

2.3 Managing Symptoms of PSP: **Swallowing, Eating Difficulties and Saliva Control**

This Help Sheet gives further information about the swallowing, eating and saliva control problems experienced by people with Progressive Supranuclear Palsy (PSP for short) and suggests how these symptoms may be managed. The information here is a guide; it is important to discuss all symptoms and management strategies 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 in different people.

Eating and swallowing

People with PSP commonly experience problems with eating and swallowing. The medical term for swallowing problems is 'dysphagia'. PSP affects the ability to control and coordinate muscles, including those used in chewing and swallowing and in lifting food and utensils to the mouth. Problems with eye movements, particularly an inability to look down, also cause difficulties in seeing the food and guiding it to the mouth.

Some people can accurately describe their swallowing problem. Others may not recognise that they have a swallowing problem and may take too much food or liquid into the mouth too quickly, causing coughing episodes or choking. Food or liquid can often go down the wrong way into the airway or lungs; this is called 'aspiration'. Sometimes food or liquid can go into the airway with no coughing; this is called 'silent aspiration'.



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





Symptoms of eating and swallowing difficulties

Symptoms may include:

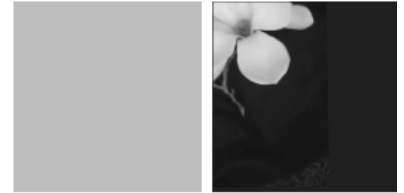
- Coughing or choking, particularly while eating
- Food sticking in the throat
- Food left unswallowed in the mouth, or taking a long time to swallow
- A 'wet' or 'gurgly' voice
- Increased phlegm in the throat (sometimes called 'a frog in the throat') and an associated difficulty clearing this
- Weight loss
- Dehydration
- Repeated chest infections; at the most extreme, pneumonia.

Managing eating and swallowing problems

It is very important to successfully manage eating and swallowing problems to avoid further problems such as choking, dehydration, weight-loss and chest infections. Speech pathologists (previously known as speech therapists) are also experts in swallowing. They can give individual advice on management strategies, such as the best possible sitting position and managing the consistency of food and fluid to minimise the risk of aspiration or choking while maintaining adequate nutrition. It is a good idea to keep a record of swallowing difficulties as they occur and to share this information with your neurologist and/or speech pathologist.

General strategies that people with PSP and their families and carers have found useful in managing eating and swallowing problems include:

- Sitting up as straight as possible and keeping the head in a slightly chin-tucked position when eating or drinking.
- Placing the plate of food close and raising it to eye-level to reduce the need to look down. (As an interim measure, try placing a phone book underneath the plate to raise it up. An occupational therapist can advise on height-adjustable tables and trays, or contact the Independent Living Centre on: 1300 885 886 or visit www.ilcaustralia.org.au).
- Experimenting with different plates and utensils. For example, a spoon is easier to use than a fork, plates with a rim can help keep food on the plate, and utensils with a modified grip can also help.
- Allowing plenty of time to get through the meal without rushing.
- Minimising distractions such as TV.
- Taking small amounts of food at a time and finishing one mouthful before taking another.
- Avoiding food with different consistencies such as soups with chunks of vegetables or pasta. These will be easier to manage if blended into one consistency.



Some further strategies to manage specific eating and swallowing problems:

Things to look out for:

What helps?

Eating or drinking too quickly or over-filling the mouth

- Supervision of meals, with frequent verbal prompts given to swallow each mouthful and to take appropriate amounts
- Take small amounts of liquid at a time and top up frequently
- Use a teaspoon or other small spoon.

Difficulty clearing phlegm ('frog') from throat (due to thickened saliva, weak cough and/or weakened swallow)

- Cut down on dairy products (milk, cream, cheese, ice cream) as these can thicken secretions.
- Sip hot water with slices of lemon or orange juice. Citrus juices and dark grape juice can thin secretions making them easier to swallow.
- Use a nebulizer (steam) mask to moisten and thin secretions.

Slow, laborious chewing

- Avoid chewy food and try softer, moist food, for example, mince, tender chicken, pasta or fish in sauce.

Food sticking in the throat

- Avoid dry, crumbly food
- Add gravy or sauces
- Sip liquid in between mouthfuls of food.

Difficulty swallowing tablets

- Take one tablet at a time
- Put each tablet in a spoonful of yoghurt, pureed fruit or something easy to swallow. **(Do not crush medications unless approved by your doctor or pharmacist)**

Foods or liquid going down the wrong way

- Mix thin foods and liquids with a commercial thickener or with thicker food such as potato or pureed fruit
- Be alert to the symptoms of pneumonia including increased chest congestion, chronic low grade fevers, increased cough and change in sputum.

Weight loss

- Monitor weight
- Try nutritional supplements such as Sustagen to increase weight.

Help Sheet 2.3

Managing Symptoms:
**Swallowing, eating
and saliva control**

As the condition progresses, some people may experience severe problems with swallowing, and medical treatment may be required. Please see our Help Sheet on Managing Symptoms Later in Life for further information.



Cookbooks for people with swallowing difficulties

There are a number of cookbooks offering a range of recipes for easy-to-swallow meals. Overseas produced cookbooks may require you to modify recipes for different measurements and available ingredients. Some of these cookbooks are listed below, along with information about how to order copies. You could also check with your local library, if the books are not on the shelf your library may purchase them or order them from another library.

Good looking and easy swallowing: creative catering for texture modified diets

By: Julia Farr Centre Foundation, South Australia
Authors: Martin & Backhouse.

This book contains information about the swallowing process, how to manage dysphagia, equipment for modifying the texture of meals and how to ensure a nutritious diet is provided. It includes recipes and information about the nutritional value of each dish and how to modify dishes to make serves either bite size, easy chew, finely chopped, or smooth and thick.

Contact for further information:

Julia Farr Group,
104 Greenhill Rd, Unley, South Australia 5061
Ph: (08) 8373 8300, Fax: (08) 8373 8373
email:admin@juliafarr.org.au

Under the Magnolia Tree.

This soft food cookbook for people with PSP is available through PSP Europe. You can order and pay on-line at: www.pspeur.org and follow the links to shop/publications.

The cost is £8 plus air postage to Australia of £4.75 and a donation for handling of £2.30. You can also order by sending an international money order for £15.25 payable to PSP Europe to: PSP House, 167 Watling Street West,
Towcester, Northamptonshire NN12 6BX, United Kingdom.
email: psp@pspeur.org

Easy-to-swallow, Easy-to-chew Cookbook.

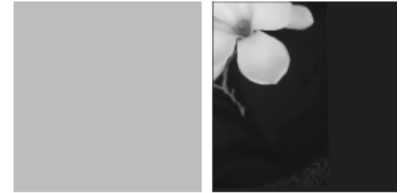
By Donna L. Weihofen, JoAnne Robbins, and Paula A. Sullivan.

Over 150 tasty and nutritious recipes for people who have difficulty swallowing. Published by John Wiley & Sons Inc. (2002), ISBN: 0471200743.

I-Can't-Chew-Cookbook. By J Randy Wilson. Published by Hunter House Publishers (2003), ISBN: 0897934008.

Website: www.easytoswallow.co.uk

This website contains recipes for soups, main courses and desserts that people find easier to swallow.



Saliva control

Saliva plays an important function in the mouth. It helps to break down food and protects the mouth from drying out and cracking. Saliva is produced in the salivary glands and different glands produce different types of saliva. Thick, mucoid saliva is produced in the glands located under the tongue and the jaw, while thin, runny saliva is produced when glands in the upper mouth are stimulated by the chewing action.

We all produce about a litre-and-a-half of saliva every day, but in health we swallow frequently. People with PSP have difficulty controlling and coordinating the muscles involved in swallowing saliva, causing saliva to pool inside the mouth. PSP also affects the muscles involved in chewing, reducing the production of thin saliva and resulting in pooled saliva that is thick and ropey and difficult to clear. People with PSP also tend to breathe through the mouth, which can cause a dry mouth and make pooled saliva even harder to clear. It should be noted that some medications can also cause saliva to dry up thus creating a dry mouth.

There are a range of strategies to help with these symptoms. The following suggestions are a guide. It is important to discuss all symptoms with your neurologist and the best health worker for advice on saliva control, a speech pathologist.

To reduce saliva production

Foods and drinks that can help reduce your saliva production:

- Ginger: try sipping ginger tea or sucking pieces of dried ginger if there is no risk of choking
- Dark grape juice, which can be purchased in any large supermarket
- Sage tea, which is often available from health food shops
- Pineapple juice or sucking fresh pineapple
- Pawpaw or papaya, either the fruit or juice

Other strategies to help saliva control

- Keep your head as upright as possible
- Keep your mouth closed when reading, listening or watching TV
- Keep some tissues, a hanky or a towel handy. Dabbing at saliva rather than wiping it away will cause less irritation to your skin. Vaseline or a barrier cream applied to the corners of your mouth may help prevent them becoming sore.
- Remind yourself to swallow your saliva at regular intervals, for example every two minutes. Your speech pathologist can recommend a swallow reminder if you are forgetting to swallow.
- Keep your mouth as clean as possible as this will reduce the amount of secretions in the mouth and reduce the risk of aspiration.
- Increase your mobility of the mouth and tongue with dynamic exercises, for example, say the following words or make the following sounds:

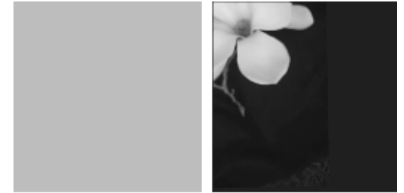
Oooo-arr, Ooo-arr.

Ta-ta-ta.

But-ter-fly, but-ter-fly.

Over-the-counter remedies

Before using any of the over-the-counter medications that claim to dry up saliva, such as sea-sickness tablets and cough or cold remedies, discuss these with your health professionals as some can cause side-effects.



Medications to help saliva control

All of the following possible treatments should be discussed with your neurologist or other health professional before proceeding:

- **Atropine eye drops** used under the tongue (**NOT** in the eyes) can help to dry secretions and are particularly beneficial if taken about 30 minutes before mealtimes. It may take a few weeks before they become effective.
- **Glycopyrolate** is available only in injectable form, may dry out the mouth and provide some temporary relief.
- **Other medications** can have the beneficial side-effect of reducing the amount of saliva in the mouth, including some antidepressants and medications for pain and sleep.
- **Hyoscine** is commonly used for drying saliva and comes in patch form. However it must be used with caution in people with PSP because it can cause confusion or hallucinations.
- **Botulinum Toxin** (Botox® or Dysport®) injections into the salivary glands can also be effective for some patients. Treatment usually lasts 3-4 months and can be repeated. Your neurologist can arrange this treatment.

Managing thick saliva

Strategies that can be useful in managing thick saliva include:

- Drinking plenty of liquid – at least 1 ½ to 2 litres a day
- Avoiding dairy products and other mucus-thickening foods
- Avoiding caffeinated drinks and alcohol
- Taking pineapple juice or pureed pineapple, which helps dilute saliva
- Sucking on crushed ice
- A water-based gel spread over the lips and inside the mouth. This helps to maintain moisture in the mouth at night

To manage a dry mouth

- Drink plenty of liquid
- Take frequent sips of water. Consider using a sports-bottle to reduce spills
- Avoid alcohol and smoking as these can both increase dryness
- Avoid mouthwashes that contain alcohol
- Apply lip balm or Vaseline to lips regularly
- Remove dentures at night
- Discuss the use of artificial saliva or alternative medication with members of your team of health professionals



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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