



Key Messages

About PSP & CBD

- PSP & CBD are cruel and devastating neurological diseases.
- They are caused by the progressive death of nerve cells in the brain, leaving people unable to balance, walk, talk, eat, swallow, drink and see.
- They are associated with an accumulation of a protein called tau in certain parts of the brain. Tau is also associated with Alzheimer's and Parkinson's.
- Whilst there are differences between PSP & CBD, many people with CBD do develop features of PSP and vice versa.
- At least 5,000 people are living with PSP & CBD in the UK, but this number could be more than 10,000 as many are misdiagnosed with other conditions.
- Half of people with PSP received an incorrect diagnosis first, with 30% initially diagnosed with Parkinson's.
- Issues and delays around diagnosis mean people are being prescribed the wrong medication and are left with little or no support.
- Life expectancy is between seven to ten years, from onset of symptoms.
- There is currently no treatment and no cure, but there is hope.

About PSPA

- PSPA is the only national charity offering support and information to people living with PSP & CBD, while supporting research into treatments and ultimately, a cure.
- PSPA funds research to help us understand the development of PSP & CBD, improve diagnosis and discover effective treatments.

- PSPA is determined to make health professionals more aware of these devastating diseases, because with early and accurate diagnosis, people can get the support they need, when they need it.
- PSPA provides information and support for families and helps them access assistance from statutory and other public or voluntary bodies.
- To find out more about PSPA visit www.pspassociation.org.uk or find us on Facebook and Twitter.

Research messages

- PSPA funds and promotes research to lead us closer to effective treatments and, ultimately, a cure.
- PSPA supports and collaborates with scientific and clinical research communities in the UK and the rest of the world. We are proud to be hosting the first International Research Symposium on PSP & CBD in London this autumn.
- PSP is an ideal testbed for new therapies that target tau.
- PSP could play an important role in the development of treatments for Alzheimer's and Parkinson's.
- PSPA research funding is targeted to projects with the most potential to attract further co-funding, or that will leave a legacy in terms of infrastructure. Our PROSPECT study is a good example of this and has generated a number of collaborations meaning that our original grant has generated increased funding or resources for more extensive research. This includes contributions from the research arm of the NHS, funding from other charities and use of the infrastructure for a major clinical trial.
- PROSPECT is a national multi-centre study that follows people living with PSP and CBD from the earliest stages of the disease. Researchers collect spinal fluid and blood samples, brain images and a vast amount of clinical information at each study appointment. This will provide an accurate disease model that should provide an invaluable benchmark for future clinical trials.

Standard descriptions that can be used when writing

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 that families notice, particularly apathy, impulsive behaviour, changes in empathy and language changes.

Other signs of CBD may include progressive numbness and loss of use of one hand. There may 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.

Gradually the arm and/or leg on one side is affected and then the arm and/or leg on the other. People with CBD often have trouble controlling one hand when doing everyday things such as writing or tying shoelaces – tasks that involve individual muscle movements we take for granted. Eye movements can also be disturbed but this is less common than in PSP.

There are currently no treatments for CBD but there are a number of ways to help manage the symptoms and simple practical solutions that can help get around some of the problems people living with CBD experience.

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

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, Alzheimer's, Stroke or Multiple System Atrophy and misdiagnosis is common.

The condition gets its name because:

- Progressive – it steadily worsens over time
- Supranuclear – it damages the nuclei that control eye movements
- Palsy – it causes weakness.

Each case of PSP is unique and symptoms can be experienced with varying degrees of severity and at different stages of progression.

Like many other chronic conditions there is no cure for PSP. However, many of the symptoms can be managed to help people achieve the best possible quality of life.

PSP tends not to run in families and the disease is not believed to be inherited. However, research indicates that some people may have a genetic disposition which makes them more susceptible.

About PSP & CBD – standard description – (113 words)

To follow is a standard description of PSP & CBD that may be useful when writing about the diseases:

PSP & CBD are progressive neurological conditions affecting 6,000 adults in the UK, but this number could be more than 10,000 as many are misdiagnosed with other conditions. Both diseases are caused by the progressive death of nerve cells in the brain, leaving people unable to balance, walk, talk, eat, swallow, drink and see. PSP & CBD are associated with an over-production of a protein called tau in certain parts of the brain.

Over time people progressively become locked in a failing body, and most die between seven – ten years after symptom onset. Some may experience changes in thinking and behaviour, with a proportion experiencing a form of significant cognitive change. There is no cure, but there is hope that the accelerating pace of research into PSP & CBD will lead to future effective treatments to limit the devastation these diseases cause.

About PSP and the work of PSPA – emotive description (413 words)

This week in the UK, ten people will hear the devastating news that they have PSP or CBD, and that they will gradually lose the ability to balance, walk, talk, eat, swallow, drink and see. They will be told there is no cure and that they have a life expectancy between seven - ten years. For nearly half of those receiving a diagnosis of PSP they will have received a wrong diagnosis first. Often meaning that by the time they find out they have PSP or CBD, they will have already lived with the diseases for a number of years.

Despite its devastating impact, both PSP & CBD remain little understood. A diagnosis of PSP & CBD is extremely frightening, leaving those affected unsure of what to do next and where to turn. Without the right support, they can be left feeling fearful, isolated and alone. Many people with PSP & CBD can deteriorate incredibly quickly, so it is vitally important for them to get the support of specialists in a range of areas as quickly as possible. People with PSP & CBD can often be in touch with up to 20 different health and social care professionals at any one time, therefore a co-ordinated multi-disciplinary approach is vital.

PSPA was set up by a husband who lost his wife to the tragic disease. Appalled by the lack of awareness and support for people with PSP & CBD, he ran the charity from his kitchen table with the single goal of improving the lives of all those affected by PSP & CBD.

Thanks to his determination, the charity not only provides invaluable support and advice to families and healthcare professionals, it also funds research into developing life-changing treatments. Now xx years later, the hope of finding a cure for PSP & CBD may finally be within our reach.

But this can only happen with your continued support to the PSPA. By raising awareness about PSP & CBD, you can promote earlier diagnosis and advance research into treatments that can stop the progression of PSP & CBD.

Earlier diagnosis leads to opportunities to participate in clinical trials which are crucial to understanding more about the disease. The more we understand about PSP & CBD, the more we can deliver on our promise of the care today and the cure tomorrow.

Together, we can stop the progression of PSP & CBD in its tracks. Together, we can give hope to all those affected by the disease.