PSPA
CREATING A BETTER FUTURE FOR PEOPLE LIVING WITH PSP & CBD

STATE OF NHS CONTINUING HEALTHCARE

Experiences of NHS Continuing Healthcare among people living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD)

BACKGROUND

Progressive supranuclear palsy (PSP) & Corticobasal degeneration (CBD) 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. Symptoms include problems with balance, speech, swallowing, vision, and cognition. These symptoms are progressive and can present at different times or in a different order in each case, with new symptoms sometimes appearing quickly. Both conditions are terminal with a life expectancy of an average of seven years.

There are no treatments and no cure for either PSP or CBD, however symptoms can be managed by health and care services. PSPA estimates that around 10,000 people in the UK are living with PSP or CBD, although only around half have an accurate diagnosis.

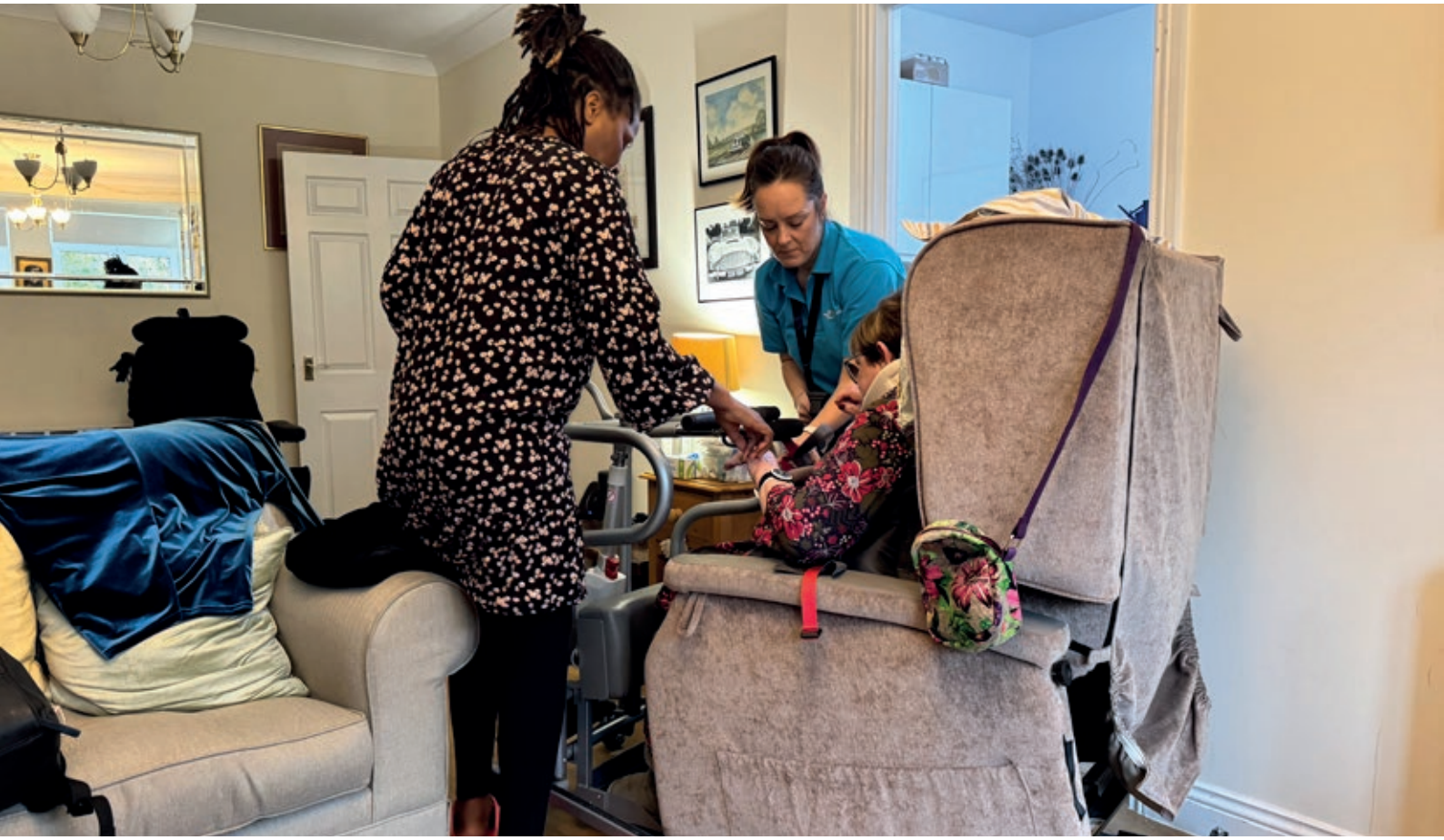
Most people living with PSP & CBD do not need to be cared for in hospital and can be supported to live in their own homes or in a nursing or care home. People living with the conditions will often need support from a physiotherapist or occupational therapist for mobility issues, a speech and language therapist for problems with speech and swallowing, an orthoptist for vision issues, a clinical neuro psychologist to help with cognition and mental wellbeing, social care for support with daily living and eventually to specialist palliative care. Ensuring that this care and support is well-coordinated is essential to maintaining their quality of life.

NHS Continuing Healthcare (CHC) can be a lifeline for people living with PSP & CBD and their families. In addition to funding the cost of their social care support, CHC can ensure that the various health and social care professionals involved supporting a person to manage their symptoms and daily living coordinate and communicate, not only with each other but with the person and their family and carers.

However, CHC does not always work as well as it should. Recent reports from the Nuffield Trust[1] and Age UK[2] have shown that fewer people are being found eligible for CHC than in previous years, with significant postcode lotteries existing across England and Wales, and that CHC is becoming less available as a long-term intervention to support people with complex needs – like those living with PSP & CBD – to live well.

In late 2024 PSPA contacted our service users to understand how the experience of people affected by PSP & CBD with CHC compares to the national picture. Their reflections and stories, as well as the most up-to-date national data, are included in this report.

"PSPA ESTIMATES THAT THERE ARE 10,000 PEOPLE IN THE UK LIVING WITH PSP & CBD."



WHAT IS NHS CONTINUING HEALTHCARE?

CHC is a package of health and social care provided outside of hospital, either in a person's own home or in a care or nursing home, which is arranged and funded by the NHS. It is available to people who have significant ongoing care needs that arise from a 'primary health need' – that is, that the primary reason for both their health and social care needs is caused by their health.

CHC is organised into two 'streams' – the Standard pathway, for those who have long-term or complex needs for their ongoing care, and the Fast Track pathway which is for those whose condition is rapidly deteriorating and who may be nearing the end of life.

When a healthcare professional believes that somebody needs CHC they will refer them to an initial 'Checklist' to determine whether they may be eligible. If the person meets the criteria, they will then have a full assessment using a 'Decision Support Tool,' looking at their needs across areas such as mobility, communication, cognition and other care needs. Their needs in these areas are ranked from 'low' to 'severe,' with four areas having an additional rating of 'priority' above 'severe.'

If the person's needs meet the thresholds in the 'Decision Support Tool' – if they have any 'priority' need or sufficient 'severe' and 'high' needs – they are eligible for CHC. Funding will be made available, and services and support must be planned to meet their needs.

CHC is available via the NHS in England and Wales. In Northern Ireland it is available via Health & Social Care. In Scotland, CHC was replaced by Hospital Based Complex Clinical Care in 2015.

"CHC IS AVAILABLE TO PEOPLE WHO HAVE ONGOING CARE NEEDS ARISING FROM A PRIMARY HEALTH NEED."

CASE STUDY

BILL AND SUSAN'S STORY

Bill Holmes, from Bradford, cares for his wife Susan who was diagnosed with CBD in 2016. He explains how CHC funding helped him and Susan as her needs progressed.

"We were just about managing. Her mobility was gradually deteriorating so I helped her to get dressed in the mornings. But over time she started to experience falls. She had one particularly bad fall and ended up in hospital for ten days. They wouldn't discharge her until there was a care plan in place.

The temporary care plan was for two carers to come in every morning to wash and dress Susan. We soon saw the value of having carers and how it made life feel a little more manageable, so when the temporary care package ended, we started to self-fund. The district nurse and specialist neurology nurse, along with the occupational therapist, speech and language therapist and physios were all involved at this stage. It was the neurology nurse who said we should have a CHC assessment. This was the first time we'd heard of it.

The neurology nurse did the application, and we were contacted by a CHC assessor who initially suggested a meeting by phone. When I said that Susan wouldn't be able to manage a phone call they agreed to meet in person. The meeting was with the CHC assessor, a social worker and our neurology nurse. I'd been through the Decision Support Tool before the meeting and marked Susan's needs against it; comparing notes with the CHC assessor, I was surprised to see that there were some places where they had marked Susan's needs higher than I had.

It was clear they had been given a lot of information from the neurology nurse in advance of the meeting. Not long after we were told Susan would receive CHC funding and that it would include respite care for me. The respite care consisted of up of 42 days a year when Susan could stay in a nursing home to give me a break from being a full-time carer. It was also made clear that the package could be increased if needed.

With the carers, the support from the multidisciplinary team and myself, Susan's needs were managed at home, and we managed to avoid emergency hospital admissions. She had two short stays in the nursing home – when she went for her third stay, a decision was made that she should live there permanently.

I felt a mixture of emotions when I was told. I wanted Susan to stay at home with me, but at the same time I recognised that her needs were increasing. Susan had made the decision herself. It wasn't that she didn't want to be at home. Perhaps she was worried about the demands on me and felt it was easier all round for her to move into the home.

Susan's care package was extended to cover her move to the nursing home. She is being well looked after but sadly her condition has continued to deteriorate. She has no mobility or practical use of her arms. She has also almost completely lost her speech and now communication is very difficult to impossible.

" IT'S HARD TO SEE MY WIFE OF 19 YEARS LIKE THIS. BUT THE SUPPORT OF THE NURSING HOME AND CHC HAS HELPED MAKE A DIFFICULT SITUATION MANAGEABLE."

HOW CAN CHC HELP PEOPLE WITH PSP & CBD?

Both PSP & CBD are progressive and degenerative neurological conditions. They cause the premature loss of nerve cells in the brain, leading to increasing and eventually severe challenges with mobility, balance, speech, vision, swallowing and cognition.

Symptoms are unpredictable and can fluctuate from day to day or even from hour to hour, with new symptoms often presenting quickly. Eventually both conditions are terminal, with an average life expectancy of around 5 to 7 years.

The impact on a person living with PSP or CBD can include:

- **Difficulty with daily living such as dressing and eating**
- **Mobility problems such as unsteadiness, 'frozen gait,' balance problems and falls, with many eventually becoming immobile**
- **Communication difficulties such as slurred or reduced speech, with many eventually becoming unable to speak**
- **Psychological challenges including changes in mood, depression, apathy and changes to mental capacity**
- **Progressive changes resulting in increasing care needs, which often fall on family members, and a loss of independence which can be difficult to accept.**

With symptoms that are sufficiently progressed, it is likely that a person living with PSP or CBD would meet the 'high' or 'severe' thresholds under the CHC Decision Support Tool for Mobility, Communication, Psychological and Emotional Needs, Nutrition, Cognition and Behaviour. Depending on how their condition affects them, they may also rank highly on the thresholds for Continence and Other Significant Care Needs.

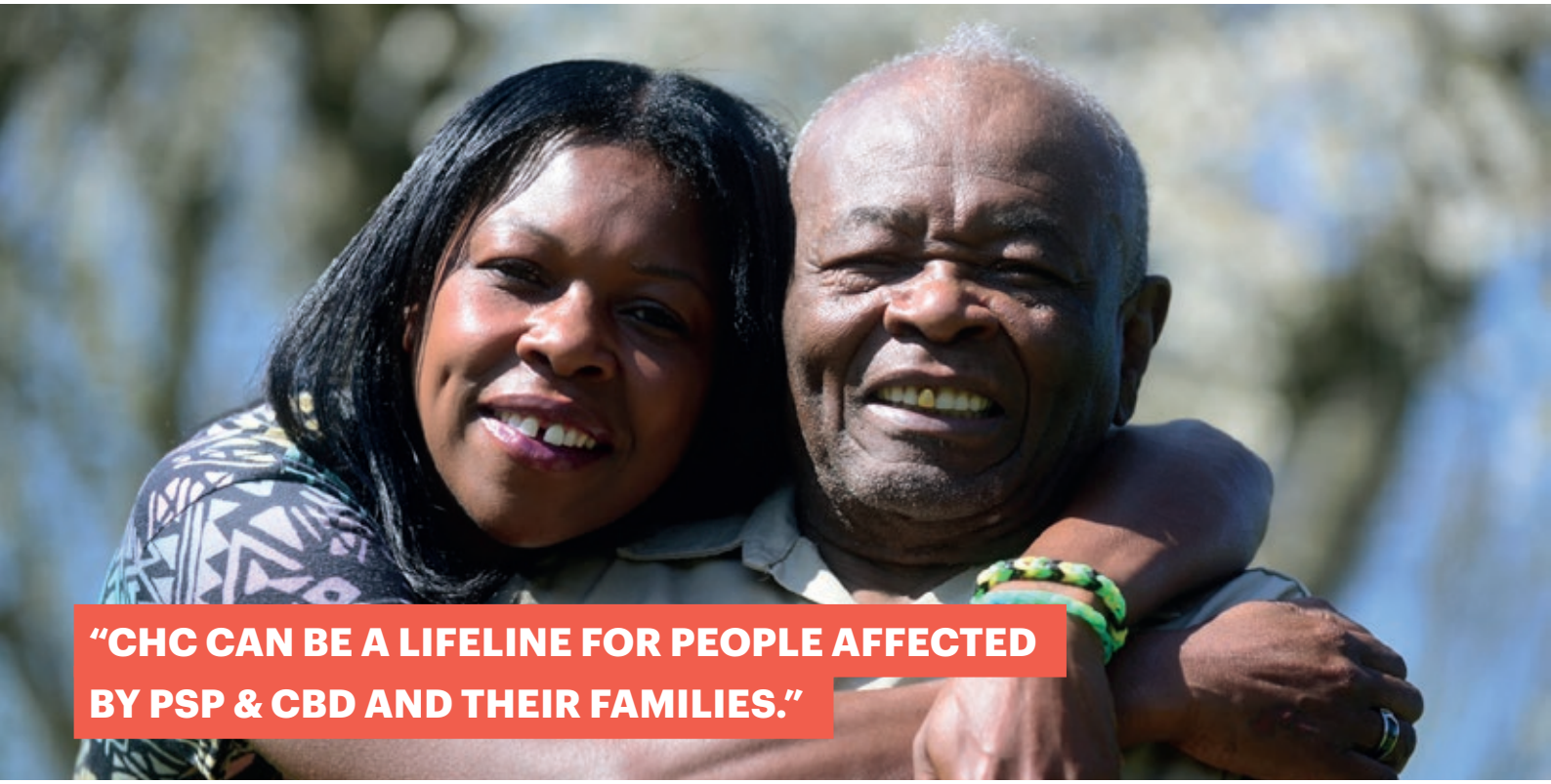
"We had no idea what was wrong. Over four years she had so many tests. She was in a wheelchair by the time she had a diagnosis."

"We were fairly confident my wife would score highly on the majority of domains. By this stage she needed constant nursing care."

As there are no treatments or cure for PSP or CBD, supporting people living with the conditions involves managing varied physical and cognitive symptoms and can require support from a range of both health and social care professionals to help them in their daily lives. In addition to support managing symptoms from professionals that may include a nurse, physiotherapist, orthoptist, speech and language therapist, occupational therapist, dietitian and clinical psychologist, people living with PSP or CBD are likely to require support with daily living from social care.

"The falls were becoming more frequent, and my husband's mobility and speech was deteriorating. Getting him up and down the stairs was becoming especially challenging, he needed help to feed himself and I couldn't leave the house unless I had somebody who could sit with him."

"The care package provided two carers to come to our home four times a day, and one carer to stay overnight three times a week. The carers are good, we are very lucky with them."



"CHC CAN BE A LIFELINE FOR PEOPLE AFFECTED BY PSP & CBD AND THEIR FAMILIES."

CHC can be a lifeline for people affected by PSP & CBD and their families, fully funding the cost of social care support with daily living that they need because of their condition. This can include support with personal care like getting up, washing, dressing and using the toilet, help with household tasks like shopping, cooking meals, eating and drinking, daycare support with physical, leisure and social activities, and providing respite breaks for family carers.

"Our experience of CHC has been very good. It has made a huge difference to our lives and enabled me to keep my wife at home. I also get respite breaks as part of the care package. The respite breaks make a huge difference. Being able to have days out or focus on DIY projects, helps me to recharge. Even if it is just to have a lie-in, it makes the world of difference."

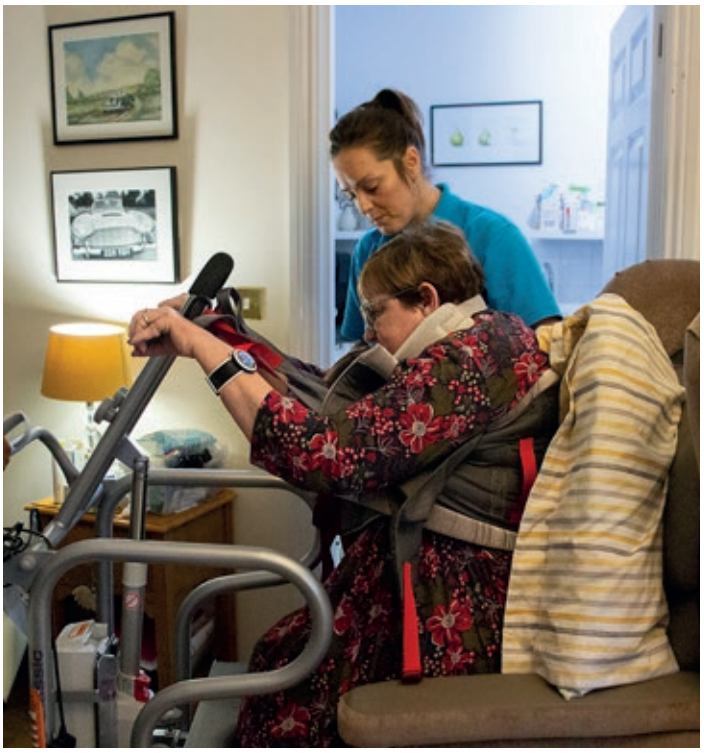
Most people affected by PSP & CBD will require support with some or all of these activities – many will need round-the-clock care, especially as their condition progresses. The cost of paying for this social care support – which is necessary because of their health condition – is a significant burden to people living with PSP & CBD and their families; the typical hourly rate for a carer to visit the home is £20, a live-in carer can cost more than £800 per week and a room in a care or nursing home can be more than £700-850 per week[3]. By alleviating this cost, CHC is a crucial financial safety net to families affected by PSP & CBD.

"I received a call to say that we were being granted CHC funding. The relief was huge. I'd been told that his care would have cost £3,000 a week. I don't know how we would have managed that. It's hard to describe how stressful it felt leading up to the meeting."

"Paying for carers four times a day alongside all the other costs would have been over £100,000 a year. Securing CHC funding has taken away a huge amount of anxiety and stress. Caring for someone full time is hard enough without worrying about the finances."

In addition to lifting the financial burden of social care support brought on by their condition, CHC can also act as a vital enabler of the coordinated health and social care support people living with PSP & CBD need. Once a person is found eligible for CHC, their local Integrated Care Board or Health Board must ensure that the services and support they need is arranged and provided to them – or arrange a personal health budget (either notional or cash) so they can organise their care in a way that works for them.

"Living with CBD has been immensely difficult but in some ways I'm luckier than many. At least I can safely leave her for a couple of hours knowing that she will not fall out of bed. I know there are some who are unable to leave their partner unattended for any length of time."



This process of planning and arranging the care a person needs can be vital when a person has a complex condition like PSP or CBD, with many different health and care professionals involved in supporting them. Too often, people affected by PSP & CBD and their families tell us that the care they receive is not joined-up or coordinated, with gaps in support between different professionals and especially between health and care services that leave people living with the conditions struggling on their own and put significant additional burdens on unpaid family carers.

"Securing the package has also meant that we feel more connected to the NHS. I know my husband is getting the good personal care and as his wife and carer that gives me peace of mind."

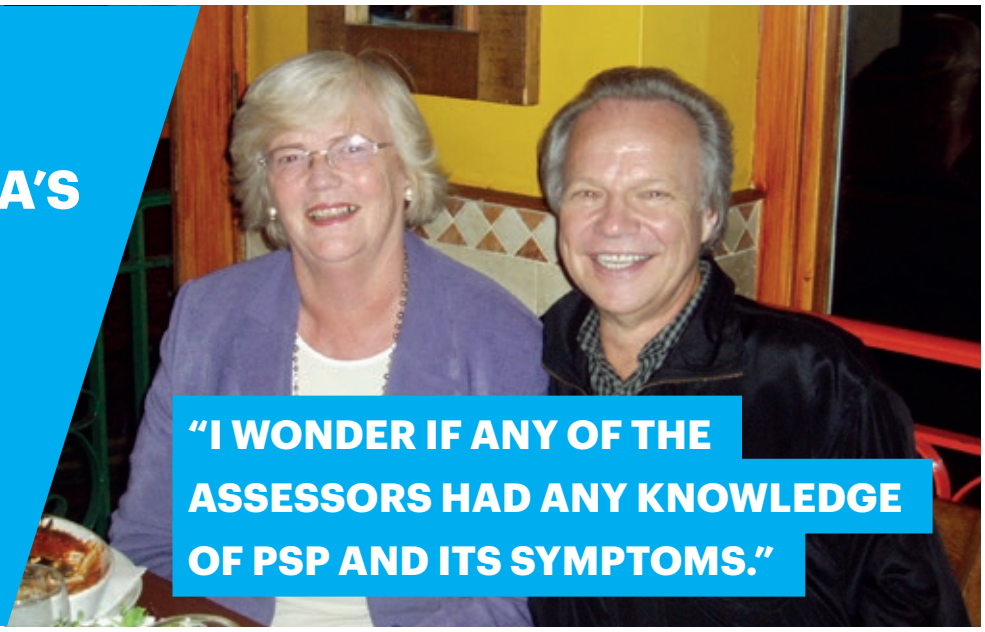
CHC can be a key facilitator of the coordinated care people with PSP & CBD need, ensuring that the support they receive is person-centred and relevant professionals are communicating with each other and with family carers. By ensuring that care is also well-planned and properly coordinated, CHC can also help stop people living with PSP or CBD from reaching a crisis point and therefore avoid unplanned, emergency admissions to hospital. With emergency admissions costing the NHS billions of pounds each year and disrupting planned care, by supporting people to stay out of hospital CHC is not only better for them but better for the wider NHS too.

"I think I was extremely fortunate that the assessor had encountered PSP before and she also saw my husband. She scored several things higher than I did. Funding was granted almost immediately, and a place was secured at a nursing home."

CASE STUDY

BOB AND SANDRA'S STORY

Sandra Ruskin, from Durham, was diagnosed with PSP in 2019. Her husband Bob explains how Sandra was denied CHC funding four times.



"I WONDER IF ANY OF THE ASSESSORS HAD ANY KNOWLEDGE OF PSP AND ITS SYMPTOMS."

"When Sandra was first diagnosed, we coped quite well without any help. I managed as best as I could, but as Sandra deteriorated, she started to fall more frequently. Social services arranged for carers to come in three times a day. That care was negatively impacted by the Covid pandemic and by Brexit; several care providers in our area collapsed. Eventually it was recommended Sandra move into a care home – the only one with space was 44 miles away.

I wasn't aware of the process for CHC funding, it was a social worker who suggested getting an assessment. The assessment was carried out at the care home, with me, Sandra, the resident nurse and social worker in attendance, while the CHC assessor was on the phone. He couldn't even see Sandra. Later, we heard CHC funding had been refused. I wasn't sent a copy of the report, just a letter to say Sandra had been unsuccessful.

Eventually Sandra deteriorated further, and we were advised the care home could no longer meet her needs; she had to move into a nursing home. Around the time she moved into the nursing home I was told by social services that they were withdrawing their support; Sandra was the nursing home's responsibility now. That left me very much on my own.

The nursing home suggested another CHC assessment and appeared confident we would be awarded funding. This assessment was held in the nursing home; by then I'd lost contact with social services so there was a new social worker there who we'd never met. The resident nurse from the home was there and a CHC assessor. Again, CHC funding was refused.

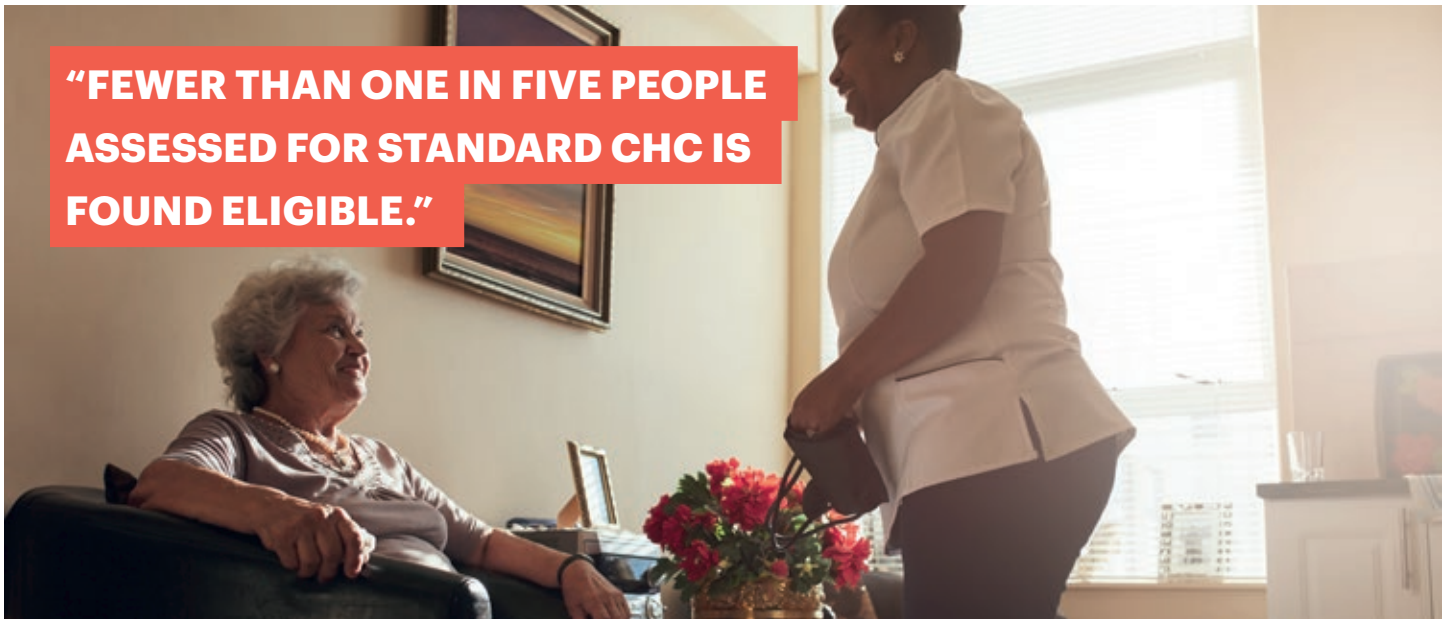
Four months later Sandra was reassessed – I wasn't even told this was being arranged. It was farcical, the assessment was done over Zoom with the assessor online and just me and a nurse in the room, no social worker. Unfortunately, the nurse with us on this day was quite inexperienced and had little knowledge of the assessment process, so I wasn't confident this time. Once again, the CHC application was turned down.

I asked for a meeting with Sandra's consultant to make sure we were doing all we could to make Sandra's time left tolerable. I told him about our experiences with CHC and he said he would write describing in full Sandra's condition and requesting a full reassessment. This was arranged within a week – this time, the CHC assessor came in person, the more experienced resident nurse from the home was also there and a new social worker. This meeting went smoothly, and they even went to see Sandra in her room to get an idea of her condition.

Unfortunately, this fourth CHC assessment was also unsuccessful. Four times Sandra has been turned down for funding. She's bedridden, needs a hoist to get her in and out of bed, has little to no mobility and her swallowing is becoming critically difficult, and she has no speech. I wonder if any of the CHC assessors we saw had any knowledge of PSP and its associated symptoms or had read any of the reports from people involved in her care.

The staff from the nursing home are surprised too, they say other patients who aren't as bad as Sandra have been given CHC funding. Crucially these patients were assessed before her; I have a feeling the brakes have been put on due to financial restrictions, and we're left to deal with the consequences on our own. Without CHC, so far, we've spent over £160,000 on fees."

WHAT IS GOING WRONG WITH CHC?



People living with PSP & CBD and their families tell us that, instead of being a lifeline that they can rely on, CHC is often not working as it should. People with significant ongoing care needs are not being referred for CHC assessment as early as they should, and despite the impact of their conditions too many are being found ineligible for CHC after being assessed.

"Going through the checklist I was fairly confident he should have an assessment. I was told my husband didn't have any nursing needs so wouldn't be eligible. I couldn't believe it. Honestly this was the lowest point in our entire PSP journey. I was desperate and felt very alone."

According to NHS England data, in Q3 of 2024/25 20% fewer people were being assessed for the Standard Pathway of CHC compared to 2017/18 (the earliest figures in NHS England's dataset), while there was a 17.5% increase in Fast Track assessments[4]. This raises concerns that people who would benefit from CHC funding are not being referred for assessment early enough when CHC could help them to live well, but only being referred towards the end of life when their conditions have rapidly deteriorated. It may also be the case that, due to funding pressures, people are being assessed more critically than in previous years and fewer people who would benefit from CHC are being found eligible as a result.

"My husband was first put forward by the care home he was in. There were two people doing the interview. Unfortunately, he was far too positive about his condition, and he was turned down."

"The professionals involved with dad's daily care didn't seem keen on getting involved as its extra paperwork for them. I found out the details online."

The data shows that in addition to a fall in CHC assessments, the number of people being found eligible for CHC has fallen since 2017/18, from 27% to just 19% (in 2024/25)[5]. This means fewer than one in five people assessed for CHC is now being found eligible for a package of care under the Standard Pathway.

"My local hospice told me that even with all their expertise they could not obtain NHS CHC funding for their patients at the end of life care even for the last few weeks. The system is in disrepair."

These national-level figures hide substantial variation across England, with people finding it significantly easier to be assessed for and to be found eligible for CHC in some parts of the country than others. In the Lancashire & South Cumbria and Leicester, Leicestershire & Rutland Integrated Care Board areas 31% of people assessed were found eligible for CHC under the Standard Pathway, compared to just 5% in the North East London and Shropshire, Telford & Wrekin Integrated Care Board areas. There is a more than seven-fold difference between the Integrated Care Board area where the highest and lowest number of people were found eligible for CHC (5.82 people per 50,000 population compared to 0.81 people per 50,000)[6].

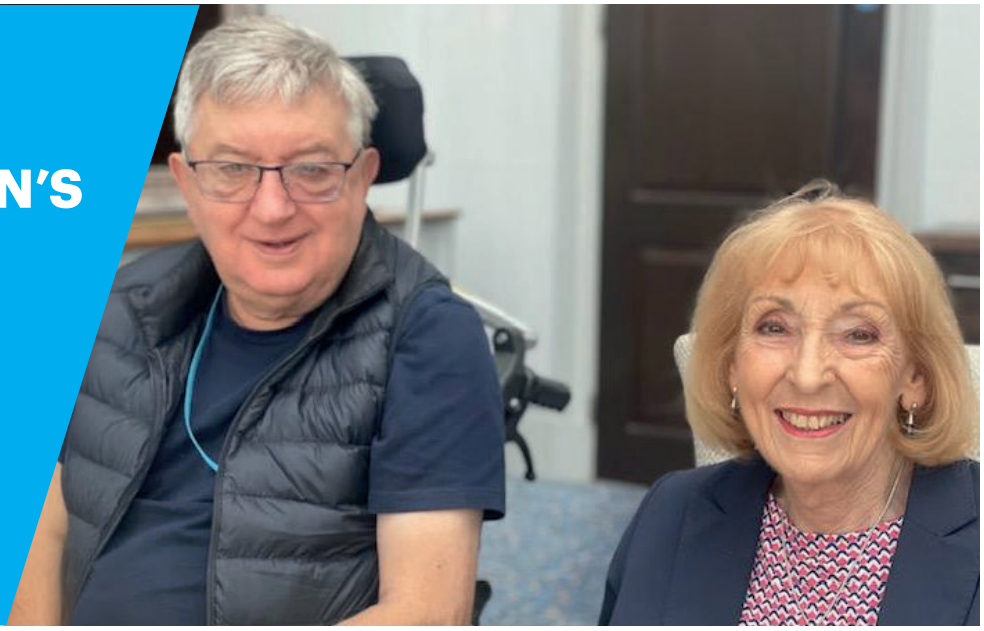
People are also waiting longer than they should to hear whether they are eligible for CHC. According to the National Framework for Continuing Healthcare, people assessed for CHC under the Standard Pathway should wait no more than 28 days for a decision as to whether they are eligible for CHC. According to the most recent NHS England data, one in four (24%) people assessed are waiting more than 28 days for a decision, with similar variation across the country. In the Sussex Integrated Care Board area, for example, 97% of assessments were completed within 28 days, but in the Gloucestershire Integrated Care Board area this was just 61%[7].

"Dad was assessed for NHS CHC. He achieved the funding just before he died, and it was backdated by three months. From the original meeting it took three months to get a final response."

CASE STUDY

JOYCE AND COLIN'S STORY

Joyce Shearsmith, from County Durham, cares for her husband Colin who lives with PSP. She explains how they experienced a battle to get CHC funding and were unsuccessful in their first attempt.



"It's been hard to care for Colin while also looking after myself. My number one fear is what happens to Colin if something happens to me. After I had a fall and broke my hip, Colin had a temporary care package that gave us six weeks with carers coming in four times a day.

We were funding Colin's care ourselves. Lots of people said that we should ask about CHC. I started researching the eligibility criteria, called CHC and did the initial assessment. At that time Colin still had some mobility and could use his rollator, although he would fall quite a bit. We then had the second assessment where we were told by the CHC assessor that Colin didn't qualify for CHC funding.

I was not impressed with either the CHC assessor or the social worker who did the assessment. The social worker appeared unprofessional and unprepared, and the nurse assessor's medical knowledge seemed sketchy. Her administration skills were also poor, for example she miscalculated Colin's total score.

While we didn't secure the funding, we did learn a lot about how we should proceed in the future. By the autumn Colin had deteriorated, and I had to go back into hospital for a hip replacement – he needed to go into a nursing home while I recovered, and my consultant was very clear that there was no way I could continue to be Colin's carer and that it would hamper my recovery if I attempted it.

Colin had deteriorated rapidly while he was in the nursing home. I wanted him out of there as quickly as possible. From my hospital bed I researched all the local care agencies and then selected the one I felt most comfortable with to provide 24-hour care at our home. The cost was huge, at £2,000 a week it wasn't something that we could continue to fund on our own.

Once again, we contacted CHC about an assessment to secure a care package that would keep Colin at home and ensure that I'd be able to continue to care for him. By this stage in our PSP journey, we were wise to things and generally more prepared. At the second assessment my son and daughter were both present, along with Colin's occupational therapist. The social worker was also there with two CHC assessors. Throughout the entire meeting the two CHC assessors contradicted themselves.

CHC agreed to three carer visits per day with one carer. CHC agreed to fund 60% with us self- funding the remaining 40%. We wanted to continue to use the care agency that provided the 24 hour care, but they were more expensive than the ones CHC recommended. I spent two days researching the agencies CHC suggested. Going through the list I saw that one had failed its CQC inspection, some were unable to take Colin on, and the rest had very poor reviews. In the end CHC agreed to us continuing with the agency we were using.

Securing CHC funding has been something of a battle. However, getting awarded 60% of care costs has made a big difference. We now pay approximately, depending on weekends, £611 a week for Colin's care, which while not ideal, is doable for us."

"MY NUMBER ONE FEAR IS WHAT HAPPENS TO COLIN IF SOMETHING HAPPENS TO ME."

WHAT IS THE IMPACT ON PEOPLE WITH PSP & CBD?

Being found ineligible for CHC funding, or not even referred for an assessment under the Standard Pathway, has a significant impact on people living with PSP & CBD and their families. In the first instance, they will potentially be liable for all of their social care costs – despite these needs coming as a result of their condition, a 'primary health need' as described in the National Framework for Continuing Healthcare.

As outlined earlier these costs can be significant – a person with PSP or CBD who needs daily visits from a social care worker may need to pay more than £14,000 per year (for an hour's visit in the morning and one in the evening), while somebody with significant care needs who requires live-in carer to help them may incur costs of more than £40,000 per year[8].

"My husband was declined for CHC, so we were told it was down to us to cover the costs of a nursing home. That sent me into a spiral - I didn't sleep for six weeks in fear we were going to lose our home."

Entering the social care system does not guarantee that somebody will receive social care or receive it promptly – as Age UK has found, the number of people receiving long-term social care from their Local Authority has fallen in recent years while more than one in four people who have asked their Local Authority for a social care assessment waits more than six months to get one[9].

Without the benefit of CHC to help coordinate their care, people living with PSP & CBD and their families are also more likely to experience care that is uncoordinated and not joined-up, with family carers having to take on a greater burden of caring and having to fill in the gaps between different care providers and between health and social care services. They are more likely to reach a crisis point and more likely to end up being admitted to hospital on an unplanned or emergency basis – admissions which should be avoidable, and which come at significant additional cost to the NHS.

"The new care agency started with three visits a day. Things started okay but within a couple of weeks they'd deteriorated. The carers appeared untrained and unwilling to do things that would help her. The manager would call me every day. I felt overwhelmed by it all. I felt like we were jumping from one crisis to another."

Even for those who are found eligible for CHC (fewer than one in five people assessed under the Standard Pathway) the process of applying for CHC is complex and can be frustrating, especially for those living with a complex condition like PSP or CBD, where symptoms can make it hard to read and fill in forms, to communicate with an assessor and to understand a complicated assessment process.

"It was a very intense application process. You must carefully complete the complex application, read and re-read and take your time! Assemble supporting paperwork. Do a draft at home. You need a helpful doctor or nurse – there is plenty of administration involved."

In addition to these frustrations, delays in hearing whether they will be eligible can be frustrating – one in four people assessed for CHC under the Standard Pathway wait more than a month to hear if they will receive CHC funding – and can leave people with PSP & CBD and their families stuck in limbo while they wait to hear if a package of care will be arranged for them. As PSP & CBD are progressive conditions, a long wait to hear about eligibility can often mean that by the time a decision is made the person's symptoms have changed, which can make a fundamental difference to the support they need.

"I was not impressed with the assessor's lack of knowledge; he didn't know the names of the different drugs which had been prescribed by our local GP. After about six weeks we were informed my husband would not be getting NHS CHC funding."

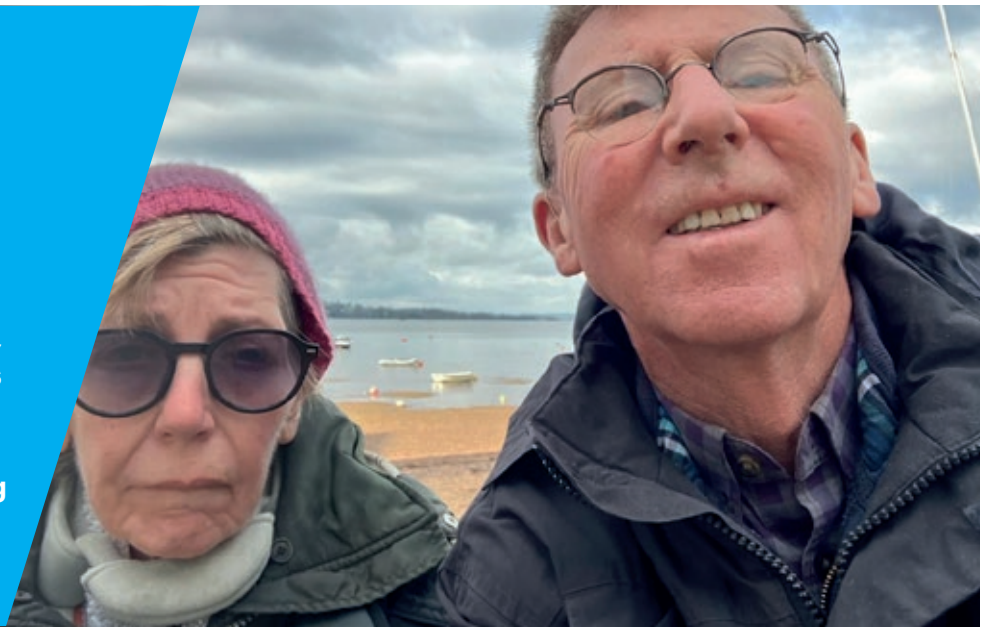
"When the meeting actually took place two people from CHC turned up and fired questions at her. The stress had a big impact. Thankfully the decision was made to continue the funding, but it was a horrible thing for her to go through."

These delays often mean that even when somebody is eligible for CHC funding, it often comes too late to be of real help to support a person living with PSP or CBD to live well with their condition. Often, by the time a package of care is arranged a person's condition will have deteriorated or they will have had to pay for costs out-of-pocket until a decision is made.

CASE STUDY

STEPHEN AND SUSAN'S STORY

Stephen Whitefield, from Devon, cares for his wife Susan who was diagnosed with PSP in 2020. He explains how Susan's CHC application was rejected, leaving the couple to fund all aspects of her care themselves.



"The first inkling we had that something wasn't right was when Susan's speech started to deteriorate. Susan was a professor at University of Exeter and concerns had been raised by students and staff. She was referred to a neurologist and diagnosed with PSP in March 2020.

At first, she could still do a number of things, but over time they've gradually been eroded. She started with a walking stick before transitioning to a walker, and now she is in a wheelchair. Her movement is poor, she is incontinent, and her voice is very quiet now and increasingly she is unable to speak at all, so we communicate with thumbs-up and down.

We've tried to carry on life as normally as possible, but PSP brings with it a gradual decline across all dimensions. As soon as you have things in place, the condition moves on and you have to try to keep up with it. Around two years ago I realised I could no longer continue to care for Susan by myself.

Initially we had just one carer, but as Susan's needs increased our carer put together a team of carers using her own contacts. We now have a regular team of carers who care for Susan. This arrangement continues to work really well for us. It's literally been a lifesaver. All the carers we have are wonderful and we are very grateful to them.

Six months ago, our local Parkinson's nurse suggested we do a CHC assessment. She came to the house to do the initial assessment and said she was confident we would pass it. But we didn't. This took us all by surprise, but it appears that we failed simply because we are managing the situation with the care that I have put in place for Susan. During the assessment I was asked about falls. Susan doesn't fall because we make sure that doesn't happen. In the eyes of CHC that means we don't need a care package.

At the moment we are paying £4,000 a month for care. We can do this because I'm still working and we no longer go on holidays, go out for meals or spend any money on activities and interests. All the money we have now funds Susan's care. The cost is significant, and it is our largest expense, but we have arrangements that are stable and meeting Susan's needs. We need to focus on trying to enjoy the time we have left together. I appreciate we are fortunate that I'm able to continue earning and that we are able to do this.

Ultimately, I think we're not eligible for CHC funding because we are coping, and we are doing it all ourselves. We are grateful for the support we do get from the Parkinson's nurse, the occupational therapist and our local hospice, but for day-to-day care, that's clearly on us to manage and fund.

My own experience of CHC and hearing about other people's experience have shown me that CHC is not fit for purpose. The system is unfair, patchy and it forces people to play games to ensure they secure the funding and the care package. The whole system is broken."

"CHC IS NOT FIT FOR PURPOSE - THE WHOLE SYSTEM IS BROKEN."

WHAT NEEDS TO CHANGE?

NHS Continuing Healthcare should be a lifeline for people living with PSP & CBD and their families. A fully-funded package of care to meet their personal needs, ensuring that all professionals involved in a person's care are coordinated and that their care is planned, is essential – for many people it makes the difference between being able to stay at home and having to be cared for elsewhere, and for carers it can be the difference between being able to cope with caring for their loved one and reaching a crisis.

The people affected by PSP & CBD who shared their experiences with us are clear that when it works, CHC can be an indispensable source of relief. It covers the costs of complex and often round-the-clock care that would be impossible for many to afford by themselves, gives respite to family carers and ensures people living with the conditions can make the most of their lives with PSP or CBD despite their symptoms.

"My experience of CHC was extremely positive. I know from talking to others with PSP that many are not so lucky."

Too often, however, this isn't happening. National data shows fewer people are receiving CHC via the Standard Pathway than before, with falling numbers of people being referred for CHC assessment and less than one in five people who is assessed being found eligible. People are waiting too long to hear if they will be eligible, with one in four people waiting more than a month for a decision on their CHC application. There are significant variations across the country, with people living in some areas far less likely to be given CHC funding than in others and waiting longer for decisions.

The experiences of people living with PSP & CBD and their families mirror these national trends. Our community have experienced a range of issues reflected in the national data – having to fight to even get a CHC assessment, grappling with a frustrating and complicated assessment system where too often assessors are unfamiliar with their condition, waiting substantial periods of time for a decision and being found ineligible for CHC funding despite significant and ongoing care needs brought on by PSP or CBD, a 'primary health need.' Without CHC funding, families face a struggle to organise and pay for the care their loved one needs, and people living with the conditions are at higher risk of experiencing poorly-coordinated care and unplanned, emergency admissions to hospital.

"Everyone with PSP or CBD, like my father, should be supported by CHC yet the stress we have witnessed as a family is both unnecessary and cruel."

People living with PSP & CBD deserve better than a system that has often become a roll of the dice – with some people receiving fully-funded care that meets their needs and ensures their care is coordinated, while others with very similar needs are denied funding and support and left to rely on paying for their own care in a broken social care system.

They need a CHC system that is consistent, person-centred and where decisions about support reflect the reality of living with a progressive condition like PSP or CBD, which can affect different people very differently and place an often unbearable burden on family carers. They need to have confidence that the people assessing them will understand how progressive conditions can affect people living with them and their families, and that decisions about whether they are eligible for support will be the same no matter where they live.

RECOMMENDATIONS

To address what has gone wrong with NHS Continuing Healthcare:

1 The Department for Health & Social Care should improve the CHC checklist and Decision Support Tool so that they more effectively measure the care and support needs of people with fluctuating or progressive conditions, allow for carers' experience and expertise to be properly considered and that the impact of caring for the person being assessed on family members is considered.

2 The Department for Health & Social Care should improve training for professionals who assess people for CHC to ensure that they understand the eligibility criteria and how to use the Decision Support Tool, and ensure that training to conduct assessments reflects the fact that many conditions are fluctuating or progressive.

3 The Department for Health & Social Care and Integrated Care Boards should require a professional who has knowledge of the person being assessed, their condition, needs and aspirations to be part of all CHC assessments.

4 The Department for Health & Social Care should review and reform the National Framework for Continuing Healthcare to address undue variation between Integrated Care Board areas and postcode lotteries in CHC, and ensure that eligibility decisions are made within the 28 days set out in the framework.

5 The Department for Health & Social Care should ensure that Integrated Care Boards are sufficiently funded to provide CHC funding to every person who is eligible to receive it to ensure that budget pressures do not affect a person's likelihood of being assessed as eligible for CHC.

We believe, together we can improve diagnosis for the 10,000 people living with PSP & CBD, saving time, resources and helping patients to get the care they need faster.

1. Nuffield Trust (2024). Falling through the gaps? A closer look at NHS Continuing Healthcare.
2. Age UK (2024). Continuing to care? Older people let down by NHS Continuing Healthcare.
3. NHS England. Paying for your own care (self-funding).
4. NHS England. Statistics: Continuing Healthcare and NHS-funded Nursing Care, Quarterly Data Q3 2024/25.
5. Ibid.
6. Ibid.
7. Ibid.
8. NHS England. Paying for your own care (self-funding).
9. Age UK (2024). State of the Health and Care of Older People in England.