Palliative feeding for comfort: A practical guide for relatives and carers about food and fluid in advanced disease / severe frailty

Carer Information Leaflet

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Introduction
This guide provides practical guidance on ‘comfort feeding’ to help reduce risks and maintain or enhance enjoyment of eating and drinking and quality of life. It is important to be aware that comfort feeding may not meet all of a person’s nutritional needs.

This information is about conditions which can affect peoples’ 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. However for some people tube feeding is not possible, not in the person’s best interests, or the person themself may chosen to refuse tube feeding.

This is when ‘palliative feeding for comfort’ may be suggested. ‘Palliative feeding for comfort’ or ‘comfort feeding’ means continuing to eat and drink 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:

- Chew / swallow food or drinks
- Keep food and drink in the mouth
- Food left in the mouth after eating
- Food or drink ‘going down the wrong way’ and causing coughing

Food or drink that ‘goes down the wrong way’ can cause chest infections or pneumonia. Some people who have a swallowing difficulty do not 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.

Health care staff who can help

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

The local SLT team can be contacted for help and advice if required.

People with swallowing difficulties may also be referred to a Dietitian for nutrition advice and support. Dietitians will give advice on how to make sure that the right food and fluid texture provides the nutrition that we need. Dietitians and SLTs therefore often work closely together.

Practical advice - Swallowing

- Advice may be given to have a soft, mashed or pureed food and thickening drinks may also be advised. These textures can be safer to manage for people with a swallowing difficulty
- Information sheets on ‘Soft Diet’ and ‘Pureed Diet’ are available on: http://www.careadvicebuckinghamshire.org/s4s/WhereILive/Council?pageId=2055
- Food that is very cold can be better 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 as advised by Dietitians.
Practical advice - Mouth care
Good mouth care (such as brushing teeth, rinsing mouth with mouthwash if able) can really help to reduce the risk of a chest infection by reducing the amount of bacteria in the mouth and improving comfort and wellbeing.

Practical advice - Nutrition
• Offer small amounts of food and drinks frequently during the day. Many people with a swallowing difficulty cannot eat or drink large amounts at one time.
• Offer foods and drinks that you know the person likes.
• ‘Normal’ healthy eating guidelines (eating a diet low in fat and sugar, avoiding 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 http://www.bucksformulary.nhs.uk/docs/avc/

Practical advice - Prescribed medicines
• If swallowing medicines is difficult, tell the person’s GP, 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.
• Some people with a swallowing difficulty are advised to have thickened drinks. Thickening drinks slows down how quickly they move, which can make them easier and safer to swallow. If the person needs thickened drinks, any liquid medicines might need to be thickened too.
• The persons GP will be asked to prescribe a thickener to use in all drinks. In Buckinghamshire a thickener called ‘Resource ThickenUp Clear’ is usually used. 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 with dementia may need to be reminded about the meal, snack or drink. They may also need to be reminded to swallow each mouthful.
• If you are helping someone to eat, make sure 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 e.g. small tub of custard or smooth yogurt, 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 hear of stories in the media which make them anxious, or they are worried that they may not be given food or drinks if 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".

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.

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're able to tell people.

End of life
People may worry that as a person approaches the end of their life and their food and fluid intake reduces, that the person will feel hungry and thirsty.

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 Practical advice above should help you.

How can I help reduce healthcare associated infections?
Infection control is important to the well-being of our patients and for that reason we have infection control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to or after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser. Staff will let you know if this is the case.

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