

Written evidence submitted by PSPA (ASC0076)

Health & Social Care Committee inquiry Adult Social Care Reform: The Cost of Inaction PSPA submission

About PSPA

PSPA is the UK's only charity supporting people living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD, also known as Corticobasal Syndrome or CBS). PSP & CBD are rare, progressive, and life-limiting neurological conditions that typically affect people later in life. There are no treatments and no cure for either condition, 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 4,000 have an accurate diagnosis.

PSPA works to enable people living with PSP & CBD and their families to live their best possible lives by providing information and support, and to improve the quality of life of people living with PSP & CBD through research, education, and awareness-raising. We also campaign for the changes needed to create a better future for everybody affected by PSP & CBD.

Not all of the questions asked by the Health & Social Care Committee are relevant to PSPA's work to support people living with PSP & CBD and their families. Our response covers those areas of relevance to our work only.

Summary

The crisis in adult social care has severe consequences for people with conditions like PSP & CBD. Many people living with the conditions receive inadequate support – in 2022, PSPA's Patient Survey found nearly half of respondents needing social care receiving either no support or an unsatisfactory service.

Insufficient social care leads to costly NHS pressures, including delayed hospital discharges and avoidable emergency admissions due to preventable issues like falls. Local Authority spending on social care has risen sharply, however significant service gaps persist, forcing families to bear significant financial and caregiving burdens. Annual care costs for individuals frequently exceed £40,000, with unpaid carers filling systemic gaps at great personal and economic cost.

Reform of the social care system is essential to reduce these pressures, improve care quality, and alleviate the financial burden on families. Strengthening public funding and integrating health and social care would enhance outcomes for patients, reduce inequalities, and support unpaid carers, whose contributions are critical yet unsustainable without systemic change.

PSPA is a member of the Care & Support Alliance and supports the Alliance's Show Us You Care campaign, which calls for social care reform that:

1. Addresses the shortfall in current social care spending and puts in place a long-term funding commitment to meet current and future demand.

2. Addresses the core issues facing the workforce, including pay, conditions, career development and skills recognition, as part of a new, fully funded social care workforce strategy.
3. Enables local authorities to tackle social care assessment and carer's assessment waiting lists through enhanced dedicated funding.
4. Develops a new National Carers Strategy including investing in carers' breaks, introducing paid carer's leave, and urgently reviewing Carer's Allowance and other social security benefits carers can claim.
5. Removes social care charging entirely for working-aged disabled adults so they don't have to part-fund their care from state benefits designed to pay for daily living costs, like food and heating.

How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?

For people living with conditions like PSP & CBD, there are no treatments or cures. The support people living with these conditions need involves managing their symptoms and ensuring that they can experience the best quality of life possible, for as long as possible. While the primary need most people living with PSP & CBD have is for healthcare services such as neurology, physiotherapy, speech and language therapy and eventually to palliative care, the conditions' progression can leave people with significant physical and cognitive impairments and very high support needs, meaning much of the care and support they require comes from social care.

In 2022 PSPA conducted a Patient Survey of our service users. Of those who reported that they needed social care, 35% reported that they were not receiving support from social care services but would like to, while 14% (around one in five of those receiving social care) reported that they were receiving an unsatisfactory service.

Failure to reform adult social care has led to significant additional financial and operational pressures on the National Health Service, which have a corresponding impact on patients and the wider public. These pressures range from delayed transfers of care (DTOC), an increase in unplanned and emergency admissions to hospital and additional spending pressures on Local Authorities, leading to individuals experiencing a reduced quality of care from both health and social care services, additional pressures on unpaid and family carers and the exacerbation of existing health inequalities.

Lack of social care provision either in the home or in other community settings (such as a care home) leads to delayed discharges from hospital for patients who are otherwise ready to be discharged, but who will have social care needs upon leaving hospital. Recent estimates suggest that the direct cost of these delays to the NHS is £395 per day¹; with significant increases in delayed discharge cases over recent years (e.g. 12,223 average daily delays in June 2024, of which 61% can be attributed to patients waiting for home care, a bed in a care or nursing home, or short-term social care support such as reablement²) these costs run to hundreds of millions of pounds each year. A recent estimate from the King's Fund suggests that the annual cost of delayed discharges runs to £1.89 billion³.

¹ [The hidden problems behind delayed discharges and their costs](#). The King's Fund. 30 March 2023.

² [Delayed discharges from hospital](#). The Nuffield Trust. 29 August 2024.

³ The King's Fund 2023 *Op. Cit.*

In addition to delaying discharges from hospital, a lack of social care provision in the home or community also drives emergency or unplanned admissions into hospital. In September 2024, an average of 45,500 people visited hospital A&E departments in England each day and an average of 13,314 people were admitted in an emergency⁴. Many of these admissions will have been avoidable and caused by issues such as falls – a common experience for people affected by movement disorders like PSP & CBD – which could have been prevented with better social care support. These avoidable admissions are not only disruptive for patients and their families but often lead to prolonged periods in hospital – frequently compounded by the issue of delayed discharges – which lead to significant additional costs to the NHS.

The cost of social care to Local Authorities is also significant and pressures on Local Authority budgets are growing. Expenditure on social care costs by councils has risen by 15% in the last decade to £23.69 billion annually⁵, with adult social care now accounting for 40% of all Local Authority spending on services⁶. The absence of a long-term funding settlement for social care has led to Local Authorities relying on short-term solutions such as raising council tax or diverting funds from other areas, as well as an increasing number of councils issuing Section 114 notices in recent years.

The impacts of these pressures on people who need social care, and their families, are significant. Age UK has previously estimated that more than 1.5 million older people in the UK have unmet care needs and that this could rise to 2.1 million by 2030 without reform to social care⁷. We know that unmet care needs lead not only to poorer health outcomes but also to poorer wellbeing.

For people living with PSP & CBD, with appropriate support from both health and social care services in the community, most should be able to be cared for in their home or in community settings such as a care home; we know that this is where the majority of people with the conditions wish to receive their care. Avoidable admissions and prolonged stays in hospital, driven by poor-quality or absent social care support, are very disruptive to patients and directly impact on their quality of life.

Cost pressures also impact on the quality of social care received by individuals, with many people affected by PSP & CBD reporting that the support they receive from their Local Authority is inadequate to meet their needs. For example, people living with the conditions often receive only a limited number of short visits from social care workers each day, while communication between health and social care professionals involved in a person's care, as well as with that person and their family, is often poor. This leads to people living with the conditions experiencing insufficient support from social care services and increased pressure on family and unpaid carers.

Unpaid and family carers are a lifeline for people living with conditions like PSP & CBD. Carers UK estimates that they contribute £445 million to the UK economy every day through providing care and support that would otherwise need to be provided by professional social care services; at £162 billion per year this is equivalent to 'a second NHS' in England & Wales⁸. However, unpaid carers bear the brunt of the impact of inadequate social care provision; the average carer in the UK provides more than 26 hours of care every week, with many providing much more, with impacts on

⁴ [NHS key statistics: England](#). House of Commons Library. 25 October 2024.

⁵ [Adult Social Care Statistics in England: An Overview](#). NHS England. 20 February 2024.

⁶ [Adult social care in England: what next?](#) Institute for Fiscal Studies. 10 October 2024.

⁷ [Age UK General Election Manifesto 2019](#). Age UK. 9 November 2019.

⁸ [Key facts and figures about caring](#). Carers UK.

their own finances and employment as well as their physical and mental health and wellbeing. Carers of people living with PSP & CBD frequently report facing significant challenges, from balancing caring with working, getting breaks and respite from caring, getting adequate financial support and being supported by the health and care system.

In addition, the costs to the NHS of failure to reform social care diverts funding away from other services, which is experienced by patients as a reduced quality of care and support from the healthcare system. In PSPA's 2022 Patient Survey, people living with PSP & CBD reported a 13% fall (from 69% to 56%) in their overall satisfaction with health and care services, with two in four (40%) reporting that they do not receive the health or social care they need when they need it and more than half (57%) reporting that they and their family members and carers were not well supported by health and social care services.

What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

The cost of social care to individuals is significant; the National Audit Office has estimated that £8.3 billion is spent on privately purchased social care annually⁹. With most publicly-funded care only available to those with the highest needs and lowest means (those with income and assets worth more than £23,250 are not normally eligible, a figure which for residential care includes the value of their home), most people who need social care in England are expected to contribute towards the cost of publicly-funded services or to pay for their own social care. The Department for Health & Social Care estimates that one in seven people will face costs of more than £100,000 over their lifetime¹⁰.

Estimating the cost to an individual is difficult and will vary significantly depending upon their needs and what local providers charge. For somebody receiving care in their own home, assuming two hours of care per day of home care at a cost of £25 per hour¹¹, costs could reach more than £18,000 per year – for somebody living with a complex condition like PSP or CBD, their care needs will likely be in excess of two hours' support daily. For those requiring residential care, this can cost around £800 a week for a place in a care home and £1,078 a week for a place in a nursing home¹² – or around £41,000-£56,000 depending on their needs.

Even where an individual is eligible for some support with the cost of their care, they are often required to pay out of pocket towards their costs – either because they are required to pay a contribution based on their means (if they have between £14,250 and £23,250 in income and assets) or, frequently, because publicly-funded care support is insufficient to meet their needs and they are required to pay privately to supplement this. As outlined above, pressures on Local Authority budgets often mean that individuals are found eligible only for a small number of limited-time visits per day; for somebody living with PSP or CBD, who may require round the clock care as their condition progresses, this is inadequate to meet the complex care needs they have. Should somebody living with PSP or CBD require support from a live-in carer due to their substantial care needs, this can cost as much as £800-£1,600 per week (or £41,600-£83,200 annually)¹³.

⁹ [The adult social care market in England](#), National Audit Office. 25 March 2021.

¹⁰ [Key facts and figures about adult social care](#). The King's Fund. 1 July 2024.

¹¹ [How much does care cost?](#) Age UK.

¹² *Ibid.*

Often, the burden of shortfalls in the funded care an individual living with PSP or CBD is entitled to receive falls upon family members and other unpaid carers. As outlined above, carers in the UK provide an average of 26 hours of care every week, with many providing significantly more. For people who are caring for a person with a complex condition like PSP or CBD, caring is often a full-time job, with family members providing most of the care a person receives. In addition to the impacts on carers' physical and mental health and wellbeing, there is a significant additional financial pressure caused by this burden, with many carers needing to reduce or give up work to provide care.

Addressing the excessive cost of social care to individuals will have significant benefits for people living with conditions like PSP & CBD. Ensuring that a greater proportion of the complex social care support that people living the conditions need is publicly-funded, and properly funding the wider social care system so that individuals are not required to pay to supplement publicly-funded care with privately-funded support, will reduce the direct financial burden of conditions like PSP & CBD on families, which can run to tens of thousands of pounds per family every year.

As well as reducing the direct costs people face, this will also reduce the additional burden placed on family and unpaid carers who are frequently required to fill in the gaps between their loved one's needs and the professional care that they are entitled to and can afford. In addition to the benefits to carers' wellbeing, the economic impact of reducing the burden on family carers – through enabling them to participate more fully in the labour market, a reduction in benefit spending and lower healthcare spending on addressing the poor wellbeing of carers – would be significant.

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¹³ [Paying for your own care \(self-funding\)](#). NHS.