

PSP Support Network

A PSP Support Network for people with PSP and their families is co-ordinated by Sue Lacy. The support network offers resource information and telephone enquiries to help network people with PSP, carers and families. Contact Sue Lacy, c/- NZ Post Mail Counter, Hawera or email sue.lacy@clear.net.nz

Further resources on the internet

There is a lot of information about PSP available on the internet, the following sites may be of interest:

www.neurosy.org/disease/psp/psp-answers

www.neurosy.org/disease/psp/stages

www.neurological.org.nz/html/article.php?documentCode=21

www.neurosy.org/disease/psp/challenges

The Parkinsonism Society of New Zealand (Inc)

Parkinsons New Zealand is a voluntary, non profit organisation that offers support, education and information to people with Parkinsonism conditions, the most common being Parkinson's disease.

Parkinson's NZ has divisions and support groups nationwide.

We can offer

- ▶ Further information on Parkinson's and Parkinsonism conditions including PSP
- ▶ Regular up-to-date information through our national magazine
- ▶ Responsible reporting of recent research
- ▶ Books and audio-visual material
- ▶ Local meetings and education programmes
- ▶ Advice on health and welfare assistance available
- ▶ Support from a professional Field Officer in your area.

Contact

Parkinsons New Zealand
P O Box 10 392

Wellington

Phone: 04 472 2796

Fax: 04 472 2162

Donation line: 0900 36 773

Freephone: 0800 473 4636

0800 4 PD INFO

www.parkinsons.org.nz

Your local contact:

Progressive Supranuclear Palsy PSP

**Some answers to your
questions about PSP**



Your Society provides:

- ▶ **Field Officer Service**
- ▶ **Education**
- ▶ **Support**

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Progressive Supranuclear Palsy (PSP)

What is PSP?

PSP is a rare degenerative neurological condition often presenting with similar symptoms to Parkinson's disease.

The disorder's long name indicates that the condition begins slowly and continues to get worse (progressive), causes weakness (palsy) by damaging certain parts of the brain above pea-sized structures called nuclei that control eye movements (supranuclear).

What causes PSP?

The cause of PSP is not known. Scientists have come up with several theories as to why the brain would degenerate in such a way. These theories include that PSP could occur as a result of a virus type particle that enters the body and then takes years to produce obvious effects, it could be the result of a rare genetic mutation, or it could be caused by a mystery particle in the air or water. None of these reasons have been proven.

Who gets PSP?

Middle aged to elderly adults – in New Zealand roughly 6 in 100,000 people over the age of 60. This figure will rise as more doctors become familiar with the clinical signs and diagnosis is more accurate. It is thought that the disease has a long incubation time before signs are evident.

Symptoms of PSP?

The key clinical signs of PSP are:

- ▶ Unsteady walking and frequent unexplained falls mainly backward
- ▶ Stiffness of the neck and limbs
- ▶ Visual problems – an inability or reduced ability to look up or down, light sensitivity, slow blinking of eyelids and difficulty to maintain eye contact
- ▶ Slow, slurred muted speech
- ▶ Difficulty swallowing
- ▶ Slowness of movements generally.

How is PSP diagnosed?

Often symptoms are vague and diagnosis is difficult. PSP is often mistaken for Parkinson's, Alzheimer's or depression especially in the early stages of the condition. An assessment by a specialist is essential to determine the diagnosis. There is no specific diagnostic test for PSP.

Is PSP terminal?

No. Although PSP in itself is not fatal, the disease does get progressively worse, and patients often die from complications such as pneumonia and inability to swallow. The average life expectancy is given as seven to nine years from diagnosis, but this can vary.

What is the treatment?

Currently there is no form of active treatment or a cure for PSP. A variety of medications and other forms of therapy can help control the symptoms.

Treatment focuses on alleviating the symptoms, so people with PSP could benefit from working with physiotherapists, speech therapists, dieticians and occupational therapists.

Does PSP affect the person's thinking?

Normally not but this can occur. It is important to remember that the person will take longer to answer questions. However the person may have difficulty controlling laughing or crying, and may show depression, apathy and impaired judgment.

To the person with PSP and their family

The diagnosis of PSP has significant impact on those close to the patient. As the condition progresses so does the need for care. Carers/families may feel isolated, frustrated and chronically tired. Infinite patience is needed. Carers/families will need support and should utilise support services. Support services can be contacted directly or referral can be made through your doctor or health professional.