

Eating, swallowing and saliva control in Parkinson's

Some people with Parkinson's may find they have problems with eating, swallowing and controlling their saliva.

This information looks at the issues you may face, explains why they happen and what help is available. It also has information and practical tips for family, friends and carers.

Eating and swallowing

How can eating and swallowing problems affect your day-to-day life?

Eating is a social activity and problems that affect chewing and swallowing can have a big impact on how much you enjoy meal times. For example, some people with Parkinson's have told us that they feel self-conscious or embarrassed while eating because of their symptoms.

What symptoms should I look out for?

It's important to look out for symptoms related to difficulties with eating and swallowing. These can develop slowly over time and you may not notice them, so family, friends or carers should know what to look out for too.

If you're not able to swallow properly, you may experience:

- drooling
- inability to clear food from the mouth
- food sticking in the throat
- a gurgly voice
- coughing when eating or drinking

- choking on food, liquid or saliva
- problems swallowing medication
- pain when swallowing
- discomfort in the chest or throat
- These things can lead to a number of long-term problems, including:
- not eating enough to maintain good general health (known as malnutrition)
- not drinking enough, which can lead to other medical issues, like constipation or dehydration
- loss of appetite
- being less able to manage to eat certain foods (even though you may still enjoy them)
- heartburn or reflux
- a chest infection caused by food or liquid going into the lungs rather than the stomach. If the food we swallow enters the windpipe instead of the food pipe (oesophagus), the body reacts by coughing to stop it getting into the lungs. But in some cases, people with Parkinson's can experience '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. It can lead to problems like aspiration pneumonia, where the lungs become damaged or infected.
- food blocking the airway and stopping breathing (known as asphyxiation)

Talk to your GP as soon as you can if you have problems with eating or swallowing – they may refer you to specialists who can help.

Why do I find it difficult to eat and swallow?

Less efficient jaw and face muscles

Parkinson's can cause the muscles in your jaw and face to be less efficient, which affects the control you have over chewing and swallowing. Less efficient muscles may also reduce the tightness that you have when closing your lips, making it hard to swallow.

Problems with tongue muscles

Parkinson's can also cause problems in the tongue muscles. The tongue is important in swallowing. We use it to move food around and push it to the back of the mouth to trigger the swallowing reflexes. Parkinson's can also impair the reflexes that protect our windpipe from food and drink. A problem coordinating breathing and swallowing may make this problem worse.

Slow muscles carrying food to your stomach

Parkinson's may also slow down the muscles carrying food down into your stomach. Food moving slowly down your food pipe to your stomach can make you feel full up. But once it arrives at your stomach you realise you're still hungry. By this time the food on your plate may have gone cold and be unappealing.

Dry mouth

Dry mouth can be another feature of Parkinson's and can affect the comfort and pleasure of eating and drinking. Saliva helps us to break down food as we chew it and enables us to taste our food. Tasting your food produces more saliva that lubricates what you're chewing and makes chewing and swallowing comfortable.

Practical problems with eating and drinking

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

What can help?

If you're worried about, or are experiencing, any of the problems above, the following professionals can help:

- Speech and language therapists work with people with swallowing problems. Clinical guidelines say you should be able to see one. In most areas you'll be able to contact a speech and language therapist through the speech and language therapy department at your local hospital. Your GP, specialist or Parkinson's nurse can also refer you.
- Occupational therapists can provide advice or equipment to make eating and drinking easier. Your GP, specialist or Parkinson's nurse can refer you.
- Dietitians can offer advice about eating a good diet and about types of food that may be easier to swallow. If you've lost weight they may recommend nutritional supplements. Again, your GP, specialist or Parkinson's nurse can refer you.
- Your Parkinson's nurse or specialist will be able to suggest alternative medication options if you struggle to swallow – for example, a patch or liquid instead of hard tablets.

Find out more: see our information on speech and language therapy, occupational therapy, diet and drug treatments for Parkinson's.

What happens when you see a speech and language therapist?

Your speech and language therapist will start by asking about your swallowing difficulties, for example what happens when you try to swallow, or if it's different with different types of food. They may want to examine your mouth and observe you while you take small mouthfuls of food or drink, or even at a mealtime. If necessary, they may refer you for further tests. These include the following:

- 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 an X-ray department. You'll be asked to eat and drink foods mixed with a substance that shows up on an X-ray. It can help pinpoint any swallowing problems.

You may also be referred to other health professionals, including an ear, nose and throat specialist or a gastroenterologist, who specialises in the digestive system.

Treatments and management options for eating and swallowing

Following an assessment, your speech and language therapist will work with you and other relevant specialists, such as a dietitian, to come up with a self-management plan to suit your needs.

This might include:

- adjusting your sitting posture and head posture when eating or drinking
- exercises to strengthen your lips, tongue and throat muscles, cough strength and breath hold during swallowing

- changing your diet to make food and liquid easier and safer to swallow. This may include avoiding hard, dry or crumbly food, moving on to softer, moist food, or thickening drinks to make them move more slowly in the mouth
- avoiding taking mouthfuls of food or drink that have different consistencies together, like cornflakes and milk, or peas and gravy
- changing how you eat and drink, particularly the speed you eat and your mouthful size, to 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 levodopa (one of the main drugs for Parkinson's) may improve your swallowing, though the overall benefits of levodopa for swallowing are still unclear

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

Equipment to help with eating, drinking and swallowing

There is a variety of special equipment you can use to help you eat and drink more safely and comfortably.

For example, you could use a special straw that stops drinks falling to the bottom of the straw once they've been sucked up. You can also use adapted cups that are shaped to allow you to drink without tilting your head.

Your speech and language therapist can tell you more about the equipment available.

Find out more: see our information on daily living equipment for Parkinson's.

Support for families and carers

Speech and language therapists can also work with your family, friends and carers. Sometimes your family may not realise that swallowing problems are the reason why meal times are difficult for you. Helping them understand your problems and giving practical advice on what to do can help make everyone feel less anxious and make meal times more enjoyable.

Practical tips to help with eating and drinking

Speech and language therapists can give you useful techniques and exercises to practise to help with swallowing problems. As well as following their advice, 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 before you've chewed properly.
- Avoid taking another mouthful until you're sure you've cleared your mouth and throat.
- Take your time.
- Sit upright in a chair that supports your body.
- Reduce distractions, such as watching TV.
- Refill your cup or glass when it's half empty, so you don't have to tilt your head back to drink, which can make food or drink go down the wrong way.
- Try drinking very cold liquids, which can encourage swallowing, first thing before breakfast or with a meal.

- Try drinking thicker drinks, which move more slowly and are easier to control, so are less likely to go down the wrong way. Powdered thickeners are available on prescription, as are pre-thickened juices. Your speech and language therapist will be able to help you with this.

When swallowing food or drink the following process can help:

- Take a small mouthful 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 to squeeze hard with all the muscles in your mouth and throat. This will push food down to your stomach and stop it getting stuck in your throat.
- Try licking with your tongue round your mouth to check all the food is gone.
- Repeat the process.

Eating out

Some people with Parkinson's may find that eating out with family and friends becomes difficult. You might get anxious about messy eating, or being unable to cut up your food or control it on the fork or spoon.

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

One lady, whose husband has Parkinson's, says her strategy when eating out, if they become aware of being watched, is to get up quietly and say, "I'm so sorry if we're 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 the restaurant first to make sure they can provide what you need.

However, some people with Parkinson's may prefer to eat somewhere private – it's important to let people know what your preference is.

Some people with Parkinson's have told us that because they eat slowly, it sometimes gives the impression they're bored or have finished their meal. Because of this waiters take their plate away. If this happens, remind them that you need to take your time.

Families who find eating with a relative who has Parkinson's difficult should talk about the problem. Explain to children that their relative hasn'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.

What causes problems with saliva control?

When you have Parkinson's, the natural tendency to swallow slows down. We all swallow many times a day, but the 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 you swallowing it, it can overflow from the corners of your mouth. This may happen when you're concentrating on other things, like watching TV or doing 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.

What problems can lack of saliva control cause?

If you have problems with drooling or dribbling this may lead to irritation, discomfort, cracks and infections around your mouth. This can make some everyday activities, like talking, eating meals or having a drink, difficult. Constant need to change clothes can also be irritating.

What can help me manage my saliva?

In some cases, improving your posture or the way you sit can help. Physiotherapy or occupational therapy may be beneficial. For example, an occupational therapist may be able to recommend a tilting chair that will help your head and neck stay upright. Your GP, specialist or Parkinson's nurse can refer you to these therapists.

It's also important to remember to swallow often, 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.

Sipping water can prompt swallowing and help clear the pooled saliva. If you have problems with saliva flowing from your mouth when you lean forward, try humming to keep your lips together.

There is a 'swallow prompt' app you can download to use on your smartphone or tablet that may also be helpful – you can find out more at speechtools.co/swallow-prompt.

Find out more: see our information on physiotherapy and occupational therapy and Parkinson's.

How can speech and language therapy help?

A speech and language therapist can teach you a number of useful techniques to help with saliva control. For example, making sure you can seal your lips well 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 the simple exercises below 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're going to whistle or kiss someone, hold for a count of four, and relax.

Find out more: see our information on speech and language therapy and Parkinson's.

Treatments

Your GP or specialist may suggest the following to help control problems with saliva:

- Drugs that can help control saliva production. People with Parkinson's tolerate some of the drugs used to control saliva better than others. Clinical guidelines say your doctor should only consider drugs after other ways to control saliva, like speech and language therapy, have failed.

- Injections of botulinum toxin (Botox) into the salivary glands. This interrupts nerve messages from the brain that tell the glands to produce saliva. It's 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.

Discuss all these procedures with your GP, as they're not suitable – or necessary – for everyone.

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 is also important to keep your mouth healthy, and stop problems like sores, bad breath, infections, tooth decay and gum disease.

Some tips for dealing with a dry mouth include:

- Get advice about your diet. Some foods make dryness worse. Your GP can refer you to a dietitian.
- Take frequent sips of water, so you're not dehydrated.
- Use lip balm to keep lips moist, particularly the corners of the mouth.
- Remove and clean dentures at night to give your mouth a chance to recover.
- Ask your dentist or doctor about the possibility of using artificial saliva. Specialist dry mouth products are available on prescription.
- Suck sweets or chew gum to help increase saliva and reduce dryness. But 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. 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 **NHS 111** or visit **www.nhs.uk**

For dentists in Scotland call **NHS 111** or visit **www.nhs24.com**

For dentists in Northern Ireland speak to your GP or visit **servicefinder.hscni.net**

Find out more: see our information on mouth and dental issues in 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. They can also make contact with 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 their 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 to talk to someone about being matched with a volunteer.

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

We have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit parkinsons.org.uk/selfmanagement

Our website parkinsons.org.uk has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at parkinsons.org.uk/localtoyou

Visit parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.

Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

Hannah Reynolds, independent speech and language therapist

**Nick Miller, Emeritus Professor at the Institute of Health and Society and Newcastle University
Institute for Ageing**

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

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 **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**
If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and 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.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

Eating, swallowing and saliva control (PKFS22/2018)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to **Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**, or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in I care for someone with Parkinson's
 I have a friend or family member with Parkinson's I'm a professional working with people with Parkinson's
 Other (please specify)
-

2. Where did you get this information from?

- GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser
 Ordered directly from us Call to the helpline
 Other (please specify)
-

3. Has it answered all your questions?

- Yes, completely Yes, mostly Not sure Partly Not at all

4. How easy was it to understand?

- Very easy Easy Not sure Quite difficult Very difficult

5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot It helped a little No change It didn't help It made things worse

6. What is your ethnic background?*

- Asian or Asian British Black or Black British Chinese Mixed White British White other
 Other (please specify)
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you? Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk

parkinsons.org.uk



Last updated November 2018 We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
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