

Eating, swallowing and saliva control in Parkinson's

Some people with Parkinson's may find they have problems when eating and swallowing. Some people may produce too much or too little saliva. And some may also find that their problems with swallowing leads to drooling.

This information sheet looks at the issues you may experience, explains why they happen and what can be done to help. It also contains information and practical tips for family and friends.

Eating and swallowing

The medical term for issues with eating and swallowing is dysphagia.

There are four main problems that can be linked to swallowing problems.

- A chest infection caused by food or liquid from the mouth going into the lungs rather than into the stomach (known as aspiration pneumonia).
- Not eating enough to maintain good general health (known as malnutrition).
- Not drinking enough, which can lead to other medical complications, such as constipation or dehydration.
- Food blocking the airway and stopping your breathing (known as asphyxiation).

It is very important to talk to your GP as soon as you can if you have problems with swallowing.

Some problems with swallowing may not always be obvious to someone with Parkinson's. If the food that we swallow enters our wind pipe instead of our food pipe, our body reacts by coughing in order to stop food entering the lungs.

But in some cases people with Parkinson's can have what's called 'silent aspiration'. This is when food enters the wind pipe and goes down into the lungs without any of the usual signs of coughing or choking. This can lead to problems such as aspiration pneumonia.

How can eating and swallowing issues affect day-to-day life?

Swallowing and eating problems can impact on your quality of life, both at home and socially. Eating is a social activity and physical changes affecting chewing, swallowing and manual skills can have a big impact on how much you enjoy eating and sharing meal times with others.

People may worry about mess caused at meal times and the time it takes to eat. They can also be anxious about swallowing anything for fear of choking. Family and friends may also worry about them choking and what to do if this happens.

Eating less and weight loss is a common effect of swallowing problems. You may not enjoy eating, feel embarrassed, experience panic or become anxious before meals. Swallowing difficulties may also make it harder to take your medication.

You may not notice the changes in your swallowing because these happen slowly over time, but your partner, family or close friends may be able to point them out to you.

It is important to know that there is help to overcome swallowing problems.

Why do I find it difficult to swallow and eat?

Parkinson's can cause the muscles in your jaw and face to weaken, which affects the control you have over chewing and swallowing. The weakened muscles may also reduce the tightness that you have when closing your lips. If you can't close your lips tightly it will be hard to swallow.

Not being able to chew food properly and then swallow it can also be an issue. Some bits of food may remain in the mouth after swallowing. This is called 'piecemeal swallowing' and it can happen to people with Parkinson's. If you don't know that you have this food left in your mouth it may trickle down to your throat when you are not ready for it and this may lead to coughing or choking.

Parkinson's can cause difficulties in the muscles of the tongue. The tongue is important in swallowing because it is used to manipulate food so that it is ready for swallowing. The tongue also pushes the food to the back of the mouth to trigger the swallowing reflex.

Parkinson's may also affect the muscles carrying the food down into your stomach and slow it down. Eating slowly may give the impression that you're bored or have finished your meal, which means people could take your plate away. If this happens remind people that you need to take your time.

Food moving slowly down your food pipe (or oesophagus) to your stomach can make you feel full up. But once

“Eating is not a problem, but swallowing can be troublesome when I drink water. I tend to choke, but find that if I tuck my chin in it helps me to swallow without the liquid going down the wrong way. Drinking with a straw is also helpful.”

Judy, diagnosed in 1990

it arrives at your stomach you realise you are still hungry. By this time the food on your plate may have gone cold and be unappealing.

While eating, the frequent swallowing may mean that your saliva is used up, causing a dry swallow, which can feel uncomfortable.

Some Parkinson's medications can alter the taste in your mouth or cause a dry mouth. We need saliva to taste our foods, as it helps to break up the solid food into smaller parts which can then be tasted. Tasting our food produces more saliva that lubricates what you are chewing and makes chewing and swallowing comfortable. Saliva also helps to start digestion. If everything tastes dull or metallic then it's not enjoyable and less saliva is produced.

If you have any of these symptoms it may indicate that you have swallowing problems:

- weight loss
- drooling
- inability to clear food from the mouth
- food sticking in the throat
- a gurgly voice
- coughing when eating or drinking
- choking on food, liquids or saliva
- problems swallowing medication
- pain when swallowing
- discomfort in the chest or throat
- heartburn or reflux
- repeated chest infections
- loss of appetite

What can help?

If you are worried about, or are experiencing, any of the problems above, you should get advice from a speech and language therapist who works with people with swallowing problems.

These professionals can suggest exercises and tips to overcome some of the challenges you are experiencing.

In most areas you will be able to contact a speech and language therapist through the speech and language therapy department at your local hospital. You may also be referred by your GP, specialist or Parkinson's nurse. A Parkinson's nurse is a qualified registered general nurse with specialist experience, knowledge and skills in

“ I choked on a piece of fruit tart and staggered away from the table in distress but unable to speak. Everyone at the table fell silent and it seemed a long time before anyone thumped me on the back. It worked, but make sure that your family and friends know how to cope with such an incident. ”

Diana, diagnosed in 2004

Parkinson's. They play a vital role in the care of people with Parkinson's. You can read more about them on page 9.

Find out more: see our information sheet *Speech and language therapy and Parkinson's*.

Tests used to diagnose swallowing problems

If swallowing is a problem, a speech and language therapist will ask about your swallowing difficulties, for example what happens when you try to swallow, or if it is different with different food consistencies.

Then they might examine your mouth and observe you while you take small mouthfuls of food or drink, or even at a meal time. If needed, you may be referred for further tests. These include:

- fiberoptic endoscopic examination of swallowing (FEES) – a small flexible tube with a light at the end is passed down the nose into the back of the throat to observe food and liquid as it passes over the back of the tongue
- videofluoroscopy – this is carried out in the X-ray department. It involves being videoed while you are eating and drinking foods mixed with a substance that shows up on an X-ray. It can help pinpoint any swallowing problems

Referrals may be made to other health professionals for further examinations, such as an ear, nose and throat specialist or a gastroenterologist who specialises in the digestive system.

Treatments and management options

Following an assessment of your particular problems, a speech and language therapist will work with you and other relevant specialists, such as a dietitian, to come up with a management plan to suit your needs. This might include:

- adjusting your sitting posture and head posture when eating or drinking
- using special equipment to help you eat and drink more safely and comfortably. For example, you may use a special straw that prevents drinks from falling to the bottom of the straw once they have been sucked up
- exercises to strengthen your lips, tongue and throat muscles to make your swallowing more effective
- changing your diet to make foods and liquids easier and safer to swallow. This may include avoiding hard, dry or crumbly foods, moving on to softer, moist foods, or thickening drinks to make them move more slowly in the mouth
- avoiding taking mouthfuls of food or drink that have different consistencies, for instance cornflakes and milk, or peas and gravy
- adapting your pattern of eating and drinking, particularly the speed you eat and your mouthful size, to make meal times more efficient and reduce the risk of coughing and choking
- talking to your GP, specialist or Parkinson's nurse about the timing and doses of your medication. Eating your meals shortly after taking some medications may improve your swallowing, though the overall benefits of levodopa (one of the main drugs for Parkinson's) for swallowing remain unclear
- improving breathing techniques

Using these and other methods, the therapist can limit the risk of choking, coughing and things going down the wrong way and make swallowing less difficult and meal times more comfortable.

Speech and language therapists can advise and work with your family and carers. Sometimes your family may not realise that swallowing problems are the reason why meal times are difficult for you.

Helping them to understand the problems and providing practical advice on what to do can help reduce anxiety and make meal times more enjoyable for everyone.

Practical tips to help with eating and drinking

Speech and language therapists can provide you with useful techniques and give you exercises to practise to help with swallowing problems. You can also try the following:

- before swallowing, lower your chin towards your chest to reduce the chance of food or drink going down 'the wrong way' into the lungs
- try to take small mouthfuls. This will give you more control over your chewing and swallowing and will reduce the possibility of food slipping to the back of your throat without having been properly chewed
- avoid taking another mouthful until you are sure you have cleared your mouth and throat
- take your time when having food or drink

When swallowing food or drink:

- remember to take a breath in first
- take small mouthfuls of food or drink, close your lips, chew well, and then take a deliberate swallow
- swallow again to make sure all the food or drink has gone
- try licking with your tongue round your mouth to check all the food is gone
- repeat the process

When you swallow, try to squeeze hard with all of the muscles in your mouth and throat. This will help to get food down into your stomach and stop it getting stuck in your throat.

You may find it helpful to refill a cup or glass when it is half empty, so you do not have to tilt your head back to drink. Tilting your head backwards may sometimes make food or fluids go down the wrong way. You can also use modified cups that are shaped to allow you to drink without tilting your head. Your occupational therapist can advise you on this.

Very cold liquids can stimulate a swallow and can be useful first thing before breakfast or with a meal. Thicker drinks move more slowly and are easier to control. Powdered thickeners are available on prescription, as are pre-thickened juices. Your speech and language therapist will be able to assess you and advise on this.

What other things can affect my ability to eat and drink?

Sometimes issues with eating and drinking are not to do with the physical aspects of swallowing, but more to do with the practical side of eating and drinking. These may include difficulties getting food up to the mouth or balancing a cup to drink. Tiredness at meal times can also be an issue.

There are ways around these problems and health professionals can offer advice and information to help overcome them.

Occupational therapists can provide advice or equipment on ways to make eating and drinking easier. You may be referred to an occupational therapist by your GP, specialist, Parkinson's nurse, or you can often refer yourself through your local social services or social work department.

Dietitians can offer advice about getting a good diet and about the types of food that may be easier to swallow. If you have lost weight they may recommend nutritional supplements. You may be referred to a dietitian by your GP or specialist.

Find out more: see our booklet *Diet and Parkinson's*.

Eating out

Some people with Parkinson's may find that eating out with families and friends becomes difficult. They are anxious about messy eating, being unable to cut up their food or control it on the fork or spoon. Families or friends can also become embarrassed for them.

People with Parkinson's and their carers have told us that the experience can be less embarrassing if those around them are told why there are problems.

One lady describes having a strategy when she eats out with her husband who has Parkinson's. If they become aware of being watched, she gets up quietly and says to the people in question, "I am so sorry if we are troubling you. My husband has Parkinson's." She says people become caring and interested and they enjoy their meal in peace.

It can be useful to take any drinking or eating aids out with you when you eat away from home. You could also phone a restaurant first to make sure that they can provide a modified diet of soft or puréed food. However, some people with Parkinson's may prefer to eat in a place out of public gaze and it is important to let people know what your preference is.

Families who find eating with a relative who has Parkinson's difficult should try talking about the problem. Explain to children that their relative with Parkinson's haven't changed as a person, but their Parkinson's can make eating hard for them and they need support, time and understanding.

The important thing to remember is that you have to feel safe and comfortable when eating and that good nutrition is necessary for good health.

Saliva control

Many people with Parkinson's develop problems controlling their saliva, which can lead to drooling or dribbling. The medical term for this is sialorrhea. Research shows that this can affect more than half of people with Parkinson's.

When you have Parkinson's, the natural tendency to swallow slows down. We all swallow many times a day, but the rigidity and slowing down of movement that people with Parkinson's experience may reduce this. If you swallow less, saliva can pool in your mouth and, instead of being swallowed, it can overflow from the corners of your mouth. This may happen when you're concentrating on other things, such as watching TV or doing daily chores.

Some people with Parkinson's can have a stooped, head-down posture and may find it hard to seal their lips. This can make it harder to control saliva flowing from the mouth.

If you have problems with drooling or dribbling this may lead to sores and cracks developing at the corners of

your mouth. This can make some everyday activities, such as talking, eating meals or having a drink, difficult. It can also lead to problems with your teeth and infections in your mouth, such as oral thrush or candida.

What can help me manage my saliva?

In some cases, things such as improving your posture or the way you sit can help. Physiotherapy or occupational therapy can also be beneficial. For example, an occupational therapist may be able to recommend a tilting chair that will help your head and neck to stay upright.

You can be referred to these therapists through your GP, specialist or Parkinson's nurse (if you have one).

Find out more: see our information sheets *Physiotherapy and Parkinson's* and *Occupational therapy and Parkinson's*.

How can speech and language therapy help?

Making sure that your lips have a good seal is very important, as it will stop saliva flowing from your mouth. Your speech and language therapist can help you with this. You can also try these simple exercises at home in front of a mirror. They'll help you become more aware of what your lips are doing and how tightly you need to hold them closed to keep saliva in.

- Close your lips as tightly as possible and hold for a count of four, relax, then repeat five times.
- Smack your lips together as if puffing on a pipe.
- Stretch your lips in a wide smile, hold for a count of four and relax.
- Purse your lips as if you are going to whistle or kiss someone, hold for a count of four and relax.

It is also important to remember to swallow frequently, as this will stop saliva pooling in your mouth. Some people with Parkinson's find that chewing gum or sucking sweets helps them to swallow more frequently. But try to make sure these are sugar-free to help avoid tooth decay.

There is also a swallow reminder brooch, which makes a beeping noise to tell you when you should swallow (your speech and language therapist can tell you where to get this). If you have problems with saliva flowing from your mouth when you lean forward, try humming to keep your lips together.

Find out more: see our information sheet *Speech and language therapy and Parkinson's*.

Medication

There are drugs that can help control saliva production. These can be prescribed by your GP or specialist.

There are other treatments to help reduce the production of saliva and help reduce saliva building up in your mouth. These include:

- injections of botulinum toxin (Botox) into the salivary glands. This interrupts nerve messages from the brain that tell the glands to produce saliva. The effect of these injections can last up to six months, but it is important to discuss this with your GP, as this treatment may have side effects, such as causing your mouth to be too dry
- radiotherapy, which helps to restrict the glands that produce saliva
- surgical treatment options, such as salivary gland removal

All of these procedures should be discussed with your GP, as they are not suitable for everyone. Some of the drugs used to control saliva are tolerated better by some people with Parkinson's than others.

Dry mouth problems

Many people with Parkinson's experience dry mouth problems, and this may be linked to Parkinson's medication. Because saliva acts as a lubricant during chewing and swallowing, a dry mouth may feel uncomfortable. Saliva also has antibacterial properties that protect your teeth and mouth from decay and neutralise acidic foods.

Some tips for dealing with a dry mouth include:

- getting advice about your diet. Some foods make dryness worse. You can be referred to a dietitian by your GP
- taking frequent sips of water, so you're not dehydrated
- using lip balm to keep lips moist, particularly the corners of the mouth
- removing and cleaning dentures at night to give your mouth a chance to recover
- asking your dentist or doctor about the possibility of using artificial saliva. Specialist dry mouth products are available on prescription
- sucking sweets or chewing gum help to increase saliva and reduce dryness. But try to make sure these are sugar-free to help avoid tooth decay and other mouth problems

It's important to visit your dentist for regular check-ups because a dry mouth and pooling of saliva and food in the mouth can cause problems with the health of your mouth and teeth.

For details of your local NHS dentists in England and Wales call **0845 46 47** or visit **www.nhs.uk**

For dentists in Scotland call **08454 242 424** or visit **www.nhs24.com**

For dentists in Northern Ireland call **028 2534 1130** or visit **www.hscni.net**

Find out more: see our information sheet *Dental health and Parkinson's*.

More information and support

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them to manage symptoms. They can also act as a liaison between other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings. Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see a specialist for changes to or queries about their Parkinson's drugs. Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at parkinsons.org.uk/nurses

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email hello@parkinsons.org.uk

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline and they will match you with a peer support volunteer.

Our helpline can also put you in touch with one of our local information and support workers, who provide one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at parkinsons.org.uk/localtoyou. You can find details of our local groups and your nearest meeting at parkinsons.org.uk/localgroups. You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.



Eating, swallowing and saliva control in Parkinson's (2013)

If you have comments or suggestions about this information sheet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to **Resources and Diversity, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Or you can email us at **publications@parkinsons.org.uk**. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this information sheet from?

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other

How useful have you found the information sheet? (1 is not useful, 4 is very useful) 1 2 3 4

Have you found the publication easy to read/use? Yes No

Has this resource given you information that might help you manage your condition better?

- NA
- It hasn't helped
- It has helped a little
- It has helped a lot

What aspects did you find most helpful?

Were you looking for any information that wasn't covered?

Do you have any other comments?

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we'll be in touch.

- Membership
- Information review group (who give us feedback on new and updated resources)

Name.....

Address.....

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- What is your ethnic background? Asian or Asian British Black or Black British Chinese Mixed White British White other Other (please specify)

We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Services team on **020 7932 1303** or visit our website at **parkinsons.org.uk/support**. Thank you.

Parkinson's UK

Free* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm, Saturday
10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website

at **parkinsons.org.uk/publications**

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

References for this information sheet can be found in the Microsoft Word version at **parkinsons.org.uk/publications**

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