

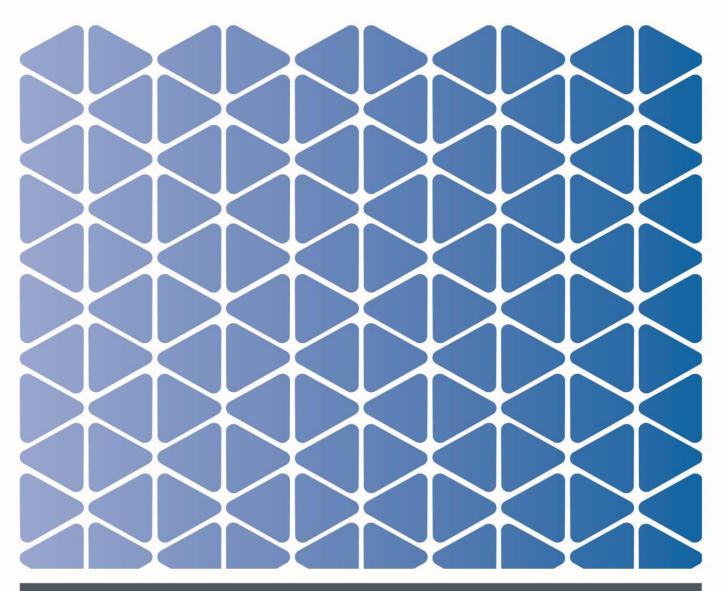


PATIENT INFORMATION

FEEDING AT RISK

(Eating and Drinking with Acknowledged Risks)

Information for Patients, Relatives and Carers





Feeding at Risk

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Swallowing Problems and Dysphagia

Swallowing problems, known as **dysphagia**, can be caused by a variety of conditions such as dementia, frailty, stroke, head and neck cancer, learning disability, general acute (short duration) or chronic (long term) illness, or neurological conditions e.g. Parkinson's disease Multiple Sclerosis, Motor Neurone Disease.

If your dysphagia is more severe there can be an increased risk of food, drinks and saliva 'going down the wrong way.' This means food, drinks or saliva may go through the windpipe (trachea) and into the lungs, rather than through the food pipe (oesophagus) and into the stomach. This is known as **aspiration**. Coughing, choking, a wet/gurgly sounding voice and feeling more short of breath when eating and drinking can be signs of aspiration. Sometimes these symptoms do not occur but food, drinks or saliva are still entering the lungs; this is known as **silent aspiration**.

Aspiration can develop into a chest infection known as **aspiration pneumonia** (an infection in the lungs). This can be serious or even fatal.

Speech and Language Therapists specialise in the assessment and management of dysphagia. They can provide advice to help compensate for the swallowing problem with the aim of reducing the risk of aspiration. This may include diet and fluid modification, strategies and positions to optimise safer eating and drinking.

Sometimes these changes are not beneficial or are not appropriate, and so the aspiration or choking risk cannot be significantly reduced.

Clinically Assisted Nutrition and Hydration

If your dysphagia is more severe and your swallow is unsafe, nil by mouth with alternative nutrition and hydration may be an option. This means not having any food or drink by mouth. Instead a feeding tube can be inserted via the nose (**nasogastric tube** – short term) or directly into the stomach (PEG; **percutaneous endoscopic gastrostomy** – longer term). This can reduce the risk of aspiration and choking, whilst optimising nutrition and hydration. The risk cannot be entirely eliminated as saliva or specialist tube feed can be aspirated.

Alternative nutrition and hydration is not always suitable for everyone. Here are some of the reasons;

- You may not want to have a feeding tube
- Tube feeding will not maintain or enhance your quality of life e.g. in more advanced dementia
- The risks of tube feeding e.g. infection risk, trauma to the food pipe or stomach, pain or discomfort) outweigh the benefits.

If you have **either** an unsafe swallow **and/or** malnutrition and dehydration cannot be avoided **and where** tube feeding is not suitable **then** 'feeding at risk' should be considered.

Feed at Risk*

Feed at risk describes when you continue to eat and drink orally despite a significant risk of aspiration and choking. A potential consequence of this may be malnutrition and dehydration; your swallowing difficulty may mean you are unable to eat and drink enough to meet your nutrition and hydration needs. Feed at risk is often appropriate where quality of life is the highest priority; enabling you to continue to eat and drink for enjoyment, comfort and pleasure.

This option may be appropriate for one or more of the following reasons;

- Advanced stage of illness and/or poor prognosis
- Swallowing is not likely to improve
- Eating and drinking takes priority over swallow safety in terms of quality of life and/or comfort
- As a consequence of the dysphagia, it is no longer achievable or appropriate to aim to meet full nutritional requirements to prevent weight loss and/or maintain nutritional status
- Tube feeding options have been declined or are inappropriate.

If a feed at risk approach is the most suitable, the medical team will discuss advance care planning with you or the people most closely involved with you. This will include how future aspiration related pneumonias will be managed. It may be that further admissions to hospital and/or antibiotic treatment are not appropriate and the focus should be on optimising your comfort.

Speech and Language Therapists may be able to provide food and drink consistencies which can reduce but not eliminate the risk of aspiration or to provide the most comfort

when swallowing. Sometimes there are no safer food and drink textures or you may not wish to alter your food and drink choices; you should then have your preferred food and drinks.

In some cases Dietitians may be able to advise on fortifying certain foods and/or prescribe oral nutritional supplements to help increase your nutritional intake. However, each case is considered individually as fortification/oral nutritional supplements are not always appropriate.

You will be included in the decision making process along with relevant medical and health professionals. If you do not have the ability to make a decision on your feeding management (you lack **mental capacity**) then support from family or significant others may be sought to make a **best interests decision**. If you have previously expressed your wishes on this topic these will be considered in making the decision. If you have questions about mental capacity, please discuss these with the medical or health professionals involved.

Once a feeding at risk decision is made, it does not have to be permanent. Here are some reasons;

- Occasionally a person's swallowing does improve. Following re-assessment by a speech and language therapist you may be able to eat and drink safely, with or without modified food and fluids or other strategies.
- You may want to re-consider having alternative nutrition and hydration, if this option is suitable, rather than continuing to eat and drink at risk.
- You are eating and drinking sufficient quantities, so have significantly reduced your malnutrition and dehydration risk.

It is important that this is discussed with your doctor to help review the available options.

* Feed at risk is the term adopted by Worcestershire Acute Hospitals Trust. Other terms may be eating and drinking with acknowledged risk, risk based feeding, comfort feeding.

Tastes for Pleasure

For some people eating and drinking by mouth may no longer be comfortable or achievable e.g. you are not awake enough or if it causes distress. If this happens then 'tastes for pleasure'* can be provided. 'Tastes for Pleasure' means that your favourite flavours can be given during mouth care (cleaning and hydrating the mouth). These flavours can be anything from tea, coffee, to orange squash or even Prosecco. 'Tastes for pleasure' is not a form of nutrition and hydration and is only suitable for people on an end of life care pathway*** (where you are considered to be within the last few days of life); it is acknowledged that eating and drinking sufficient quantities to sustain life is no longer the priority, but the focus is on comfort. You can request further information about Tastes for Pleasure.

**Tastes for Pleasure is the term adopted by Worcestershire Acute Hospitals Trust.

***Worcestershire Acute Hospitals Trust uses the Individualised Last Days of Life Care Plan for Adults for patients who are nearing the end of their life.

With acknowledgement and thanks to West Suffolk NHS Foundation Trust and the Royal College of Speech and Language Therapists

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.