Eating and Drinking with Acknowledged Risk (EDAR) Previously known as Palliative Feeding for Comfort

A practical guide for relatives and carers about food and fluid for patients with advanced disease / severe frailty

Introduction

This guide provides practical guidance on Eating and Drinking with Acknowledged Risk (EDAR), to help reduce risks of infection and maintain or enhance enjoyment of eating, drinking and quality of life. It is important to be aware that this may not meet all of a person's nutritional needs.

This information is about conditions which can affect the ability to swallow safely. People with some advanced diseases can have difficulty swallowing which can put them at risk of chest infections or pneumonia. Tube feeding is sometimes considered instead of continuing to eat and drink by mouth. However, for some people tube feeding is not possible, not in their best interests, or they may have chosen to refuse tube feeding.

This is when Eating and Drinking with Acknowledged Risk (EDAR) may be suggested. EDAR means continuing to eat and drink by mouth, despite the risk that doing so might cause a chest infection or pneumonia.

Effects of having a swallowing difficulty

Having a swallowing difficulty can cause one or more of the following:

- Difficulty chewing or swallowing foods
- Difficulty swallowing drinks
- Keeping food and drink in the mouth
- Food left in the mouth after eating
- Food or drink 'going down the wrong way' and causing coughing
- Recurrent chest infections

Food or drink that 'goes down the wrong way' can cause chest infections or pneumonia. Some people who have a swallowing difficulty do <u>not</u> choke on food or drink, even if it 'goes down the wrong way'. This means food or drink can 'go down the wrong way' without anyone being aware it has happened.

How healthcare staff can help

Patients who develop a swallow difficulty can be supported by a Speech and Language Therapist (SLT). SLTs will give advice on the safest food and fluid textures.



The Local SLT team in the community are based at Amersham Hospital, and can be contacted for help and advice, if required. Our contact number is 01494 323440. Our working hours are Monday – Friday, 8.30am – 4.30pm.

Patients with swallowing difficulties may also be referred to a Dietitian for nutrition advice and support. Dietitians will give advice on how to ensure the right food and fluid texture provides the nutrition needed. Dietitians and SLTs therefore often work closely together.

Practical advice – Swallowing

- Advice may be given to have soft, minced, or pureed food. These textures can be safer to manage for people with a swallowing difficulty.
- Information sheets are available on: https://iddsi.org
- Thickening drinks may also be advised but only where this is necessary
- Food that is very cold can be better to swallow than food that is lukewarm e.g., chilled yoghurt.
- Strongly flavoured food (e.g., very sweet, spicy, sharp etc.) can be better than bland flavours.
- Soft and pureed frozen meals are available to buy from several companies e.g., Wiltshire Farm Foods, Oakhouse Foods, Mrs Gills. These meals are made to the textures advised by SLTs and can also help to meet nutritional needs advised by Dietitians.

Practical advice – Mouthcare

To improve comfort and wellbeing, good mouth care (such as brushing teeth, rinsing mouth with mouthwash if able) can help lower the risk of a chest infection by reducing the amount of bacteria in the mouth.

Practical advice – Nutrition

- Offer small amounts of food and drinks frequently during the day. Many people with a swallowing difficulty may not manage to eat or drink large amounts at one time.
- Offer foods and drinks that you know the person likes.
- 'Normal' healthy eating guidelines, such as eating a diet low in fat and sugar, snacking between meals etc. **do not apply**.

'Food first' information sheets on Eating well for small appetites, Homemade sip feeds and Fortifying food for care homes are available from your GP, Dietitian or the internet

Patient information - Buckinghamshire Healthcare NHS Trust (buckshealthcare.nhs.uk) Select Nutrition and Dietetics from the list

Practical advice – Prescribed medicines



- If swallowing medicines is difficult, tell the person's GP, pharmacist, specialist Nurse or Community Nurse. The GP may be able to stop some medicine and others may be changed to soluble or liquid medicines, which can be easier to swallow. If liquid medications also need to be thickened, the Pharmacist can provide advice and support.
- We advise some people with a swallowing difficulty to have thickened drinks. Thickened drinks move more slowly and can make drinks easier and safer to swallow.
- The GP will be asked to prescribe the thickener "Nestle Resource Thicken Up Clear" (the thickener used in Buckinghamshire Healthcare NHS Trust) The amount of thickener needed by each person is likely to be different but will usually be at least 5 tubs (125g tub) per month.

Practical advice for people with Dementia

- Try to provide meals, snacks and drinks when the person is most alert.
- During any meal, snack or drink, the person may need to be reminded about the meal, snack, or drink and to swallow each mouthful.
- If you are helping someone with dementia to eat, ensure they have swallowed the last mouthful before offering another.
- Use gentle, physical prompts to help the person to eat by him or herself e.g., try putting the fork, spoon or cup in the person's hand and gently guiding it to his or her mouth.
- Try to keep the place where the person is eating as calm and free from distraction as you can.
- Some people with dementia develop a taste for very sweet foods and may prefer those to savoury foods.
- If a person with dementia wakes often during the night, it may be because of hunger. Try to keep some small snacks at hand that they can manage e.g., small tub of custard or smooth yoghurt, soft crisps such as Quavers.

Advance care planning

Many people are very concerned about how they will be cared for as they approach the end of their lives. Some may have read or heard stories in the media which make them anxious or worried they may not be given food or drinks when they feel hungry or thirsty.

Concerns like these are normal and giving some thought to what care or treatment you would accept, can help reduce these concerns. Thinking and talking about your wishes for how you are cared for in the final months of your life is called "advance care planning".

IMPORTANT – Check with Relatives and/or Family if there is a Lasting Power of Attorney set up and in place for HEALTH & WELFARE

People usually carry out advance planning because they have a condition that is expected to get worse, and which may mean they will not be able to make decisions or communicate their decisions in the future. Initially please speak to your GP about putting this in place.

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Anyone can plan for their future care, whether they are approaching the end of life or not. Advance care planning can let people know your wishes and feelings, while you are able to tell people.

Patient information – Advance Care Plan template – Buckinghamshire Healthcare NHS Trust (buckshealthcare.nhs.uk)

End of Life (Palliative Feeding for Comfort)

People may worry that as a person approaches the end of their life and their food and fluid intake reduce, that the person will feel hungry and thirsty. However, it is often the case that the person may not feel hungry or thirsty, and this is a natural part of the body slowing down.

Frequent mouth care can help to reduce feelings of thirst. Offer frequent sips of fluid and help with cleaning teeth or dentures if the person would like this.

If the person is hungry, the Nutrition and Swallowing advice on Page 2 should help you. Offer the person whatever they would like to eat and drink, as long as it is not causing distress or discomfort.

Patient information – Care in the last days of life at home – Buckinghamshire Healthcare NHS Trust (buckshealthcare.nhs.uk)

Contact information

Speech and Language Therapist (SLT), Community and Outpatient Services, Amersham Hospital 01494 323440

Nutrition and Dietetics 01296 831990 (select option 3 for community dietetics) Monday to Friday, 8.30am to 4.30pm.

Please remember that this leaflet is intended as general information only. We aim to make the information as up-to-date and accurate as possible, but please note that it is subject to change. Please therefore always check specific advice on any concerns you may have with your GP.

How can I help reduce healthcare associated infections?

Infection prevention & control is important to the well-being of our patients and for that reason we have infection prevention & control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. Please follow our infection prevention and control guidelines when visiting our healthcare sites. Further information is available on our website

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Infection Prevention and Control - Buckinghamshire Healthcare NHS Trust (buckshealthcare.nhs.uk)

Patient Advice Sheet

If you would like a copy of this information on audiotape, **in large print** or translated, please call the Patient Advice Liaison Service on 01296 831120 or email <u>bht.pals@nhs.net</u>

