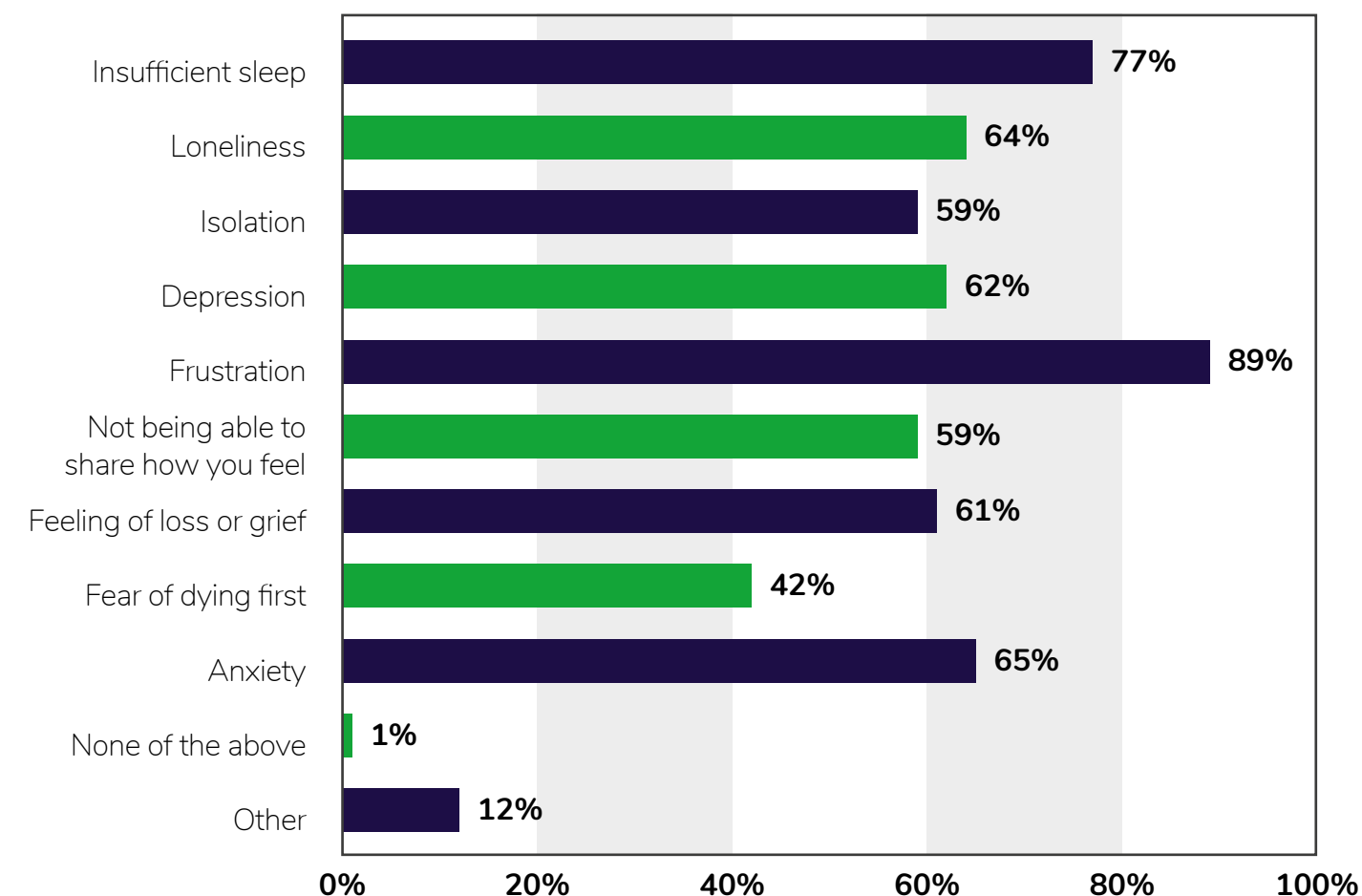




I had a carer's assessment about 18 months ago. I mean, all it really did was, they said yes, I was a full-time carer for Bryan, and because of that, I was entitled to a one-off payment from Bristol City Council for a treat. So, I had a one-off payment, but I mean, it didn't achieve anything else, really, no."

Daisy, carer of a person with Parkinson's dementia

Have you experienced any of the following?



Of those who had a carer's assessment, the main types of support people received according to our survey were:

- someone to help take over caring so they could take a break (25%)
- they were put in touch with groups/got advice about benefits for carers (for example, Carer's Allowance) (22%)
- they were able to access **respite care** (day centre or short stay in a residential home) (15%)
- no support was offered (21%).

Often those who have had an assessment find the resulting support does not meet their needs. Only a quarter of the people we surveyed said this support has made a positive difference to their lives.

Respite care

Despite the impact on carers' wellbeing, people with Parkinson's-related dementia have found respite care hard to access and often unavailable at all during the pandemic.

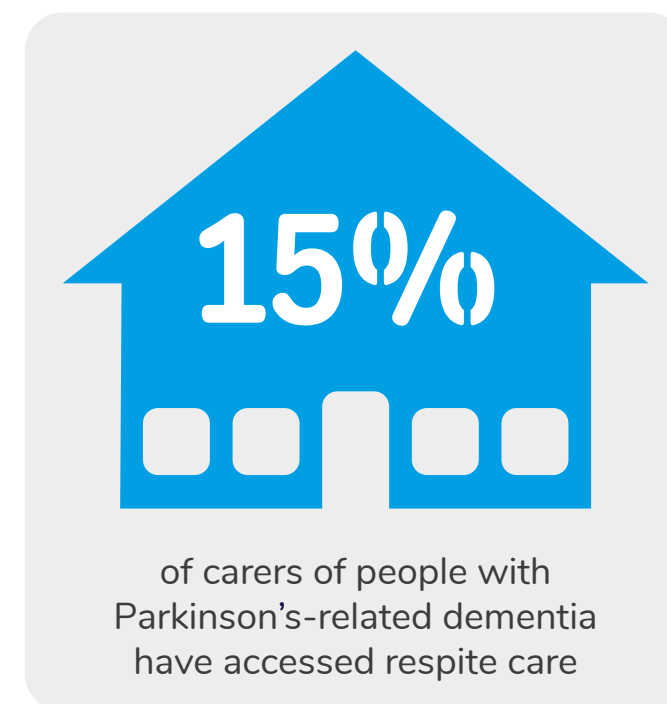
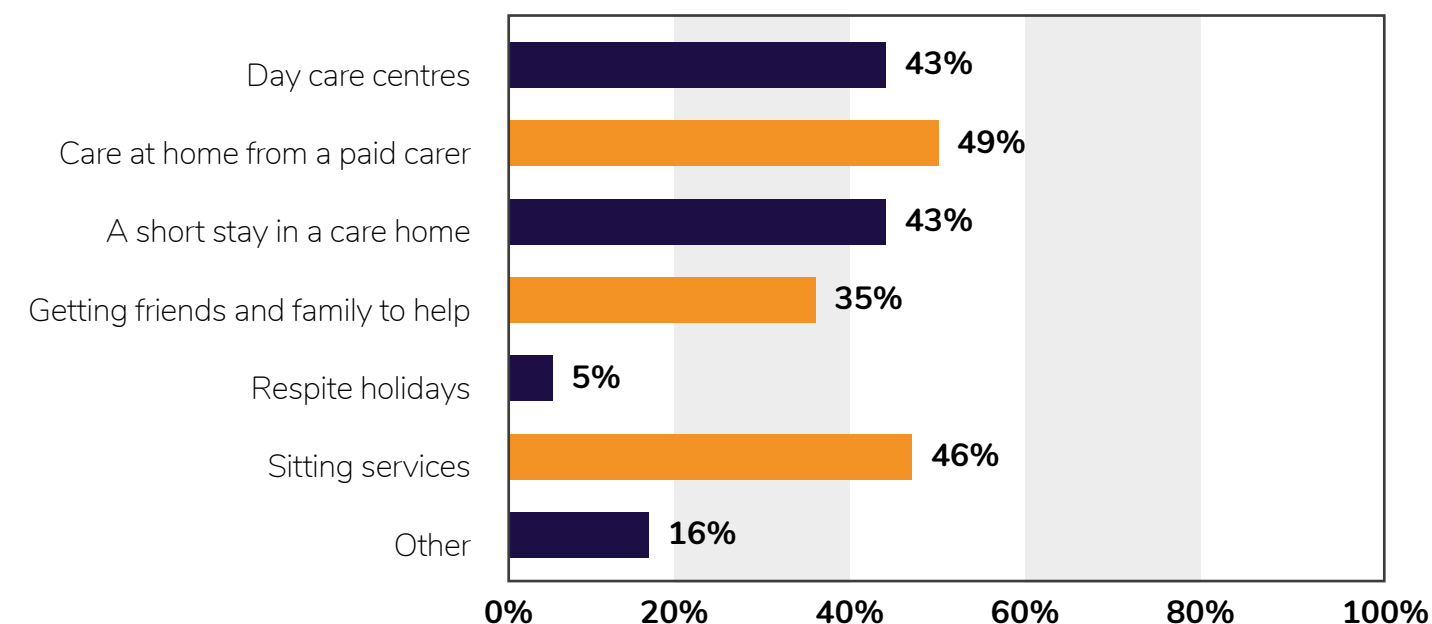
We found that a significant number of carers we surveyed (68%) were unaware of any respite care available in their local area. Only 22% said that there was respite care available locally.

Where respite was available, the chart below shows what type:

"This additional three hours, when [the carer] came, was supposed to be respite for me and the day centre, yes, but it wasn't, because I was so exhausted getting him there. I'd go home and I'd have a cup of tea, and then I was waiting for the phone to ring, because I knew that she was going to ring me, and she did, saying please come and get him, we can't cope with him, so it didn't work out."

Janine, carer of a person with dementia with Lewy bodies

What form of respite care is available?



While 22% of carers said respite was available locally, only 70% of them have been able to access it. This suggests that just 15% of carers who took part in our survey have received respite care.

In two-thirds of cases, respite care incurred a financial charge. Depending on the type of respite care available (for example, a day centre or a week in a care home) this could range from £15 to £2,000.



Yes, I mean, it's been a real kick in the guts for him to have these delusions, I find it really hard."

Alice, carer of a person with Parkinson's dementia

Parkinson's psychosis – how to help?

One of the recurring themes from the interviews we held with carers of people with Parkinson's-related dementia was their loved one experiencing distressing hallucinations and delusions. Yet they were provided with little or no guidance or support to help the person experiencing these symptoms of psychosis.

Management of psychosis is further complicated due to a lack of evidence on whether antipsychotic drugs are effective for people with Parkinson's-related dementia.⁵³

Furthermore, certain antipsychotics can cause severe neuroleptic reactions (including cognitive decline, parkinsonism, drowsiness, and falls)⁵⁴ in people with Parkinson's-related dementia.⁵⁵ These can be fatal and can lead to a high risk of mortality in the long run.⁵⁶

Our carers' survey showed 75% of the people they cared for had experienced hallucinations and 51% delusions. Of those experiencing these symptoms, the majority (55%) found them distressing and 42% found them tolerable.

We found carers had varying degrees of confidence in their ability to support the person they care for when they were particularly distressed by these symptoms. Only 21% said they felt confident in supporting their loved one in these situations, while 45% felt somewhat confident, 20% under-confident and 14% not confident at all.

We asked if carers ever felt 'at risk', leaving the question open to their interpretation of what 'at risk' meant. Of those who responded, 33% said they did feel 'at risk'. The majority (62%) did not and 5% said they did not know. Those who said they felt 'at risk' gave details of what 'at risk' meant to them. This included experiencing aggressive or challenging behaviour towards them or others from the person experiencing psychosis.

However, despite these challenges, very little or no support is offered to carers on what to do in these situations. Only 5% of those surveyed were offered any training or information on how to support a person with Parkinson's-related dementia who is experiencing distressing delusions or hallucinations.

"Well, dealing with the day to day changes, sometimes things can go on fairly smoothly and then other times he can become extremely agitated and I have been advised by the Admiral nurse that he shouldn't be given any drugs to deal with the agitation because of the effect that may have on the Lewy body disease. If you give any of these kind of calming drugs, the effects can be quite severe on somebody with Lewy body or Parkinson's dementia. So at the moment we just have to try to work through it really, until he goes to sleep which is usually the point at which the agitation is over. I find that extremely challenging because he doesn't respond to reasoned argument."

Cheryl, carer of a person with Parkinson's dementia

Also concerning is that only 16% of carers of people with Parkinson's-related dementia had been offered advice or guidance by health professionals on how to support a person experiencing distressing delusions or hallucinations.

"I've seen varying advice [about delusions and hallucinations], because I noticed in one of the clinic letters I typed that the consultant told a daughter not to agree with her mother when she sees funny, you know, somebody walking in the room, you must never say, 'Yes, I can see her.' You should always say 'No, they're not there.' I've had conflicting advice where you should perhaps go along with it a bit more with the person, a bit more gently. You know, so no. I suppose I could have asked, actually, I could have asked somebody how I deal with it."

Alice, carer of a person with Parkinson's dementia

These findings are supported by results from our survey of health professionals, where only 9% had training or information sessions in their area for unpaid carers that covered neuropsychiatric or neuropsychological symptoms. 59% said they were unaware of any such opportunities in their area for carers and 31% confirmed that there were no sessions in their area.

The majority of health professionals responding to our survey provided information or signposted carers to information and support on hallucinations and delusions in people with Parkinson's. However, there clearly needs to be more support for carers.

In fact, 88% of healthcare professionals want to see training or information sessions for unpaid carers on how to support a person with Parkinson's-related dementia experiencing distressing hallucinations and delusions. There was also strong support, 79%, for better training for NHS staff who care for people with Parkinson's-related dementia on how to support the patient's loved ones. Almost half agreed longer appointments were needed to focus more on these symptoms.

Recommendations

- **Integrated care systems** should fund and ensure training/education is available for unpaid carers on the neuropsychological and neuropsychiatric symptoms of Parkinson's-related dementia. This should include how to support the person with Parkinson's-related dementia if they are experiencing distressing delusions or hallucinations.
- **The government** must work with local authorities to ensure there is adequate funding to provide unpaid carers of people with Parkinson's-related dementia with the breaks they need.
- The **Department of Health and Social Care** must assess provision of respite care for people with Parkinson's-related dementia, and publish its findings. This should include an audit of the training day centre staff receive, including on Parkinson's and dementia.

Social care

People with dementia make up the majority of people receiving social care in the UK with 70% of care home residents having dementia⁵⁷ and 60% of those receiving care in their own home.⁵⁸ As a person’s condition progresses, they are likely to need more help with day to day living and personal care. Dementia is common among residents with Parkinson’s in care homes and is the leading reason for admission to care homes for people with the condition.⁵⁹

From our survey of carers of people with Parkinson’s-related dementia, we found that 42% have paid care in their home, or have had it in the past. 7% of those surveyed cared for someone living in a care home or nursing home.

Quality of care – understanding Parkinson’s and dementia

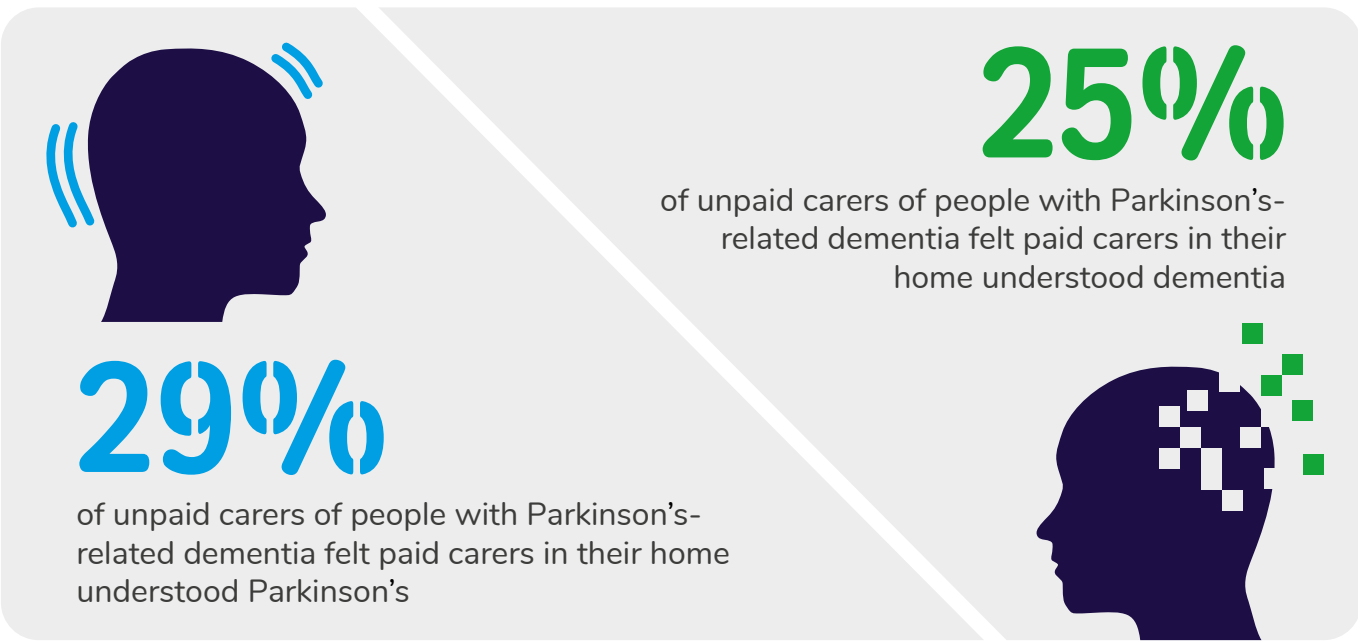
“One carer said, ‘Okay, Tim, stand up, up you get, out of bed,’ and I said, ‘The reason you’re here is Tim can’t do that.’ He asked, ‘Well, what do I do?’ I told him, ‘Well, you have to transfer him from the bed to the chair,’ to which he replied, ‘What’s transfer?’ I showed him and, in the end, I was the one who transferred Tim and put him in the shower. This sort of thing just went on and on.”

Stevie, carer of a person with Parkinson’s dementia

A common theme from the interviews with people with Parkinson’s-related dementia and their families was a lack of understanding among care workers of either Parkinson’s or dementia. Friends and family often need to step in and show the paid carer how to care for someone with Parkinson’s or dementia.

When asked if paid care staff at home understood the needs of the person relating to their Parkinson’s, only 29% of carers said yes, while 38% said it could be improved. Similarly, for dementia, just 25% said the paid carer understood their needs, while 41% said it could be improved. Research also suggests that care home staff’s understanding and awareness of Parkinson’s-related dementia is limited and that they can find it difficult to deal with hallucinations and delusions, in addition to the condition’s other symptoms.⁶⁰

Research conducted by Firefly Illuminating Research and the University of the West of Scotland into care of people with Parkinson’s-related dementia in care homes in England and Scotland highlighted that care home staff found symptoms such as hallucinations, medication for hallucinations, and unusual sleep disturbances difficult to manage.⁶¹ While care home staff in the study rated their knowledge of dementia as high more broadly, they gave lower ratings for their knowledge of Parkinson’s-related dementia.⁶² There was a clear need to improve care home staff training in the condition.



Care and support plans

Through our carers’ survey, we found that only 22% of people with Parkinson’s-related dementia had a care plan in place, while 62% did not and 16% were unsure. If you’re assessed as having care and support needs you should have a care and support plan put in place.

Concerningly, only 19% of carers said the person they cared for was involved in discussing and agreeing their care plan. And only 27% of carers were involved in creating the care plan. Care and support plans are meant to enable people in need of care and their carers to express their views, and for support to be personalised to their needs. This would not appear to be the case in practice.

Accessing care – navigating the system

We heard many examples through our interviews with people with Parkinson’s-related dementia and their carers of challenges to get access to the care and support they so desperately needed. This included many care homes refusing to take their loved ones as they were not able to provide care for someone with Parkinson’s-related dementia.

“The first verbal carer’s assessment I recall, in 2016, conducted in our home with a hospital matron and a social worker, was to ascertain whether I qualified for some help with my husband’s care... It was a lengthy, detailed interview with me fighting back the tears; to have to give in to the realisation that I needed help with my husband was very difficult for me and I felt a failure... these two professionals assured my husband and I that we definitely did qualify and that their assessment would result in an effective care package forthcoming within two weeks.

“After six weeks, we’d heard nothing more until a phone call told me that our two assessors had left the NHS and had left no paper trail so the assessment had to be repeated... It was the first of many unbelievable and incompetent dealings we experienced with this sort of thing and with the local authority.”

Stevie, carer of a person with Parkinson’s dementia



Fewer than half (44%) of the carers of people with Parkinson's-related dementia we interviewed were provided with information on how to arrange care in the home. Of those who were provided with information, the majority received this from social services, as well as from Parkinson's nurses and occupational therapists. When asked about the difficulty of getting care put in place, 22% found it 'hard' and a further 12% found it 'almost impossible'. 54% found it OK and only 13% found it easy.

The time between their first enquiry to their local authority or care provider and their first visit from a carer averaged 19 weeks. The longest wait reported was over a year and four months.

“That was horrendous, I went to view some care homes in Hertford and Ware, because I live in Hertford and Ware is very close by, and all these homes declined, said no. I couldn't believe it, because I'd been to these homes and I saw that they had empty bedrooms, and then one of the nurses in the hospital, we just happened to be chatting, because you know they wanted his bed, and I said I can't understand it, [she said] because your husband is too noisy, they're all declining, so I said what do we do now? So then, we then, we are in Hatfield, that's why we are in Hatfield. I want my husband closer, I mean it's costing £50 a week in petrol money, my savings are going down, my children are now complaining because it's taking them nearly an hour to get here to visit dad, why isn't he in a home closer?”

Janine, carer of a person with dementia with Lewy bodies

Continuing healthcare funding

NHS continuing healthcare – also known as NHS continuing care or NHS CHC – is free healthcare provided outside of hospital that is arranged and funded by the NHS. It may include paying for care costs typically funded by a local authority under the banner of social care, such as fees for a care home, but where these arise due to a specific health need.

When delivered effectively, it can enable people to go on living as full a life as possible. It can also have the benefit of reducing anxiety and minimising pressure on family and friends. However many who apply for this funding face an overly bureaucratic process, with assessors who often don't understand Parkinson's. Many are denied funding they are entitled to. Many of the people we interviewed mentioned this difficulty.

Parkinson's UK is the current co-chair of the Continuing Healthcare Alliance of 19 charities and organisations that believe NHS continuing healthcare needs to improve.

In 2016 the Alliance produced a report called *Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?* which found nine major issues with the system, from lack of consistency to unacceptable delays – all of which resonate in the stories we heard from carers of people with Parkinson's-related dementia.

“He's CHC-funded, but I couldn't even begin to tell you how difficult it was to get that funding. In the end, I had to employ a solicitor, and I don't honestly think we'd have got it if we hadn't used his services. For that, I got enormous support from an internet forum called Care To Be Different, and if it hadn't been for that site, I wouldn't have even known that CHC funding existed. They provided so much information and so much help. They were amazing, and they recommended the solicitor who, in the end, managed to secure the CHC funding. I think I probably did more work to get that funding than I ever did to get a degree. You know, it was like studying for months and months with my daughter. It was the most horrendous battle.

“Well yes, and as I say, you know, it was a six-month battle, and we still have to face a review every 12 months when they try to take it away. I would say that was probably one of the most stressful six months I've had to experience, you know, since we began this Parkinson's journey.

“The nursing home charges £57,000 a year, and that's not one of the most expensive ones in our area. So, we did get it, but I do think other people need a lot more help with that.”

Vivian, carer of a person with Parkinson's dementia



I have paid out £60,000 to date... where do they think it's coming from? It's mind blowing, I don't really know what is going to happen to me financially soon when this money goes, I'm living on a shoestring, paying these bills. I'm not going on holiday, having wonderful days out, weekends away."

Janine, carer of a person with dementia with Lewy bodies

Paying for care

People with Parkinson's-related dementia often have complex needs, making care expensive. They often find themselves caught between NHS CHC and their local authority (social care) in a battle of who should pay for their care. In England those not awarded CHC funding, and who have assets over £23,250, end up paying vast sums for their care, as seen in the example above.

Our survey of carers of people with Parkinson's-related dementia shows people paying an average of £1,483 per month for home care, with one person paying £9,500 per month.



Recommendations

- **The government** must make sure that the recently announced £500 million of funding for training the social care workforce includes training on Parkinson's, Parkinson's dementia and dementia with Lewy bodies for social care staff directly providing care.
- Parkinson's UK is a member of the Care and Support Alliance and supports its seven principles for social care reform. The principles seek to ensure funding of social care is put on a sustainable footing, and access to care and quality of care are improved (see appendix 1 for the full list of principles).
- For NHS continuing healthcare to improve, the **Department of Health and Social Care, NHS England, local commissioners and local authorities** must implement the recommendations set out in the Continuing Healthcare Alliance report *Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?*. The recommendations call for changes to the NHS continuing healthcare assessment and decision-making processes to make the system fairer for individuals in need of care (see appendix 2 for the full list of recommendations).

Integration of health and social care

Accessing healthcare from care homes

A recurring theme from the interviews with carers and people with Parkinson’s-related dementia resident in care homes was a sense that they had reduced access to the health services they need to live well with their condition.

“I did make an appointment, or my wife did, to see a physio, but it hasn’t been very successful. It’s hardly had any comeback. I mean, my wife may say different to that, but there hasn’t been any comeback or progression in what type of physical activity I need. I need something which is pretty, sort of, basic, but also, which will keep me amused for about 20 minutes or so, but I don’t seem to be getting that. It’s probably because there isn’t anything available.”

Barry, who has Parkinson’s dementia

“With a phone call, I managed to speak to one doctor who was somewhat helpful but I did get the impression that I should only rely on the care home now for Tim’s treatment.”

Stevie, carer of a person with Parkinson’s dementia

“Oh his legs are not weight-bearing at all now, they get my husband out of bed now, every other day for a couple of hours because of bedsores. When he left the hospital I wanted that written in the notes. When he came here the initial interview said I wanted a physio, nothing like that has happened, a GP does do his rounds once a week, my husband has deteriorated since he has been here, when he came in he could talk, and now, it’s probably part of the disease as well, there’s no stimulation.”

Janine, carer of a person with dementia with Lewy bodies

Our survey of health professionals found that, in most cases, key professionals based in the community could be accessed by people with Parkinson’s-related dementia. Although coverage is far from universal – for example, only 64% of respondents said neurologists or geriatricians could be accessed in the community. More concerning, this figure dropped to 45% when professionals were asked about access to a neurologist or geriatrician for people with Parkinson’s-related dementia who are housebound.

The Alzheimer’s Society’s report *Fix Dementia Care – NHS and Care Homes*⁶³ also found that 44% of care home managers it surveyed said the NHS isn’t providing residents with dementia with adequate and timely access to NHS secondary care.

The NHS Long Term Plan recognises that community NHS services have historically been under-resourced. In fact, the Plan’s first commitment is: “We will boost out-of-hospital care, and finally dissolve the historic divide between primary and community health services.”⁶⁴

It is important that people with Parkinson’s-related dementia have the same access to the health services they need to live well no matter whether they are living at home or in residential care, receiving paid care or not. This is clearly not the case for many people, and we welcome the recognition of the issue in the NHS Long Term Plan commitment to boost out-of-hospital care.

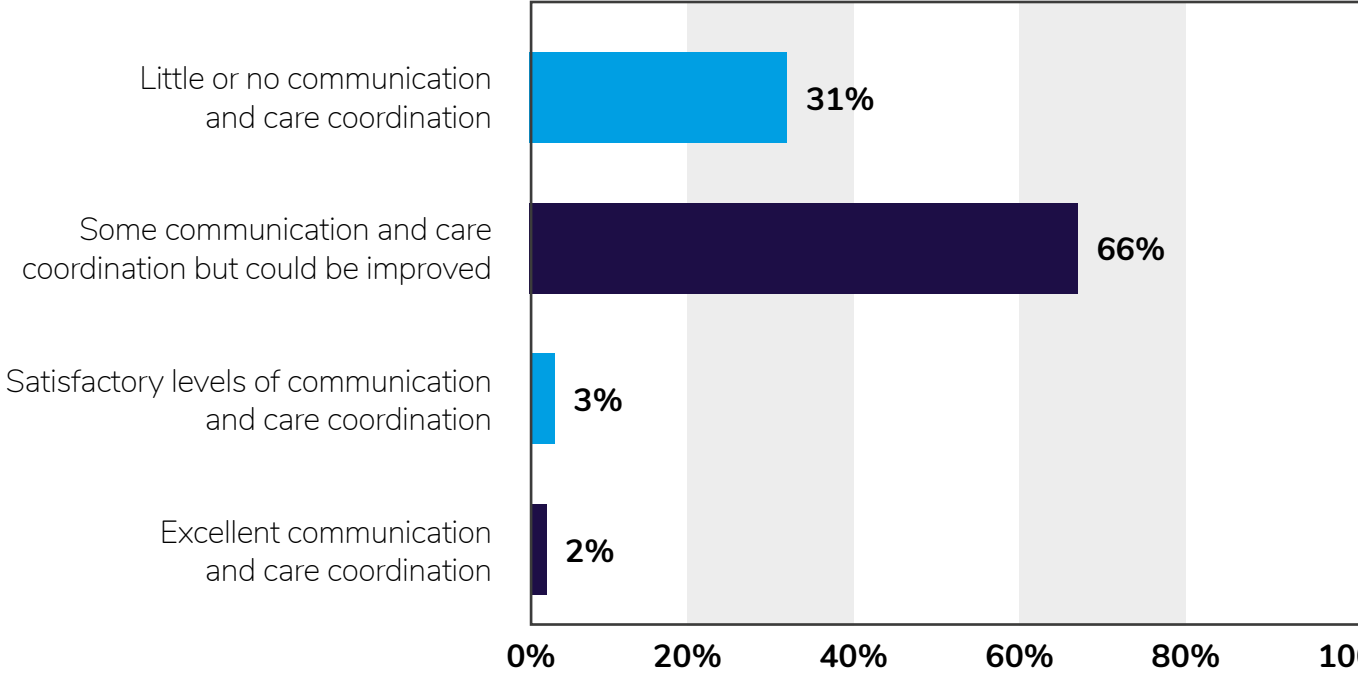
However more needs to be done to make sure NHS services are available and, crucially, to improve links between health and social care services to ensure people with Parkinson’s-related dementia can access them when necessary.

Communication and care coordination between health and social care

One of the telling statistics from our survey of health professionals is that only 11% of those working in the NHS had access to patient notes or records from social care. When asked about communication and care coordination with social care staff in their area, 31% said there was ‘little or no communication and care coordination’, while 66% said there was ‘some communication and care coordination but it could be improved’.

This is symptomatic of the lack of integration between health and social care services as they are set up currently. Improved communication and care coordination could help ensure that people with Parkinson’s-related dementia living in care homes have improved access to the healthcare services they need.

How would you describe communication and coordination of care with social care staff (those providing care in the home and in care homes) in your area?



Conclusion

Improving dementia diagnosis rates has been acknowledged as an important issue across the UK. However, a breakdown of data is not available for those with Parkinson's-related dementia at a local level. This makes it difficult for the health and social care system to plan and improve clinical management. This is important as the symptoms of Parkinson's-related dementia will mean that people have fluctuating needs and may be at higher risk of falls.⁶⁵ So therefore complex packages of care may be required.

We found that healthcare professionals need to take account of a person's dementia when providing care and treatment for their Parkinson's symptoms. While the majority of professionals do take measures to adapt their appointments, it's clear that further training is needed to support professionals. To deal with the complexity of an individual's Parkinson's and their dementia, longer appointments are needed so professionals can better meet their needs.

People with Parkinson's-related dementia can experience a broad range of symptoms requiring input from many different specialities. Unfortunately we found care within the NHS is uncoordinated. There is a disconnect between the different specialisms, often putting additional strain on carers, who have to join the dots between the professionals involved. A more cohesive approach, such as operating as a multidisciplinary team and having a named contact for the person with Parkinson's-related dementia and their carers, could improve care coordination.

Particularly concerning are our findings about the care people with Parkinson's-related dementia receive in hospital when admitted for a reason other than their Parkinson's or dementia. There appears to be very little understanding of their particular needs, leading to poor quality care in a chaotic environment not suitable for them. Getting medication on time in hospital has long been problematic for people with Parkinson's. It is worrying that only 33% of those admitted to hospital said they received their medication on time.

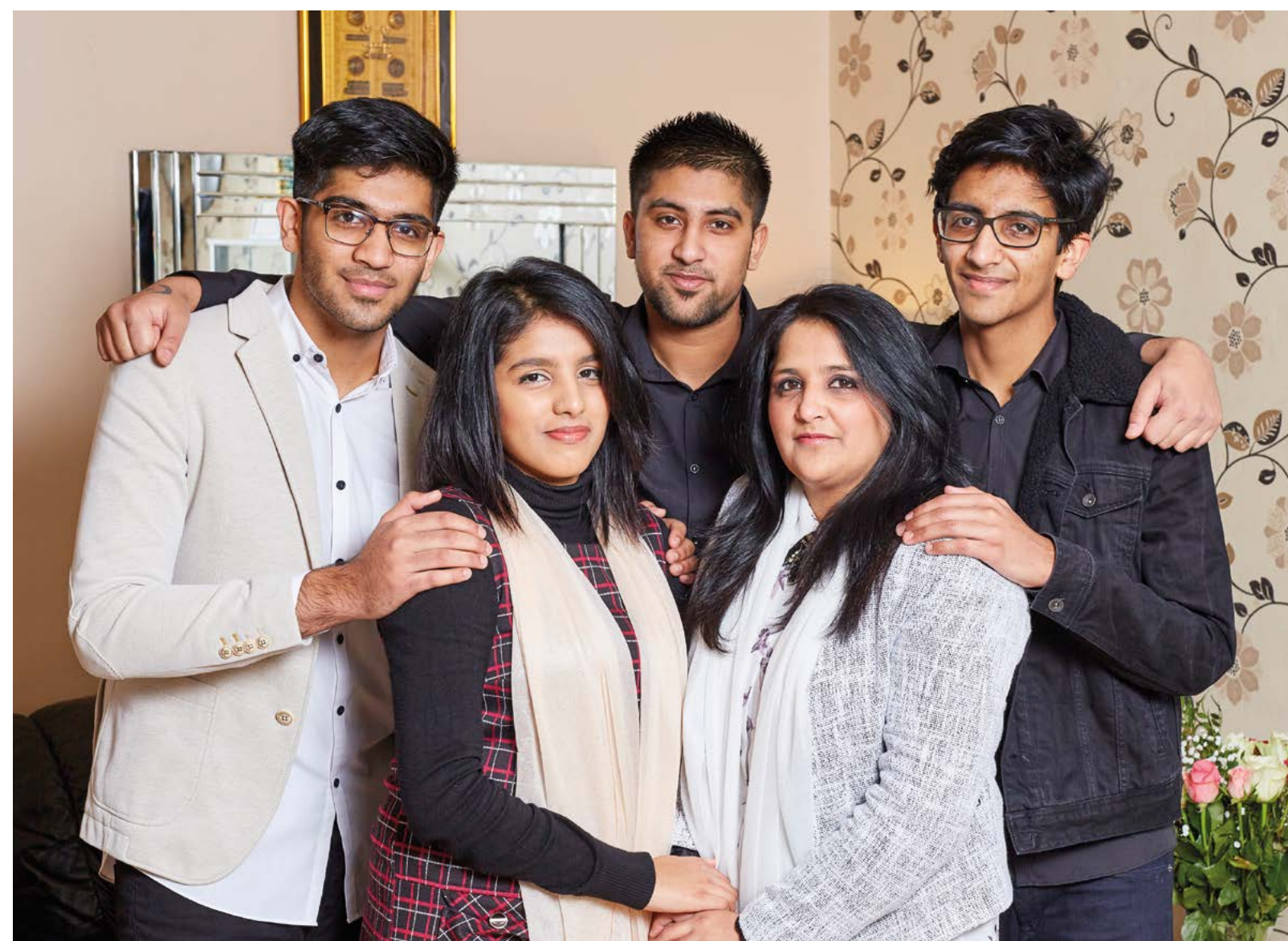
We heard from carers of people with Parkinson's-related dementia about the involved nature of their caring role and the negative impact it can have on their wellbeing. Yet the social care system has let down carers as it fails to support their own needs as well as those of the person they're caring for. This is demonstrated in the lack of respite care. Even when respite care is available, it often doesn't meet their needs.

One of this report's standout findings is the absence of support for unpaid carers in dealing with distressing hallucinations and delusions. In some cases this can lead to the person with dementia exhibiting aggressive or challenging behaviour that in turn can be very distressing for their carer. Yet there is scant evidence of training or education being available for carers in how to deal with these symptoms, or advice being given by healthcare professionals. Support for carers in how to manage symptoms of psychosis in people with Parkinson's-related dementia needs to be addressed urgently.

People with Parkinson's-related dementia are at the sharp end of the social care crisis. We heard how paid carers in care homes or who provide care in the home often have little understanding of Parkinson's and dementia. There's an obvious need for investment in training so paid carers can better support people with Parkinson's-related dementia.

Carers and people with Parkinson's-related dementia told us navigating the social care system was challenging, with little advice or guidance given on how to seek support. Those without access to NHS continuing healthcare funding and who don't qualify for state-funded social care have ended up paying astronomical care costs, leaving them in financial difficulty. This highlights the urgent need for social care reform in England.

Finally, we found people with Parkinson's-related dementia had difficulty accessing the NHS services they needed when they were resident in a care home or if they were housebound. This is a result of the need for more services to be available in the community setting (out-of-hospital care) and poor communication and care coordination between NHS services and their counterparts in social care. For people with Parkinson's-related dementia, who have complex and multiple needs around both their physical and mental health, there is a clear case for better integration of health and care services.





Appendices

Appendix 1

The Care and Support Alliance’s seven principles for social care reform:

1. Provide immediate and sufficient funding to stabilise the social care system and ensure it does not collapse in the worst affected areas.

Looking to the medium term the government must bring forward a plan to create a fair, effective and sustainable care system with the following features:

2. Risk must be pooled on a compulsory whole (adult) population basis, funded through taxation.
3. Care should be free at the point of use.
4. There must be an independent, standardised national eligibility threshold and assessment process for social care.
5. Eligibility should be set at a ‘moderate’ level to enable those in need of community and preventative support to access it; any proposed solution must not tighten eligibility criteria or otherwise reduce access to social care.
6. Any proposed solution must address the care and support needs of working age disabled adults and those with long-term health conditions as well as those of older people.
7. Any proposed solution must ensure increased support for unpaid carers, e.g. increased breaks and core support, including helping carers to juggle work and care and increased Carer’s Allowance and carers’ benefits.

Appendix 2

Below are key recommendations set out in the Continuing Healthcare Alliance report *Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?*

For NHS CHC to improve, the Department of Health, NHS England, clinical commissioning groups and local authorities should initiate the following changes:

- Ensure multidisciplinary teams are composed of professionals who are experienced when making decisions around NHS CHC, with knowledge of the person, their condition(s), needs and aspirations.
- Design and deliver a mandatory programme of training for professionals who organise and assess people for NHS CHC to ensure they understand the eligibility criteria and how to use the current decision tools.
- Rewrite the checklist and Decision Support Tool so they more effectively measure individuals’ healthcare needs against the lawful limit of care that the local authority can provide.
- Introduce an option for professionals to select if they agree that someone should not be reassessed for eligibility for NHS CHC. For people marked down as permanently eligible, reviews should only look at changing needs, for example, where someone may need increased support.
- Prevent people with long-term, serious health conditions being forced into residential care, or living at home with unsafe levels of care, by ensuring packages of care are needs-driven and not purely financially motivated.
- Publish data on how many people apply for NHS CHC – whether they are successful or not – as well as the number of people who proceed past the checklist stage to the full assessment.

References

- ¹ NHS Digital, Recorded Dementia Diagnoses, March 2020 to February 2021 (accessed 1 October 2021) <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/august-2021>
- ² Aarsland D, Kurz MW. The epidemiology of dementia associated with Parkinson's disease. *Brain Pathology*, 2010;20(3): 633-39
- ³ Aarsland D, Zaccai J, Brayne C. A systematic review of prevalence studies of dementia in Parkinson's disease. *Movement Disorders*, 2005; 20(10):1255-63
- ⁴ Ibid
- ⁵ Aarsland D, Kurz MW. The epidemiology of dementia associated with Parkinson's disease. *Brain Pathology*, 2010; 20(3):633-39
- ⁶ Gomperts SN. Lewy Body Dementias: Dementia With Lewy Bodies and Parkinson Disease Dementia. *Continuum* (Minneapolis, Minnesota), 2016; 22(2 Dementia):435-463
- ⁷ Mehanna R, Bajwa JA, Fernandez H, Wagle Shukla AA. Cognitive impact of deep brain stimulation on Parkinson's disease patients. *Parkinson's Dis*, 2017; published online 22 November
- ⁸ Department of Health and Social Care (2009) Living Well With Dementia: a national dementia strategy (accessed 1 October 2021) <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>
- ⁹ Department of Health and Social Care (2012) Prime Minister's challenge on dementia (accessed 3 November 2021) <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia>
- ¹⁰ Department of Health and Social Care (2015) 'Prime Minister's challenge on dementia 2020' (accessed 1 October 2021) <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>
- ¹¹ Conservative Party Manifesto (2019) Get Brexit Done – Unleash Britain's Potential Page 12. (accessed 1 October 2021) <https://www.conservatives.com/our-plan/conservative-party-manifesto-2019>
- ¹² Ibid
- ¹³ Carden D (2021) Dementia: Research UK Parliament: Written question, 18 March, HC171711, <https://questions-statements.parliament.uk/written-questions/detail/2021-03-18/171711>
Whately H (2021) Dementia: Research UK Parliament: Written answer, 25 March, HC171711, <https://questions-statements.parliament.uk/written-questions/detail/2021-03-18/171711>
- ¹⁴ NICE (2018) Dementia: assessment, management and support for people living with dementia and their carers NICE guideline [NG97] (accessed 3 November 2021) <https://www.nice.org.uk/guidance/ng97>
- ¹⁵ NICE (2017) Parkinson's disease in adults NICE guideline [NG71] (accessed 1 October 2021) <https://www.nice.org.uk/guidance/ng71>
- ¹⁶ NHS Digital, Adult Social Care Activity and Finance Report, England – 2019-20 (accessed 1 October 2021) <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2019-20>
- ¹⁷ Prime Minister's Office, Number 10 Downing Street (2021) Oral statement to Parliament PM statement to the House of Commons on health and social care: 7 September 2021 (accessed 1 October 2021) <https://www.gov.uk/government/speeches/pm-statement-to-the-house-of-commons-on-health-and-social-care-7-september-2021>

- ¹⁸ Nuffield Trust, Care providers, care users and workers will feel short-changed by proposed health and social care levy and reform, press release (accessed 1 October 2021) <https://www.nuffieldtrust.org.uk/news-item/care-providers-care-users-and-workers-will-feel-short-changed-by-proposed-health-and-social-care-levy-and-reform>
- ¹⁹ Age UK and Care and Support Alliance, Response to PM's social care reform announcement, press release (accessed 1 October 2021) <https://www.ageuk.org.uk/latest-press/articles/2021/age-uk--csa-response-to-pms-social-care-reform-announcement/>
- ²⁰ King's Fund, The King's Fund responds to the announcement of a health and social care levy, press release (accessed 1 October 2021) <https://www.kingsfund.org.uk/press/press-releases/health-and-social-care-levy>
- ²¹ Alzheimer's Society, Dementia Strategy for Northern Ireland (accessed 1 October 2021) <https://www.alzheimers.org.uk/about-us/policy-and-influencing-national-policies/dementia-strategy-northern-ireland>
- ²² Alzheimer's Society NI Conference 2021 (accessed 1 October 2021) <https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/northern-ireland-conference-2021>
- ²³ Department of Health (Northern Ireland) (2016) The Mental Capacity Act (NI) 2016 (accessed 1 October 2021) <https://www.health-ni.gov.uk/mca>
- ²⁴ Department of Health (Northern Ireland) (2019) Dementia Care Pathway Document, Full Version (accessed 1 October 2021) http://www.hscboard.hscni.net/wpfb-file/dcp_booklet-pdf/
- ²⁵ Department of Health (Northern Ireland) (2011) Improving dementia services in Northern Ireland – a regional strategy <https://www.health-ni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy>
- ²⁶ Department of Health (Northern Ireland) (2016) Dementia Learning and Development Framework <http://www.hscboard.hscni.net/dementia/learning-development-framework/>
- ²⁷ Department of Health and Social Services (2018) Dementia action plan 2018 to 2022 (accessed 1 October 2021) <https://gov.wales/dementia-action-plan-2018-2022>
- ²⁸ Improvement Cymru (2021) The All Wales Dementia Care Pathway of Standards – enabling improvements in the provision of dementia care for individuals and their carers (accessed 1 October 2021) <https://gov.wales/dementia-action-plan-2018-2022>
- ²⁹ Scottish government website (accessed 5 October 2021) <https://www.gov.scot/policies/mental-health/dementia/>
- ³⁰ Parkinson's UK Scotland (2019) People. Parkinson's. Scotland. What do we know about services and support for people with Parkinson's in Scotland? (accessed 1 October 2021) <https://www.parkinsons.org.uk/sites/default/files/2019-02/Services%20in%20Scotland%202018.pdf>
- ³¹ Giuntoli C et al (2014) Incidence of dementia in Parkinson's disease: the PINE Study *Journal of Neurology, Neurosurgery and Psychiatry*; 85:e4
- ³² Alzheimer Scotland (2009) Charter of Rights for People with Dementia and their Carers in Scotland (accessed 1 October 2021) https://www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf
- ³³ Scottish government (2011) Standards of Care for Dementia (accessed 1 October 2021) <https://www.gov.scot/publications/standards-care-dementia-scotland-action-support-change-programme-scotlands-national-dementia-strategy/>
- ³⁴ Scottish government (2017) Health and Social Care Standards (accessed 1 October 2021) <https://www.gov.scot/publications/health-social-care-standards-support-life/>
- ³⁵ Scottish government (2010) Scotland's National Dementia Strategy (accessed 1 October 2021) https://www.alzscot.org/sites/default/files/images/0002/6109/First_Dementia_Strategy.pdf
- ³⁶ Scottish government (2013) Scotland's National Dementia Strategy: 2013-16 (accessed

- 1 October 2021) <https://www.webarchive.org.uk/wayback/archive/3000/https://www.gov.scot/Resource/0042/00423472.pdf>
- ³⁷ Scottish government (2017) National Dementia Strategy 2017-2020 (accessed 1 October 2021) <https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/>
- ³⁸ National Records of Scotland (2021) Deaths involving coronavirus (COVID-19) in Scotland Week 38 (20 September 2021 to 26 September 2021) (accessed 1 October 2021) <https://www.nrscotland.gov.uk/files/statistics/covid19/covid-deaths-21-report-week-38.pdf>
- ³⁹ Alzheimer Scotland (2021) COVID-19: the hidden impact. A report on the impact of the COVID-19 pandemic on people with dementia and carers living at home (accessed 1 October 2021) <https://www.alzscot.org/sites/default/files/2020-12/Coronavirus%20the%20hidden%20impact%20report%20final.pdf>
- ⁴⁰ Ibid
- ⁴¹ NHS Healthcare Improvement Scotland website (accessed 1 October 2021) <https://ihub.scot/news/redesigning-primary-care-to-provide-post-diagnostic-support-for-people-with-dementia>
- ⁴² Public Health Scotland (2020) Care Home Census for Adults in Scotland Statistics for 2009 – 2019 (accessed 1 October 2021) <https://publichealthscotland.scot/publications/care-home-census-for-adults-in-scotland/care-home-census-for-adults-in-scotland-statistics-for-2009-to-2019/>
- ⁴³ Scottish Government (2021) National Care Service for Scotland: A consultation (accessed 1 October 2021) <https://www.gov.scot/publications/national-care-service-scotland-consultation/>
- ⁴⁴ NHS Digital, Recorded Dementia Diagnoses, March 2020 to February 2021 (accessed 1 October 2021) <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/>
- ⁴⁵ O'Brien JT, Taylor J-P, Thomas A et al, Improving the diagnosis and management of Lewy body dementia: the DIAMOND-Lewy research programme including pilot cluster RCT, 2021; ORE Open Research Exeter, University of Exeter (accessed 1 October 2021) <https://ore.exeter.ac.uk/repository/handle/10871/125132>
- ⁴⁶ Kane JPM, Surendranathan A, Bentley A et al, Clinical prevalence of Lewy body dementia, 2018; *Alz Res Therapy* 10, 19 (accessed 1 October 2021) <https://alzres.biomedcentral.com/articles/10.1186/s13195-018-0350-6#citeas>
- ⁴⁷ UK Parkinson's Excellence Network, 2019 UK Parkinson's Audit summary report (accessed 1 October 2021) <https://www.parkinsons.org.uk/sites/default/files/2020-07/CS3524%20Parkinson%27s%20UK%20Audit%20-%20Summary%20Report%202019.pdf>
- ⁴⁸ Lancaster University and Parkinson's UK, The Impact Of Coronavirus Restrictions On People Affected By Parkinson's – The Findings from a Survey by Parkinson's UK (accessed 1 October 2021) <https://www.parkinsons.org.uk/sites/default/files/2020-07/Parkinson%27s%20UK%20Covid-19%20full%20report%20final.pdf>
- ⁴⁹ Taylor JP, McKeith IG, Burn DJ, Boeve BF, Weintraub D, Bamford C, Allan LM, Thomas AJ, O'Brien JT, New evidence on the management of Lewy body dementia, 2020; *Lancet Neurol.* Feb;19(2):157-169 (accessed 1 October 2021) <https://pubmed.ncbi.nlm.nih.gov/31519472/>
- ⁵⁰ Ibid
- ⁵¹ Vatter S, Stanmore E, Clare L, McDonald, McCormick SA, Leroi I, Care Burden and Mental Ill Health in Spouses of People With Parkinson's Disease Dementia and Lewy Body Dementia, 2020; *Journal of Geriatric Psychiatry and Neurology*, Vol. 33(1) 3-14 (accessed 1 October 2021) <https://journals.sagepub.com/doi/pdf/10.1177/0891988719853043>
- ⁵² Lancaster University and Parkinson's UK (2020) The Impact Of Coronavirus Restrictions On People Affected By Parkinson's The Findings from a Survey by Parkinson's UK (accessed 1 October 2021) <https://www.parkinsons.org.uk/sites/default/files/2020-07/Parkinson%27s%20UK%20Covid-19%20full%20report%20final.pdf>
- ⁵³ Taylor JP, McKeith IG, Burn DJ, Boeve BF, Weintraub D, Bamford C, Allan LM, Thomas AJ, O'Brien JT, New evidence on the management of Lewy body dementia, 2020; *Lancet Neurol.* Feb;19(2):157-169 (accessed 1 October 2021) <https://pubmed.ncbi.nlm.nih.gov/31519472/>
- ⁵⁴ McKeith I Ballard C. Grace J. Holmes C. (1998) Neuroleptic sensitivity in dementia with Lewy bodies and Alzheimer's disease *Lancet*, volume 351, 9108, P1032-1033
- ⁵⁵ Aarsland D, Perry R, Larsen JP, McKeith IG, O'Brien JT, Perry EK, Burn D, Ballard CG, Neuroleptic sensitivity in Parkinson's disease and parkinsonian dementias, 2005; *J Clin Psychiatry.* May;66(5):633-7 (accessed 1 October 2021) <https://pubmed.ncbi.nlm.nih.gov/15889951/>
- ⁵⁶ Weintraub D, Chiang C, Kim HM et al, Association of antipsychotic use with mortality risk in patients with Parkinson's disease, 2016; *JAMA Neurol*; 73:535-41 (accessed 1 October 2021) <https://pubmed.ncbi.nlm.nih.gov/26999262/>
- ⁵⁷ Prince, M et al (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society
- ⁵⁸ Carter, D (2015) Dementia and Homecare: Driving Quality and Innovation by the UK Homecare Association
- ⁵⁹ Walker RW, Palmer J et al, Experience of care home residents with Parkinson's disease: Reason for admission and service use, 2014; *Geriatr Gerontol Int*, 14(4)
- ⁶⁰ Jackson GA, Newbronner L et al, Caring for people with dementia with Lewy bodies and Parkinson's dementia in UK care homes – A mixed methods study, 2017; *European Geriatric Medicine*, 8(2) (accessed 1 October 2021) <https://www.sciencedirect.com/science/article/pii/S1878764917300049>
- ⁶¹ Firefly illuminating research and the University of the West of Scotland, Improving Care for People with Dementia with Lewy Bodies and Parkinson's Disease Dementia in Care Homes, 2016 (accessed 1 October 2021) <https://www.sciencedirect.com/science/article/abs/pii/S1878764917300049?via%3Dihub>
- ⁶² Jackson GA, Newbronner L et al, Caring for people with dementia with Lewy bodies and Parkinson's dementia in UK care homes – A mixed methods study, 2017; *European Geriatric Medicine*, 8(2) (accessed 1 October 2021) <https://www.sciencedirect.com/science/article/pii/S1878764917300049>
- ⁶³ Alzheimer's Society (2016) Fix Dementia Care – NHS and Care Homes (accessed 1 October 2021) https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_nhs_and_care_homes_report.pdf
- ⁶⁴ NHS England, NHS Long Term Plan, 2019 (accessed 1 October 2021) <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- ⁶⁵ Fernando E, Fraser M, Hendriksen J, Kim CH, Muir-Hunter SW, Risk Factors Associated with Falls in Older Adults with Dementia: A Systematic Review, 2017; *Physiotherapy Canada*, 69(2):161-170

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