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Feeding options if you have swallowing problems after a stroke

Information for patients, relatives and carers

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How do we swallow?

Swallowing happens without us needing to think about it (a reflex). It can happen when we see or smell food, and when you put a spoon in your mouth.

We put the food or drink into our mouth, close our lips, chew with our teeth, move the food to the back of our mouth with our tongue, and then swallow.

The food or drink then goes down our food pipe (gullet/ oesophagus) into our stomach. Our throat helps to protect the windpipe by closing it off while we swallow. If this does not happen quickly enough, or we breathe in as we swallow, we cough to clear this. We all know what it is like when something goes down the wrong way.

Why is swallowing affected after a stroke?

After a stroke swallowing can be affected for a number of reasons:

- Some of the muscles involved in swallowing, like the lips, cheeks, tongue and throat, may be weak.
- Not being able to feel parts of the mouth or throat (less feeling).
- Problems putting all of the steps together into a smooth action.
- Problems protecting the windpipe (airway).
- Problems recognising food/ drink/ spoons. This means the swallowing reflex does not work.
- A mix of any of the above.

Sometimes when people have problems with their swallowing, they can drool or have spit (saliva) dribble out of their mouth. If saliva, food or fluids goes down the wrong way onto their chest, it can cause breathing problems and make them sick. Some people can swallow their saliva safely but cannot manage food and drink, as we use different types of swallowing to manage saliva. The greatest risk of infection always comes from saliva because it often has germs (bacteria) from the mouth.

How long does this problem last?

After a stroke almost half of patients have trouble swallowing in the first few days. For this reason, all patients that have had a stroke will have a bedside nurse swallowing test within the first 4 hours of being in hospital as per NICE guidelines. If you pass this, you can then eat and drink. If you do not, then you will be given some fluid through a vein (a drip). The test is repeated after 24 hours. If you still have a problem, you will be seen by a Speech and Language therapist. They may suggest a special diet, thickened fluids, or that you are not able to swallow safely and need to stay ‘Nil By Mouth’ (NBM).

Most people who have had a minor stroke will often be able to swallow again in the first 2 weeks.

Evidence shows that if you are over 85 years your swallowing recovery will be less. If you already had problems before your stroke where you needed people to care for you, for example, dementia, this may also affect your swallowing recovery. It will also affect your recovery in general.

Modified fluid and diet

After your swallowing test, the nurse or the Speech and Language therapist may feel that your swallowing is not quite normal. They may suggest that your drinks have a special powder added. This will make them thicker. Or that food that is either cold, or softer than normal (for example pureed) so it is safe for you to manage.

The ward will be able to give meals of this modified texture.

As the days pass your swallowing may improve. The amount of powder that you need in fluid, and / or the texture of your food, will change. This should only be done under the guidance of the nursing staff or Speech and Language therapist.

For some patients a soft diet may become their new normal, mainly for older patients with false teeth, or if you had a swallowing problem before the stroke.

What feeding options are there in the first few days?

Nasogastric (NG) tubes - a flexible tube that is passed up your nose, down the back of the throat and gullet into the stomach.

Benefits

- Allows all of the nutrients, calories, water and medication needed to go straight to the stomach.
- You do not need to have sedation or an anaesthetic to have an NG tube fitted

Possible problems

- Uncomfortable to pass. Some patients are aware of something at the back of their throat.
- Patients may pull it out on purpose or by accident. Sometimes to keep a tube in place the staff might use things like mittens (gloves that stop you using your hands) or a Nasal Bridle (a way to tie the tube into the nose). These may help keep the tube in place in the short–term.
- This cannot be used long-term as they can cause problems to the food pipe.

What feeding options are there in the longer term?

The best result is being able to swallow again or being able to swallow modified diet and fluid for example, thickened fluid and pureed diet.

When this does not happen the doctors will talk to you and your family to try to make a choice in your best interests about either **feeding at risk** or artificial feeding by a **Percutaneous Endoscopic Gastrostomy (PEG) tube**. This is a tube inserted into the stomach through the tummy (abdomen). It needs a camera test (endoscopy) with sedation and local anaesthetic.

This is a choice made by the medical team, but the views of the patient and family or friends will be considered. In an ideal world a patient would have made an advanced care plan or discussed their wishes whilst they were well that is, when they had capacity. Not many people do this though.

Long term artificial feeding does not improve the **quality of life.** It will not make the difference between a patient walking again or not. This has been proven in many clinical trials.

It does not change the **quantity of life** in most people who have had a stroke. They do not live longer. In fact they may have more time in hospital due to complications.

Although a procedure may be possible, it may not always be the best thing to do.

There is a very small group of stroke patients who have other medical conditions affecting their swallow that will improve in time. In this case a PEG tube may be useful. However, most patients who have this degree of swallow problem a PEG may not be in their best interests due to how bad their stroke was.

PEG tubes are used in a number of medical conditions. This leaflet is just about stroke patients.

Percutaneous Endoscopic Gastrostomy (PEG) tubes

Benefits

- It is a permanent tube (although it can be taken out after 6 months if needed).
- Patients can be fed in a way that suits them, for example, having feeds overnight.
- Medicine can be given through the PEG tube too.

Possible problems

- It has a risk of bleeding, infection or perforation (rupture of the gullet or stomach) at the rate of about 1 in every 100 patients
- This is a type of ‘invasive procedure’. This means that some surgery is involved. Patients need to be able to lie still and open their mouth when asked.
- Patients will not get taste or social enjoyment of food or drink
- Confused patients can still pull or dislodge the tube, although this is much less than with NG tubes.
- Patients may still get chest infections due to saliva going into the lungs (aspiration) or food coming back up the gullet (reflux).
- There is no evidence that a PEG will improve stroke recovery or raise length of life except in a very small group of patients who doctors will be able to identify and advise.

- It will not improve quality or quantity of life for most patients.
- Patients are very likely to still get other complications caused by the how bad their stroke was (infections, pressure sores, further strokes, heart attacks) and die despite being fed.
- Some studies show that PEG tube fed patients have more admissions to hospital in their last few months of life.

Feeding with risk

This means giving a patient food or fluid (either normal or modified texture) whilst knowing that there is a major risk of it going down the wrong way. This can cause an infection, which may lead to death.

Benefits

- Patient gets a taste of food / fluid
- Eating is a social pastime and can be good for the patient
- Sometimes practice makes the swallow better. Textures can be changed over time

Possible problems

- May upset patient.
- May upset the person feeding the patient.
- May have a higher risk of choking.
- Can take a lot of time and patience to feed a patient. They may get very tired
- May not be able to take enough food / fluid to meet all dietary needs. They may lose weight / become more ill
- If an infection develops, this may not respond to treatment and treatment may not be in the patients best interests.

Life expectancy will be limited. The focus of care would be on improving the quality of the patients life for as long as possible

Multi-disciplinary team members

Nurses, doctors, speech and language therapists, and dieticians will all be involved. You can ask any of them about this.

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