

ABOUT PSPA

PSPA is the UK's leading centre of knowledge, experiences and support for people living with PSP or CBD, their families and health and social care professionals.

Our work is reliant on voluntary donations and the dedication and commitment of our volunteers.

Everyone's experience of PSP & CBD is different, and how the condition may affect your day-to-day life can vary.

By providing information about PSP & CBD we hope this leaflet will answer some of your questions. It also has information that may be helpful for family members, carers and friends.

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

AN INTRODUCTION TO PROGRESSIVE SUPRANUCLEAR PALSY (PSP) AND CORTICOBASAL DEGENERATION (CBD)



PSP

Margaret Powell House
415a Midsummer Boulevard, Milton Keynes MK9 3BN

Tel: 01327 322410

Email: info@pspassociation.org.uk

www.pspassociation.org.uk

Registered charity number England and Wales 1037087 and Scotland SC041199

HOW WE CAN HELP

- Our confidential helpline and information service offers practical and emotional support from Monday to Friday 9am-9pm. Telephone 0300 0110 122 Email helpline@pspassociation.org.uk
- Our Helpline Care Navigators offer a listening ear as well as information on symptom management, improving quality of life, guidance on our services and other specialist services you may be entitled to. They strive to ensure people have access to local support and can act as a link to health professionals in your area.
- Our support groups provide the opportunity to meet others and share experiences.
- We publish a wide range of information, including a step by step guide to living with PSP & CBD.
- Our online forum Healthunlocked is a safe place for families affected by PSP & CBD to share experiences.

ABOUT PSP

Progressive Supranuclear Palsy (PSP) is a neurological condition caused by the premature loss of nerve cells in certain parts of the brain.

A protein called tau builds up in certain areas of the brain and forms into clumps (neurofibrillary tangles), which are believed to damage the nerve cells. Over a period of time this can lead to difficulties with balance, movement, vision, speech and swallowing.

There are no simple tests or brain scans for PSP. In its early stages, symptoms can resemble those of other neurological conditions such as Parkinson's disease, Alzheimer's, Stroke or Multiple System Atrophy and misdiagnosis is common.

Each case of PSP is unique and symptoms can be experienced with varying degrees of severity and at different stages of progression. Early symptoms may include loss of balance, falls (often backwards) stiffness and eye problems – including difficulty looking up or down.

PSP is life-limiting and there is no cure. Although the disease will progress, symptoms can be managed to help achieve the best possible quality of life.

ABOUT CBD

Corticobasal Degeneration (CBD) is a degenerative brain disease affecting people from the age of 40 onwards. Although there are similarities to PSP, with similar nerve cell damage and the build-up of a protein called tau in certain parts of the brain, the classical clinical picture is quite distinct.

However, people diagnosed with CBD may go on to develop features of PSP and vice versa. Overlap between the two conditions is now well recognised.

Cognitive problems are common in CBD and are often one of the first symptoms families notice, particularly apathy, impulsive behaviour, changes in empathy and language. Other signs of CBD may include progressive numbness and loss of use of one hand. There can also be jerking of the fingers, slowness and awkwardness and the feeling of having an 'alien limb' – with complex unintentional movements of one limb causing problems with normal motor tasks.

There are currently no treatments for CBD but there are a number of ways to help manage the symptoms.

As with PSP, there are no simple tests or brain scans to help neurologists diagnose the condition. CBD is often initially misdiagnosed as a Stroke or Parkinson's disease.