



Understanding PSP

PROGRESSIVE SUPRANUCLEAR PALSY

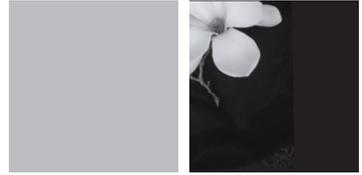


PSP
Australia



Facts about PSP

- PSP is considered a rare condition.
- There are currently around 1300 Australians diagnosed with PSP, although many others may have the condition but be wrongly diagnosed.
- Many doctors and health workers have little understanding of PSP and many have never treated anyone with the condition.
- It has similar symptoms to Parkinson's, but PSP affects a different part of the brain.
- Symptoms usually begin between the ages of 60 and 70.
- PSP can affect people from all cultures and lifestyles.
- PSP is not contagious and does not run in families.
- Symptoms can be managed with a range of therapies and treatments, but symptoms become progressively worse over time.
- People with PSP are at risk of developing serious complications such as pneumonia, choking, head injury and fractures. As the condition progresses, these complications can cause death.
- There is no known cure or prevention; however, research is currently underway, giving us hope for the future.



What is PSP?

Progressive Supranuclear Palsy (PSP for short) is a neurological condition. In other words it is a condition that affects the brain. The part of the brain affected by PSP is the part that controls activities such as walking, eye movements, balance, speech and swallowing.

PSP is a progressive condition, meaning that the symptoms get worse over time. There is no known cure and we do not know of any way of preventing it. Treatments and therapies are available to manage the symptoms of PSP, but these will not slow its progression.

We do not know what causes PSP, but it is associated with an over-production of a protein called 'tau' in certain areas of the brain. Clumps of tau (called 'tangles') build up and these are believed to cause damage to nerve cells.

Researchers have found no evidence of any link between PSP and exposure to chemicals or toxins.



Treatment

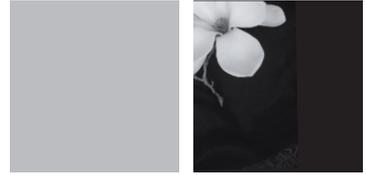
A variety of treatments and therapies are available to help manage the symptoms of PSP.

It is important that people with PSP see a neurologist, preferably one with expertise in movement disorders such as PSP and Parkinson's.

Depending on symptoms, it is also important to seek the advice of other health workers with expertise in the condition, such as a physiotherapist, occupational therapist, speech pathologist (speech therapist) or counsellor. Parkinson's Australia can provide information about neurologists and other health professionals in your area.

Medications used to treat people with Parkinson's can have some effect in treating PSP. However they do not work as well or for as long as they do for people with Parkinson's. Some antidepressant medications can be useful in treating some of the movement problems experienced by some people with PSP.

Remember, managing symptoms is the key to making the most of life with PSP.



Symptoms

PSP has a wide range of symptoms. Few people experience all symptoms and their severity and progression varies widely between individuals. Symptoms can also fluctuate from day-to-day.

Symptoms of PSP include:

- Stiff muscles
- Walking difficulties, such as shuffling
- Balance problems and dizziness
- Falls, particularly backwards
- Slow movements
- Mild shaking of hands
- Eye problems, such as difficulty moving the eyes or vision problems
- Speech problems, including slurring
- Swallowing and eating difficulties
- Slow thinking and difficulty organising thoughts and ideas
- Personality changes, such as lack of interest, irritability and/or depression.

Symptoms get worse over time. The average life expectancy after diagnosis is approximately seven years. There is significant variation between individuals and with good symptom control, some people live significantly longer.



Care for Carers

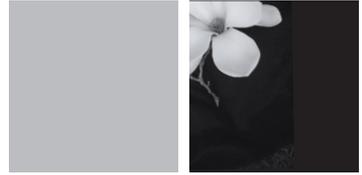
Carers are family members or friends who provide unpaid support for someone with an illness or disability.

Caring for someone with PSP is physically and emotionally demanding. It can also be rewarding and many carers experience satisfaction at being able to help their loved one. Even so, carers can not do it all on their own.

Carers need time to look after themselves. Maintaining social networks and a healthy lifestyle are important. By taking regular breaks and getting help when it's needed, carers are better able to manage the demands of caring.

People with PSP need an increasing level of care over time. It is important to put strategies in place in the early stages of the condition so that the needs of carers and the person with PSP can continue to be met in the future.

Services are available to give carers a break and to support them with someone to talk to. Some carers may also be eligible for financial assistance. For more information contact the carer association in your state or territory on **1800 242 636**, or contact Parkinson's Australia on **1800 644 189**.



Getting Help

PSP is a complex and challenging condition. It is important to get help and to communicate your needs. Here are some starting points for getting help:

Parkinson's Australia provides information and support for people with PSP and their families and carers.
Phone 1800 644 189 or visit: www.parkinsons.org.au

Support groups provide support and information in a friendly, supportive and encouraging environment where people may share their feelings and experiences with others. Parkinson's Australia can put you in touch with a support group in your local area.

Commonwealth Respite and Carelink Centre can also provide information about respite, personal care, home delivered meals and home help services in your local area. Telephone: 1800 052 222 or visit: www.commcarelink.health.gov.au

The PSP Information Kit provides easy-to-read information for people with PSP and their families and carers to help manage symptoms and make the most of living with PSP. Contact Parkinson's Australia to purchase a copy.

PSP Australia has a website and is currently developing content including information and links to other internet sites.

Visit: www.psp-australia.org.au



For support and information contact
Parkinson's Australia on **1800 644 189**
or visit: **www.parkinsons.org.au**



To speak to us in a language other than English
phone 131 450 and ask for an interpreter in your language to
connect you to Parkinson's Australia in your state or territory.
This is a free service.

This brochure was produced by PSP Australia Support
Group. The information here is presented as a guide; it is
important to discuss all symptoms and health issues with
your neurologist and other health workers.

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