

Patient information

Feeding with acknowledged risks Information for patients and their families

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 your relative is experiencing swallowing problems, there may be a risk of food, drink and saliva "going down the wrong way" and entering the windpipe or lungs. **This is known as aspiration.**

Aspiration can be uncomfortable for you or your relative 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 be very dangerous, 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 advise on strategies and positions to enhance safer eating and drinking.

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

Alternative nutrition and hydration

If you or your relative has 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**) or via the nose (**nasogastric tube**). This aims to significantly minimise the risk of aspiration. However, the risk cannot be completely eliminated as saliva or refluxed feed could still be aspirated.

For some people, despite having an unsafe swallow, alternative nutrition and hydration is not felt to be appropriate as:

- The risks of long-term tube feeding (e.g., infection risk, trauma to the food pipe or stomach, pain and discomfort) outweigh the benefits.
- Tube feeding is refused by the patient
- 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.

When people who have an unsafe swallow with all food and drink and are not suitable for tube feeding, feeding with acknowledged risks should be considered.

Feeding with acknowledged risks

Feeding with acknowledged risks is when a person continues to eat and drink despite a significant risk of aspiration and / or choking. This option is often appropriate when ensuring quality of life is the highest priority. It allows continued enjoyment, comfort, pleasure and social interaction associated with eating and drinking. Feeding with acknowledged risks may therefore be appropriate for one or more of the following reasons:

- Advanced stage of illness
- 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.

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 minimising pain.

If the choice is made to continue feeding with acknowledged risks, a speech and language therapist 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.

The decision to continue feeding with acknowledged risks is normally made by the patient themselves, with support from their family or significant others and relevant medical professionals, particularly if there are issues around the patient's ability to make important decisions for themselves. The patient's wishes and cultural and ethical beliefs are key to making the decision. It is also important to note that a decision to continue feeding with acknowledged risks is not permanent. If you or your relative decides that they 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.

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