



# A guide to...

# Risk acknowledged feeding Patient Information

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## **Unsafe Swallowing**

Swallowing problems (**dysphagia**) can be caused by a variety of conditions including dementia, stroke, neurological disorders (e.g. Parkinson's disease, Multiple Sclerosis, Motor Neurone Disease), learning disability and general acute or chronic illness.

If you, or a relative, are experiencing swallowing problems, there may be a risk of food, fluid and saliva "going down the wrong way" and entering the windpipe or lungs, this is known as **aspiration**.

Aspiration can be uncomfortable and result most notably in coughing and spluttering when eating and drinking. However, sometimes aspiration can occur with no immediate signs or symptoms, this is known as **silent aspiration**.

Aspiration can have a negative impact to health, particularly if it is happening regularly, as it can lead to **aspiration pneumonia** (an infection in the lungs). In some cases, these pneumonias can be fatal.

Speech and Language Therapists specialise in the assessment and treatment of swallowing problems and in many cases can find ways to compensate for the swallowing problem and significantly reduce the risk of aspiration. They may suggest modified diet or fluid consistencies or advice on strategies and positions to enhance safer eating and drinking.

However, for some patients, even with such compensatory strategies, their swallow is not safe and the risk of aspiration cannot be significantly reduced.

#### Alternative nutrition and hydration

If you have an unsafe swallow, **nil by mouth** with alternative nutrition and hydration is sometimes an option. This means not having any food or drink by mouth. Instead, a feeding tube can be inserted directly into the stomach (Percutaneous Endoscopic Gastrostomy) as a longer term option or via the nose (Nasogastric Tube) as a shorter term option. This aims to significantly minimise the risk of aspiration. However, the risk cannot be fully eliminated as saliva or regurgitated feed could still be aspirated.

There are many people who, despite having an unsafe swallow, are unsuitable candidates for alternative nutrition and hydration for the following reasons:

- The risks of long-term tube feeding, for example: infection risk, trauma to the food pipe or stomach, pain and discomfort, outweigh the benefits
- The patient refuses tube feeding
- Tube feeding would not maintain or improve quality of life.

It is important to note that there is currently no evidence to suggest that long term tube feeding prolongs the life expectancy of people with progressive conditions such as dementia.

Risk acknowledged feeding should be considered when people have an unsafe swallow with all food and drink consistencies and are not suitable for tube feeding.

## **Risk Acknowledged Feeding**

Risk acknowledged feeding is when a person continues to eat and drink despite the risk of aspiration and/or choking while acknowledging the potential for a negative health impact due to aspiration and/or not being able to fully meet their nutritional requirements. This option is often appropriate when ensuring quality of life is the highest priority. It allows continued normality and social interaction associated with eating and drinking. Risk acknowledged feeding may therefore be appropriate for one or more of the following reasons:

- Advanced stage of illness where the person's swallow safety is not likely to improve
- When the preference to eat and drink takes priority over swallow safety.
- Tube feeding options are declined or inappropriate
- To have tastes of food or fluid which are pleasurable.

The decision to eat and drink with acknowledged risk is normally made by the patient themselves, with support from their family or significant others and relevant medical professionals. If there are concerns around the patient's ability to make important decisions for themselves, then a mental capacity assessment is carried out and the patient's wishes, as well as cultural and ethical beliefs are key to making the decision.

The medical team may also want to discuss with you and or your relative how any future aspiration-related pneumonias will be managed. It may be felt that further admissions to hospital and antibiotic treatment would not be appropriate and the focus should instead be on ensuring comfort and minimizing pain.

If the choice is made for risk acknowledged feeding, speech and language therapists may be able to outline food and drink consistencies that can reduce but not eliminate the risk of aspiration, thereby making eating and drinking a little safer. However, in some instances food or fluid modification will not improve the safety of the swallow at all and the person should eat and drink whatever they wish.

It is also important to note that a decision to risk feed is not permanent. If you, or your relative, decide that you no longer want to eat and drink with risk, this should be discussed with your doctor who will help you to reconsider the available options.

# Sensible precautions when eating and drinking include:

- You must be alert and sitting upright
- Assistance and supervision as required e.g. hand over hand feeding so that you can remain as independent as possible in feeding yourself
- Take small mouthfuls, slowly
- Be aware your appetite may be smaller than normal
- Smaller, more frequent meals/snacks and drinks may be easier
- Take plenty of time for each mouthful to be swallowed
- Avoid the use of straws and spouted cups unless advised, as these may increase risk of choking or aspiration

• It is important to have foods and drinks you enjoy but bear in mind advice you have been given about the safest/most comfortable consistencies.

#### Oral hygiene

Good oral hygiene is important for comfort, and to ensure that bacteria do not build up in the mouth which can be carried to the lungs and lead to increased risk of chest infections.

- Your mouth should be cleaned frequently, a minimum of twice daily. You may need assistance from nursing/care staff.
- Dentures should be removed and cleaned daily. If dentures are very loose it may be best to keep them out, depending on your preference. Avoid leaving dentures in when lying back.
- Ensure you sit upright and lean forward to avoid toothpaste falling back into the throat during mouth care.
- Use a small amount (pea sized) fluoride toothpaste on a small soft toothbrush.
- Clean teeth and tongue gently using a toothbrush.
- Ensure you clear/rinse your mouth after. The water should not be swallowed. If you are unable to rinse, use lightly moistened pink sponge swabs around the gums and tongue to clear the toothpaste.
- Apply gel to lips to keep moist.

If you would like to discuss the information in this leaflet further, please speak to your doctor or speech and language therapist.