

Progressive Supranuclear Palsy (PSP) and Corticobasal degeneration (CBD)

Information for patients and carers



Progressive Supranuclear Palsy (PSP) is a neurological disorder and is defined by the accumulation of a particular protein called Tau. This protein gradually destroys cells in many areas of the brain, leading to serious and permanent symptoms which include problems with balance and gait, visual disturbance, swallowing and cognitive difficulties.

Currently there is no cure for PSP but there is on-going research into the causes of PSP and CBD with a view to new treatments and finding a cure.

What is PSP?

Early symptoms can present as Idiopathic Parkinson's disease and some patients may wait 2-3 years before your Neurologist reaches a differential diagnosis of PSP.

PSP may be referred to as Parkinson's plus syndrome or Parkinsonism. These are general terms which refer to a group of Neurological disorders that cause movement and non-motor problems similar to those seen in Parkinson's disease.

The differential diagnosis may be reached if you have frequent falls, generally falling backwards, Parkinson's disease medication is ineffective, gaze palsy (inability to look up or down) speech and swallowing changes and early cognitive decline.

PSP is a rapidly progressing neurological disorder and although it is a very individual disease, average life expectancy is 6-7 years.

What is CBD?

Corticobasal degeneration is caused by the protein Tau clumping together in the brain cells causing them to stop working and to die earlier than normal. Just like PSP, CBD is a neurodegenerative condition and can be referred to as Parkinsonism or a Parkinson's plus syndrome. CBD is also referred to as Corticobasal syndrome or CBS.

Symptoms may take a few years until a definitive diagnosis is achieved as they may mimic other neurological conditions such as Parkinson's disease, stroke or dementia.

The classical presentation is usually one-sided symptoms with an arm or leg becoming awkward, stiff or clumsy. Sometimes one hand will move on its own which is known as 'alien limb'.

Changes in memory, cognition, speech, vision, clumsiness (apraxia) and alien limb are all part of 'cortical' changes. The 'basal' part of the name refers to changes in an individual's movement which includes slow and stiff jerky movements (myoclonus) and sometimes contractions or limb dystonia. All the movement symptoms put an individual at higher risk of falls.

Psychological problems in CBD may include irritability, apathy, personality changes, anxiety or depression and difficulty making decisions.

Patients can present differently with individual symptoms, so care needs are to be tailored to each individual.

Life expectancy varies between 5-10 years can affect anyone from 40-90 years old. It is a rare condition.

PSP Association

This is a national charity providing advice, support and information to people living with PSP and CBD including carers and health care professionals. They provide educational resources, practical and emotional support along with financial advice.

Driving and PSP/CBD

You are legally obliged to inform the Driver and Vehicle Licensing Agency (DVLA) and your insurance when you have received your diagnosis. You will be medically assessed based on severity of symptoms and a decision will be made whether you can continue to drive.

Treatment

In some instances, you may start and continue with medication that is used to treat Parkinson's disease. Some people with PSP/CBD report a mild benefit from taking these types of medication.

The medication commonly used is:

- Co-beneldopa (levodopa and benserazide) available in unbranded and branded formulations called Madopar, in standard and modified release capsules or dispersible tablets.
- Co-careldopa (levodopa and carbidopa) available as unbranded and branded formulations called Sinemet tablets.
- Amantadine capsules, also known as Symmetrel is sometimes used in PSP and although the evidence is weak there has been some documented benefit on rigidity and can improve balance, speech, alertness and motivation.

The role of the multi-disciplinary team

You will remain under the care of a Neurologist and the Movement Disorders Nurse Specialist team. This is to ensure your care is tailored to help relieve and manage your individual symptoms.

The multi-disciplinary team (MDT) offers the best approach for management of symptoms and works towards improving quality of life.

The MDT can comprise of:

Movement Disorders Nurse Specialist:

- A source of help, support and information for you, your carers and health professionals.
- To provide advice over the telephone or by email and to review you in either the clinic or at home.
- Work with your consultant, GP and other health professionals to optimise your treatment plan.
- Provide information about medication and prescribe or recommend medications for symptom management.
- Refer you to other health professionals such as Physiotherapists, Speech and Swallowing team and community occupational therapists.

Physiotherapist

Provide advice, practical guidance and support for mobility issues, such as impaired gait, falls and balance.

Speech and swallowing therapist

Provide advice, practical guidance and support for communication and swallowing difficulties and provision of communication aids.

Palliative care team

Provide advice, practical guidance and support for pain control, counselling and psychological support and day therapies.

You may require support from other members of the multi-disciplinary team such as a social worker, mental health team, dietician, orthoptist and or ophthalmology. These referrals are usually generated by your General Practitioner (GP) as advised by your Neurology specialist team.

Thinking ahead and Advanced Care Planning (ACP)

Early discussions regarding ACP are particularly important because of the communication difficulties that people with PSP/CBD can experience. Although these conversations may be difficult, they are vital in seeking your views on treatment desires and wishes towards your future care.

These conversations can be held with your GP, Specialist Nurse, Neurologist and or the Palliative care team. There are legal documents that can protect your wishes such as Advanced Decision to Refuse Treatment and Lasting Power of Attorney for Health and Welfare. For more information contact your specialist team

Research and brain donation

As a regional Neurosciences Centre, we are involved in clinical research trials for all movement disorders; you may be asked if you wish to take part. This is entirely voluntary and can withdraw from a trial at any time.

Brain donation

An individual's decision to donate their brain to PSP and CBD research after they die creates a long-lasting legacy, one donated brain can support multiple research projects over many years.

If you wish to discuss further, you can speak to your specialist team or to find out more information please go to PSP association website or contact Queen Square Brain Bank in London **0207 837 8370**.

Useful contact numbers and websites

Movement disorders Nurse Specialist team

Call: **0113 392 6689**

Email: pd.nurse@nhs.net

PSP and CBD Association

Phone: **0300 011 0122**

Email: helpline@pspassociation.org.uk

Website: <https://www.pspassociation.org.uk>

Parkinson's UK

Helpline and information service **0808 800 0303**

Email: helpline@parkinsons.org.uk

Website: <https://parkinsons.org.uk>

Text relay: **18001 0808 800 0303** (textphone users only)

DVLA

Phone: **0300 790 6806**

Website: www.dvla.gov.uk

Carers UK

Phone: **0808 808 7777**

Email: **advice@carersuk.org**

Website: **www.carersuk.org**

Carers Leeds

Phone: **0113 380 4300**

Email: **advice@carersleeds.org.uk**

Website: **www.carersleeds.org.uk**

Age UK

Phone: **0800 055 6112**

Website: **www.ageuk.org.uk**

National Hospice Information

Phone: **0207 520 8200**

Website: **www.hospiceuk.org**



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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