

2.1 Managing Symptoms of PSP: **Movement Problems**

This Help Sheet gives further information about the movement-related symptoms of Progressive Supranuclear Palsy (PSP for short), such as stiffness, muscle cramps, walking and falling. It also suggests therapies, treatments and strategies for managing these symptoms. The information here is presented as a guide; it is important to discuss all symptoms with your neurologist and other health professionals.

PSP is a rare neurological condition affecting the parts of the brain that control walking, eye movements, balance, speech and swallowing. PSP has a wide range of symptoms, but few people experience them all and symptoms vary from person to person. It is a progressive condition, meaning that the symptoms tend to worsen over time. However, the severity and rate of symptom progression varies widely.

Difficulties with movement and balance are a common feature of PSP. The problems are caused by a breakdown in messages between the brain and the body. The problem is not with the muscles and joints themselves, although as movement becomes more and more difficult the muscles may stiffen due to lack of movement.

Exercise – Keep moving to keep moving

Regular exercise helps to keep the muscles supple and the joints moving. Daily walking or swimming are good forms of exercise for people with PSP. Other forms of gentle exercise can also be very helpful in managing movement-related symptoms, including Tai Chi and strength-training programs. Be aware, however, that advancing balance problems can make these exercises difficult or dangerous. Even when walking or standing becomes too difficult to manage, it is important to keep exercising. To accomplish this there are a series of passive stretching exercises that can be performed when seated.



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Muscle cramps due to stiff muscles and reduced movement can be a painful symptom of PSP.

Treatments for muscle cramps can include:

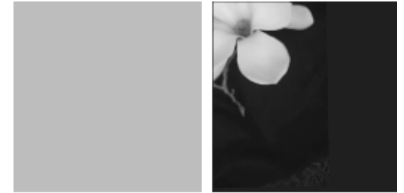
- **Gentle massage** or passive exercise to the affected area. Try one of the many electric or battery operated massage devices now available.
- **Heat packs**, such as a 'Wheat Bag', which can be heated in the microwave. Please note: people who are diabetic should not use heat packs without doctor's advice.
- **Injections of botulinum toxin** (Botox ® or Dysport ®) to the muscles in an effort to relieve pain and spasm. Botulinum toxin prevents the muscle from contracting, thereby reducing muscle spasms. Treatments will probably need to be repeated every 3 or 4 months. Discuss this with your neurologist.
- **Other medications** may also be considered by your neurologist to help with muscle cramps.

Walking difficulties and falls are a common problem for people with PSP. It is important to minimise falls because they can result in serious injury, particularly as people with PSP often fall backwards. Simple strategies you can use to minimise the risk of falls and reduce the chance of injury include:

- Wearing comfortable, well-fitting flat shoes. A physiotherapist can advise on the best shoes to wear.
- Removing low objects such as rugs, low coffee tables and floor clutter.
- Repairing loose carpet and uneven or slippery surfaces, remembering that people with PSP often walk with a shuffle and have difficulty looking down.
- Keeping items that are regularly needed close at hand.
- Thinking about different and safer ways of doing things and considering the consequences before undertaking risky tasks that may result in a fall.

Services and professionals that can help

The following services and professionals can help minimise movement problems, maintain safety and maximise independence and quality of life. Many are provided at a low cost and Medicare now funds a limited number of visits to an allied health professional such as a physiotherapist when you are referred by a General Practitioner for an Enhanced Primary Care Plan. You can find out what services are available in your area by contacting Parkinson's Australia.



Physiotherapists can help with:

- Advice on stretches that can help stiff muscles and joints to move more freely.
- The provision of an exercise program to maintain muscle strength.
- Techniques to make movements more automatic and strategies to manage movement difficulties, such as turning over in bed.
- Advice for carers on the safest and best way to assist the person with PSP; for example, safe lifting techniques.

Occupational therapists can help with assessment of the home environment and advice on equipment and strategies to maximise safety, independence and wellbeing.

Movement Disorder Clinics in some areas provide specialist services to help manage movement problems such as those caused by PSP and Parkinson's.

Equipment and independent living aids are available and in some cases may help manage movement problems and assist with daily activities:

- **Walking frames** can help ease walking difficulties and reduce the risk of falling. Your physiotherapist is the best person to advise on the type of walking frame suited to your individual needs.
- **Wheelchair** use can help to increase mobility and maintain independence. For example, it can be useful when attending a crowded event. The wheelchair should be individually fitted with the advice of a physiotherapist or occupational therapist.
- **Home safety equipment** such as grab-rails, ramps, accessible toilet and shower facilities and hoists can help to maintain safety and independence at home. Your occupational therapist can advise on these items.
- **Elbow pads and hip or head protectors** can provide important protection for people with severe balance problems and protect them from fractures in the event of a fall.

Costs for some of these items may be subsidised for some people. Your physiotherapist or occupational therapist can advise on available



equipment and help you to obtain what you need.

Independent Living Centres can also provide information and advice about resources to make every-day living easier. To contact the Independent Living Centre in your state or territory telephone the ILC Infoline on 1300 885 886 or visit: www.ilcaustralia.org.au

It can be a good idea to introduce independent living aids before they are needed, so that both carers and the person with PSP become familiar and practiced at using them.

Remember: PSP is a progressive condition and symptoms will get worse over time. It is important to plan ahead for future needs, for example, by installing equipment to reduce the risk of falls at home ahead of time rather than waiting until after a serious fall.

Medications to help with movement problems

- **Dopamine medications**

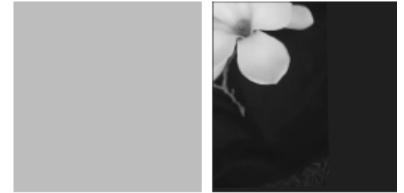
Dopamine is the brain chemical that is lacking in people who have Parkinson's disease. Some medications used to treat Parkinson's can help treat some of the movement-related symptoms of PSP. Unfortunately, dopamine medications do not work as well in PSP as they do in Parkinson's because in PSP dopamine is not the only brain chemical affected.

There are a number of different dopamine medications and side-effects are common. They can include nausea, constipation, confusion, hallucinations, and behavioural problems such as feeling an uncontrollable need to gamble, have sex or pursue hobbies. Side effects can usually be treated. It is important to discuss all symptoms, side-effects and treatments with your neurologist.

- **Amantadine** (sold under the brand name **Symmetrel**) may be more effective than other dopamine drugs in treating movement symptoms of PSP because it affects more than just the dopamine system. Unfortunately the benefits often do not last longer than a few months. Side effects include dry mouth, constipation, confusion and swelling of the ankles.

- **Antidepressant medications**

Some of the movement problems experienced by people with PSP appear to improve with the use of antidepressant medications. We do not fully understand the reasons for this; however, we do know that the improvement in movement is not related to the medication's ability to relieve depression. Side-effects may include constipation, dry mouth, confusion and difficulty urinating.



Treatment found to have no benefit in PSP includes many different medications, some surgical procedures and Alzheimer's disease medications.

Remember: treatment options are evolving all of the time and it is important to regularly discuss the latest treatment options with your neurologist. For example, recently co-enzyme Q10 was suggested as a useful agent to reduce disability over the long term. This study was preliminary and further studies are planned.

For further information about living with PSP, including the full range of PSP Australia Help Sheets, visit: www.psp-australia.org.au

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