

in brief

PROGRESSIVE SUPRANUCLEAR PALSY (PSP)



What is Progressive Supranuclear Palsy?

Progressive Supranuclear Palsy (PSP) was described in 1963 by Drs. Steele, Richardson and Olszewski and for a period was known by these names. Historically, a photo from 1890 and a description by Charles Dickens (1857) are thought to represent PSP.

The cause of PSP remains unknown but it is associated with an over production of a protein, tau, in certain areas of the brain. This protein forms clumps or 'tangles' and it is thought these cause damage to the nerve cells.

Genetic factors have been investigated but it is usually a sporadic condition. There is no proven link between chemicals or toxins.

PSP typically affects people in their early-mid 60's and as the name suggests is a progressive neurodegenerative condition.

It is a rare condition affecting approximately 1500 Australians although there may be others not correctly diagnosed. Although it is rare it is the most common of the Atypical Parkinson's conditions. Medication used in the treatment of Parkinson's is usually of little or no benefit in PSP.

Diagnosis of PSP is based on the clinical signs which may resemble Parkinson's with some unique differences. The symptoms vary between individuals and the severity and rate of progression also run an individualized course.

The main symptoms which are suggestive of PSP are visual changes mostly related to impaired downward gaze. This can lead to early frequent falls because of difficulty looking downwards.

Other common symptoms include:

- Muscular stiffness
- Gait (walking) changes
- Balance difficulties
- Falls (generally backwards)
- Slow movement (Bradykinesia)
- Mild tremor
- Facial expression changes
- Speech changes
- Slower thinking (Bradyphrenia)
- Apathy and other personality changes

Magnetic Resonance Imaging (MRI) may show the 'humming bird sign' which suggests a diagnosis of PSP.

As there are currently no treatments available for PSP, management of the symptoms and support for the person with the condition and their family is essential.

This is available through the multidisciplinary team approach.

- A Physiotherapist will assess mobility, provide appropriate walking aids and help maintain safe mobility as long as possible.
- A Speech Pathologist will assess and manage swallowing and communication changes.
- An Occupational Therapist will assess and provide equipment and strategies to maintain independence.
- Specialist nursing care is available through Movement Disorder and Parkinson's Clinics
- Social Workers are essential in organising support systems and respite
- Clinical Psychologists can assist with emotional needs and mood changes
- Parkinson's Nurse Specialists also specialise in PSP.
- Review by an optometrist with experience of PSP is recommended.

It is recommended that a diagnosis of PSP is made or confirmed by a Neurologist who has an interest in Movement Disorders. This will require a referral from a General Practitioner. Ongoing monitoring by a medical specialist is essential.

It is essential that the family unit is supported from the time of diagnosis as dealing with the implications of PSP can be far reaching.

Discussions around options of accessing respite and residential care may be of benefit and guidance through the Aged Care Assessment Team (ACAT) process is recommended.

Appointing an Enduring Power of Attorney for financial matters, an Enduring Guardian for medical matters or making an Advanced Health Care Directive are considerations for future planning.

The information in this brochure is intended as a guide for those diagnosed or affected by a diagnosis of Progressive Supranuclear Palsy (PSP). All symptoms and health issues should be discussed with the treating medical team.

For further information about PSP contact your State based Parkinson's office.

A PSP Information Manual is available from Parkinson's Victoria (03 8809 0400)

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This brochure was made possible by a generous donation from the Main family in memory of Maggie.



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Prepared in collaboration with:

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