PSPA SURVEY 2025 - REPORT FINDINGS

CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD

THE STATE OF PSP & CBD

Findings from the PSPA Survey 2025

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EXECUTIVE SUMMARY

Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD, sometimes called Corticobasal Syndrome or CBS) are rare, progressive and terminal neurological conditions that affect movement, speech, swallowing, vision, cognition and behaviour, and over time lead to a progressive loss of independence, high levels of practical need, and substantial emotional strain. Despite their severity, PSP & CBD remain poorly understood, with too many people affected by them left trying to navigate health and care services that do not consistently recognise, anticipate or respond to their needs.

This report is based on PSPA's 2025-26 survey of 650 people either living with PSP or CBD, or who are carers of people with the conditions. The findings present a stark picture of life with PSP & CBD – long and uncertain routes to diagnosis, severe day-to-day impact, significant emotional and financial burden, escalating need over time, and carers under intense and sustained pressure.

Diagnosis remains too slow, too inconsistent and too often wrong

For many respondents, the route to an accurate diagnosis of PSP or CBD remains too long and too complex. While around a third were diagnosed within a year of symptoms beginning, 40% waited three years or more, and more than one in ten waited at least five years for an accurate diagnosis. More than a quarter visited their GP at least three times before being referred to neurology, and many were referred to multiple professionals before reaching the specialist input needed for diagnosis. Even after referral, delays persisted, with one in eight waiting more than a year to be seen by a neurologist.

Misdiagnosis of PSP & CBD remains a major problem. A majority of respondents were initially misdiagnosed, most commonly with Parkinson's disease. The survey also shows that symptoms are too often understood separately rather than holistically, with people being routed through eye services, ENT, physiotherapy, speech and language therapy and other services before anyone recognises the wider neurological pattern. These detours add time, uncertainty and distress, and delay access to the right support. More than a third of respondents also reported seeking private healthcare to help obtain an accurate diagnosis, raising serious concerns about NHS capacity, equity and patient confidence.

There is no single diagnostic journey for PSP & CBD. Respondents were more likely to report different initial symptoms depending on their diagnosis, and CBD also appeared less straightforward to diagnose in some cases, with respondents less likely to report diagnosis at a first neurology appointment and more likely to report longer waits to diagnosis. This reinforces the need for improved awareness of PSP & CBD across a broader range of health and care professionals, and for greater recognition of distinct and atypical presentations.

Daily life with PSP & CBD is marked by severe impact, worsening symptoms and declining independence

PSP & CBD have a profound and escalating impact on everyday life. A majority of respondents described the impact of the condition as severe, while almost all said their condition had worsened in the previous six months. More than half said that every day is challenging, underlining that these are not conditions that sit in the background of people's lives – for most people affected by them, PSP & CBD shape almost every aspect of daily functioning.

Respondents reported that PSP & CBD most commonly affect movement, communication, eating and drinking, memory or thinking, vision and mood or mental health. The practical consequences of these symptoms are extensive – respondents reported challenges washing, dressing, preparing meals, maintaining social participation and living independently. These findings underline that PSP & CBD should not be understood only in clinical terms, but as conditions that alter what people can do, how they live, and how much support they need to manage everyday life safely and with dignity.

The survey also highlights a fragmented experience of care and support. Only around a third of respondents said they had a named care coordinator, while a similar proportion said they did not but would like one. Around half reported that healthcare professionals were poorly informed about PSP & CBD. In practice, this means too many people and families are left coordinating multiple services themselves, repeatedly explaining the basics of the condition, and trying to navigate their care without continuity between the health and care professionals they encounter.

The burden of PSP & CBD is emotional and financial as well as physical

The burden of PSP & CBD extends well beyond physical symptoms. Most respondents reported regularly experiencing depression, anxiety, frustration or stress related to the condition, underlining that the mental health impact of the conditions is a core part of life with PSP or CBD. Women were more likely than men to experience cognitive impacts from the conditions or mental health impacts, suggesting that this burden may not be experienced evenly. Mental health impacts also appeared especially prominent earlier after diagnosis, when people are adjusting to their condition and experiencing uncertainty about the future.

Around two-thirds of respondents also reported new costs associated with PSP or CBD, while others also reported higher existing costs, lower income, or greater difficulty managing their household budget. Although most respondents were receiving some form of disability benefit, many still reported struggling to manage financially. The report also highlights concerns that PSPA has previously raised about low access to NHS Continuing Healthcare (CHC), despite the high levels of dependency and care need associated with the conditions. Only 23% reported receiving CHC or

its Scottish equivalent, while a similar proportion did not know what it was. This suggests that financial strain, especially including the high cost of social care, is being compounded by inconsistent access to the support intended to help people with substantial health needs.

Support for PSP & CBD cannot be limited to help managing the physical and neurological symptoms of the conditions. Emotional support, welfare advice, help with entitlements and improved access to support with the cost of social care are all central to whether people affected by the conditions feel able to cope.

Progression is one of the strongest drivers of need – but support often lags behind

As time since diagnosis increases and the conditions progress, respondents become more likely to describe the impact of PSP or CBD as severe, more likely to say every day is challenging, and more likely to report growing difficulty with daily tasks and social participation. The period around three to five years after diagnosis appears especially pressured, with particularly high levels of severity, constant daily challenge and dependency all reported.

The balance of need shifts over time. Earlier after diagnosis, mental health and cognitive impacts appear especially prominent, while later stages are increasingly dominated by physical dependency and the need for round-the-clock, hands-on support. This underlines that progression is not simply a matter of symptoms worsening, but it changes the kind of support that people and families need.

Yet formal support from health and care services often appears later, only once burden is already substantial. Awareness and uptake of NHS CHC increase in later stages, and carers are more likely to report having had a Carers Assessment. In the first year after diagnosis, however, most carers had not received an assessment, and many people living with PSP or CBD had not been made aware of CHC. This suggests a system that is too often reactive rather than anticipatory, with support following crisis instead of getting ahead of it.

Carers are essential, but under intense and sustained pressure

Family carers are essential to life with PSP & CBD, but the PSPA Survey shows clearly that many are under very substantial strain. Around two-thirds reported providing more than 50 hours of care per week, spending several hours each day on personal care tasks. More than half said they regularly feel emotionally overwhelmed or stressed, and large numbers described loneliness, isolation and a negative impact on their overall wellbeing. Caring for somebody living with PSP or CBD is intensive, sustained and often the defining fact of a carer's life.

As the conditions progress, the burden on PSP & CBD carers becomes even more intense. The number of hours spent caring increases, personal care becomes more hands-on, and stress and isolation become more chronic. Female carers were more likely than male carers to report health problems, feeling emotionally overwhelmed, loneliness and negative effects on their wellbeing, while CBD carers also appeared in

some respects to face especially intense caring roles. These findings underline that carers are not a uniform group, and that some may face particularly heavy and sustained burdens.

Support for PSP & CBD carers exists, but appears too patchy and too late. Carers Assessments become more common later in the journey, but often not early enough. Most were not receiving Carers Allowance or financial support linked to their caring role despite the financial impact of caring for somebody with the conditions. The findings suggest that formal recognition as a carer alone is not enough – if carers are unsupported in their role, reliance on formal health and care services increases and the wider care arrangement becomes harder to sustain, with consequences for both carers and the people they support.

THE FINDINGS IN THIS REPORT POINT TO A CLEAR CASE FOR CHANGE - THE CHALLENGES FACED BY PEOPLE WITH PSP & CBD ARE NOT INEVITABLE.

What the report calls for

Taken together, the findings in this report point to a clear case for change. PSP & CBD are rare, progressive and terminal conditions, but the challenges described by people affected by them in the PSPA Survey 2025 are not inevitable consequences of the conditions alone. They are failures in recognition, coordination, support and timing within the health and care services that people rely on. People affected by PSP & CBD need systems that recognise the seriousness of these conditions, understand how needs grow over time, and respond earlier, more consistently and more holistically than is too often the case today.

PSPA therefore calls for action in five broad areas:

- Faster, more accurate diagnosis, with better awareness of PSP & CBD across primary and secondary care and clearer routes to specialist expertise.
- Health and care services that reflect the full practical impact of living with PSP & CBD, including better access to care coordination.
- Mental health and emotional support embedded in routine care for PSP & CBD, alongside stronger advice and support on benefits and entitlements.
- Earlier planning, regular review and stage-sensitive support that anticipates progression rather than waiting for crisis.
- Better support for carers, including earlier Carers Assessments, stronger emotional support, and recognition of carers as a core part of the care team.

INTRODUCTION

Background

Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD, sometimes called Corticobasal Syndrome or CBS) are rare, progressive and life-limiting neurological conditions that typically affect people later in life – onset between ages 60 to 65 is typical, but people can be affected from their 40s.
Both conditions are terminal, with a life expectancy of an average of seven years.

There are no treatments or cure for either PSP or CBD, however symptoms can be managed by health and care services. PSPA estimates that around 10,000 people living in the UK are living with PSP or CBD, although research suggests prevalence could be higher due to around half of people with the conditions initially experiencing delayed diagnosis or misdiagnosis.

A diagnosis of PSP or CBD comes with profound consequences for the person living with the condition as well as the family and carers who support them. The conditions affect movement, speech, swallowing, vision, cognition and behaviour – these symptoms are progressive and can present at different times or in a different order in each case, with new symptoms sometimes appearing quickly. Over time, PSP & CBD lead to a loss of independence and very high levels of practical and emotional need.

Despite their severity, PSP & CBD remain poorly understood outside of specialist settings, with too many people affected by them left trying to navigate systems that do not consistently recognise, anticipate or respond to their needs.

About this report

As the UK's only charity dedicated to supporting people living with PSP & CBD, PSPA is committed to understanding the experiences of people affected by the conditions and ensuring that our work is informed by the needs and priorities of people living with them. In the second half of 2025 PSPA asked people living with PSP or CBD, and carers of people with the conditions, to share their experiences through our third PSPA Survey[1]. The survey asked people affected by PSP & CBD to share their experiences of diagnosis, daily life, caring, research and support. It was designed to provide a clearer picture not only of what life with PSP & CBD looks like today, but also of where systems are working, where they are falling short, and what needs to change.

The findings paint a stark picture. They show high levels of dependency, substantial day-to-day challenge, widespread emotional strain, significant financial pressure and major demands on carers. They also point to persistent problems getting an accurate diagnosis, gaps in care coordination, inconsistent access to financial or social care support, and a system that often responds reactively to crisis rather than anticipating changes in need associated with progressive conditions like PSP & CBD.

At the same time, the experiences of our community highlight where opportunities for improvement exist. They show clear priorities for policy and practice change, including improving awareness of PSP & CBD among professionals, reducing delays and misdiagnosis, strengthening support for carers, improving access to financial and practical help, and ensuring that care is better coordinated as needs increase over time.

This report brings together the main findings from the PSPA Survey. It is intended to inform policymakers, health and social care leaders, clinicians, researchers and others involved in planning or delivering support for people affected by progressive, neurological and terminal conditions like PSP & CBD.

Behind every statistic in this report is a family adapting to a life irrevocably changed by a diagnosis of PSP or CBD. Their experiences are not isolated individual stories, but evidence of where the systems in place to support them need to do better.

THERE ARE NO TREATMENTS OR CURE FOR EITHER PSP OR CBD, HOWEVER SYMPTOMS CAN BE MANAGED BY HEALTH AND CARE SERVICES.

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[1] The first two PSPA Surveys were conducted in 2016 and 2022 respectively

About the PSPA Survey

This report is based on findings from the third PSPA Survey of people living with PSP or CBD and carers of people with the conditions.

The PSPA Survey was completed by 650 people either living with a diagnosis of PSP or CBD, or by a carer or family member of somebody with a diagnosis, between August 2025 and January 2026.

78%

of respondents were either living with or caring for a person with PSP compared to 22% affected by CBD.

64%

of respondents were carers compared to 36% living with the condition.

90%

of respondents live in England compared to 5% in Scotland and 5% in Wales.

80%

of respondents were already retired or had reached State Pension Age.

(This is to be expected from conditions which typically affects people later in life)

Limitations of the PSPA Survey include that its sample was drawn from PSPA service users rather than a true prevalence sample and the fact that the sample is not weighted, meaning some subgroup sizes are smaller than others.

This report draws on both headline results from the PSPA Survey and detailed crosstab analysis, which was used to identify meaningful differences in experience between different groups. Unless otherwise stated, all statistics referenced in this report are drawn from the third PSPA Survey.

DIAGNOSIS – TOO SLOW, TOO INCONSISTENT, OFTEN WRONG

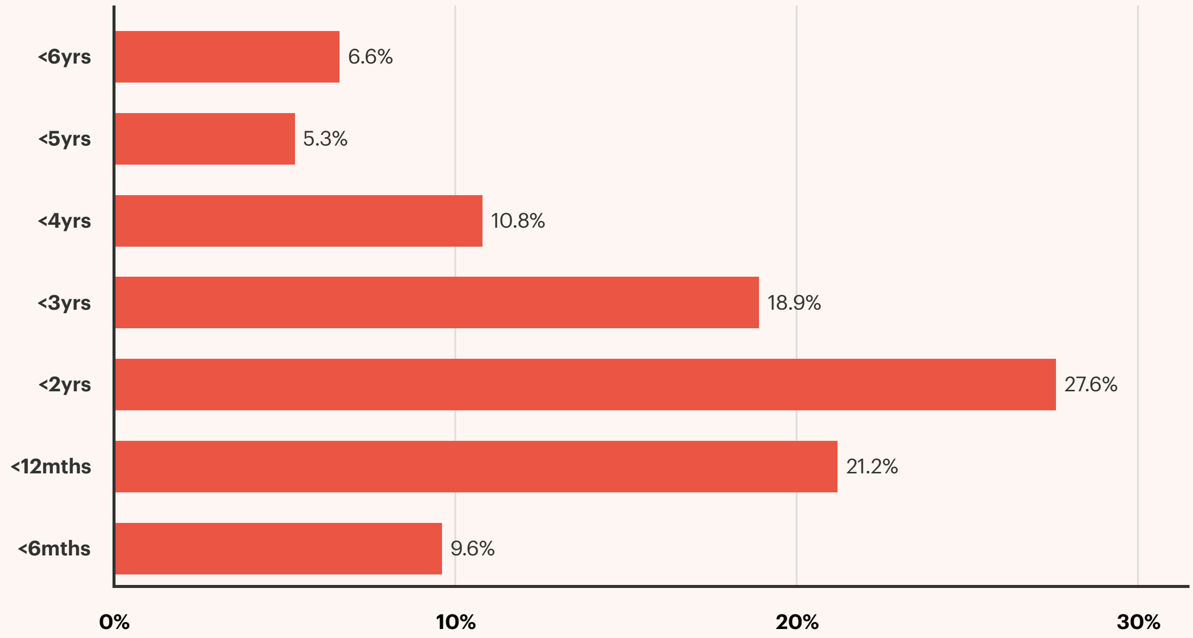
Diagnosis is the point at which people affected by PSP & CBD should receive clarity, information, support and the ability to plan for the future. A timely and accurate diagnosis helps people affected by the conditions to understand what is happening to them, ask questions, access appropriate advice, and start making decisions about care, work, finances and family life.

When diagnosis is slow or wrong, people lose valuable time, remain unsupported, and can be left navigating services that are not responding to the reality of their condition. For too many people affected by PSP & CBD, the route to an accurate diagnosis remains too slow and too complex. Misdiagnosis remains more common than a correct initial diagnosis, too many people are experiencing prolonged routes to diagnosis, and more than a third report using private healthcare to help them secure the right answer. Taken together, these findings point to a diagnostic pathway that is too slow, too variable and too dependent on persistence, luck or the ability to pay. In practice, this means months or years of confusion and frustration, as symptoms progress while people and their families are still searching for answers.

Delays and complexity in the diagnostic pathway

For many respondents to the PSPA Survey, diagnosis took considerable time from the onset of symptoms. While around one in three (32%) were diagnosed within a year of symptoms beginning, significant numbers (40%) reported waiting three years or more, and some considerably longer than that – more than one in ten people (12%) affected by PSP or CBD wait five or more years to receive an accurate diagnosis.

Fig 1.
Reported time to accurate diagnosis of PSP or CBD from first symptoms (%)



This variation of experience demonstrates that the health and care system can diagnose PSP or CBD within an acceptable timeframe, but does so inconsistently – for too many, it remains prolonged, fragmented and difficult to navigate.

This fragmentation typically takes the form of repeated contact with primary care before being referred on, and then seeing multiple health and care professionals before being referred to a specialist neurologist who can make a diagnosis of PSP or CBD. One in four respondents (27%) visited their GP at least three times, after symptoms begun, before receiving a referral to a neurologist, with a substantial minority (14%) seeing their GP five or more times before referral. Almost half of respondents (44%) were referred by their GP to another healthcare professional before being referred to a neurologist, with 12% being referred to three different professionals before receiving a neurology referral.

Fig 2.
GP visits before Neurology referral (%)

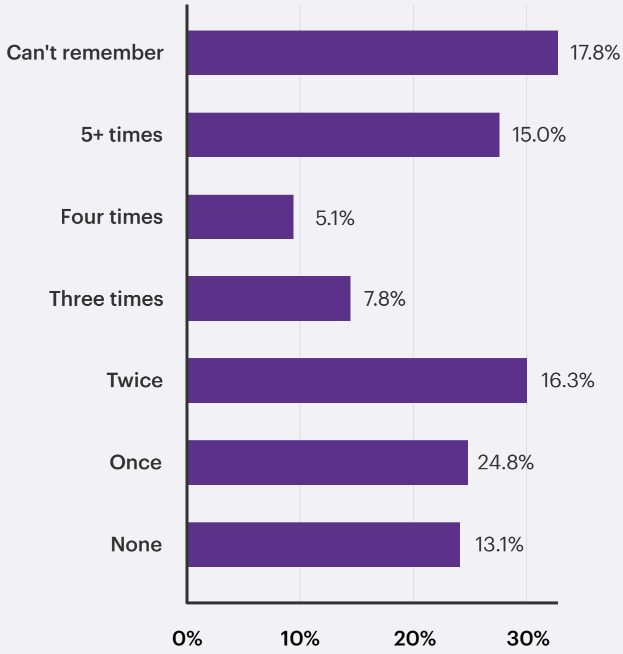
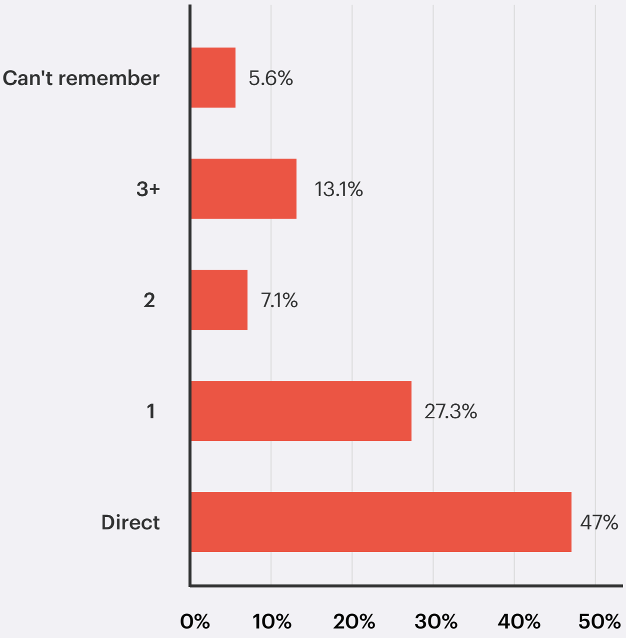


Fig 3.
Visits to other HSCPs before Neurology referral (%)



These findings indicate that for a substantial minority, the symptoms of PSP & CBD are not recognised quickly enough as needing specialist input, not sufficiently recognised as a neurological issue, or not acted on quickly enough. For too many, the experience of diagnosis involves passed between multiple, disparate services before their condition is identified.

Even after receiving a referral to neurology, many respondents reported more frustrating delays and waits before receiving the clarity they need. One in four (27%) waited at least six months to see a neurologist after referral, with one in eight (12%) waiting more than a year before being seen. For progressive neurological conditions like PSP & CBD these waits are significant. Symptoms continue to progress, often rapidly, and delays at this stage can prolong a person’s uncertainty and postpone access to information and support.

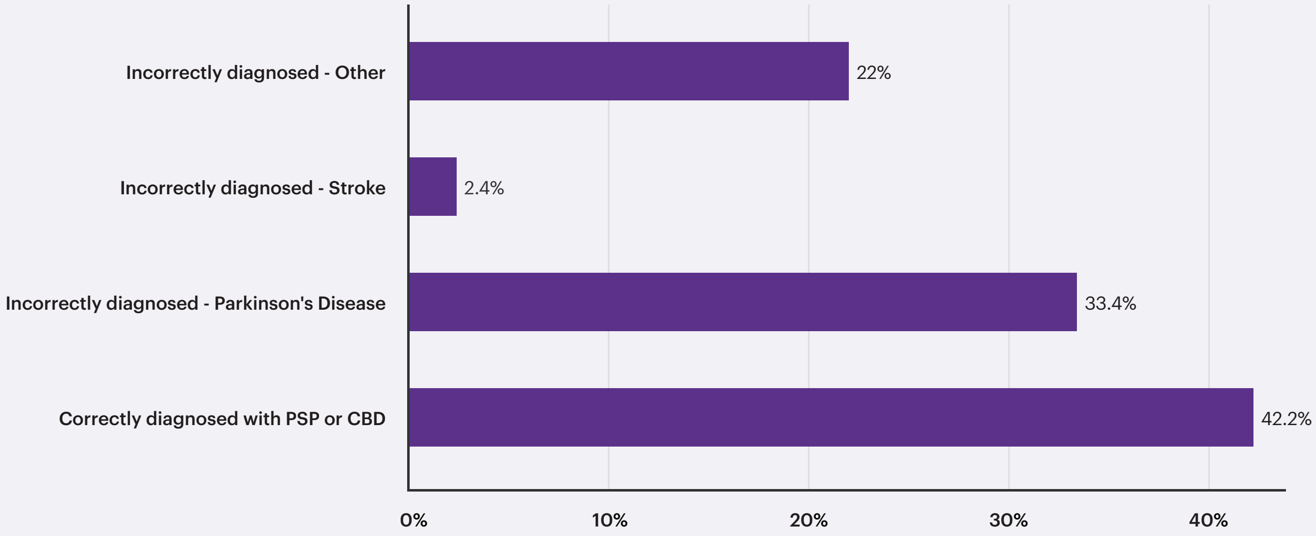
Taken together, these findings point to several pressure points in the health and care system that make the diagnostic pathway for PSP & CBD difficult to move through: repeated GP consultations, indirect referral routes, and delays before specialist review. Each of these pressure points not only add time which a person facing a progressive and terminal condition can ill-afford, but they also add an extended period of uncertainty, confusion and distress before the right diagnosis is reached.

Misdiagnosis and inappropriate pathways

This uncertainty is only compounded by the extent to which misdiagnosis remains a feature of the diagnostic experience for people affected by PSP or CBD. A majority of respondents (58%) reported being initially misdiagnosed with another condition – this experience has remained consistent through the three PSPA Surveys in 2016, 2022 and 2025, indicating that efforts to improve the diagnosis of PSP & CBD have had little effect for a decade.

Parkinson's disease was the most common initial misdiagnosis, affecting one in three respondents (33%) overall. Others were initially diagnosed with conditions varying from Stroke, Multiple System Atrophy, Dementia and Functional Neurological Disorder. This is not surprising in one sense; PSP & CBD are rare conditions and in earlier stages their symptoms may overlap with other neurological or age-related conditions. However, the scale of misdiagnosis reported here is still striking.

Fig 4.
Initial diagnosis (%)



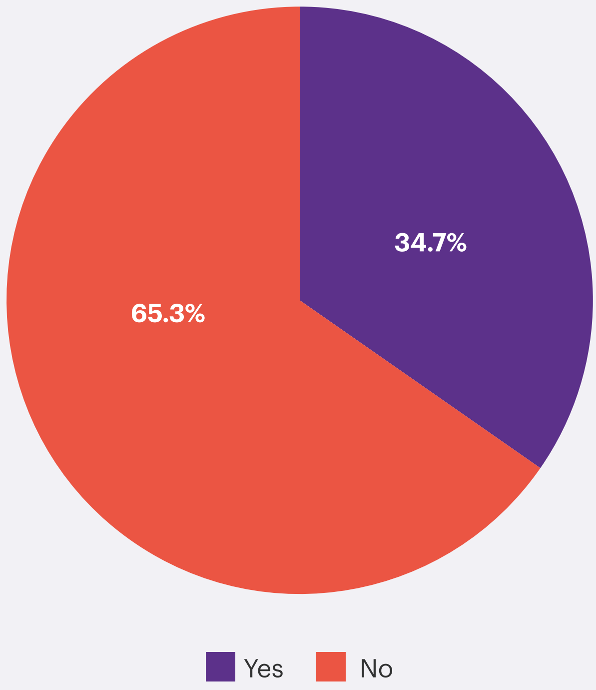
The route to accurate diagnosis often involves contact with services outside neurology. Respondents reported being referred to a range of professionals before diagnosis, including eye services, ENT, physiotherapy, geriatric medicine, speech and language therapy and memory services. These detours indicate that too often, the symptoms a person is experiencing are being understood separately as opposed to holistically, leading to too many moving into pathways that address individual symptoms in isolation without recognising the wider pattern of PSP or CBD. A person with falls and eye problems may encounter one route; a person with speech change or movement difficulty another; a person with cognitive or behavioural changes another still. When no one service is seeing the whole picture clearly, delay and misdiagnosis become more likely.

The consequences of misdiagnosis are practical as well as emotional. A person who has been told they have Parkinson's disease rather than PSP or CBD may receive information, advice and expectations that do not reflect what is actually happening to them. They may not be connected to the right support and may be confused and frustrated when the pace or pattern of progression does not fit what they have been told to expect. For carers and families, misdiagnosis can prolong uncertainty and make planning more difficult, at precisely the point when clear information is most needed.

Private care and unequal access

One of the most striking findings from the PSPA Survey is the proportion of respondents who reported seeking private care to help them obtain a diagnosis. More than a third (35%) said they had done so.

Fig 5.
Prevalence of seeking private healthcare to obtain an accurate diagnosis (%)



This figure should be a warning sign that too often the NHS is too slow, too uncertain or not leading people affected by PSP & CBD quickly enough to the right expertise. Seeking private care may be an attempt to speed up access to a specialist neurologist, secure a second opinion, or move past a point of diagnostic uncertainty that feels intolerable. For some families, it may reflect a loss of confidence that the NHS will deliver timely answers.

PSPA is concerned at the frequency with which people affected by PSP & CBD report seeking private healthcare during their diagnosis journey. Not everyone can afford private consultations, investigations or repeat specialist appointments. If private care is becoming an informal way to shorten the route to diagnosis, then access to timely answers is not being experienced equally. Those with the means to pay may be able to move faster; those without face longer waits and greater uncertainty.

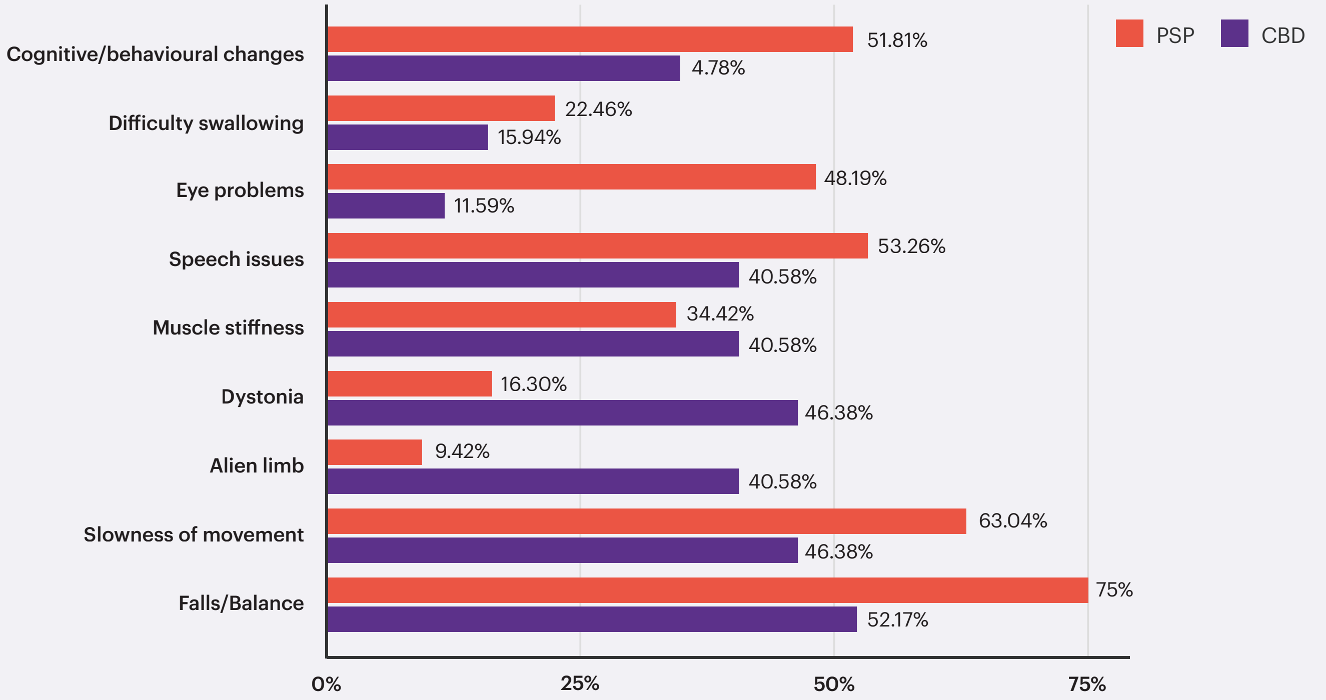
Secondly, the scale of private care use raises wider questions about NHS capacity and patient confidence in the system. An NHS that is functioning well should not leave so many people feeling that they need to step outside it to obtain the right diagnosis. The findings indicate that private healthcare is not marginal or exceptional; it is becoming an important part of the diagnostic story for a substantial minority of people affected by PSP & CBD.

Different conditions, different diagnostic journeys

In addition to the substantial similarities in experience, there are also important differences in the diagnostic journey experienced by those affected by PSP and those affected by CBD. Respondents to the PSPA Survey reported meaningfully different early symptom profiles and, as a result, different routes through the system.

Respondents with PSP were more likely to report falls, eye problems, speech issues, and cognitive or behavioural changes before diagnosis. Respondents with CBD were much more likely to report muscle or movement issues, such as alien limb and dystonia. These differences can shape how people are initially understood by professionals and which services they encounter first, which may in turn affect how quickly they are then referred on to a specialist neurologist and able to receive a diagnosis.

Fig 6.
Reported symptoms of PSP & CBD before diagnosis (%)



The survey indicates that CBD may, in some cases, be less straightforward to diagnose than PSP. CBD respondents were less likely to report being diagnosed at their first neurology appointment (19%, compared to 31% for PSP), more likely to wait several months before seeing a neurologist (49% seen within six months, compared to 56% for PSP) and more likely to wait longer for an accurate diagnosis (40% waited three or more years, compared to 35% for PSP).

This indicates that there is no single diagnostic journey for PSP & CBD. Different symptom profiles, different referral routes and different experiences of recognition appear to shape how people affected by each condition reach diagnosis. It is important that healthcare professionals recognise the distinct presentations of each condition, or they risk missing important variations in how the conditions emerge.

What these findings mean

These findings highlight significant challenges in a system that is still struggling to deliver timely and accurate diagnosis consistently enough for people affected by PSP & CBD. This matters profoundly; for people living with progressive neurological conditions, a delayed or inaccurate diagnosis defers certainty, access to the right support and the ability to plan for the future.

There are positive signs in the data: many respondents were diagnosed reasonably quickly, many reached neurology without prolonged delay, and the overall pathway does work relatively efficiently for some. But for too many, the experience of diagnosis is a more troubling picture of repeated GP visits, indirect referrals, long waits for answers, frequent misdiagnosis and recourse to private healthcare to get results.

The substantial variation in experience is likely to be shaped by several factors, from symptom presentation to postcode lotteries in access to certain services in the UK. But whatever the causes, the effect is the same: too many people affected by PSP & CBD are waiting too long, being told the wrong thing, or having to push excessively hard to get answers.

It is also clear that diagnosis of PSP & CBD cannot be treated as a problem for neurology alone. The other services a person encounters – initially their GP but then other services from physiotherapy, eye services and others – are a key part of the diagnostic picture and improving recognition of the signs of PSP & CBD among these professionals, not just neurologists, will reduce delays in receiving an accurate diagnosis.

What needs to change

Diagnosis is the first major point of contact people have with the healthcare system as their symptoms begin to progress. Too often, it is also the point at which that system proves slow, fragmented or difficult to navigate. If care and support for people affected by PSP & CBD are to improve more broadly, improved diagnosis is essential.

The findings in this chapter point to a number of clear priorities for policy and practice.

Improving awareness of PSP & CBD among practitioners in primary and secondary care are critical to speed up recognition of the conditions and referral to neurology. Those referral pathways must be clearer and more reliable, with people able to reach specialist assessment without multiple, avoidable detours. Reducing delays between first presentation, referral and diagnosis should be a priority.

Access to the specialist neurologists able to make a diagnosis of PSP or CBD also needs to improve. That includes capacity, workforce and waiting times, but also access to professionals with the relevant expertise to recognise rare conditions. The use of private care at the level reported in this survey suggests that too many people do not feel able to rely on the NHS for a timely and accurate diagnosis.

Recommendations

- Improve awareness of PSP & CBD – including atypical presentations – across primary and secondary care, including general practice, neurology, ophthalmology, ENT, rehabilitation, geriatrics and memory services, so that people are less likely to be routed through inappropriate pathways before diagnosis.
- Reduce delays in referral and specialist review by improving clarity and consistency in pathways for people with suspected rare neurological conditions.
- Improve access to specialist diagnostic expertise within the NHS, including workforce capacity and access to clinicians with experience of PSP & CBD.
- Reduce reliance on private diagnosis pathways, so that access to timely and accurate diagnosis is not shaped by ability to pay.
- Use diagnosis as an early intervention point, ensuring that accurate diagnosis leads quickly to information, care planning and access to support.

MAGGIE AND CHRIS'S STORY

Maggie Chapman's husband Chris was diagnosed with PSP in 2021.

"Existing health conditions masked Chris's initial PSP symptoms for some time. It wasn't until Chris was experiencing backwards falls and increased anxiety around 2017, that we realised something else was going on.

"Investigations began at one hospital's ENT department. Chris was then referred to Neurology, where the consultant knew something was wrong but not what it was – 'multi-functional disorder' was stated. Moving to another hospital and requesting a referral to the Falls Clinic around 2020, professionals there mentioned CVA and Parkinsons, and then discarded those. Chris's PSP diagnosis wasn't confirmed until he was referred to a new Neurology Department, where brain scans picked up the distinct hummingbird shape in summer 2021.

> **"A LACK OF AWARENESS AMONG HEALTHCARE PROFESSIONALS IS ALSO FRUSTRATING AT TIMES."**

"I had heard of PSP before; I'd read some articles about David Attenborough's brother, John, who quietly battled with the disease. I was able to tick off so many symptoms and similarities with what Chris was experiencing, so the diagnosis wasn't too much of a shock and this allowed me to focus more on the practicalities.

"I like to think I'm a resourceful and organised person, but due to the nature of PSP, caring for Chris, as he progresses, has been a steep learning curve. Trying to stay ahead of the next change, the next challenge isn't always possible. As hard as you try to get things in place before you need them, the healthcare system isn't always quite set up to work that way, especially in the last few years.

"Waiting times to see professionals or access equipment can scupper any plans you might have to get ahead of things. We're currently on a three-month waiting list for an assessment for a specialist bed for Chris, one which you can move to sit the person upright to enable safe feeding and medicating, he doesn't have the strength or mobility to prop himself up now. It took also around a year to get an assessment for a replacement wheelchair.

"A lack of awareness among healthcare professionals is also frustrating at times. It can feel quite daunting, having to explain what is happening, what you need, and why, to people you usually would rely on to give you such answers. We have been really fortunate with the care and support we have received from our GP and the medical practice though. The consultant said a GP may only see one case such as ours in their working life.

"As knowledgeable as professionals can be, they don't know what it is like to support someone with the condition each day, and often they are working to plans which assume there is a typical progression route for the condition. Which there isn't. The community of carers I have found through PSPA have been vital to our experiences. Every time I face a challenge or a difficult decision, I know other carers will provide tried and tested ideas."

LIVING WITH PSP & CBD – DAILY CHALLENGES AND DECLINING INDEPENDENCE IN A FRAGMENTED SYSTEM

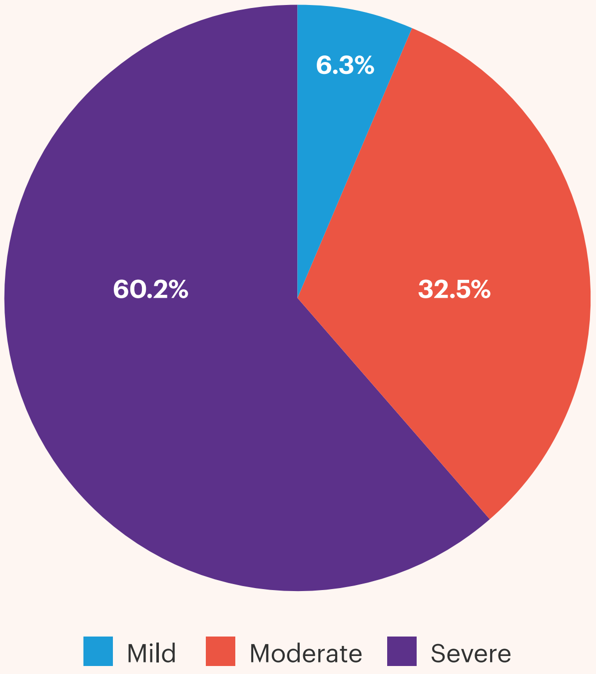
A diagnosis of PSP or CBD shapes almost every aspect of a person's day-to-day life: movement, communication, eating and drinking, independence, relationships, and the ability to take part in ordinary routines and social activities. The impact of living with these progressive, highly restrictive conditions can leave those affected by them facing substantial dependency and loss of independence for the rest of their lives.

Supporting people to live as well as they can, for as long as they are able, with PSP or CBD is not simply a question of managing their symptoms well; it is often the impact on the ordinary tasks of life – washing, dressing, eating, leaving the house and simply communicating with others – where the full weight of the conditions is most felt. Many people affected by PSP & CBD report that their daily lives are characterised by severe impact and a declining standard of living; most describe their condition as worsening and that they face challenges every day. Despite these profound impacts, the lived reality of PSP & CBD is often not fully visible in policy or service design – while rare conditions like these are often discussed in terms of diagnosis, specialist care or research, the everyday impact on people's lives can be harder to see.

A picture of severe and worsening impact

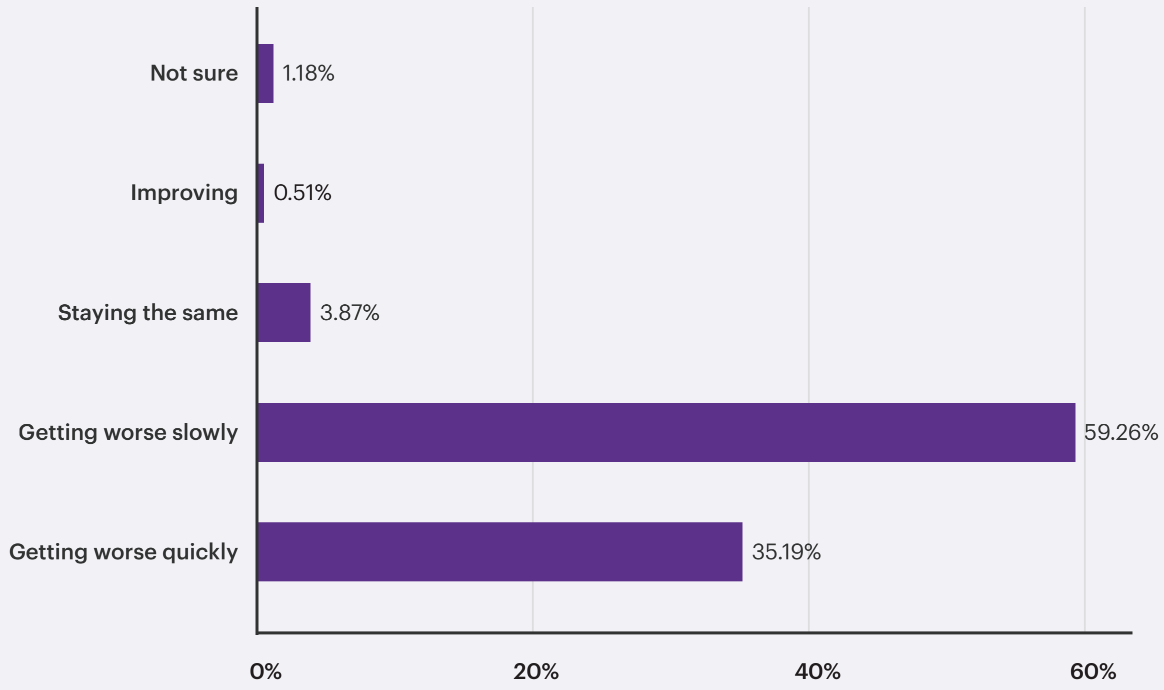
PSP & CBD have a profound impact on a person's quality of life. A clear majority (61%) of respondents to the PSPA Survey described the impact the conditions as severe – needing full-time care or assistance) – while around a third (32%) described it as moderate – needing regular help with daily life and activities. This severity is associated with a very substantial loss of function and dependence on support from family or other carers as detailed later in this chapter.

Fig 7.
Reported severity of PSP & CBD (%)



As progressive conditions with symptoms that advance over time, this burden is not static but is marked by continuing deterioration and an increasing severity, with the future often uncertain and need increasing unexpectedly and quickly. Most respondents (94%) reported that their experience of the conditions was getting worse over the six months prior to completing the PSPA Survey, and only a very small minority (4%) said that things had remained the same.

Fig 8.
Reported changes in condition over past six months (%)



It is therefore unsurprising that more than half of respondents (58%) said that they find every day challenging, while a further fifth (19%) reporting that their daily life is often challenging. The challenges of living with PSP or CBD are frequent, persistent and central to the everyday experience of a person and their family. Only a small proportion (4%) of respondents reported little or no challenge in daily life.

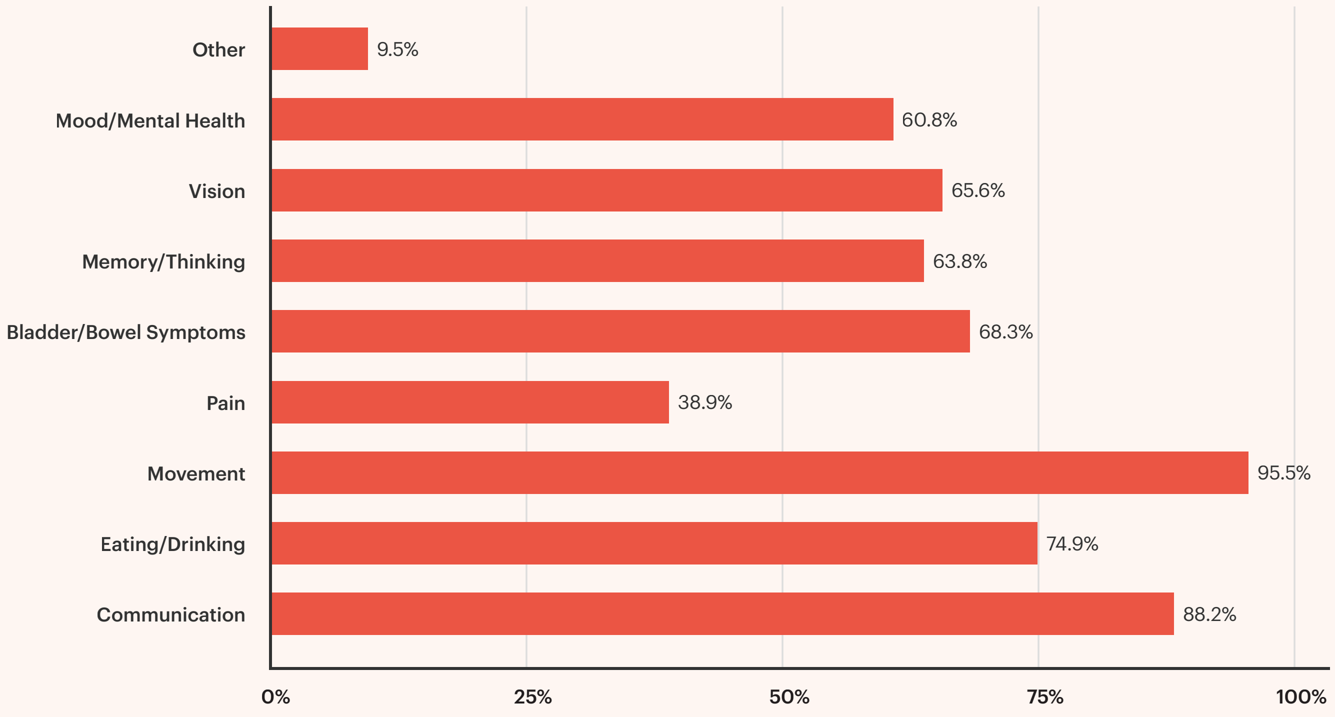
As PSP & CBD progress, this impact rises markedly, with a clear shift in respondents to the PSPA Survey reporting moderate to severe impact over the years following diagnosis. Earlier in the journey, some respondents still describe their condition as moderate (65% of those diagnosed less than six months before completing the survey and 37% of those diagnosed a year before participating); later, severe impact becomes increasingly dominant (84% of those diagnosed more than three years ago). The proportion of respondents saying that every day is challenging also increases over time (73% of those diagnosed more than three years ago).

In this context, with those affected experiencing severe impact, worsening symptoms and constant day-to-day challenge, it is vital that services and support for people living with PSP & CBD need to be built around substantial and often escalating levels of need. It is not enough to understand PSP & CBD simply as neurological diagnoses; they are progressive and ultimately terminal conditions which reshape daily life in fundamental ways, and services for those affected should anticipate the likelihood that support needs will intensify.

The practical reality of living with PSP and CBD

The most common health impacts reported by respondents were movement (96%), communication (88%), and eating and drinking (75%). Other significant impacts of PSP & CBD include problems with memory or cognition (64%), vision (66%) and mood or mental health (61%). These are all core functions that shape whether someone can live their lives independently, express themselves clearly, maintain nutrition and continue to participate in ordinary daily activities.

Fig 9.
Reported health impacts of PSP & CBD (%)

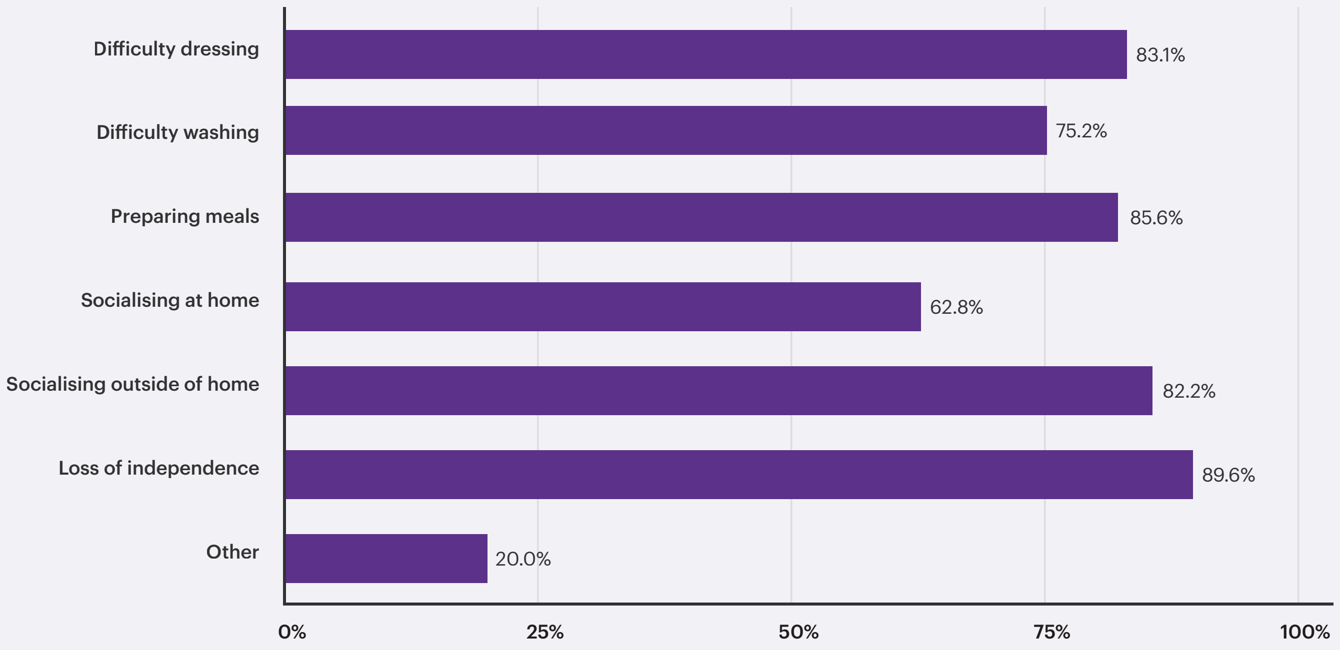


The practical impact of experiencing many or all of these symptoms at once is inevitably life-altering, with those affected by PSP & CBD less able to maintain routines, relationships and social contact in the way they once did. Respondents were asked to report on the impact the conditions have on their daily lives; loss of independence was among the most reported consequences (90%), alongside difficulty maintaining social life both outside the home (84%) and at home (69%).

Respondents also reported substantial difficulty with personal care and household tasks. Many respondents reported problems with washing (79%), dressing (86%), preparing meals (87%) and other basic activities.

These impacts directly affect a person's independence and leave them heavily dependent upon family or other carers, health professionals and social care services in their daily lives. It is therefore vital that social care in particular is seen not as a secondary issue for those affected by PSP or CBD, but essential support that is central to what it means to live well, safely and with dignity with the conditions.

Fig 10.
Reported impacts on daily life of PSP & CBD (%)



Again, these impacts only become more pronounced as time passes after diagnosis and the conditions progress. Over time, respondents were more likely to report increasing difficulty with dressing, washing, social participation, pain, bladder or bowel symptoms, and eating and drinking. This highlights how daily life with PSP & CBD becomes increasingly hands-on and dependency-driven as the disease progresses. Early in the journey, some people may be dealing primarily with emerging neurological symptoms and uncertainty; later, the burden is more likely to be dominated by physical dependency and the practical realities of requiring more support in ordinary daily tasks.

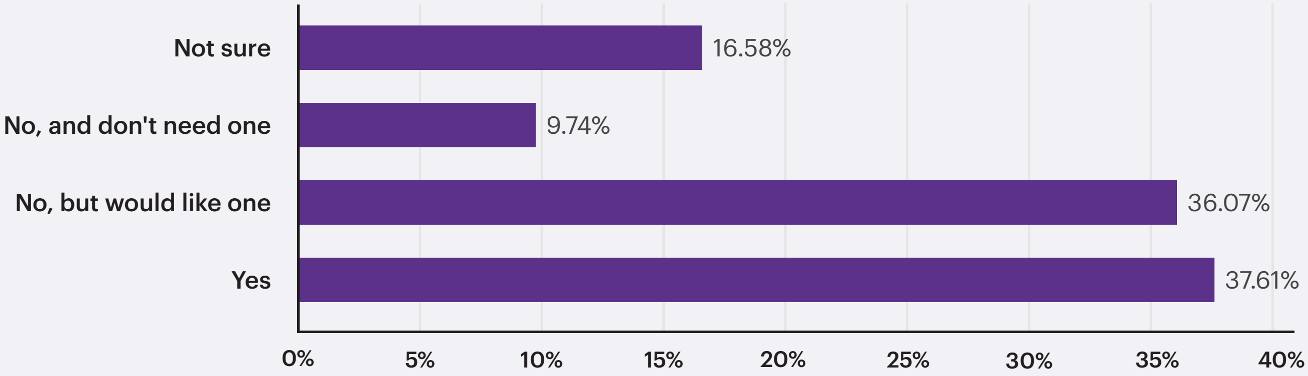
Taken together, these findings show that daily life with PSP & CBD is shaped by profound practical restriction. The conditions affect movement, communication, eating and drinking, independence and social participation in ways that go far beyond – and must be understood as more than – isolated symptoms. They alter what people can do, how they do it, and how much support they need in order to continue everyday life.

Care coordination and professional knowledge

The daily reality of living with PSP & CBD is often experienced within a health and care system that is fragmented and difficult to navigate. One of the clearest indicators of this is the low proportion of respondents to the PSPA Survey who reported having a single named person coordinating their care. Only around a third (38%) said they did have such a person, while a similar proportion (36%) said they did not but would like one.

Given the nature of PSP & CBD, as highlighted above care involves multiple services and professionals over time and often at the same time. Without clear coordination, individuals and families are left trying to link those disparate services together themselves – arranging appointments, repeating information, chasing support, and trying to understand who is responsible for what. Having a named care coordinator within a multi-disciplinary team that is working together in a patient's best interest can make a complicated care and support plan for manageable; too often that is not happening, and families are left fending for themselves.

Fig 11.
Proportion of respondents with a named care coordinator (%)



A lack of awareness of the conditions among health and care professionals further complicates how easily families can navigate their health and care – constantly having to explain PSP or CBD to new professionals from first principles, often because those professionals are different even within the same service from one appointment to the next, is profoundly frustrating for people affected by the conditions and increases the chances of professionals making poor care or support choices. Around half of respondents to the PSPA Survey (49%) said that healthcare professionals were poorly informed about PSP and CBD. Only a minority (21%) described professionals as typically very well informed. Addressing awareness and understanding of the conditions – and improving continuity of care so that individual professionals can build knowledge and a relationship with patients over time – the extent to which people living with PSP & CBD feel recognised, supported and appropriately advised.

CBD respondents were less likely than PSP respondents to say professionals were well informed (5% said very informed, compared to 18% for PSP), and more likely to say that they were not well informed (68%, compared to 51% for PSP). This indicates that CBD is especially vulnerable to under-recognition by health and care professionals, and therefore a risk that people with CBD face an additional layer of disadvantage even within a community already dealing with rare and poorly understood conditions.

Taken together, these findings highlight the challenges people with PSP & CBD face in only managing the impact of their condition itself, but doing so while grappling with a lack of coordination between services and continuity of care and uneven professional understanding. Improving both the coordination and continuity of care, and improving professional understanding of rare conditions like PSP & CBD, has the potential to substantially improve the experience and quality of life of those affected by the conditions.

What these findings mean

The findings in this chapter underline the life-altering nature of a diagnosis of PSP or CBD. The conditions are associated with severe impact, worsening symptoms, high levels of dependency and substantial disruption to a person's ability to complete everyday tasks and engage independently in everyday life and social participation. The practical burden on those affected by the conditions is extensive, affecting many areas of life previously taken for granted – from preparing and eating meals and leaving the home to simply moving around and communicating freely.

PSP & CBD are not only clinically complex; they are deeply disruptive to every aspect of a person's life. For most respondents to the PSPA Survey, the conditions are not a background feature of life, but instead profoundly shape how each day unfolds – with a majority reporting that every day is a challenge.

These findings also show that support for people living with PSP & CBD must reflect the practical reality of the conditions. Too often, health and care services focus narrowly on diagnosis, clinical review or managing symptoms in isolation, and may therefore be failing to address the full scale of day-to-day impact. The sheer range of overlapping health and practical effects that stem from a diagnosis of PSP or CBD, as well as the increasing severity of these impacts over time, underline the importance of support services that look at a person experiencing PSP or CBD holistically, understanding how the interaction of symptoms affecting movement, communication, eating, personal care, independence and social participation interact and impact their lives.

They also highlight the importance of well-coordinated care and a continuity of care between appointments, delivered by well-informed health and care professionals. Too often people are carrying the burden of coordination and navigation themselves. In a well-functioning system, people should not have to become their own care coordinators or have to constantly explain the basics of their condition to new health and care professionals who are unfamiliar with them. The findings indicate that too many currently do.

TOO OFTEN, HEALTH AND CARE SERVICES FOCUS NARROWLY ON DIAGNOSIS, CLINICAL REVIEW OR MANAGING SYMPTOMS IN ISOLATION, AND MAY THEREFORE BE FAILING TO ADDRESS THE FULL SCALE OF DAY-TO-DAY IMPACT.

What needs to change

Health and care services typically address progressive conditions like PSP & CBD, for which there is no cure, in silos. As there is no single treatment for either condition, services focus on managing symptoms – those living with the conditions may see a physiotherapist for issues affecting their movement, a speech and language therapist for communication issues, an ophthalmologist for vision issues, and so on.

The findings in this chapter point to a need for services and support that more fully reflect the overlapping impacts on health and daily life experienced by people living with conditions like PSP & CBD, and are designed around supporting those with the conditions to better manage the realities of daily living in a coordinated way.

More reliable and timely access to individual services like physiotherapy, occupational therapy, speech and language therapy and others can support people affected by the conditions to manage their symptoms. This must be supported by readier access to medical equipment, home adaptations and other forms of support, so that people affected by PSP & CBD have access to the full range of medical and practical support they need to make a meaningful difference to daily functioning and quality of life.

Care coordination must also be improved. People with PSP & CBD should have clearer access to named points of contact or better-defined coordination arrangements, particularly as needs become more complex over time. The current gap between the number of people who have a named coordinator and the number who want one suggests a significant area of unmet need.

Professional knowledge about the conditions needs to improve across all services that a person with PSP or CBD is likely to access, not only within neurology. Families interact with a wide range of services, and the confidence they place in the system depends in part on whether professionals appear to understand the condition and its implications. This is particularly important for CBD, where confidence in professional understanding appears weaker.

Finally, support for those affected by the conditions should be designed with progression in mind. Because severity and dependency increase over time, the support a person needs in the period immediately following their diagnosis may not be sufficient later. Regular review of care needs, anticipatory planning and timely escalation of support are all vital to ensure that care remains suitable as the conditions progress.

Recommendations

- Ensure health and care services reflect the full practical impact of PSP & CBD, including their effects on movement, communication, eating and drinking, personal care, independence and social participation.
- Improve access to therapies, aids, adaptations and symptom management, including physiotherapy, occupational therapy, speech and language therapy, equipment and home adaptations.
- Ensure health and care services plan for increasing need over time, with regular review and anticipatory support as severity and dependency grow.
- Improve care coordination, with clearer named contacts or more defined coordination arrangements for people living with PSP & CBD and their families.
- Improve professional knowledge of PSP & CBD across disciplines, including primary care, community services, therapies, social care and hospital-based teams, not only neurology.

JANE'S STORY

Jane Terry was diagnosed with PSP in February 2026.

When Jane first began to experience unexplained falls, her GP referred her to NHS Ear, Nose and Throat specialists. When those investigations didn't reveal a cause, she was sent to Podiatry, and later to Neurology when professionals suspected Parkinson's. Each time she was referred to a new service, she faced a waiting time of around seven months.

Frustrated by the delays and still without answers, Jane decided to seek a private consultation. She secured an appointment with a private neurologist within a week, a stark contrast to her previous NHS waits.

In 2025, Jane was diagnosed with Parkinson's and initially felt hopeful. She knew there were medications that could help, and she looked forward to regaining the strength and mobility so she could get out and enjoy walking again, something that had become an essential source of therapy and social connection since her husband died three years earlier.

However, when Parkinson's medication didn't make any difference, further investigations began. After 18 months of appointments, referrals, and uncertainty, Jane finally received a diagnosis of PSP in February 2026.

"It's quite a frightening diagnosis to receive, especially when you live alone," Jane explains. "Within a relatively short period of time, I've gone from being very independent and active to relying on family and friends for support."

Jane is currently living in rented accommodation while essential works are completed on her home ahead of selling it. "My balance and mobility aren't what they used to be, so I need to find somewhere that will suit my needs better. I plan to visit some assisted living properties so I know help will be on hand if I need it."

Beyond the practical challenges, Jane has also found the condition quite isolating.

"I'm lucky my daughter lives close by, I see her most days, and she takes me out every weekend, so I get a good airing. I see friends about once a week too."

But one of the hardest losses has been giving up the independence of walking her dog. "After my husband died, walking became my therapy, getting out, chatting to others."

"IT'S QUITE A FRIGHTENING DIAGNOSIS TO RECEIVE, ESPECIALLY WHEN YOU LIVE ALONE."

Reflecting on her situation, Jane says: "I find it sad on days like yesterday, when the sun is shining but I can't go out unassisted, so I'm stuck inside. Adapting to needing support with so many parts of my life is difficult. And knowing there isn't anything that can improve my condition, it's a lot to take in and deal with alone."

MENTAL HEALTH AND FINANCIAL PRESSURE

The burden of PSP & CBD is not only physical. Alongside the physical symptoms that progress as the conditions develop, many people affected by them are also coping with significant emotional strain, new and increased financial pressures, and systems that are often difficult to navigate. Mental health support to help those affected by the conditions cope with the emotional impact of a diagnosis, and support from the social security system, are crucial to ensure that the full range of impacts on a person's life with PSP & CBD are addressed.

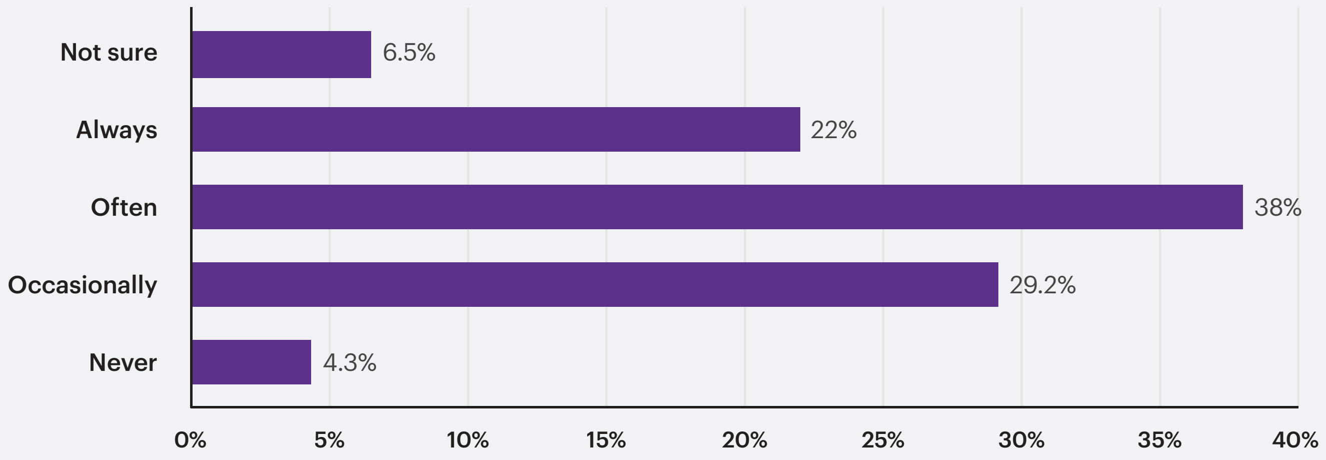
Frequently, however, our community tells us that the challenge of living with PSP or CBD lies not only in the impact of the condition itself, but in the wider practical and systemic consequences that come with it – and which are often unsupported by the health, care and social security systems. Support for people affected by the conditions can too easily focus on clinical symptoms alone, ignoring the emotional impact a person is coming to terms with and the practical impact of their changed circumstances. This includes anxiety, frustration and low mood; additional costs and financial insecurity; and uncertainty about what support is available. These pressures shape quality of life and the ability to cope with a diagnosis of PSP or CBD profoundly.

Mental health and emotional burden

People affected by PSP & CBD are not only coping with the neurological and physical symptoms of their condition; they are also coping with the devastating emotional impact of a terminal diagnosis and coming to terms with the reality that their condition will progressively affect the rest of their lives. For many, this can result in significant anxiety, frustration and stress. as part of the same experience.

A majority of respondents to the PSPA Survey (60%) reported regularly experiencing depression, anxiety, frustration or stress related to their condition – with more than a fifth (22%) saying they experience these feelings constantly. Very few (4%) reported no emotional or mental health impact at all, underlining the extent to which mental health challenges are a core part of everyday life for those affected by PSP & CBD and not a secondary or incidental impact.

Fig 12.
Reported feelings of depression, frustration or stress related to PSP & CBD (%)



This is understandable in the context of a terminal and progressive disease – both PSP & CBD progressively affect a person's ability to live, move around and communicate independently, leading to uncertainty, loss of confidence, isolation and a growing need for support. As outlined in the previous chapter, more than half of respondents (58%) said that every day is challenging – a high mental health burden both exists in the context of and contributes to this daily challenge. For many respondents, distress is not simply a response to diagnosis in the abstract; it is tied to the daily experience of increasing difficulty, reduced autonomy and uncertainty about what comes next.

Female respondents were more likely than male respondents with PSP & CBD to report impacts on memory or thinking (79%, compared to 55% for men) and on mood or mental health (70%, compared to 57%). These findings should be interpreted carefully, but they suggest that women who responded to the PSPA Survey were more likely to experience a heavier emotional and cognitive burden. That may reflect differences in symptom experience between men and women, or a higher likelihood among women to self-report mental health concerns.

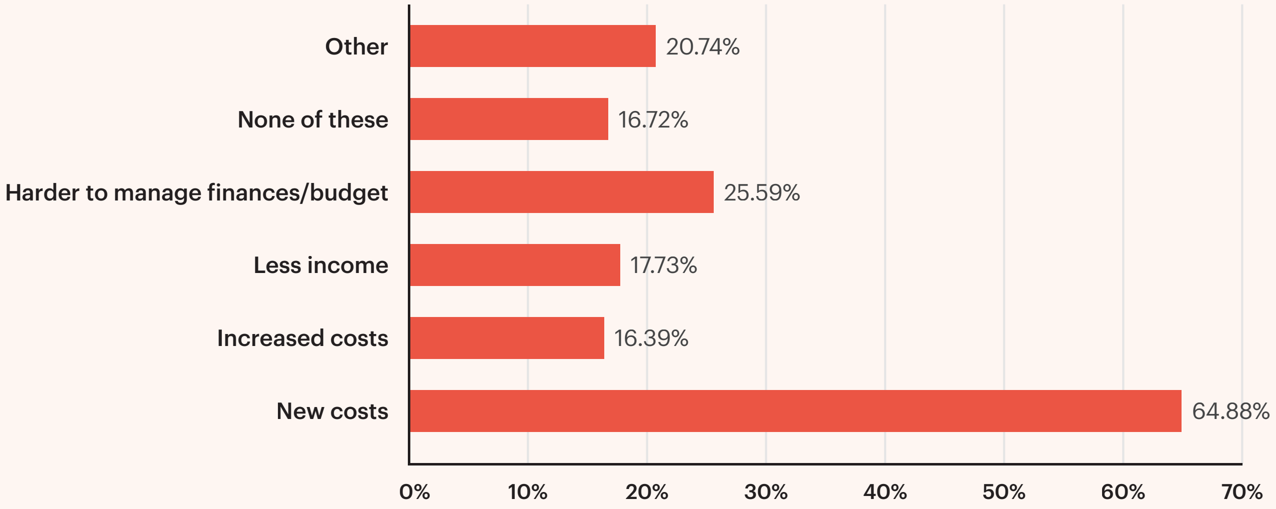
Emotional and cognitive impact appears to be especially prominent earlier in the journey. Those respondents diagnosed within the six months before taking the survey were more likely to report mood or mental health symptoms (80%) and to say they often experienced feelings of depression, frustration or anxiety (70%), while the picture reported by those diagnosed earlier is dominated by severe physical dependency and hands-on care needs. This does not mean that emotional needs disappear over time. Rather, it suggests that in earlier stages of PSP & CBD, when uncertainty is high and people are coming to terms with the condition and its implications, they are at a particular risk of mental health and emotional impact; underlining the importance of making mental health support available in the period immediately following a diagnosis.

Financial pressure and benefits

The PSPA Survey also finds that many people affected by PSP & CBD are experiencing a significant financial burden, alongside the neurological, physical and emotional burden of their condition. Around two-thirds of respondents (65%) reported facing new costs associated with the condition; these may include the cost of travel to frequent medical appointments, home adaptations, medical devices and especially the cost of paying for social care.

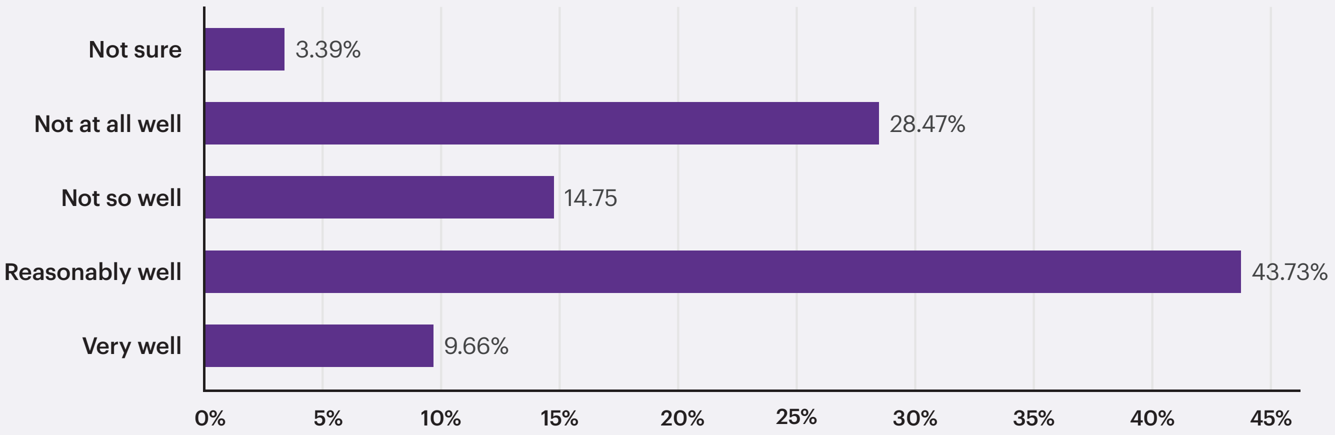
In addition to new costs, 16% of respondents reported that costs they had before have gone up since their diagnosis and one in four (26%) said they now find it harder to manage their household budget. Given that PSP & CBD typically affect people later in life and many are close to retirement age when diagnosed if they have not retired already, it is also significant that nearly a fifth of respondents (18%) say they have less household income now than before their diagnosis.

Fig 13.
Reported financial impacts of PSP & CBD (%)



What matters is not only that these costs arise, but that many respondents reported struggling to manage them. While some (44%) said they were coping reasonably well with the added costs brought on by living with PSP & CBD, almost half (43%) said they were not managing them well. This financial strain can intensify the challenge of living with the conditions; worrying about money may affect emotional wellbeing, limit choices about care or support, and place an additional burden on families already adapting to major change. For those who have had to reduce work, stop working, or take on new caring responsibilities, the impact can be particularly severe.

Fig 14.
Reported ability to manage the financial impacts of PSP & CBD (%)



84% of respondents reported that they are receiving some disability benefits; 23% are receiving the Personal Independence Payment and 61% are receiving Attendance Allowance. This is positive; however, the high level of financial strain reported by respondents to the PSPA Survey indicates that for those living with the conditions, it may be that the level of these benefits is not sufficient to address the financial impact of PSP or CBD.

Similarly, only 23% of respondents reported that they were receiving either NHS Continuing Healthcare (NHS CHC) or, in Scotland, Hospital Based Complex Clinical Care (HBCCC) – with the likelihood of receiving this increasing with time since diagnosis. A similar proportion (25%) reported that they do not know what NHS CHC/HBCCC are. Given the high level of dependency caused by PSP & CBD, and the need for social care support to help those living with the conditions live well – and the high cost of social care in the UK – PSPA is concerned in light of the reported financial burden on the community that fewer than one in four people living with the conditions is receiving CHC, while a similar number have not been made aware of it at all. As outlined in PSPA's *State of Continuing Healthcare* report (2025) , a CHC system that has increasingly become an end-of-life service and does not support people earlier in their lives means that those who do not receive support with the cost of social care via CHC often face extremely high care costs as a result.

What these findings mean

Taken together, the findings in this chapter demonstrate that the burden of PSP & CBD goes beyond the neurological and physical symptoms of the conditions. Many people affected by them are also living with significant emotional distress and major financial pressure, with support that is either insufficient or too hard to access. These pressures are interlinked; dealing with a loss of independence and worsening symptoms may cause emotional strain and lead to additional financial pressures, and those financial pressures may further exacerbate the mental health impact a person is facing – each burden can intensify the others.

This has important implications for policy and practice. Support for PSP & CBD cannot be limited to clinical management of symptoms and improving the coordination and delivery of care alone. Emotional wellbeing and financial security are central to whether people feel able to cope with the impact of a diagnosis of a progressive and terminal condition.

Support with benefits and entitlements does not appear to be reaching everybody who needs it; PSPA remains concerned at the low rate of people living with PSP & CBD who are receiving NHS Continuing Healthcare (CHC) despite the conditions causing exactly the primary health need outlined in the National Framework for Continuing Healthcare that should lead to CHC being put in place. Even when support is provided, in the form of disability benefits, this does not always appear to materially improve how well families are able to manage the financial impact of PSP or CBD. Advice, signposting and help to access benefits and entitlements can materially affect whether people are able to cope with the everyday consequences of PSP & CBD.

What needs to change

The findings in this chapter point to several priorities for policy and practice.

First, mental health and emotional support must be embedded in routine care pathways for PSP & CBD. Mental health and emotional strain are too widespread among people living with the conditions to be treated as peripheral issue; psychological support, signposting, peer support and recognition of emotional needs should form part of good condition management from an early stage.

Second, advice and support on benefits and entitlements should be strengthened. The survey suggests that many families are facing significant new costs and that a substantial proportion are struggling to manage them. Access to practical information, welfare advice and support to navigate entitlements could materially improve people's ability to cope.

Finally, systems need to become easier to navigate. Information about mental and emotional support, social security entitlements and NHS Continuing Healthcare should be clearer and more accessible. People affected by rare progressive conditions should not be left to discover essential support only after prolonged trial and error.

The burden described in this chapter is significant, but it is not inevitable. Emotional strain and financial pressure are not simply unavoidable features of PSP & CBD; better support and better system design could make a meaningful difference.

Recommendations

- Embed mental health and emotional support in routine PSP & CBD care pathways, recognising anxiety, frustration, stress and low mood as common parts of the condition experience.
- Improve access to NHS Continuing Healthcare for people living with PSP & CBD, including improving training for clinicians undertaking assessments and ensuring a healthcare professional with knowledge of the condition being part of the assessment team.
- Strengthen advice and support on benefits and entitlements, including signposting and practical help to access disability-related benefits and carer support.

KATE AND JIM'S STORY

Kate Harris's husband Jim was diagnosed with PSP and CBD in 2022.

"Jim's journey started around six years ago. Increasing unsteadiness on his feet, falls, and speech difficulties led to a diagnosis of Parkinson's during Covid. The lockdown meant there was little help or support available, only a prescription of Parkinson's medication.

"Once the Covid vaccines were available, Jim had a bad reaction which affected his spinal cord. Over the next 18 months this intensified his symptoms, which turned out to be an overlap of both PSP & CBD. During this time Jim lost all mobility and became doubly incontinent. With no friends or family nearby, I couldn't look after him at home alone and had no choice but to find a live-in care facility for Jim, four miles away.

"Jim is largely confined to his bed. We have had the stress of self-funding this because his condition just seemed to fall under the care radar. To date the cost of care has tallied up to around £120,000.

"Feeling a bit helpless about the situation and knowing Jim's saving would eventually run out, I did some research and learned about CHC Funding. With Jim immobile and doubly incontinent, needing around the clock care, I thought applying would be straight forward. But I was wrong. Twice my application was refused.

"I would detail the extent of Jim's conditions – his legs are totally rigid and immobile, his arms are progressing in the same way, so he can't move any part of himself unaided. He cannot eat unaided, I visit every day and I feed him most meals. He regularly contracts UTI's, bed sores and chest infections, so the nurse practitioner is always writing scripts for antibiotics. Jim's speech is also now affected, so communicating his needs can be extremely difficult. And although he can have moments of clarity, which can surprise the both of us, his cognition is largely impaired too.

> **"IN MARCH, WE FINALLY HAD A POSITIVE OUTCOME. WE HAVE BEEN AWARDED FUNDING."**

"I read every word of the 189-page guidance document on the NHS website ahead of my latest CHC application. I wanted to ensure I was as clued up as I could be about the process and what different terms meant, in the real world. I then submitted my third CHC Funding application in February and for the third time someone came out to assess him.

"In March 2026, we finally had a positive outcome. We have been awarded funding to cover his care fees going forward. The only difference between this application and the previous one was that Jim could no longer hold a spoon to feed himself.

"Looking back, it feels like Jim was discriminated against because he didn't fit under the banner of Alzheimer's or dementia. Despite his longstanding issues with his mobility, it seems only now he cannot use any limb usefully, and his cognition has declined, that they've taken notice. It feels like he didn't tick enough boxes.

"It's been a stressful and quite isolating experience, but I cherish the six-days a week I spend with Jim."

PROGRESSION – SUPPORT LAGGING BEHIND INCREASING NEED

Life with a progressive condition like PSP or CBD is not static and need does not remain constant after diagnosis. As time passes, the severity of the conditions increase, dependency grows, and people living with the condition and their families face a growing practical and emotional burden. People affected by the conditions need support which not only recognises but anticipates that needs change in both scale and character over time, and is shaped by their changing circumstances.

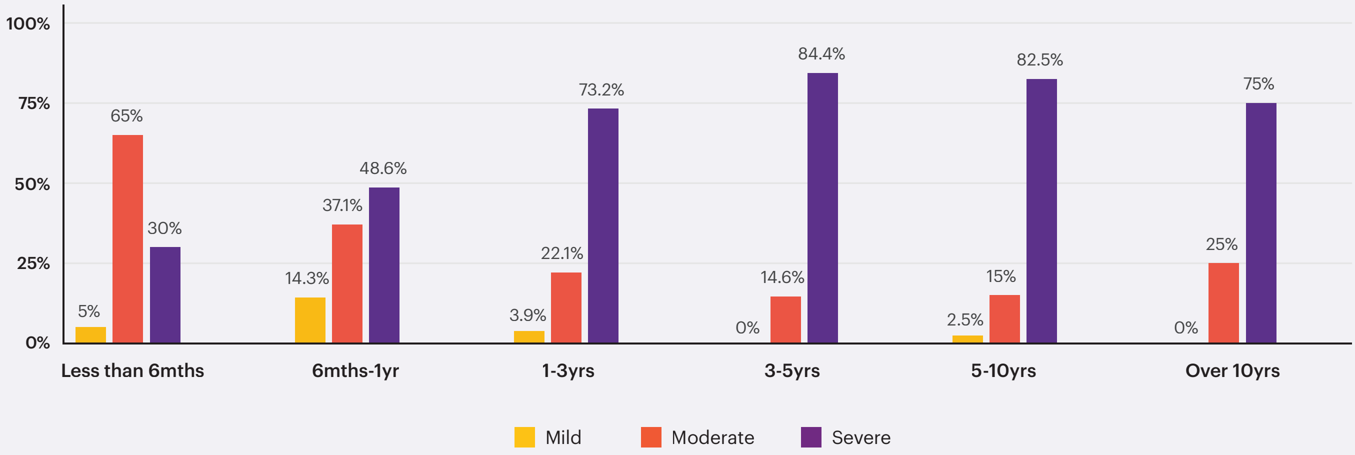
Frequently however, the health and care system only responds when need becomes acute and the burden of the conditions is already substantial – too often, people affected by PSP & CBD experience support as isolated moments of intervention or crisis response. People living with the conditions and their families are often left absorbing the burden of progressing symptoms and an increased burden themselves while health and care services catch up with these new circumstances.

More than describing how symptoms progress and worsen over time, the PSPA Survey findings in this chapter underline the extent to which support for people affected by PSP & CBD often lags behind progression, rather than keeping pace with it.

How experience changes over time

Progression is not simply a matter of new symptoms developing over time; it is characterised by a substantial rise in the intensity of burden and dependency. Respondents to the PSPA Survey who were in the earlier stages after their diagnosis were more likely to describe the impact of PSP or CBD as moderate (65% of those diagnosed in the six months before completing the survey, 38% of those diagnosed a year before), while those who were in the later stages were far more likely to describe it as severe (84% of those diagnosed three to five years before completing the survey).

Fig 15.
Reported severity of PSP & CBD over time since diagnosis (%)



Similarly, in the early period after diagnosis, respondents were more likely to be more positive about the impact of PSP & CBD on their daily lives (31% of those diagnosed within a year before completing the survey described daily life as not challenging or only 'sometimes challenging'). Over time, a much larger proportion reported that they found every day challenging (75% of those diagnosed three to five years before completing the survey).

As the conditions develop, the daily life becomes more characterised by these challenges and difficulty is more likely to become the baseline reality of living with PSP & CBD.

Functional dependency and a need for increasingly hands-on support with the basic activities of daily living also increase over time. Respondents were much more likely to report difficulty with washing, dressing and other personal care tasks as time since diagnosis increases. Problems with social participation, pain, bladder or bowel symptoms, and eating and drinking also become more prominent over time.

This increasing severity translates into higher support need from personal care, greater restriction in daily activities, and a reduced ability to manage independently. This is the point at which families often begin to carry more intensive caring responsibilities, and where pressure on formal services is likely to grow as needs become more complex.

The PSPA Survey findings indicate that the period around three to five years after diagnosis of PSP or CBD is especially pressured. This is the point at which severe impact becomes highly prevalent, daily challenge becomes particularly constant, and support needs become especially intense. While progression is continuous, this period stands out as the point at which the cumulative burden on both the person with the condition and those around them becomes especially heavy.

The changing shape of need

As need rises over time, it also changes in character. In the earlier stages after diagnosis, respondents were more likely to report memory or thinking difficulties (85% of those diagnosed in the six months before completing the survey) and mood or mental health impacts (80%). While these issues do not disappear later, it is understandable that in the early period after a diagnosis of PSP or CBD, people may be grappling with uncertainty, trying to understand the condition, adjusting emotionally, and making sense of changes that feel frightening or difficult to predict.

As time goes on, the burden of the conditions increasingly dominated by physical dependency and care intensity. Difficulties with washing (88% of those diagnosed three to five years before completing the survey), dressing (91%), social participation (86%), communication (94%), eating and drinking (90%) and movement (99%) become more prominent. The central challenge of living with PSP & CBD shifts from understanding and adjusting to the diagnosis to coping with escalating disability and reliance on increasingly round-the-clock support.

This underlines that the progression of a terminal neurological condition like PSP or CBD is not simply a matter of new symptoms emerging over time – need does not only grow in volume, but the balance of that need shifts. Emotional and cognitive impacts are especially prominent earlier, while physical dependency and personal care needs become more dominant later. It is important that services are designed around this changing need rather than a single model of support, or they may fail to respond to the changing pattern of need over time.

THE PSPA SURVEY FINDINGS INDICATE THAT THE PERIOD AROUND THREE TO FIVE YEARS AFTER DIAGNOSIS OF PSP OR CBD IS ESPECIALLY PRESSURED.

As outlined in the next chapter, the impact on PSP & CBD family carers also shifts as the pattern of need changes. Carers become more likely to provide 50 or more hours of care each week as the time since diagnosis rises (73% of carers of somebody who was diagnosed three to five years ago), and more likely to spend several hours a day on personal care tasks (44%). At the same time, carers become more likely to report feelings of being overwhelmed (56%) or isolated (49%) by their caring responsibilities as their caring role becomes more demanding.

A reactive system rather than an anticipatory one

While the progression of PSP & CBD drives increasing need, the PSPA Survey indicates that systems are not always responding in a timely or anticipatory way. Certain forms of support become more common only in later stages – as outlined in the previous chapter, receipt of NHS Continuing Healthcare (CHC) is more likely only more than five years after a diagnosis (40%), while carers were more likely to report having had a Carers Assessment (69%) at the same stage.

It is encouraging that families affected by PSP & CBD are more likely to be able to access support as needs become more complex; however, PSPA is concerned that not only access to, but awareness of, this support is not readily available to people earlier. In the first year after diagnosis, 70% of carers have not received a Carers Assessment while 29% of people living with the conditions have not been made aware of CHC. Even as need appears to grow increasingly severe around three to five years after diagnosis, one in five (39%) of carers have still not had a Carers Assessment and 21% of people with the conditions still have not been made aware of NHS CHC.

This indicates that while the health and care system may respond to increasing need eventually, it does not always do so early enough. As severity rises, daily challenge becomes more constant and caring becomes more intensive, support appears to build more slowly and occur later – indicating a system which is often reactive, where support arrives only after families have been placed under considerable strain rather than anticipating growing need and planning for progression. If services wait for visible crisis before responding, they risk increasing both the practical and emotional burden on both the person living with PSP or CBD and those caring for them.

These findings underline that people affected by PSP & CBD do not simply need support at some point, but support which matches the pace and pattern of progression. The fact that support often appears to come later suggests that the services they are interacting with are not always designed to meet this need.

? What these findings mean

The findings in this chapter underline that the burden of a progressive condition like PSP or CBD becomes more severe and more constant over time, with the nature of need changing and leading to more dependency as the years since diagnosis pass. People affected by the conditions report growing challenge and severity as their condition progresses, with an initially high emotional and mental health burden as they come to terms with their diagnosis and an increasingly high level of physical disability and need for personal care as their symptoms progress.

This has major implications for how support should be designed. A system that responds only intermittently after diagnosis, or when a person reaches a crisis point, is unlikely to match the lived reality faced by people living with PSP & CBD. People's needs do not remain stable after diagnosis, but evolve, deepen and often intensify sharply. Support from the health and social care system therefore needs to be responsive and stage-sensitive to keep pace with that progression.

These findings indicate that current systems designed to support people affected by progressive conditions and their carers, like NHS Continuing Healthcare or Carers Assessment, are too often reactive rather than anticipatory. Access to these forms of support lags behind increase in the burden faced by people affected by PSP & CBD, following escalation rather than getting ahead of it.

What needs to change

The findings in this chapter point to a strong case for building services and support for people affected by PSP & CBD around anticipating progression, rather than waiting for crisis.

First, planning should begin earlier. From diagnosis onwards, people affected by PSP & CBD and their families should be helped to understand that these are progressive conditions likely to require increasing levels of support over time, with opportunities to plan and express their priorities and preferences for how that care will develop.

Second, support needs should be regularly reviewed. One-off assessments or sporadic interventions from services are unlikely to capture changes in intensity or the nature of need; instead, regular opportunities for support to be adjusted as PSP & CBD progress should be built into care pathways. Ensuring that more people affected by the conditions have access to a named care coordinator will help ensure this takes place.

Third, services should become more stage-sensitive. Early in the journey, support may need to focus more on information, mental health and emotional support and future planning. Later, there may be a greater emphasis on more intensive personal care, equipment and support for carers as dependency increases. Earlier access to NHS Continuing Healthcare and Carers Assessments than is currently available to many people with PSP & CBD will help ensure that this support does not lag behind increases in need.

Finally, services should recognise the importance of the middle years after diagnosis of PSP & CBD, particularly the three-to-five-year period where need appears to intensify and begin to change. This may be a point at which many families need more intensive review, better coordination and stronger proactive support.

PSP & CBD are progressive conditions in which needs increase sharply and change in character over time. Health and care services that fail to anticipate that progression are likely to leave people and families carrying too much, for too long, with too little help.

Recommendations

- Introduce earlier planning, regular review of care needs and anticipatory care support from diagnosis onwards, recognising that needs are likely to increase and change over time.
- Build stage-sensitive health and care services, with support that reflects the changing balance of emotional, cognitive, physical and practical needs across the disease course.
- Services should pay particular attention to the middle years after diagnosis, where pressure may be especially intense.
- Care planning should be designed to get ahead of crisis, rather than responding only once burden has become severe and sustained.

VIOLET AND JACKIE'S STORY

Violet Thomas's husband Jackie was diagnosed with PSP in December 2025.

"It's been a frustrating and challenging couple of years. Our GP didn't believe there was anything wrong with Jackie when he first started falling two years ago. As a family, we knew there was more to it than just 'old age', so my son paid for a private consultation in Glasgow. There, Jackie was diagnosed with Parkinson's and sent home with medication to help manage his symptoms.

"The medication only seemed to make things worse. Jackie wanted to stop taking it, but we were encouraged to persist. Eventually, on 5 December 2025, he was admitted to a specialist unit 30 miles away for tests to uncover what was truly going wrong. I thought he'd be back home in a few days.

"Instead, the consultant diagnosed Jackie with PSP. They kept him in for further observations. He was still walking when he was first admitted, but due to staff shortages, Jackie received no physiotherapy. To reduce his risk of falls, he was encouraged to stay in bed. Over time, he completely lost his strength. Now, he can no longer walk, and he even struggles to eat by himself.

"Jackie was a good-sized man when he went into hospital, but he's down to about eight stone now. The hospital food hasn't always been suitable for someone with his swallowing difficulties; initially he was only managing soup and ice cream. He is now given pureed food. Because of his weakness, he doesn't really eat unless someone is there to help and encourage him. During the day, the ward team just don't have the time. They put the meal in front of him and pop back an hour later, when it is most likely left, untouched. Now, I travel 60 miles round-trip every single day just to ensure he eats his lunch.

"WE LIVE IN A REMOTE VILLAGE, SO SECURING CARE SUPPORT IS INCREDIBLY DIFFICULT."

"The heartbreaking thing is that Jackie was deemed medically ready for discharge three months ago. To prepare, the council helped me install a wet room, a hoist, and a profile bed. He was awarded 28 hours of care per week, with two carers visiting three times a day to help. Everything is sitting at home, ready and waiting for him. The sticking point is finding the carers to do the job. The council is advertising the role with two agencies and Capability Scotland, but no joy yet.

"We live in a remote village, so securing care support is incredibly difficult. Most families here look after their own. But I'm 75 years old with my own health problems; I simply cannot manage his care by myself. My grown-up children help when they can, but they have their own jobs and families. They can't provide the hours of support Jackie needs.

"The main frustration I have now is no one at the council keeps me informed of what is happening with the carers. I must constantly check in to get updates. Neither of us want to even think about using a care home until carers become available. So, even though I'm completely exhausted, it feels like I have no choice but to continue my daily trips, sit by his bed, and wait for a carer to become available."

CARERS – ESSENTIAL, UNDER PRESSURE AND UNDER-SUPPORTED

Support from family carers is central to life with PSP & CBD. For many people living with these conditions, care provided by partners, family members and other unpaid carers is essential to manage daily routines, appointments, mobility, communication, personal care and the practical realities of living with a progressive and terminal illness. Yet being a carer often comes at significant cost to carers themselves. The PSPA Survey shows that many are providing high levels of care over long periods of time, while also experiencing a substantial impact on their own quality of life and wellbeing.

Too often family carers are treated as peripheral to the health and social care of people affected by PSP & CBD rather than as a core part of the care team and a vital part of their lives. In reality, carers are often the people holding the system together; coordinating appointments, managing communication between services, assisting with personal care, supporting decision-making, and responding to worsening need as the conditions progress. When carers are unsupported, the burden falls not only on them but the person with PSP or CBD they are caring for.

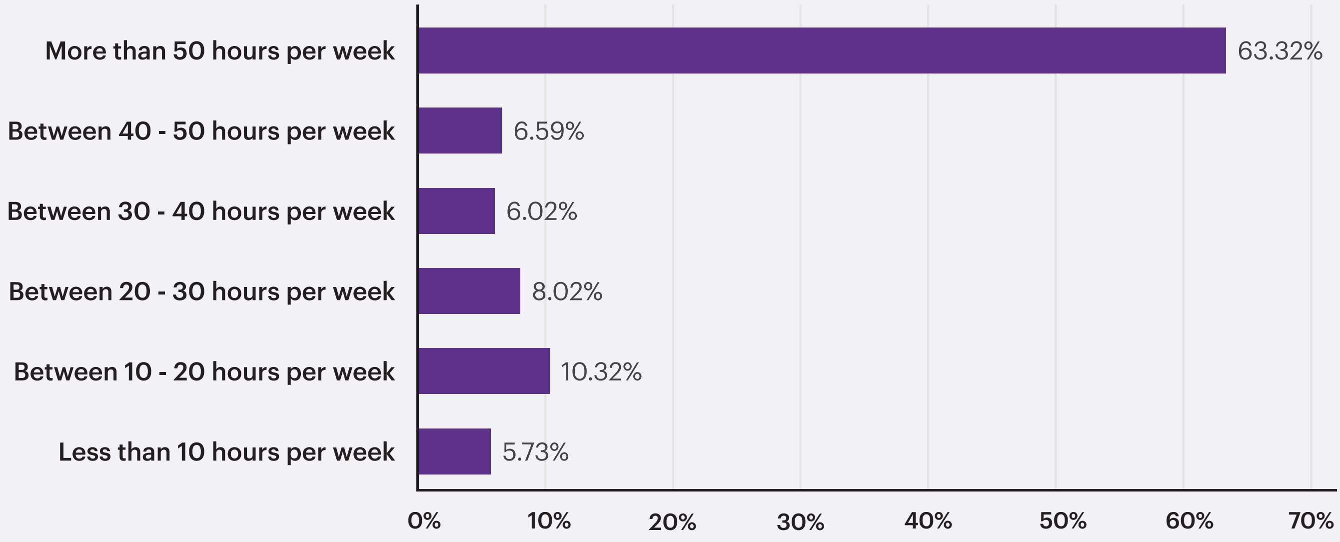
The PSPA Survey finds that many carers of people living with PSP & CBD are under intense and sustained pressure, providing care that is time-consuming, emotionally draining and isolating. Access to support with the caring role is often uneven and arrives later than need emerges, with female carers and those caring for people with CBD reporting particular burdens. Too often, their needs are not treated as a core part of supporting a person living with PSP or CBD but as a private family matter.

The intensity of caring

Caring in the context of PSP & CBD is often intensive, sustained and physically demanding. It is not simply a matter of providing reassurance or practical help from time to time – for many carers, it is the central organising fact of everyday life.

Around two-thirds of PSP & CBD carers (63%) reported providing more than 50 hours of care each week, underlining how caring for somebody with a progressive and terminal condition is a major and ongoing commitment that shapes every day. This care is often highly hands-on; a third (36%) reported spending more than four hours every day on personal care tasks, including assistance with washing, dressing, toileting, eating and other intimate or practical aspects of support. In addition to personal care, a similar proportion of carers (36%) reported spending more than four hours daily on household tasks like shopping and preparing meals for the person they care for. In effect, for many, caring is a full-time job.

Fig 16.
Reported hours per week spent caring (%)



Providing this level of care has consequences for a carer's own employment, finances, time and wellbeing; a person providing 50 or more hours of care each week is likely to face major constraints on their own routines, work, rest and social life. A majority (59%) of carers who responded to the PSPA Survey told us that they did not feel they had enough time to take care of their own needs alongside their caring responsibilities, while more than one in four (29%) reported that they had either reduced their hours at work, left work altogether or taken early retirement as a result of becoming a PSP or CBD carer.

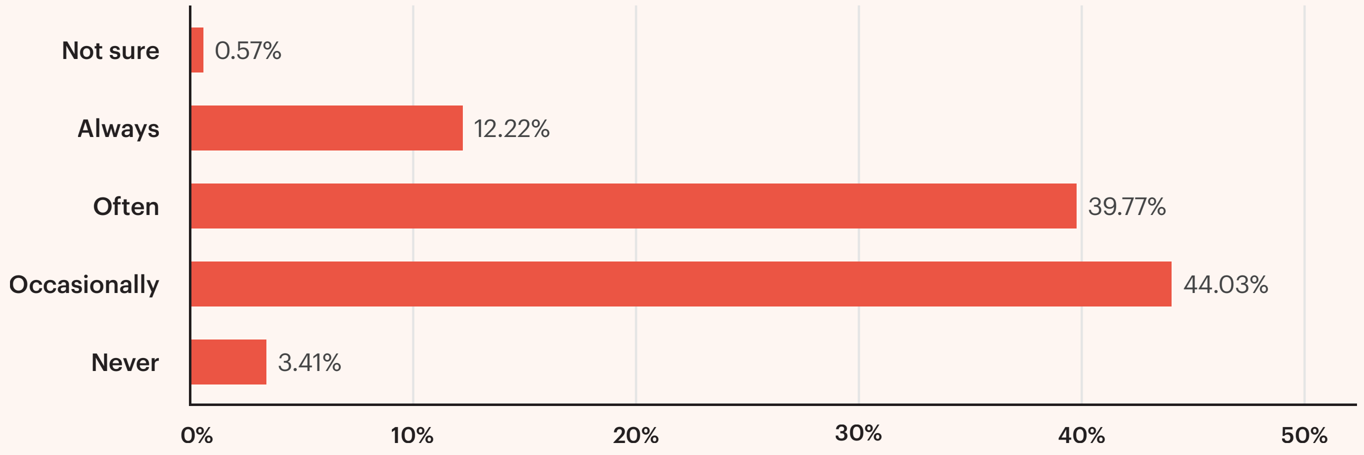
As outlined in the previous chapter, as PSP & CBD progress carers become more likely to report providing very high numbers of hours of care each week (73% of carers of somebody who was diagnosed three to five years ago) and more likely to spend longer each day on personal care (44%), underlining how the caring role for somebody supporting a loved one with a progressive and terminal condition becomes demanding not only in emotional terms, but in practical and physical terms as the disease progresses. A carer who is managing in the early months after diagnosis may face a very different reality several years later.

Stress, isolation and wellbeing

Carers of people living with PSP & CBD are not only supporting others; they are living with the consequences of that support in ways that are often serious, prolonged and cumulative. More than half of carers reported regularly feeling emotionally overwhelmed or stressed (52%), with 12% saying they experience these feelings constantly.

This is understandable given the intensity of care described in the survey. PSP & CBD carers are supporting a loved one with a terminal neurological condition that progressively affects their movement, communication, cognition, swallowing, behaviour and independence. They may be helping to manage falls, appointments, medication, personal care, emotional distress and practical household pressures, while also coping with uncertainty about the future. While feeling overwhelmed by this responsibility is unsurprising, it is also a concern.

Fig 17.
Reported frequency of feelings of stress or overwhelm from caring (%)



The PSPA Survey also points to high levels of loneliness and social isolation among PSP & CBD carers. More than a third (38%) report regularly feeling socially isolated as a result of their caring responsibilities, while three-quarters (75%) say that caring has affected their ability to maintain wider social relationships. Providing care to somebody with a condition like PSP & CBD is highly time-consuming and demanding, often leaving little time to maintain friendships, leisure activities, time away from home and ordinary social life.

The intensity of the caring role can also have a significant impact on a carer's own health and wellbeing. More than half (62%) of PSP & CBD carers reported experiencing either physical or mental health problems related to their caring responsibilities, with a third (33%) reporting experiencing both physical and mental health issues. It is therefore unsurprising that a large majority of PSP & CBD carers said that their caring role has negatively impacted their own wellbeing (77%).

Fig 18.
Reported health impacts from caring (%)

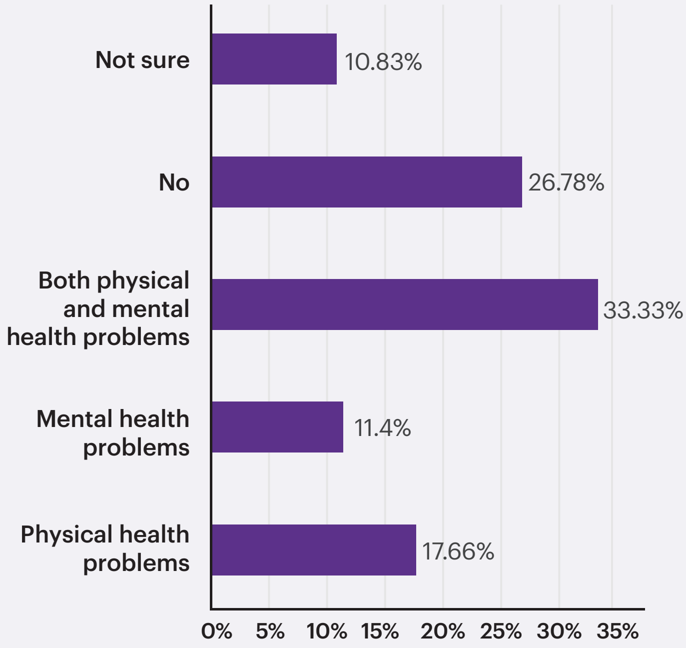
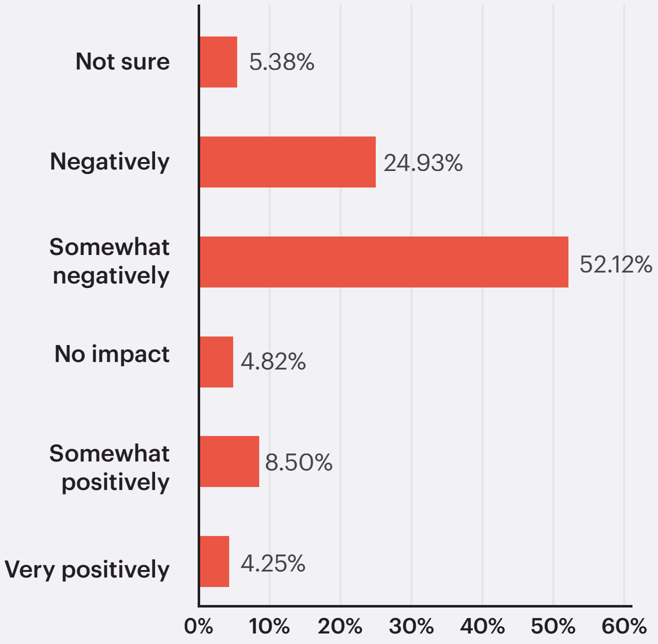


Fig 19.
Overall impact of caring on wellbeing (%)



Over time, PSP & CBD carers become more likely to say they are regularly overwhelmed by the caring role (56% of those caring for a person diagnosed three to five years ago), while isolation also becomes more entrenched, with later-stage carers more likely to report feeling lonely or isolated (49%). Similarly, the impact of caring on wellbeing appears to deepen over time, with a third (33%) of those caring for somebody diagnosed three to five years ago reporting the most negative impact on their wellbeing compared to around 20% of earlier-stage carers. The caring burden does not simply grow over time, but becomes more sustained and more difficult to step back from.

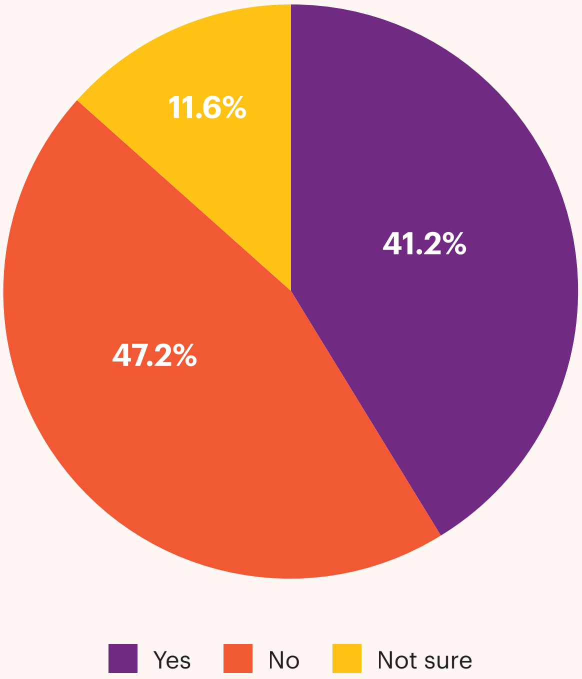
If carers are frequently overwhelmed, isolated and experiencing worsening wellbeing, this not only affects them but has broader implications for the sustainability of support for the person living with PSP or CBD; if the caring burden becomes unsustainable, a greater reliance on formal health and care services is likely, while the carer themselves is more likely to need to access health and care services themselves.

Access to support and entitlements

While assessments, entitlements and practical support for carers exist, they do not appear to be reaching carers early or consistently enough, and despite the intensity of caring and the high levels of stress reported, access to formal support appears uneven.

Almost half (47%) of PSP & CBD carers reported that they had not had a Carers Assessment from their local authority. This is a significant concern given the high level of burden reported by carers in the PSPA Survey; missing out on a Carers Assessment means missed opportunities to identify need, provide information, and connect carers with the support they need to perform the caring role sustainably. As outlined in the previous chapter, while access to Carers Assessments increases over time, with those caring for people in the later stages of PSP or CBD more likely to report having had one (45% of those caring for somebody diagnosed 3-5 years ago), in the first year after diagnosis 70% of carers have not received a Carers Assessment. If carers are not being assessed until the role has already become highly demanding, support may be arriving after substantial strain has already built up.

Fig 20.
Reported prevalence of having had a Carers Assessment (%)



Despite the high level of financial impact on a household affected by PSP & CBD, the PSPA Survey also found low levels of financial support linked to caring. More than a quarter (26%) of PSP & CBD carers reported spending in excess of £500 each month on expenses related to PSP or CBD – these expenses include the cost of transport, medical equipment, paid social care support and other expenses. A large majority (82%) are not receiving Carers Allowance, and very few (8%) were receiving any other financial support related to their caring role.

While PSP & CBD typically affect people later in life and therefore their carers are less likely to be eligible for income-replacement benefits like Carers Allowance, the additional financial pressures of the condition remain significant, and many carers are being left without financial support.

Not all carers experience the same burden

PSP & CBD carers are not a single uniform group; their experiences vary by gender, which condition the person they are caring for has been diagnosed with, and how far that person's condition has progressed. A one-size-fits-all model of carer support is unlikely to respond effectively to the differing kinds and levels of burden PSP & CBD carers are carrying.

Female carers who responded to the PSPA Survey were more likely than male carers to report health problems related to caregiving (67%, compared to 54% of male carers), frequently feeling emotionally overwhelmed (59%, compared to 44% of male carers), and a negative impact on their overall wellbeing (78%, compared to 73% of male carers). Male carers were more likely to describe stress or feeling overwhelmed as occasional rather than frequent, and more likely to report that they were not experiencing health problems or a negative impact on their wellbeing. This indicates that female PSP & CBD carers may be carrying a heavier and more sustained burden, whether because of the nature of the caring they are providing, wider gendered expectations around caregiving, differences in reporting, or a combination of these factors.

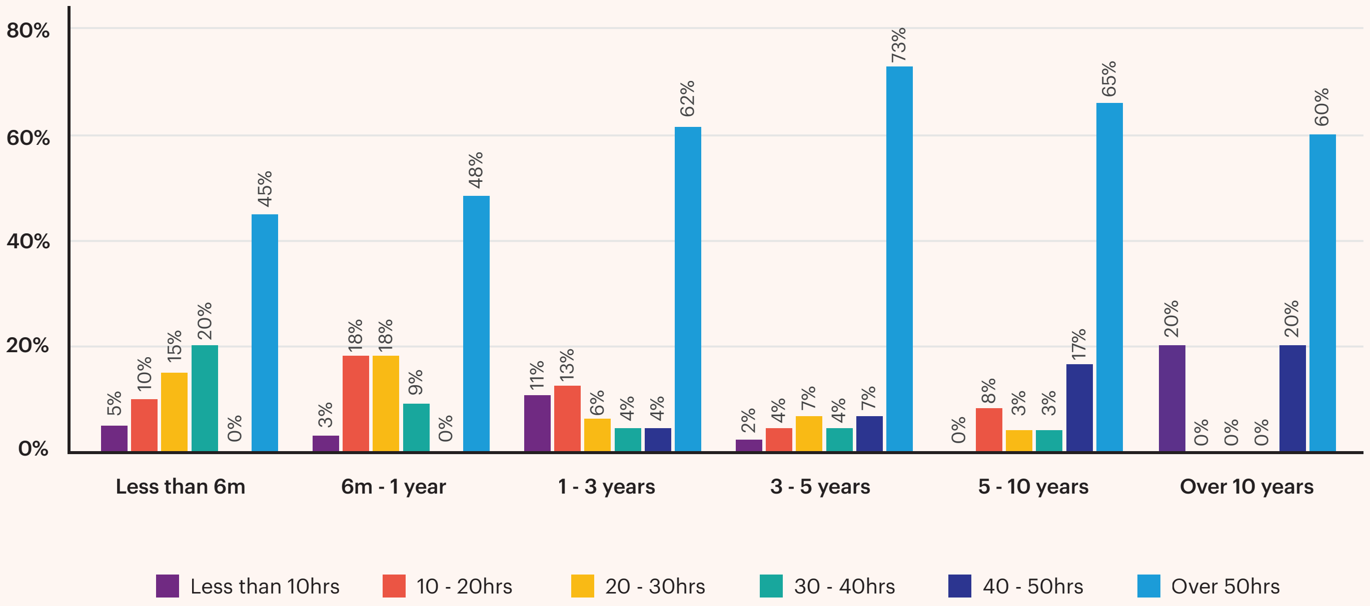
Female carers were also more likely than male carers to report having had a Carers Assessment (49%, compared to 36% of male carers). This may mean that women are more likely to be recognised as carers by services – or to self-identify as carers themselves and seek a Carers Assessment – but underlines that formal identification as a carer alone does not remove the burden they are carrying. It also indicates that male PSP & CBD carers may be relatively under-identified.

CBD carers were more likely than PSP carers to report significant time spent on intensive personal care (34% spent more than five hours a day on personal care, compared to 26% of PSP carers) and were somewhat more likely to report the most negative impact on overall wellbeing (34%, compared to 24% of PSP carers). These findings suggest that CBD may be associated with especially high severity and dependency, and that CBD carers may face particularly intense roles that deserve more focused attention.

As time since diagnosis increases, caring becomes more time-intensive, more hands-on and more emotionally draining. Carers of people diagnosed with PSP or CBD three to five years ago report a sharp increase in the hours of care they provide each week (73% report spending more than 50 hours a week caring, compared to 48% of those caring for somebody diagnosed within the last year), while social isolation deepens (49% report feeling regularly socially isolated, compared to 27% of those caring for somebody diagnosed within the last year) and the impact on carer wellbeing deepens (33% report the most negative impact on their wellbeing, compared to 21% of those caring for somebody diagnosed within the last year). It is important that support for PSP & CBD carers recognises that the care burden changes over time, and that later-stage and high-intensity caring are particularly important areas of need.

AS TIME SINCE DIAGNOSIS INCREASES, CARING BECOMES MORE TIME-INTENSIVE, MORE HANDS-ON AND MORE EMOTIONALLY DRAINING.

Fig 21.
Reported hours per week spent caring by time since diagnosis (%)



What these findings mean

Taken together, the findings in this chapter show that carers are essential to life with PSP & CBD, but are too often under intense and sustained pressure. Caring is highly time-consuming, physically demanding, emotionally draining and socially isolating. As the conditions progress, caring only becomes more intense and chronic.

Carers are not only an informal support around the edges of health and social care provision; they are often central to how everyday life with PSP & CBD are managed. Despite this, the PSPA Survey finds that their own substantial needs – for practical support with their caring role, with their own wellbeing, with financial strain and with clear recognition from the health and care system – are often insufficiently addressed.

The findings also underline that formal recognition as a carer alone is not enough. While Carers Assessments become more common later, they do not appear to arrive early enough, consistently enough, or with sufficient impact to support carers with the burden they are facing. Female carers, for example, were more likely to have had an assessment but still reported heavier burden. While it is important to improve access to Carers Assessments among PSP & CBD carers, meaningful support must follow.

Support for carers is frequently unavailable and frequently arrives too late. Too much appears to depend on individual persistence or progression to a point of visible crisis. For carers of people with progressive neurological conditions like PSP & CBD, there is a serious risk that carers are unsupported, the wider care arrangement may become harder to sustain, with the person living with the condition more likely to need to rely on more formal health and social care services.

What needs to change

The findings in this chapter underline the critical important of ensuring PSP & CBD carers are supported earlier, more consistently and in ways that reflect the intensity of caring for somebody with a progressive and terminal condition.

First, access to Carers Assessments must improve, happen early and be revisited over time. A one-off assessment is unlikely to be sufficient given how much the intensity of the caring role grows as PSP & CBD progress.

Second, emotional and practical support for PSP & CBD carers needs to be strengthened. High levels of stress and social isolation underline the need for mental health support, practical help managing day-to-day demands and respite opportunities in order to make the caring role sustainable.

Third, PSP & CBD carers should be signposted to entitlements and support earlier and more reliably. Many carers are not receiving support linked to the demands they face; ensuring that they are given information about how to access this at the point the person they are caring for is diagnosed will help reduce pressure on households already under strain.

Finally, carers should be recognised as a core part of the care team for a person living with PSP or CBD, and their wellbeing should be treated as core issue rather than a private matter. The impact on carers' physical and mental health, social connection and overall wellbeing are not secondary consequences but part of the wider impact of the conditions and should be reflected in health and social care responses.

PSP & CBD carers are doing work that is essential, demanding and often unsustainable without better support. If policy and practice are to respond adequately to PSP & CBD, they must do so not only for the person with the condition, but for the people whose care makes daily life possible.

Recommendations

- Improve early access to Carers Assessments and signposting to entitlements and Carers Allowance, as well as regular reviews of carer needs, recognising that caring needs change significantly as PSP &CBD progress.
- Strengthen emotional and practical support for carers, including support for stress, isolation, resilience and the day-to-day demands of caring.
- Ensure support reflects differing experiences within the carer community, including the heavier burden reported by many female carers and the particularly intense roles reported by some CBD carers.
- Treat carers as a core part of the care team, with recognition of the implications of caring for health, social care and the sustainability of support.

JOHN AND GILLIAN'S STORY

John Manitara's wife Gillian was diagnosed with PSP in 2023.

"After Gillian began experiencing personality changes and frequent falls, a diagnosis of PSP was confirmed at Addenbrookes Hospital in Cambridge. We had never heard of the condition before, and hearing it was terminal was a shock.

"Gillian has deteriorated quickly; she now requires 24/7 care and has lost much of her speech and mobility. I miss her blue eyes, which are often closed now, and the simple daily 'chit-chat' we used to share."

"I tried to cope alone for as long as possible, but the administrative mountain of securing equipment and benefits was exhausting. The delays in diagnosis and the constant chasing of services take away the one thing we don't have enough of – time. Every hour spent on the phone chasing a recliner chair or another item of equipment is an hour I could be spending with Gillian.

"Securing professional care support a year ago has enabled me to keep working; they have been amazing. Despite the challenges, we still make sure to enjoy moments of joy every single day."

"Family remains at the heart of our lives. With our son and daughter both getting engaged to their respective partners last year, we have two weddings to look forward to, even though it piles on more pressure to juggle work and caring. We've also adapted how we spend our time together. Since Gillian loves afternoon tea, friends will often bring a spread to the house. Eating is much slower now, sometimes taking two hours, so being in a relaxed home environment is much easier than a restaurant.

"Because Gillian's eyes are often closed, we don't really watch television anymore, but we've returned to the music we bonded over at university. When we have quiet time, I'll put on some 80s tracks and we just listen together. Our two cats bring so much value to our lives, too. They have such distinct characters, and they know I'm a soft touch.

"Time is of the essence for us now. I want to spend my spare time with Gillian, creating memories and ensuring she is comfortable, rather than battling for basic support. I wouldn't have known about half the services available if it wasn't for PSPA's Carer Support Groups. They were there to point me in the right direction, and now that I'm more used to the routine, I'm able to give back by sharing my own insights too."

"I TRIED TO COPE ALONE FOR AS LONG AS POSSIBLE, BUT THE ADMINISTRATIVE MOUNTAIN OF SECURING EQUIPMENT AND BENEFITS WAS EXHAUSTING."

CONCLUSIONS

The findings of the PSPA Survey 2025 underline the extent to which Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) are progressive, terminal and profoundly life-altering conditions that place very substantial demands on the people living with them, on the families and carers who support them, and on the systems that are supposed to respond to their needs.

Across every chapter of this report, a consistent story emerges. Too many people affected by PSP & CBD are navigating long and uncertain routes to diagnosis, often marked by repeated appointments, indirect referrals and misdiagnosis. Once diagnosed, they face daily lives characterised by severe disability, declining independence, growing dependency and constant challenge. Alongside the physical effects of the conditions, many are also living with significant emotional strain, financial pressure and a health and care system that too often feels fragmented, poorly coordinated and difficult to navigate. For carers, the burden is similarly stark – caring is frequently intensive, sustained and increasingly all-consuming, with serious consequences for carers' stress, isolation, health and wellbeing.

These are linked failures within the health and care systems and services that people affected by PSP & CBD rely upon.

A delayed or incorrect diagnosis not only leaves people affected by the conditions lacking certainty, but delays timely access to the right information, support and planning. Poor coordination of care does not simply create frustration, but increases the burden on people and families who are already coping with a life-changing diagnosis of a terminal condition and progressive disability. Inadequate access to financial support does not only leave families struggling to make ends meet, but compounds emotional strain and restricts choices about care and quality of life. When carers are under-supported, the impact does not stop with them, but reliance on formal health and care services is increased and the sustainability of care for the person with PSP or CBD is undermined.

As PSP & CBD progress, severity rises, dependency increases, and caring becomes more intensive. Yet support too often appears to lag behind this growing need. Rather than anticipating progression and helping families plan for it, health and care services often respond only once the burden has become acute. The result is that too many people are left carrying more than they should, for longer than they should, with too little help.

The report also shows that people affected by PSP & CBD do not all encounter the same challenges in the same way. CBD appears in some respects especially

vulnerable to under-recognition and lower professional confidence. The burden on carers is not evenly distributed, with some groups, including many female carers and those further on in the disease course, reporting especially heavy strain.

The experience of the PSP & CBD community, as highlighted in the PSPA Survey 2025, points to a need for change at multiple points in the system. Diagnosis needs to become faster, more accurate and less dependent on persistence or access to private care. Support for daily life needs to better reflect the full practical reality of living with PSP & CBD. Mental health and emotional support need to be recognised as core needs. Financial pressure and access to entitlements need to be addressed more effectively. Care coordination needs to improve, and carers need earlier, more consistent and more meaningful support. Above all, services need to become better at anticipating progression, rather than reacting only when people affected by PSP & CBD, their carers, and their families have already reached crisis.

This report does not suggest that nothing is working – some people do receive a timely and accurate diagnosis of PSP or CBD, some are able to access specialist input, benefits, NHS Continuing Healthcare or support for carers. But overall, the experience of the PSP & CBD community is too inconsistent, too fragmented and too unequal – people affected by the conditions should not have to rely on luck, persistence, geography or ability to pay to get the right diagnosis, the right support, or the chance to plan ahead.

The experiences shared through the PSPA Survey make a compelling case for change. They show not only where people are being let down, but where action could make the greatest difference – improving awareness and recognition of PSP & CBD, strengthening diagnostic pathways, embedding practical, emotional and financial support more effectively, improving care coordination, and recognising the realities of progression and caring. These changes could make a substantial difference to the dignity and quality of life of people affected by PSP & CBD.

THE EXPERIENCE OF THE PSP & CBD COMMUNITY, AS HIGHLIGHTED IN THE PSPA SURVEY 2025, POINTS TO A NEED FOR CHANGE AT MULTIPLE POINTS IN THE SYSTEM.

RECOMMENDATIONS

✓ Diagnosis

- Improve awareness of PSP & CBD – including atypical presentations – across primary and secondary care, including general practice, neurology, ophthalmology, ENT, rehabilitation, geriatrics and memory services, so that people are less likely to be routed through inappropriate pathways before diagnosis.
- Reduce delays in referral and specialist review by improving clarity and consistency in pathways for people with suspected rare neurological conditions.
- Improve access to specialist diagnostic expertise within the NHS, including workforce capacity and access to clinicians with experience of PSP & CBD.
- Reduce reliance on private diagnosis pathways, so that access to timely and accurate diagnosis is not shaped by ability to pay.
- Use diagnosis as an early intervention point, ensuring that accurate diagnosis leads quickly to information, care planning and access to support.

✓ Daily life

- Ensure health and care services reflect the full practical impact of PSP & CBD, including their effects on movement, communication, eating and drinking, personal care, independence and social participation.
- Improve access to therapies, aids, adaptations and symptom management, including physiotherapy, occupational therapy, speech and language therapy, equipment and home adaptations.
- Ensure health and care services plan for increasing need over time, with regular review and anticipatory support as severity and dependency grow.
- Improve care coordination, with clearer named contacts or more defined coordination arrangements for people living with PSP & CBD and their families.
- Improve professional knowledge of PSP & CBD across disciplines, including primary care, community services, therapies, social care and hospital-based teams, not only neurology.

✓ Mental health and financial pressure

- Embed mental health and emotional support in routine PSP & CBD care pathways, recognising anxiety, frustration, stress and low mood as common parts of the condition experience.
- Strengthen advice and support on benefits and entitlements, including signposting and practical help to access disability-related benefits and carer support.
- Improve access to NHS Continuing Healthcare for people living with PSP & CBD, including improving training for clinicians undertaking assessments and ensuring a healthcare professional with knowledge of the condition being part of the assessment team.

RECOMMENDATIONS

✓ Progression

- Introduce earlier planning, regular review of care needs and anticipatory care support from diagnosis onwards, recognising that needs are likely to increase and change over time.
- Build stage-sensitive health and care services, with support that reflects the changing balance of emotional, cognitive, physical and practical needs across the disease course.
- Services should pay particular attention to the middle years after diagnosis, where pressure may be especially intense.
- Care planning should be designed to get ahead of crisis, rather than responding only once burden has become severe and sustained.

✓ Carers

- Improve early access to Carers Assessments and signposting to entitlements and Carers Allowance, as well as regular reviews of carer needs, recognising that caring needs change significantly as PSP & CBD progress.
- Strengthen emotional and practical support for carers, including support for stress, isolation, resilience and the day-to-day demands of caring.
- Ensure support reflects differing experiences within the carer community, including the heavier burden reported by many female carers and the particularly intense roles reported by some CBD carers.
- Treat carers as a core part of the care team, with recognition of the implications of caring for health, social care and the sustainability of support.

PSPA

CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD

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