

Swallowing and Polio/PPS

Introduction

This factsheet is for anyone who had polio or has post-polio syndrome (PPS) who would like to learn more about swallowing problems and how they may be managed. Acid reflux (heartburn) is also covered.

Post Polio Symptoms

People who had polio years ago may now be experiencing new symptoms. These can include new or increased muscle weakness and fatigue with or without other symptoms like muscle and joint pain, muscle atrophy or wasting, breathing or swallowing difficulties or cold intolerance.

There is more information on PPS in other British Polio Fellowship leaflets.

Swallowing and polio/PPS

Some people with polio or post-polio syndrome (PPS) have swallowing difficulties (known as **dysphagia**) as a result of having had polio. If you cannot swallow properly, you may not get the full nourishment you need from food. This may cause, or worsen, malnutrition and dehydration. Swallowing problems can also make it difficult to take medication and may increase the risk of choking on food or liquid. Sometimes, food or liquids can 'go down the wrong way' into your airways (called **aspiration**), which can lead to more serious complications.

Your physical and emotional health and overall quality of life can be affected. Not all people with polio will develop swallowing difficulties but they can occur even if you did not have swallowing problems with the original polio.

It should also be remembered, other health conditions can cause swallowing difficulties and should be considered.

This factsheet explains the swallowing mechanism, why people with polio may have problems and how these may be assessed and managed.

Acid reflux (heartburn) and polio/PPS

The NHS describes **acid reflux** (or heartburn) as "*a burning feeling in the chest caused by stomach acid travelling up towards the throat*". This happens when the ring of muscle (**lower oesophageal sphincter**) at the lower end of the gullet doesn't properly close off the digestive juices from the stomach. You can have acid reflux without a feeling of heartburn; this is called **silent reflux**.

The gullet (food pipe, oesophagus) and throat can be damaged by stomach acid if reflux persists for a long time.

Acid reflux is very common; it is estimated that about 1 adult in 3 has heartburn every few days. In most cases it is not serious, can be relieved by dietary changes and antacids, and passes quickly. However, persistent and frequent reflux can damage the oesophagus and if untreated, in rare cases lead on to a precancerous condition. Macmillan Cancer Support say less than 1 in 100 people in the UK have this condition (Barrett's oesophagus) and only 3 in 100 with Barrett's develop oesophageal cancer (so 3 in 10,000 in the UK).

While there is no evidence to show that having had polio directly affects the sphincter. However, many factors related to polio may contribute to reflux such as poor swallow, scoliosis or inability to sit up straight while eating.

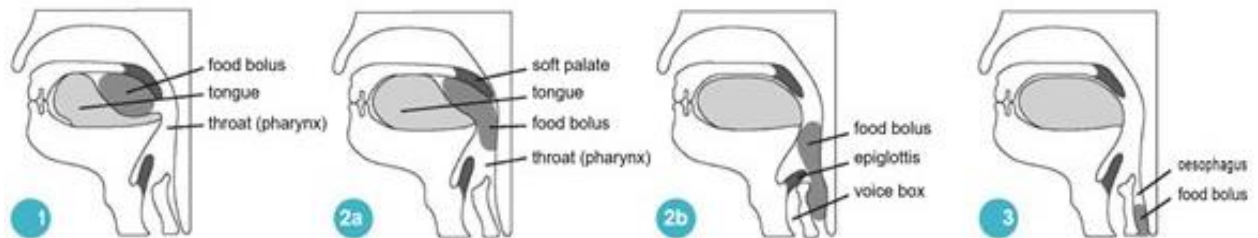
There is more about acid reflux and what can help later in this factsheet.

How we swallow

Most of us take the swallowing mechanism for granted, not realising that it needs about fifty pairs of muscles and nerves to co-ordinate a swallow. There are three stages to swallowing:

- **Oral stage:** As food is chewed, it is mixed with saliva, softening it and making it moist and easier to swallow. The tongue moves the food around the mouth while it is chewed and then forms it into a soft shape, called a bolus.
- **Pharyngeal stage:** The tongue pushes the bolus to the back of the throat. Movements of the epiglottis and vocal cords help to prevent food or drink from entering the airway.

•**Oesophageal stage:** Waves of muscular movement (peristalsis) move the food and drink down the food pipe (oesophagus) through the lower oesophageal sphincter into the stomach.



Swallowing diagram reproduced by kind permission of the MS Society.

Signs and symptoms of swallowing problems

Problems will vary in type and severity, but symptoms may include:

- Food or drink 'getting stuck'
- Increased time taken to chew and swallow, which may be worse when fatigued
- Coughing/choking
- Change to voice quality after eating or drinking, may sound wet/croaky/gurgling
- Unintended weight loss (this is also related to many other conditions and should always be investigated)
- Frequent chest infections

What are the risks to health?

If swallowing difficulties are left undiagnosed or untreated, there is a risk of malnutrition and/or dehydration, which can worsen existing health conditions. There is also the risk of aspiration, where liquid or food enter the airway and get into the lungs - "going down the wrong way". It is not always obvious that this is happening (sometimes called silent aspiration). Aspiration can lead to frequent respiratory infections or pneumonia. If you suspect you are experiencing any of these new symptoms listed above, it is important to get it investigated and managed by a speech and language therapist (SLT). They can help you manage the symptoms and prevent further complications.

If you notice any of the problems, signs or symptoms listed here, these should be checked with your GP.

Why do some people with polio have swallowing problems?

Swallowing problems have traditionally been associated with bulbar polio, where the polio virus attacked the nerves in the brainstem (the connection between the brain and the spinal cord). These nerves control swallowing, breathing and speech. However, those not originally diagnosed with bulbar polio may also develop swallowing difficulties later as a symptom of PPS, resulting from weakened swallowing muscles.

Some people with polio may have had slight or occasional swallowing difficulties for many years that remained largely unnoticed. However as we age, muscles do become weaker, so any pre-existing swallowing difficulties can become more obvious.

Getting a diagnosis

There are a number of other health conditions that can cause swallowing problems. Anxiety and fatigue can make some symptoms worse. In addition, feeling pressure to eat at the same pace as others can also make symptoms worse. Any new symptoms should be investigated.

If you think that you have a swallowing problem, it is important that you talk to your GP, who can refer you to a speech and language therapist (SLT) for investigation. The SLT will need to take a history of your speech and swallow issues, assess how you eat and drink, how you produce sounds and the movements of muscles in your face and neck.

If indicated, an instrumental swallow assessment may be completed with your consent. This may be via x-ray (videofluoroscopy) or nasendoscope (Fiberoptic Endoscopic Evaluation of Swallow, FEES). Your SLT will explain any assessment required in detail. If you see a SLT it is important to tell them about your polio history and that the impact of fatigue is discussed. The tests may require repetition to assess the impact of fatigue on swallow ability

Managing swallowing problems

Once swallowing problems have been identified, an SLT and dietitian will find the best ways to manage your condition. Different techniques help with different problems, so find those that work for you.

If you feel you need to use any of the following techniques, it is important to first check your symptoms out with your GP.

General tips and techniques

- Maintain good posture when eating. Sit upright in a comfortable chair, with the table at the correct height. Remain upright for at least 30 minutes after you finish your meal and never eat or drink while you are lying down.
- Try to eat in a relaxed environment, without the distractions of radio or television and avoid talking whilst eating and drinking.
- Avoid eating if you are very tired. Monitor any fatigue patterns throughout the day, so you get an idea when mealtimes suit you best.
- Eat and drink at a pace that you find comfortable, this might be slower than before.
- Chew your food well and ensure you swallow each mouthful before taking another.
- Avoid taking large gulps of fluids. You may be advised to avoid continuous drinking, and instead to take small sips at a time, swallowing prior to taking a further sip.
- Avoid eating or drinking textures that are fatiguing
- Take extra care with slippery or stringy food such as spaghetti, pak choi or rocket
- Only use straws if they have been recommended by your therapist.
- Try smaller, more frequent meals if you are affected by fatigue.
- Your speech and language therapist may advise for you to use modified head postures or swallow strategies if appropriate for you individually.

Adapting your food

Some foods and drinks are more problematic than others, e.g. hard, dry and chewy foods, such as tough meats, nuts, some vegetables and fruits, some types of cheese, dry foods such as breads, crispbreads, biscuits and crackers, rice cakes and popcorn, thick, sticky textured foods such as nut butters. Other problem foods include slippery foods or those with uneven textures, tough skins and rinds, seeds and pips.

Avoiding everything that has the potential to be problematic could lead to nutritional deficiencies and meals becoming monotonous and unappetising. The key is to prepare foods so that they are easier to swallow, but are still nutritious, tasty and enjoyable to eat.

Here are some suggestions:

- Gravy, tomato sauce or custard may be used to moisten dry foods.
- Mix foods that contain a lot of water, such as juicy vegetables and fruits, with drier foods.
- Thickeners such as tapioca, flour, instant potato granules or flakes, porridge oats or fine oatmeal and matzo meal may make liquids easier to swallow.
- Thicken soups with pureed vegetables and/or pulses.
- Use herbs, spices and colourful and strongly-flavoured foods to make up for a lack of variation in texture.
- To keep dishes appetising, pay extra special attention to how food is presented.
- Keep the components of a pureed meal separate.
- Use a book of easy to swallow recipes for ideas.
- Food purees may be moulded into the original shape of the food using plastic moulds- a technique increasingly used by dietitians to make pureed meals more “normal” and pleasurable to eat.

There are also specialist thickening products available, made from ingredients such as cornflour or xanthan gum, which thicken liquids without significantly changing the taste, but these should only be used after advice by an SLT.

Staying hydrated

People with swallowing difficulties may be at risk of dehydration and further health problems, if they do not maintain their fluid requirements of about 30ml per kg body weight or 6-8 cups of fluid a day. This is particularly important if you rely on thickened fluids.

Monitor your fluid intake by keeping a big jug or plastic bottle of water and a glass near you throughout the day. Take small, frequent sips. Take a bottle of water when you go out and encourage your friends and family to check that you are drinking enough.

If spillage is a problem, try using cups with spouts or built-in lids and straws (after discussion with your therapist).

Other ways of staying hydrated besides drinking water and other fluids are sucking ice cubes and eating high-water foods such as melon, watermelon, tomatoes, cucumber, citrus fruit, peaches, soups and smoothies. Ice lollies, sorbets, ice cream and jelly are some examples of high-water treats.

Getting advice from a dietitian or speech and language therapist

A dietitian can advise you about food choices and help you to plan meals, so that you are able to carry on eating a healthy, balanced diet. They may be able to advise you about high protein or high-energy drinks and/or dietary supplements if these become necessary to maintain nutritional or calorie intake.

Your dietitian will also be able to advise you about keeping hydrated and keeping your salt intake within sensible levels. Your GP can refer you to a dietitian.

Although the job title is 'speech and language therapist', SLTs are allied health professionals who also help people with eating drinking and swallowing difficulties. They can refer on to other specialists for further tests and treatment.

Dental problems

Dental problems can make chewing and swallowing more difficult, contributing to the issues described.

It is important to have regular check-ups. If you have dentures, ensure that these fit properly and you still need to take good care of your mouth. Every morning and evening, brush your gums, tongue and the roof of your mouth with a soft-bristled brush, to remove plaque and help the circulation in your mouth. If you wear partial dentures, it is even more important that you brush your teeth thoroughly every day. This will help stop tooth decay and gum disease that can lead to you losing more teeth.

When you go to the dentist if you have swallowing or breathing issues do make them aware of your issues:

- If you have breathing problems, particularly if you use breathing support such as a ventilator.
- Reclining in the dentist's chair may make breathing more difficult or saliva more difficult to manage so it is important that the dentist finds a position that is comfortable for you.
- Be aware that when using anaesthesia to numb areas in the back of the mouth, swallowing may become more difficult and the risk of choking or aspiration (inhaling food, fluids or saliva) may be higher.

Managing anxiety

Swallowing problems can be stressful and frightening, with worries about symptoms worsening and the effect on your health, family and social life. Some people are very anxious about the possibility of choking. Following the tips and techniques in this factsheet may help you feel that you are beginning to manage the problem. Seek professional help and talk to family and friends about how your swallowing problems make you feel and about the practical ways in which they may support you.

Medication and swallowing

Some medications cause a dry mouth, which can affect the health of teeth and gums, as well as the ability to chew and swallow properly, so you may wish to discuss possible alternatives with your GP.

Many people with swallowing problems may be tempted to crush tablets or open capsules. Crushing certain pills can be dangerous. Talk to your GP or pharmacist about alternative ways of taking a particular drug, such as in liquid form. For further information, see our factsheet, *"What you should know about your medication"*.

Swallowing Tablets

Unless otherwise instructed (for example, some tablets should be chewed) always swallow your tablets with plenty of water. Some tablets may react with drinks other than water - sometimes yoghurt or thick custard works better. Make sure you wash them down well as a stuck tablet can cause damage to the oesophagus; a sip may not be sufficient to wash a tablet out of your throat and into your stomach.

The NHS website (<https://www.nhs.uk/conditions/problems-swallowing-pills/>) gives advice on swallowing tablets.

DO

- take pills with water, you can take pills with other drinks or food (sometimes thicker foods are suggested such as custard or yoghurt)
- use the '**Lean Forward Technique**', leaning forward slightly when you swallow (they have a video on the website demonstrating this)

DON'T

- do not throw pills towards the back of your throat
- do not tip your head back too much when you swallow – this can make swallowing more difficult

If you are having difficulty taking tablets or capsules, discuss this with your GP and ask for a referral to a speech and language therapist (SLT). An SLT can observe you swallowing and give advice on your technique and posture or make a referral for further tests if necessary.

Acid reflux; symptoms and management

The NHS gives the main symptoms of acid reflux as

- *heartburn – a burning sensation in the middle of your chest*
- *an unpleasant sour taste in your mouth, caused by stomach acid*

You may also have:

- *a cough or hiccups that keep coming back*
- *a hoarse voice*
- *bad breath*
- *bloating and feeling sick*

Your symptoms will probably be worse after eating, when lying down and when bending over.

As said earlier, you can have acid reflux without a feeling of heartburn; this is called silent reflux. You should check out other symptoms with your doctor, for example, if your voice has changed and has become hoarse.

Acid reflux is very common and there may be no obvious cause. It can be made worse by some foods or drinks, being overweight, smoking, pregnancy, stress, some medicines or by having a hiatus hernia.

While there is no evidence to show that having had polio directly affects the muscles involved (the sphincter), there are factors related to polio that may contribute to reflux. These include

- poor swallow
- scoliosis
- immobility
- poor posture - not being able to sit upright when eating
- weak muscles in the abdomen or between the ribs (intercostal muscles)
- constipation
- associated obesity
- medication for polio/PPS symptoms

If you have occasional acid reflux there are some things that may help. Eating smaller, more frequent meals may reduce how often it happens. Be aware of which foods trigger heartburn and avoid them if possible. Being careful of your posture when eating. if you have reflux at night, then raising the end of your bed to keep your head higher than your waist might be useful. Losing weight, stopping smoking, reducing alcohol or finding ways to relax may help.

The NHS recommends that if you have acid reflux (heartburn) most days for more than three weeks, then you should see your GP, who can provide other treatment and rule out more serious causes of your symptoms.

Tell your GP about your polio history and impact, and any post-polio symptoms you may have. Your GP may refer you for further tests such as an endoscopy to examine the inside of your throat.

You can get more information from the NHS website or Patient.info. There are also UK charities which provide information, help and support if you have persistent acid reflux, such as Action Against Heartburn or the Campaign Against Reflux Disease.

To summarise

- Swallowing is a complex process under the control of many pairs of muscles and nerves. People who had polio can get new difficulties with swallowing mainly due to new muscle weakness. These problems can occur even in people not originally diagnosed with bulbar polio and may develop slowly and remain largely unrecognised.
- Symptoms of swallowing problems vary but may include: food or drink getting 'stuck', taking a long time to chew and swallow, coughing/choking, change to voice quality, unintended weight loss, frequent chest infections.
- Untreated swallowing difficulties can lead to: malnutrition, dehydration, liquid or food entering the lungs (aspiration), or respiratory infections.
- It is very important that tablets and capsules are swallowed properly with lots of water or other fluid as some can cause damage to the oesophagus if they get stuck. Use the 'Lean Forward technique' described on the NHS website.
- **If you notice any of the problems, signs or symptoms listed here, these should be checked with your GP.**
- There are some general tips as well as specialists, such as speech and language therapists and dietitians, who can help you manage the problems.
- Acid reflux (heartburn) is very common in the UK, but if it persists, can lead to serious damage to the oesophagus.
- Symptoms may include: heartburn, an unpleasant sour taste in your mouth, a persistent cough or hiccups, a hoarse voice, bad breath, bloating and feeling sick. Your symptoms will probably be worse after eating, when lying down and when bending over. You can have acid reflux without a feeling of heartburn; this is called silent reflux.
- Some factors related to polio/PPS may contribute to reflux, such as poor swallow, scoliosis, immobility, or inability to sit up straight while eating.
- **The NHS recommends that if you have acid reflux most days for more than 3 weeks you should see your GP**

Glossary, other words you may hear

Dysphagia	The medical term for swallowing difficulties
Dysphonia	The name given to a problem with the voice
Bulbar polio	This occurs when poliovirus invades and destroys nerves within the bulbar (medulla) region of the brain stem at the top of the spinal cord. This region controls breathing and swallowing.
Aspiration	Breathing food or liquid into the airway/lungs
Silent Aspiration	Breathing food or liquid into the airways but without obvious symptoms, such as coughing
Pharynx	the part of the throat behind the mouth and nasal cavity, and above the oesophagus;
Pharyngeal	relating to, or situated in or near the pharynx
Oesophagus	Another word for the throat or gullet
Sphincter	special, circular muscles that open and close certain body parts, for example, at the bottom of the oesophagus
Acid reflux	When stomach acid travels upwards out of the stomach towards the throat
GORD	Gastro-oesophageal reflux disease - the condition that can develop if the oesophagus is damaged (Note that the US spell esophagus without the first 'o', so you may also hear GORD called GERD)

Recipe books

I-Can't-Chew-Cookbook: Delicious Soft Diet Recipes for People with Chewing, Swallowing and Dry-Mouth Disorders by J. Randy Wilson. Published by Hunter House Publishers (2003), ISBN 0-89793-399-0

This American book includes recipes for a wide variety of soft and easy to swallow dishes, together with nutritional guidelines and suggestions for boosting protein, calories (where appropriate) and fibre in the diet.

Recipe Collection: Easy-to-Swallow Meals.

Produced and published by the Motor Neurone Disease Association. Call 08457 626262 or visit www.mndassociation.org

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Useful organisations

Disabled Living Foundation

The Disabled Living Foundation is a national charity that provides free impartial advice about all types of daily living equipment and mobility products for older and disabled people, their carers and families.

The Disabled Living Foundation, 380-384 Harrow Road, London, W9 2HU

Helpline: 0845 130 9177 Website: www.dlf.org.uk

Royal College of Speech and Language Therapists (RCSLT)

The RCSLT is the professional organisation supporting speech and language therapists, which can provide information about swallowing problems and how to access an SLT.

RCSLT, 2 White Hart Yard, London, SE1 1NX

Telephone: 020 7378 1200 Website: www.rcslt.org

Action against Heartburn

<https://www.actionagaintheartburn.org.uk/>

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