Progressive Supranuclear Palsy

Progressive Supranuclear Palsy is an adult-onset, neurological condition that affects balance, thinking and the eyes.

What is PSP?

Progressive Supranuclear Palsy (PSP) is classified as a degenerative brain disorder. It is named after the characteristic eye movement problems that result from damage deep in the brain in an area called the midbrain. Aside from eye movement problems, PSP may affect movement and balance, thinking and speech.

PSP is sometimes referred to as atypical parkinsonism or "Parkinson's-plus" disorder as it may share some symptoms with Parkinson's. However, PSP is a distinct condition that progresses and is managed differently.

The diagnosis of PSP is "clinical", meaning that there is no blood test or brain scan that can confidently diagnose or exclude the condition.

There are many different "types" of PSP that are based on the symptoms the person experiences, particularly early on in the condition. The most common type is referred to as PSP Richardson syndrome (or PSP-RS).

PSP is rare and, based on global estimates, affects 6 to 7 out of 100,000 people. So in Australia, it is estimated that around 1,800 people are currently living with PSP (likely underestimates due to misdiagnosis of PD or another frontotemporal dementia).

The average age of onset of symptoms is between 50 and 70 years, but may be a little older or younger. Males are more commonly affected than females.

Causes of PSP

In PSP, a protein called tau builds up inside brain cells (in Parkinson's, it's alpha-synuclein, and in Alzheimer's disease, it's amyloid and tau proteins). These clumps of tau seem to spread through different parts of the brain, causing cells to stop working properly and eventually die. As more cells are lost, the connections that keep the brain functioning smoothly also break down, and symptoms occur.

We still don't know the exact reasons why these tau proteins become misfolded and accumulate, but research shows that the damage usually happens in parts of the brain that help control movement and balance, especially in a part of the brain stem called the midbrain. Sometimes the proteins accumulate in different brain areas first, or may spread differently from person to person, and this explains why different people with PSP may have very different symptoms, especially early on.

In general, PSP is not a genetic condition that is passed down in families. Only a very small number of cases are linked to changes in the MAPT gene, which doesn't work as it should; then the tau protein can form abnormally.

Researchers are exploring several possible explanations for why PSP develops:

- Random genetic changes in certain brain cells that, when combined in a particular way, may cause harm.
- Long-term exposure to something in food, air, or water that may slowly damage vulnerable parts of the brain.
- Damage from free radicals, which the body clears away, but under some conditions, they may build up.

© 2026 Parkinson's Australia

Symptoms

Remember, there is considerable variation in the symptoms and rate of progression in people with PSP. Early signs and symptoms include loss of balance and falls (often, but not always, falling backwards), a wide-eyed staring expression and difficulty moving eyes up and down (which can cause issues with reading and vision, and discomfort when looking at bright light), stiffness of muscles, particularly in the neck, which can cause headaches, and cognitive decline. Sometimes PSP may look very similar to Parkinson's with a tremor of one arm or leg.

Over the years, people usually notice progression in their symptoms. Not all people experience all symptoms, but may notice some of these changes:

- Difficulty swallowing food and fluids (called dysphagia), which can cause choking or aspiration and lung infections
- Speech issues include reduced volume and harsh or growling character; mixing up words or using the wrong word
- Difficulties with focusing, looking up or down, jerky eye movements or double vision
- Involuntary closing, or inability to open, your eyelids
- Lack of blinking, resulting in dry and irritated eyes
- Behavioural and cognitive changes ranging from irritability, impulsivity, memory problems, slow processing speed, difficulties with planning or abstract reasoning, anxiety, depression or apathy.
- Sometimes people with PSP lack insight into the severity of their symptoms, especially cognitive impairment. For example, they may insist that they are safe to drive despite visual problems, poor spatial awareness, and slow reactions.
- Personality changes are commonly reported by family and carers
- Involuntary laughing or crying if not happy or sad (emotional incontinence)
- Constipation, lack of bowel control and urinary problems may develop.

Your care

Your GP or Geriatrician is an essential member of your care team; have regular visits with them as your condition changes. They assist with chronic disease management and mental health care plans. Get a multidisciplinary care team assembled for the best outcomes. As treatment focuses on managing symptoms and improving quality of life, we recommend:

Medications: Some drugs used for Parkinson's (e.g., levodopa) may provide limited benefit. Anti-depressants may help with mood or emotional incontinence. Sometimes botulinum toxin injections can be used by your specialist to help manage stiffness and pain of the neck muscles, or to treat involuntary closing of the eyelid.

Physiotherapy and Accredited Exercise Physiologist: Physical activity helps maintain mobility, balance and reduce falls.

Speech pathologist: Help with swallowing and speech problems.

Dietitian: Help with nutritional support and food modification strategies.

Occupational therapy: Assists with daily activities and home safety (needs can be anticipated, and equipment can be accessed and installed ahead of time). Assists with OT driving assessments.

Optometrist: If eye movements are restricted, prism lenses and other strategies can be effective.

Clinical psychologist: Assists with adjusting to the diagnosis and management of depression or anxiety symptoms.

Social worker: Navigate the complexities of the healthcare system and provide support to people with PSP and their carers.

Parkinson's Nurse Specialists: Some are familiar with the condition, too.

Palliative Care & Advance Care Plans should also be put in place early for support.

© 2026 Parkinson's Australia