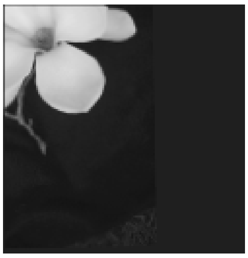


1.3 Introduction to Progressive Supranuclear Palsy (PSP)

Information for Health Professionals

This Help Sheet gives a simple introduction to this complex and challenging condition. It outlines some of the factors to be aware of in the care and treatment of patients with PSP. It lists the main symptoms and management strategies and can be individualised to show the symptoms and strategies for a particular patient.

What is PSP?

- PSP is a rare neurological condition affecting the parts of the brain that control walking, eye movements, balance, speech and swallowing.
- It is progressive and incurable, with very limited treatment options, so symptoms continue to get worse over time.
- It has similar symptoms to Parkinson's but PSP does not usually improve substantially with medications.
- There is no known cure and any known way of preventing PSP.

What are the symptoms?

- PSP has a wide range of symptoms, but few people experience them all.
- The severity of symptoms and rate of progression varies widely between individuals.
- The most common symptoms are:
    - Slow movements and muscle stiffness.
    - Balance problems, including unexplained falls, usually backwards.
    - Eye movements can become very restricted, altering vision. These problems cannot be corrected with eye glasses.
    - Personality changes, such as lack of interest, irritability, depression and heightened emotional response.

How is it treated?

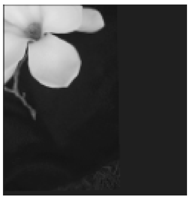
Some medications have been found to have limited success in treating PSP in some individuals. These may include dopamine and antidepressant medications. However, any responses need to be closely monitored as they may worsen symptoms.

People with PSP need the support of a team of health workers with expertise in the condition, including a neurologist and, depending on symptoms, a physiotherapist, occupational therapist, speech pathologist and counsellor.

Key things to remember in treating and caring for someone with PSP:

- Survival and quality of life is dependant on good symptom control.
- PSP is not dementia. Most people experience some change in thinking and cognition, but most people with PSP remain aware of themselves and their environment throughout the course of the condition.
- Symptoms are beyond the control of the person.

If you require further advice in relation to treatment and care of someone with PSP contact Parkinson’s Australia on
1800 644 189



PSP Symptom Sheet

This sheet has been individualised for ___________________________ (name of patient)

This sheet lists the common symptoms of PSP and outlines symptom management strategies. It can be individualised and specific strategies can be noted. Please also refer to the patient's care plan and medications list (if appropriate) for further information.

(Note to patients and their carers – please tick the symptoms and management strategies that apply to you and add any further information that may be required).

Balance and movement problems

☐ Falls frequently and unexpectedly, particularly backwards

- Avoid falls with use of mobility aids and safety equipment:
    - Walking stick
    - Walking frame
    - Wheely walker – weighted/unweighted
    - Wheelchair
- Protect against injury with pads and hip protectors
- Remove obstacles
- Expect unpredictable falls and underestimation of balance difficulties

☐ Stiff muscles

- Use heat packs
- Massage

☐ Slow movements

- Allow plenty of time

Vision and eye movement problems

☐ Inability/difficulty in looking down

- Place TV, call button, food and drink within the field of vision
- Remove low objects that may cause a trip hazard

☐ Inability to maintain eye contact

- Remember, people with PSP remain cognitively aware even if they look distant or disinterested

(continued over)

☐ Blurred vision, tunnel vision or double vision
  - Ensure safety
  - Try an eye-patch or taping over one lens
  - Consider prisms for reading

☐ Involuntary closure of eyelids (blepharospasm)
  - Gently open the lids
  - Provide opportunities to engage the person with conversation, music or talking books
  - Referral to a neurologist for Botulinum Toxin injections

☐ Dislike of bright light (photophobia)
  - Dim the lights
  - Use wrap-around sun-glasses

☐ Dry irritated eyes or excessive tearing due to reduced blinking
  - Use frequent artificial tears to avoid damage to the eye from dryness

Communication and speech problems

☐ Difficulty writing
  - Ask family members to complete necessary forms

☐ Soft voice
  - Discuss use of communication aids with family members or carer/s
    - Voice amplifier
    - Alphabet board
  - Work with speech therapist to maximise communication abilities

☐ Slow thinking
  - Allow time for a response to questions
  - Remember people with PSP remain cognitively aware

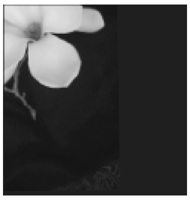
Personality and behaviour issues

☐ Irritability, impulsivity
  - Remember, it is the condition, not the person

(continued over)

This sheet has been individualised for:

______________________ (name of patient)



☐ Depression
  - Treat with medication if appropriate

☐ Slow thinking
  - Allow time, particularly for a response to a question

☐ Disinterest
  - May be a symptom of the brain changes in PSP
  - Remember that people with PSP have poor control of face and eye muscles so they may not look interested even when they are

☐ Emotional responses such as crying or anger
  - May be due to the brain changes or a response to the difficulties of living with the illness
  - Changes to the vocal chords can make the voice sound aggressive

Eating and swallowing difficulties

☐ Poor swallowing due to lack of muscle control, causing risk of aspiration
  - Supervise or assist with eating and drinking
  - Ensure patient sits upright to eat or drink
  - Allow plenty of time
  - Ensure patient takes small quantities at a time
  - Try alternating food and liquid
  - Use soft, moist food, for example, mince, tender chicken, pasta or fish in sauce

☐ Thick saliva or other secretion management issues
  - Use a nebulizer (steam) mask to moisten and thin secretions
  - Consider a referral to a speech pathologist

☐ Too much saliva
  - Avoid irritation to the skin, especially at the corners of the mouth. Vaseline or a barrier cream applied to the corners of the mouth may help
  - Ensure good dental hygiene
  - Botulinum toxin injections can reduce saliva production

(continued over)

Bowel and bladder problems

☐ Constipation due to the slowing and weakening of the bowel muscle, lack of physical activity and/or reduction of fluid or food intake:

- Ensure adequate fluid and fibre intake
- Allow plenty of time for toileting and avoid rushing
- Remember, PSP affects people's ability to move smoothly and easily, making actions such as standing, walking and sitting on the toilet difficult and slow

☐ Urgency and frequency of urination due to the interruption of the messages between the brain and the bladder

☐ Dribbling incontinence or bladder infections caused by difficulty relaxing the bladder muscle

- Use appropriate toileting aids
- Use medications if appropriate
- Use continence aids if appropriate

Other problems

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

For PSP information and support phone Parkinson's Australia on 1800 644 189