



Strategy 2022 to 2026.

Background/Introduction

Approximately 4,000 people in the UK currently live with a diagnosis of PSP or CBD. Research in 2019 estimated that as many as 10,000 people are living with either disease. The gap in diagnosis rates to possible actual rates demonstrates the scale of the challenge for PSPA to set out a road map to raise awareness for improved diagnosis, care and a better quality of life.

PSPA will celebrate its thirtieth birthday in 2024 and in recognition we want to set a bold vision to continue to grow the impact of PSPA, improving the lives of people with PSP and CBD, and honouring the vision that Michael Koe set out in memory of his late wife Sarah.

From the early days where Michael Koe set out on his own the Association has made many advances. Today, with a growing professional team of staff and volunteers, supporting over 6,000 people living with a diagnosis their carers, and health and social care professionals via the PSPA helpline, local groups, literature, support grants and national events.

Alongside providing support and information, the Association has invested hundreds of thousands of pounds in research over the past 30 years to improve the understanding of PSP and CBD and to make progress towards treatments and ultimately prevention and/or a cure. We know that many more people need our support and want the hope that treatments will exist in the future.

With awareness and diagnosis of the disease remaining low there is still a lot of work to do. Improving understanding remains a core part of the associations work. Ensuring a greater awareness and understanding amongst Health and Social Care professionals is key to ensuring an accurate and timely diagnosis, and an improved quality of life.

Strategy

In 2022 our commitment and vision for a better life for people living with PSP or CBD remains as strong as ever. We want to increase the support we provide, to raise awareness, to ramp up investment in research and to ensure that the patients voice is at the heart of what we do; from shaping the design of research through to driving improvements in the quality of PSPA services.

Our purpose is to create a better future for everyone affected by PSP and CBD.

Our goals are to:

1. Enable people with PSP & CBD and their families to live their best lives possible with high quality support and information.
2. Improve the quality of life of people living with PSP & CBD through research, education and awareness raising.
3. Put the voice of people living with PSP or CBD at the heart of what we do.

Our priorities to achieve our goals

1. Enable people with PSP and CBD and their families to live their best lives possible with high quality support and information.

Living with a diagnosis of PSP or CBD is challenging for everyone involved. Knowing that PSPA will be with you at all stages of your journey can be a huge help; our support and information can enable both patient and carer to live their best lives possible. But we can't do this alone, families need to receive high quality care from Health and Social Care Professionals (HSCP's) and the NHS more broadly and therefore we remain committed to providing high quality information to support the improvement in care across all sectors.

Our priorities from 2022 to 2026 are to:

- a) Grow the number of people who receive support from PSPA. We will do this through raising awareness of PSPA with HSCP's and the public, to ensure everyone with symptoms or a diagnosis are signposted to our services.
- b) Support carers to maintain their own health and wellbeing.
- c) Ensure services are accessible across all regions of the UK, reflecting the diversity of the communities that live with PSP or CBD.
- d) Develop innovative services that are driven by the voice of people living with PSP or CBD and meet the needs of patients and their families from diagnosis to end-of-life care.

2. Improving the quality of life of people living with PSP & CBD through research and influencing

A better quality of life is underpinned by developing a greater understanding of the causes and development of PSP and CBD. Building a network of interest in research, amongst Health and Social Care Professionals (HSCP's) and creating communities that are inspired to raise awareness is part of the roadmap to improving lives of people with a diagnosis.

By the end of 2026 we aim to have:

- a) Increased our investment in research, working towards improved diagnosis, treatments, and a cure.
- b) Raised awareness of PSP and CBD in the scientific community and health and social care sectors to advance the understanding of the disease with the aim of everyone receiving an accurate and timely diagnosis.

- c) Built a community inspired to campaign and raise awareness to improve diagnosis, support, and care across the four nations of the UK.
- d) Formed national and international collaborations across scientific community, health, social care, and the voluntary sector to maximise the benefits of research investment and awareness raising across the world.
- e) Developed our public policy influencing capabilities and changed NICE guidelines to include a care pathway for PSP & CBD.

3. Put people living with PSP or CBD at the heart of what we do by:

We will only achieve our purpose if we listen and empower people affected by PSP & CBD to help shape the support they receive. Their views will influence our priorities, what we do and how we do it. Underpinning our ability to influence public policy and public services that impact on their quality of life.

Our priorities over the next four years will be to:

- a) Give people with PSP & CBD a voice within PSPA.
- b) Ensure those opportunities are accessible across all regions of the UK and reflect our commitment to Equality, Diversity, and Inclusion.
- c) Maximise opportunities for people to participate in research.
- d) Promote the involvement of patients and public in research design.
- e) Increase the use of coproduction to develop and design services.
- f) Implement our commitments in the PSPA Equality, Diversity, and Inclusion policy to ensure equal access to participation.

Commitments

Our commitments apply to everything we say and everything we do.

- To be **courageous** in making sure the voices of people living with PSP & CBD are heard. Standing up for a better life for people and having a tenacious commitment to change, even in the face of setbacks.
- To be **ambitious** - to be the leaders in the field of PSP & CBD in the UK. To be willing to listen and learn and to strive for excellence and impact.
- To work **collaboratively**, to inspire people externally and internally, to bring their individual talents together to improve outcomes.
- To **respect**, value and recognise everyone's contribution. Empowering people and building a team which champions Equality, Diversity, and Inclusion.