

Making the decision to eat and drink with acknowledged risk of deterioration

A guide for patients, their families and carers

This leaflet explains about eating and drinking when there might be a risk of deterioration. It explains this term and why this plan might be used to manage nutrition and hydration.

If you have any further questions or concerns, please do not hesitate to contact your speech and language therapist, doctor, nurse or dietitian.

What are the risks with eating and drinking?

Many people have problems with eating, drinking and swallowing. The medical term for this is dysphagia. Some people with dysphagia have problems swallowing certain foods, liquids or saliva. It can occur in varying degrees ranging from mild discomfort or difficulty, to a complete inability to swallow.

Swallowing problems may lead to the following:

- Food and drink may enter the airway (leading to the lungs) instead of the food pipe (leading to the stomach). This is called aspiration.
- Aspiration can cause coughing, choking, discomfort and chest infections. Choking and chest infections can be a potential cause of death.
- Difficulty maintaining weight and good health.

In many cases, a speech and language therapist will be able to identify different strategies to help improve the safety of swallowing, however this is not always possible.

What does eating and drinking with acknowledged risk mean?

This refers to the plan to continue eating and drinking, despite knowing that there are risks involved with this. This is often to maintain comfort and quality of life.

How else can food and drink be given if swallowing is unsafe?

In some cases it may be appropriate to receive food and drink through a feeding tube, for example Nasogastric (NG) or Percutaneous Endoscopic Gastrostomy (PEG) tubes. Some people continue to eat and drink small amounts while also having a feeding tube, while others will be nil by mouth (i.e. will not eat and drink) and will receive all of their needs via the tube. If a patient is suitable for a feeding tube this will be discussed with them by their doctor, speech and language therapist or dietitian.

However, feeding by tube is not always beneficial. It may not help a person to live longer and may not protect them against aspiration. Placement of feeding tubes can be uncomfortable and distressing. The decision to have a feeding tube therefore needs to be made on an individual basis.

How is the decision to eat and drink with acknowledged risk made?

Each person will have a mental capacity assessment, carried out by a healthcare professional, to determine if they have the mental ability to make a decision about continuing eating and drinking after considering the risks and benefits.

If you are the patient and you have capacity to make this decision, it will be documented so you will not be made nil by mouth against your wishes. You can change your mind at any time by discussing this with a healthcare professional.

If the assessment shows that the patient does not have capacity, they will not be able to decide for themselves whether to continue eating and drinking or to consider feeding by tube. Decisions about feeding are made by a multi-disciplinary team of healthcare professionals including the medical team, speech and language therapist and dietitian, along with support from close relatives and carers. If the patient has a health and welfare Lasting Power of Attorney, the people appointed as attorneys will help make decisions or be able to make decisions on behalf of the patient.

If a person has previously made a written statement (sometimes called an advance directive or living will) stating they do not wish to be fed by tube, then these wishes will be respected. If it is felt feeding by tube may benefit the person or help them for a short period whilst they are unwell, this may be trialled for a set period of time.

How relatives and/or friends can support the patient

Depending on what has been agreed about feeding, relatives and/or friends can still offer food and drink to the patient, but they should not put pressure on them if they do not want to eat or drink. Good support can be by ensuring regular care of the patient's mouth (see below).

How eating and drinking can be made as safe as possible when risk feeding

- When eating and drinking, ensure the patient is sitting upright (in a chair if possible) and is fully alert. Avoid meals if drowsy.
- Regular good mouth care e.g. brushing teeth, cleaning dentures, dental check-ups.
- Stop eating/ drinking if this becomes distressing or if there is excessive coughing/ choking. Take a break and try again at a later time.
- If the patient is unable to feed themselves, gently place a hand over theirs to guide the fork or spoon to their mouth.
- Slow pace of eating. Ensure each mouthful is completely finished before starting the next.
- A speech and language therapist will be able to recommend the most comfortable textures/consistencies of food and drink.

What happens if the patient becomes unwell?

It is important to make plans with the medical team about treatment if the patient's health should deteriorate as a result of risk feeding. For example, plans may include how a potential chest infection or pneumonia would be treated and whether this would take place at home or in hospital. All plans for future medical treatment should be discussed on an individual basis with the patient's GP or Consultant.

If you are concerned about weight loss whilst risk feeding at home, you can request a referral to the dietetic services for support through your GP.

Who should I contact if I have questions about risk eating and drinking?

Name of Speech and Language Therapist.....

Name of Dietitian.....

Name of Consultant/Ward Doctor/GP.....

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748, Monday to Friday, 9am-5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk



Leaflet number: 4684/VER1
Date published: January 2019
Review date: January 2022
© 2019 Guy's and St Thomas' NHS Foundation Trust
A list of sources is available on request