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Eating, swallowing and saliva control in Parkinson's

Saliva management

Is drooling a common problem in Parkinson's?

Drooling or dribbling is a common problem experienced by people with Parkinson's. The textbooks refer to this as sialorrhoea.

How does it come about?

Drooling does not occur because more saliva is produced but because, without realising it, the natural tendency to swallow every now and again (even when not eating) is slowed down. This, combined with stooped, poor posture and an inadequate lip seal affects the control of the saliva in and from the mouth. As a result, saliva tends to accumulate in the mouth and, rather than being swallowed, it can overflow. Many people have poor lip closure due to their Parkinson's and a flow of saliva from the mouth will occur if the lips do not seal tightly. There is also a tendency for the head to be bent forwards so that the chin points downwards. This will make the drooling worse.

What can I do to improve my saliva management?

In some cases, simply improving posture can alleviate the problem. A physiotherapist can advise on problems of posture. Referral is usually through a GP or consultant. See PDS information sheet Physiotherapy.

An occupational therapist can advise on seating that may help. Referral is usually through self-referral to your local Social Services or via a GP or consultant. See PDS leaflet Occupational Therapy and Parkinson's.

People who experience poor lip closure may be able to close their lips with their fingers or support their head up by cupping their chin in

their hand. This can be tiring and is not very practical. There are devices which can be used to retrain lip seal and these are very effective. Your speech and language therapist can advise further. Working with the speech and language therapist to achieve good lip seal is very important. You can also try these simple exercises at home in front of the mirror:

- 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. The rigidity of Parkinson's affects the muscles involved in our automatic swallow and sometimes there can be too much saliva because a person's swallowing pattern is poor.

We all swallow more than 500 times a day and usually clear our mouths subconsciously but the rigidity and slowness of movement that people with Parkinson's experience may reduce this. As a result, a pooling of saliva occurs that can cause a soreness and rawness of the skin on the chin; clothes can become stained and many people have stale breath because of their drooling difficulties. Where a person with Parkinson's experiences extreme problems with excessive salivation, specialist help is usually required.



What specialist help is available?

Referral to a speech and language therapist for assessment and advice is important to identify the problems of poor posture, lip seal, tongue control and awareness, as well as any difficulties with swallowing that may be contributing to the problem of drooling. The speech and language therapist can also advise on techniques and exercises to facilitate a more functional swallow. In most areas, self-referral can be made to a speech and language therapist. See the PDS information sheet Speech and Language Therapy.

There are drugs that can help reduce the production of saliva. Although these drugs are licensed for other indications, it is possible to make use of their anticholinergic activity, which includes the drying of saliva. Anticholinergics must be prescribed by a doctor who can ensure that they are suitable; especially since people with Parkinson's often take several drugs and may be having treatment for other conditions as well.

Drugs with anticholinergic activity that can be used to dry saliva include:

- atropine eye drops – placed under the tongue
- hyoscine – sometimes administered as the Scopoderm patch on the skin
- glycopyrronium – tablets or administered as an injection
- amitriptyline – tablets, also used to treat pain and depression
- orphenadrine – tablets, also used to reduce tremor in Parkinson's disease
- propantheline – tablets, also used to help night-time incontinence in adults

Anticholinergics have side effects, which may be more problematic in older people. These include blurred vision and urinary retention.

Occasionally, they bring on drowsiness, hallucinations, excitement and behavioural problems. It is unwise to use over-the-counter cough or cold preparations without seeking the advice of a doctor.

Injections of botulinum toxin into the salivary glands can also be helpful. Botulinum toxin is a powerful nerve toxin which is sometimes used to treat dystonia in Parkinson's disease and is now being used to treat excessive salivation in some people. It interrupts the nerves messages to the glands that tell them to secrete. Relief from excessive salivation can, in some cases, last up to three months. However, like all drugs, botulinum toxin does have side effects and will not be suitable for everyone.

Anyone experiencing severe difficulties resistant to speech and language therapy intervention should ask their GP to refer them to a Parkinson's specialist, either a neurologist or a physician with a special expertise in care of older people. Any preparation that is prescribed will be monitored by these experts. This is especially important when preparations may not be readily available and liaison with the local pharmacy drug information unit is required.

Occasionally specialists may refer to a radiography department where radiation treatment may be given that can limit the effectiveness of the glands that secrete saliva. Others may refer to an oral surgeon to explore the possibility of an operation to remove the salivary glands. It is important to discuss these options with your doctor. Any operation can have risks and you should be aware of all that is involved. As a result surgery is not widely recommended.

Can a dry mouth also be a problem for people with Parkinson's?

Yes, dry mouth is common in people with Parkinson's and is often related to medication, especially anticholinergics or antidepressants.



If you are on these types of drugs, discuss the problem with your doctor, as changing the dosage may be helpful. Further information on dealing with a dry mouth is contained in the PDS publication Parkinson's and Dental Health. Some helpful tips for dealing with dry mouth include:

- getting dietary advice. Some foods make dryness worse. Referral to a dietician is usually through your doctor
- take frequent sips of water
- ensure you are not dehydrated. Drinking two litres of fluid a day is recommended
- apply lip balm to keep lips moist
- visit your dentist. They can remove some irritants that may be making the problem worse.
- remove any dentures at night. Give your mouth a chance to recover
- ask your dentist or doctor about the possibility of using artificial saliva
- specialist dry mouth products such as Biotene are available on prescription
- avoid alcohol and do not smoke – both make dryness worse
- do not use mouthwashes that are not prescribed by your dentist or doctor. Many contain alcohol
- do not suck sweets to increase saliva. This will only increase decay and other oral problems

Eating and swallowing

Do swallowing problems only occur with Parkinson's? Why should we worry about it?

Swallowing problems occur in many other medical conditions, including cancers of the head and neck, strokes and progressive neurological disorders, such as motor neurone disease. Changes in swallowing function have also been noted as part of the normal ageing process and in people who become physically weak as a result of any other illness.

There are four main risks associated with swallowing problems:

- asphyxiation – food blocking the airway and stopping breathing
- aspiration pneumonia – an infection on the chest as a result of food, liquid or infected secretions from the mouth going into the lungs rather than into the stomach
- malnutrition – not eating enough to maintain good general health. This may make someone more susceptible to infections
- dehydration – not drinking enough leading to other medical complications, such as constipation

It is therefore important that people experiencing difficulties swallowing alert their doctor. In a study 94% of people with Parkinson's were found to have some difficulty with swallowing during the course of the condition. The research also shows that the problems are not always noticeable to the person with Parkinson's. There is a high incidence of silent aspiration in Parkinson's – this is when food enters the airway and passes down into the lungs without any of the usual signs of coughing or choking.



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Disease Society

How can swallowing problems affect my quality of life?

Swallowing and eating problems can have a tremendous impact upon a person's quality of life at home and their social life. People with these problems may worry about any mess caused at meal times. They can also become anxious about swallowing anything for fear of choking. Their family and friends may also worry about the person choking and what to do if they do if this happens.

Many people with swallowing problems eat less than normal and lose weight. They do not enjoy eating, can feel embarrassed or even experience panic or anxiety attacks before meal times. Since eating and drinking are such essential parts of life and are also associated with meeting friends and family, it is important to note that there is help available to overcome swallowing problems.

What goes wrong with my swallow?

The muscles of the jaw and face may be weakened because of the Parkinson's, which in turn affects the control a person may have over their teeth. The weakened muscles may also reduce the tightness that a person achieves in closing their lips. Everyone has difficulty swallowing if they cannot close their lips tightly.

If a person cannot chew their food adequately it can also cause problems. Some particles of food are swallowed easily but some may remain in the mouth. This is called piecemeal swallowing and is a common feature of Parkinson's. People are unaware that they have more food to swallow and as a result may choke. Food remaining in the mouth can harbour infections.

Often the tongue bunches up in Parkinson's and this can cause food to be pushed out through the teeth instead of controlled down the throat.

Parkinson's may also affect the muscles involved in carrying the food down into the stomach and makes the process much slower.

This can give the impression of being bored with what you want to eat and people innocently removing the plate.

It can also make the person feel full up, as the food passing down the oesophagus is moving so slowly. Then when it has passed down you realise that you are still hungry. Often the time that this takes means that food still on the plate is cold and unappetising.

If a person frequently or repetitively swallows (swallow rehearsals) while eating, they will use up the saliva needed to ease food into the throat and through to the stomach. This dry swallow can be very painful.

Some of the drugs used to treat Parkinson's can alter the taste in a person's mouth or cause excessive dryness. We need saliva to lubricate the swallow and the enzymes in it to begin the breakdown of food. We also need to taste our food to create saliva. If everything tastes dull or metallic, as it is often described, then we do not enjoy the taste, we do not salivate the same way and the whole process can become tiring and laborious.

Many people complain of food sticking in their throat. Others find the drooling or dribbling too embarrassing and choose to eat alone. Drooling can be the first sign of a swallowing problem because of poor lip seal and inadequate posture.

Indications that a person may have a swallowing problem include:

- loss of appetite
- weight loss
- drooling
- inability to clear mouth from food
- food sticking in the throat



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- gurgly voice
- coughing when eating or drinking
- choking on food, liquids or saliva
- difficulty in swallowing medication
- pain when swallowing
- discomfort in the chest or throat
- heartburn or reflux
- repeated chest infections

What help is available?

Anyone worried about or experiencing any of the problems described above should seek a referral to a speech and language therapist.

As well as advising on speech and language problems, these professionals are also experts in swallowing. They can assess swallowing problems and may be able to give the person exercises to help overcome them. If this is not appropriate, the speech and language therapist will work with specialists to consider other options. In most places, self-referral to a speech and language therapist is possible. A medical referral may be required for swallowing problems and this can be done by a GP, consultant or Parkinson's Disease Nurse Specialist. See the PDS information sheet Speech and Language Therapy for more information.

What kind of tests might be used to diagnose swallowing problems?

If swallowing is a problem, a speech and language therapist may refer the person for further tests. These may include:

Videofluoroscopy – This is a videoed procedure carried out in the X-ray department. It allows the stages of the swallow to be examined in detail. The person is asked to eat and drink small amounts of food and liquid mixed with barium or another radio opaque contrast. It is then possible to watch what

happens during the biological process of the swallow and pinpoint areas where there may be problems. Different positions of the head and neck and new techniques may be tried out and the effects on swallow observed.

Fibreoptic Endoscopic Examination of Swallowing Safety (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 and into the throat. It is possible to observe how efficient the swallow is, whether the vocal cords are working normally and how well the airway is protected. Referrals may be made to other professionals for further examinations such as an Ear Nose and Throat consultant (ENT) or gastroenterologist.

Laryngoscopy – A small flexible tube with a light at the end is passed into the back of the throat to examine the throat, larynx and tongue.

As some of these procedures involve you positioning your head carefully and keeping still, the specialist will discuss the practicalities with you.

How can my problems be treated?

Following an appropriate assessment to identify the particular problems, treatment may be suggested. This might include:

- making the person with Parkinson's and their family more aware of their particular swallowing difficulties
- adjustments to the person's posture when eating or drinking
- exercises to strengthen the lip, tongue and throat muscles
- modifications to the diet to make foods and liquids easier and safer to swallow, such as avoiding hard, dry or crumbly foods



Parkinson's
Disease Society

- liaising with the medical team to ensure timing of medications allows optimal swallow function at meal times
- improving breathing techniques

Using these and other techniques, the therapist can limit the risk of choking and make swallowing less difficult and more comfortable.

Speech and language therapists may advise and work with the family of a person with Parkinson's. Sometimes the family do not realise that swallowing problems are the reason why meal times are so difficult. By helping them to understand and giving them advice on what to do to help, anxiety is reduced and they can all work together to make meal times more enjoyable.

What other problems can occur that may have an effect on my ability to eat and drink?

Sometimes eating and drinking problems are not to do with the physical aspects of swallowing, but are more to do with the practicalities of eating and drinking. These may include difficulties in getting the food up to the mouth or balancing a cup to drink. Tiredness at meal times is also common.

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

Occupational therapists can provide advice on ways to make eating and drinking easier. This may include equipment or suggesting techniques for making eating and drinking easier. Referral to an occupational therapist is either via the GP, consultant, Parkinson's Disease Nurse Specialist or self-referral through the local social services department.

Dieticians can offer advice on the best types of food to help people who have swallowing difficulties. They can also advise on ways of avoiding malnutrition, which may involve the

prescription of special nutritional supplements. The PDS booklet Parkinson's and Diet has more information on diet and the role of the dietician. Referral to a dietician is usually via the GP or hospital doctor.

Alternative feeding methods

Are alternative feeding methods sometimes used?

For some people, the solutions to swallowing problems described previously are not enough and some people may be advised to use an alternative feeding method. These may include feeding through the nose (nasogastric feeding) or with a tube directly into the stomach (gastrostomy feeding).

How can a person be fed through their nose?

This is known as nasogastric feeding. A small narrow tube is passed through the person's nostril down into their stomach. It is not a method that is used for a persistent problem with swallowing, but as a short-term solution.

How would a person get their medication if fed by this method?

Some drugs used to treat Parkinson's come in liquid or dispersible form and will easily pass down the tube. It is very important to note, however, that crushing tablets and passing them down the tube is not advised. Anyone using nasogastric feeding should discuss this issue with their doctor and pharmacist.

What about feeding directly to the stomach? How does this work?

The most common form of gastrostomy feeding is known as PEG (percutaneous endoscopic gastrostomy) feeding. This is used when people with severe swallowing problems need assisted feeding over a longer period.

It is a small feeding tube, which is inserted by a gastroenterologist under local or general anaesthetic into the stomach through the wall of the abdomen.

How will it help me?



Parkinson's
Disease Society

By fitting the PEG, a person can be given liquid feeds to build up their energy and nutritional state. This helps fight infection and improves wellbeing. This technique reduces anxiety because the specially prepared liquid feeds allow the person to obtain all the nutrition and hydration that they require. The risk of chest infections is reduced and energy levels pick up, with many people feeling more positive, less tired and not so hungry. Medications can also be given via this route.

What about having a bath?

Most people are advised to wash by hand or shower in the first two weeks after having the PEG fitted. Then the person being PEG fed will be shown how to close the tube before having a bath so that they can bathe safely. This also allows them to go swimming.

My mouth became sore and dry when my PEG was fitted – why?

Mouth and dental care is very important when using an alternative feeding method. The person may no longer be able to swallow any food or drink. Plaque builds up quickly, and gums become dry and sore. Breath is often stale and the mouth feels uncomfortable. It is very important that oral hygiene is increased, to ensure a fresh mouth and avoid the stigma and isolation of stale breath. Oral infections put people at higher risk of developing chest infections. Teeth must be brushed at least three times a day. Using a gentle mouthwash can also be helpful. See the PDS booklet *Parkinson's and Dental Health* for tips on oral health.

What about my drugs?

Anyone being fed by gastrostomy or nasogastric tube should discuss the administration of their drugs with their doctor before the tube is fitted. Medication should be given via the tube in liquid or solution form. Some drugs can be injected. The rotigotine transdermal patch, also known as Neupro, is now available, which delivers a constant dose of dopaminergic agents without the need to swallow tablets.

I am PEG fed and my friend says that I can still take food by mouth. Is it safe?

Some people do continue to take a little food and drink by mouth, even when they are PEG fed, but only after very careful assessment. This is necessary to ensure that the person has a safe swallow and will not choke or allow food to be inhaled into the lungs, which is very dangerous. The speech and language therapist will be the best person to advise on what is safe and suitable.

I find eating out embarrassing and so do the people I eat with. What can I do?

Many people find that eating out in restaurants or 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. Their partners, families or friends can also become embarrassed for them.

When we discuss this problem with people with Parkinson's and their carers connected with the PDS, we learn that it can be made less distressing 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 disease'. She says it never fails, people become caring, interested and they can then enjoy their meal in peace. However, some people with Parkinson's may prefer to eat in a place out of public gaze and it is important to find out what their preference is.

Families who find eating with a relative who has Parkinson's difficult should try to talk about the problem. Explain to any children involved that it is still dad or mum/granny or grandad, but their Parkinson's can make eating difficult for them and they need support, time and understanding.

The important thing to remember is that you have to feel safe when eating. If you are troubled by swallowing or eating problems, seek advice from a speech and language therapist. An occupational therapist can also advise on practical ways of making eating easier and equipment that may help. Some general information on eating and



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Disease Society

Information Sheet

drinking is also contained in the PDS booklet Parkinson's and Diet.

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