Buckinghamshire Healthcare NHS Trust

Palliative Comfort Feeding

BAPEN Annual Conference 2017

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November 2017

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Objectives

- To promote reflection on quality of life in nutrition and swallowing management
- To discuss the role of risk/comfort feeding
- To share the process of guideline development in Bucks
- An opportunity for case discussion

Impact of feeding problems

- Multiple areas are impacted – physical, spiritual, emotional, nutritional, social.

Reduced pleasure from eating due to effort or embarrassment.

Reluctance to eat with other people, family members reluctant to eat around the person

Conflict with differing opinions about necessity of changes

Diet changes decrease satisfaction, extra time and expense for family to prepare.

ANH may be inappropriate if:

- The risk of the procedure outweighs the benefit
- The patient themselves declines ANH or has a valid advance directive.
- The patient has poor prognosis/life expectancy.
- The patient has advanced dementia. There is little evidence that ANH will improve quality of life or prolong life in advanced dementia (Royal College of Physicians 2010).

Ekberg (2002)	**Interviewed residents in long-term care settings and found that social and psychological consequences were not well recognised or managed. Many with dysphagia avoided eating with others and less than half reported eating was enjoyable. More than 50% reported eating less and many were still hungry and thirsty after meals.**	
Davis (2007)	75% patients do not like thickener, many dislike puree (15-20% of individuals in long-term care are on this type of diet)	

Professionals are becoming more sensitive to QOL issues and more in tune with patients.

Lim et al (2016)	Found that there was no significant difference between patients and professionals values in judging the use of thickened fluids on quality of life i.e. that long-term use of thickened fluids would significantly impair quality of life (on average those allocated Grade 2 were willing to sacrifice 5 years of a 10 year life-span not to be restricted).	

Balancing Risk and Quality of Life

The case of the pink wafer biscuit.

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Quality of Life

Healthcare professionals need to be mindful of how seriously changes in eating can affect and individual

Recommendation should not be made lightly.

Increasingly healthcare professionals are emphasizing the importance of quality as well as longevity of life.

Value time spent in healthcare settings working on the mealtime experience.

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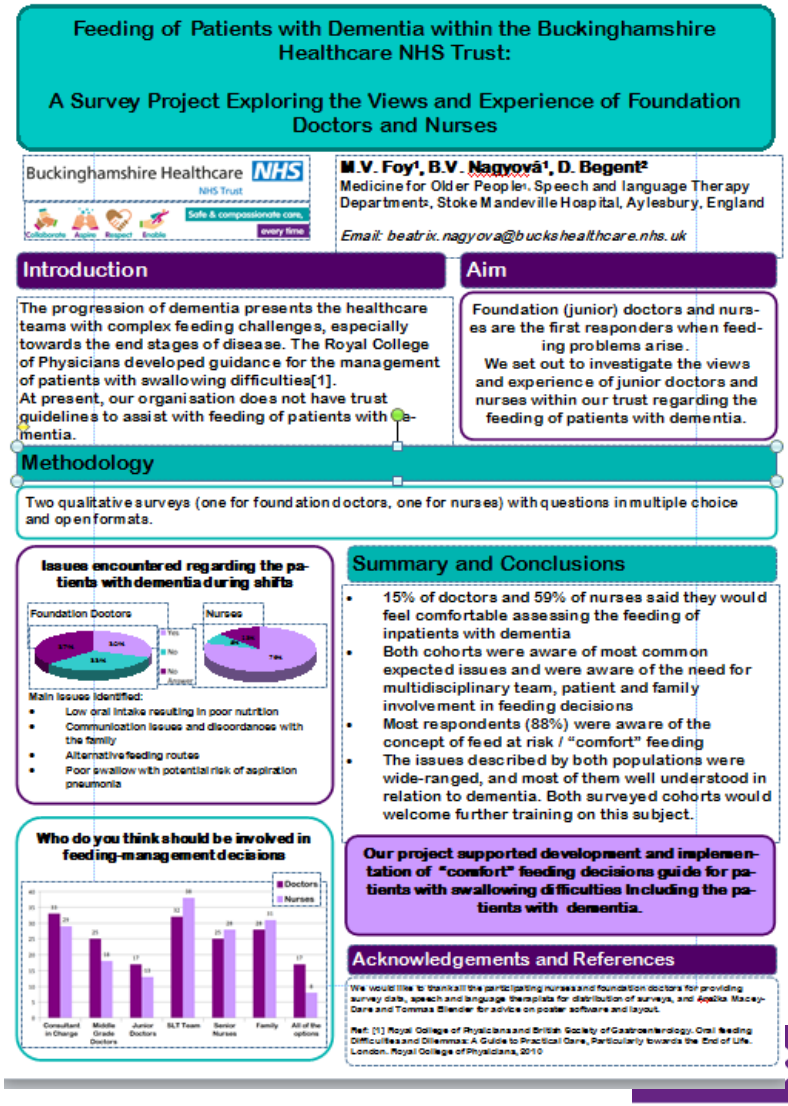
Audit of Practice in Bucks



Feeding of Patients with Dementia within the Buckinghamshire Healthcare NHS Trust:

A Survey Project Exploring the Views and Experience of Foundation Doctors and Nurses

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Introduction

The progression of dementia presents the healthcare teams with complex feeding challenges, especially towards the end stages of disease. The Royal College of Physicians developed guidance for the management of patients with swallowing difficulties[1].
At present, our organisation does not have trust guidelines to assist with feeding of patients with dementia.

Aim

Foundation (junior) doctors and nurses are the first responders when feeding problems arise.
We set out to investigate the views and experience of junior doctors and nurses within our trust regarding the feeding of patients with dementia.

Methodology

Two qualitative surveys (one for foundation doctors, one for nurses) with questions in multiple choice and open formats.

Issues encountered regarding the patients with dementia during shifts

Foundation Doctors

Nurses

Yes
No
No Answer

Main issues identified:

- Low oral intake resulting in poor nutrition
- Communication issues and discordances with the family
- Alternative feeding routes
- Poor swallow with potential risk of aspiration pneumonia

Who do you think should be involved in feeding-management decisions

Doctors
Nurses

Consultant in Charge
Middle Grade Doctors
Junior Doctors
SLT Team
Senior Nurses
Family
All of the options

Summary and Conclusions

- 15% of doctors and 59% of nurses said they would feel comfortable assessing the feeding of inpatients with dementia
- Both cohorts were aware of most common expected issues and were aware of the need for multidisciplinary team, patient and family involvement in feeding decisions
- Most respondents (88%) were aware of the concept of feed at risk / "comfort" feeding
- The issues described by both populations were wide-ranged, and most of them well understood in relation to dementia. Both surveyed cohorts would welcome further training on this subject.

Our project supported development and implementation of "comfort" feeding decisions guide for patients with swallowing difficulties including the patients with dementia.

Acknowledgements and References

We would like to thank all the participating nurses and foundation doctors for providing survey data, speech and language therapists for distribution of surveys, and Agatka Macey-Dare and Tommas Blender for advice on poster software and layout.

Ref: [1] Royal College of Physicians and British Society of Gastroenterology. Oral feeding Difficulties and Dilemmas: A Guide to Practical Care, Particularly towards the End of Life. London. Royal College of Physicians, 2010

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Findings

- Patients dysphagia towards the end of life were not being managed consistently and practice was not in line with RCP guidelines (RCP, 2010).
- There was no clear guidance for decision making.
- There were preventable admissions.
- Patients were waiting ‘nil by mouth’ for a decision.

- ‘Doctors have a responsibility to consider timely discussions, but not all may do so consistently.’ (RCP Oral Feeding Difficulties and Dilemmas 2010)

➢ **Need for a clear framework and decision making tool**

Development of the Guidelines

- Group of stakeholders came together. Representatives from CCG, patient groups, MDT from Acute and Community, Care Homes.
- Underlying principle; ‘Comfort’ or ‘risk’ feeding are terms used to describe continuation of careful hand feeding when Alternative Nutrition and Hydration is not appropriate, while acknowledging there are risks in doing so (e.g. aspiration), and minimising these risks as much as possible.
- Palliative care is defined as “the active holistic care of patients with advanced illness” (NICE 2004). The goal of palliative care is to achieve the best quality of life for patients and their families
- Although the food and drink provided may not fully meet the nutritional/hydration needs of the patient, it is intended to provide comfort and an overall feeling of wellbeing.
- The group agreed to use the term; Palliative Comfort Feeding.

Staff Leaflet

Person-Centred Care

- A feeding plan tailored to the individual and their requirements and not the needs of others or the organisation. This may require finding a balance between risk and an individual's personal wishes and comfort.
- Flexible care responding to a person's needs which may fluctuate or change quickly e.g. using thickened fluids to stop people struggling and coughing on fluids, potentially avoiding further deterioration or admission.
- Staff being aware of cognitive feeding issues and basic strategies to support people with these difficulties.
- All staff and volunteers who help feed patients should understand the signs of aspiration and swallowing difficulties.
- When admitting patients using 'nil by mouth' only when necessary and not as a matter of routine.
- Using thickened fluids to make drinking more comfortable if required in the last weeks and days of life.

Working Across Healthcare Settings

- Assessing capacity and documenting decisions about a palliative feeding plan.
- Ensuring this documentation is communicated if a patient changes healthcare setting.
- Discussing the feeding plan with families and explaining the focus of care is on comfort. Discuss the burdens and risks of tube feeding.
- Agreeing a plan if there is deterioration due to dysphagia e.g. appropriateness of anti-biotics and/or hospital admission.
- Thickener can be prescribed without a speech therapy assessment if it is going to alleviate symptoms.
- Care homes can refer directly to Speech and Language Therapy (SLT) with agreement of their covering practice. SLT can provide advice over the phone and follow up with a visit if required, supporting care home staff and responding to changing needs quickly.

NHS Aylesbury Vale Clinical Commissioning Group

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Buckinghamshire County Council

Buckinghamshire QiCT Quality in Care Team

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Palliative Comfort Feeding

Royal college of Physicians and British Society of Gastroenterology;
Oral feeding difficulties and dilemmas: a guide to practical care, particularly towards the end of life.
London: Royal College of Physicians, 2010.

'Oral intake, modified as necessary, should be the main aim of treatment.'

'Nil by mouth should be the last resort, not the initial default position.'

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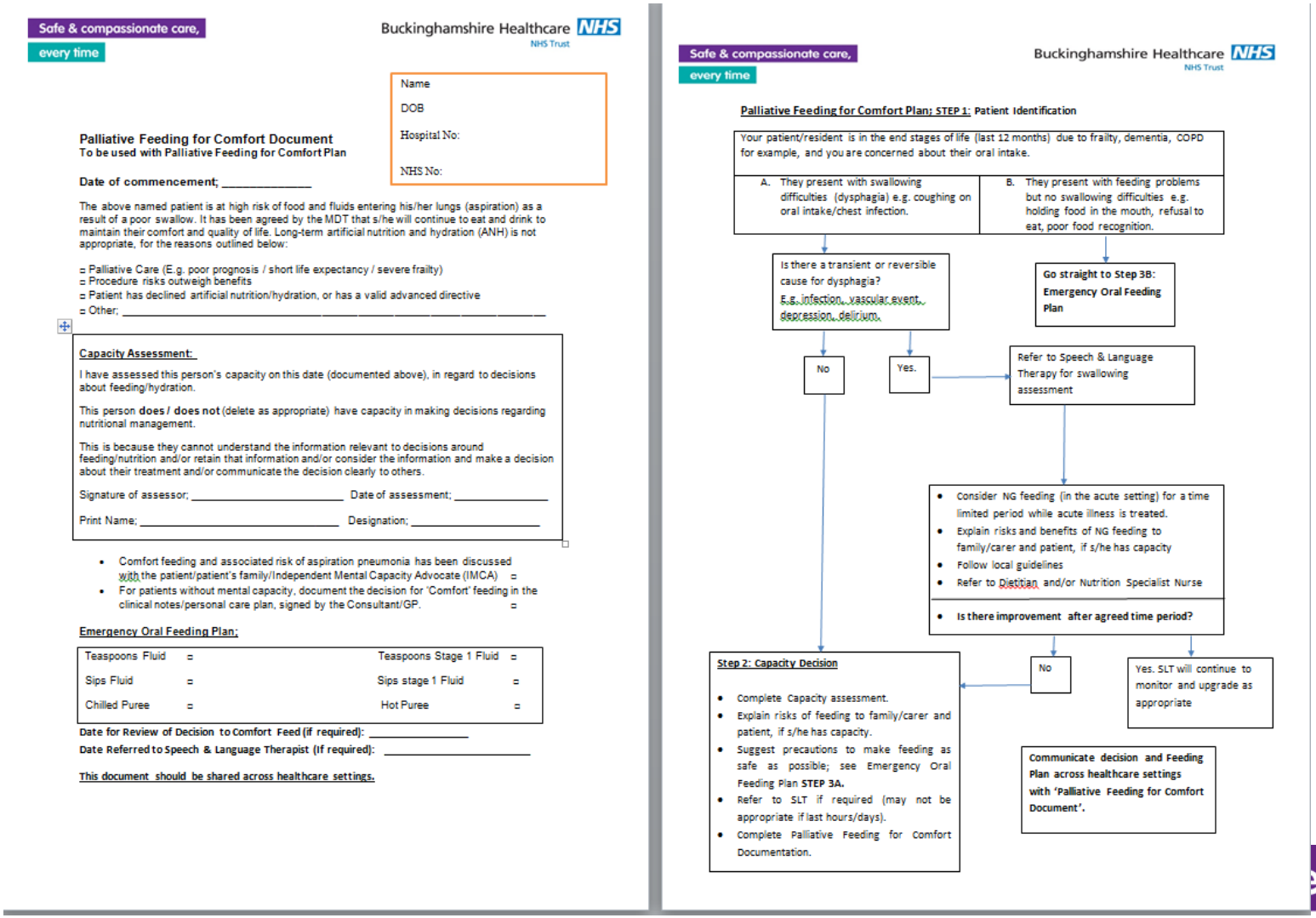
Documentation



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Name

DOB

Hospital No:

NHS No:

Palliative Feeding for Comfort Document
To be used with Palliative Feeding for Comfort Plan

Date of commencement; _____

The above named patient is at high risk of food and fluids entering his/her lungs (aspiration) as a result of a poor swallow. It has been agreed by the MDT that s/he will continue to eat and drink to maintain their comfort and quality of life. Long-term artificial nutrition and hydration (ANH) is not appropriate, for the reasons outlined below:

- ▫ Palliative Care (E.g. poor prognosis / short life expectancy / severe frailty)
- ▫ Procedure risks outweigh benefits
- ▫ Patient has declined artificial nutrition/hydration, or has a valid advanced directive
- ▫ Other; _____

Capacity Assessment:

I have assessed this person's capacity on this date (documented above), in regard to decisions about feeding/hydration.

This person **does / does not** (delete as appropriate) have capacity in making decisions regarding nutritional management.

This is because they cannot understand the information relevant to decisions around feeding/nutrition and/or retain that information and/or consider the information and make a decision about their treatment and/or communicate the decision clearly to others.

Signature of assessor; _____ Date of assessment; _____

Print Name; _____ Designation; _____

- Comfort feeding and associated risk of aspiration pneumonia has been discussed with the patient/patient's family/Independent Mental Capacity Advocate (IMCA) ▫
- For patients without mental capacity, document the decision for 'Comfort' feeding in the clinical notes/personal care plan, signed by the Consultant/GP. ▫

Emergency Oral Feeding Plan;

Teaspoons Fluid	▫	Teaspoons Stage 1 Fluid	▫
Sips Fluid	▫	Sips stage 1 Fluid	▫
Chilled Puree	▫	Hot Puree	▫

Date for Review of Decision to Comfort Feed (if required): _____

Date Referred to Speech & Language Therapist (If required): _____

This document should be shared across healthcare settings.

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Palliative Feeding for Comfort Plan; STEP 1: Patient Identification

Your patient/resident is in the end stages of life (last 12 months) due to frailty, dementia, COPD for example, and you are concerned about their oral intake.

A. They present with swallowing difficulties (dysphagia) e.g. coughing on oral intake/chest infection.

B. They present with feeding problems but no swallowing difficulties e.g. holding food in the mouth, refusal to eat, poor food recognition.

Is there a transient or reversible cause for dysphagia?
E.g. infection, vascular event, depression, delirium.

Go straight to Step 3B: Emergency Oral Feeding Plan

No

Yes.

Refer to Speech & Language Therapy for swallowing assessment

- Consider NG feeding (in the acute setting) for a time limited period while acute illness is treated.
- Explain risks and benefits of NG feeding to family/carer and patient, if s/he has capacity
- Follow local guidelines
- Refer to Dietitian and/or Nutrition Specialist Nurse

- **Is there improvement after agreed time period?**

No

Yes. SLT will continue to monitor and upgrade as appropriate

Step 2: Capacity Decision

- Complete Capacity assessment.
- Explain risks of feeding to family/carer and patient, if s/he has capacity.
- Suggest precautions to make feeding as safe as possible; see Emergency Oral Feeding Plan **STEP 3A.**
- Refer to SLT if required (may not be appropriate if last hours/days).
- Complete Palliative Feeding for Comfort Documentation.

Communicate decision and Feeding Plan across healthcare settings with 'Palliative Feeding for Comfort Document'.

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Emergency Feeding Plan

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STEP 3; Implement Feeding Plan

3A. Emergency Oral Feeding Plan for patients with Dysphagia on the Palliative Feeding for Comfort Pathway

Acute	Community
• Patient is alert and respiratory status is stable • Commence Teaspoons of water; if coughing on water thicken to Stage 1 (2 scoops Resource Thicken Up Clear per 200mls) • Commence teaspoons chilled puree e.g. yoghurt, fruit puree, mousse.	• Patient is to remain in the community. • Continue normal fluids; if coughing on water thicken to Stage 1 (2 scoops Resource Thicken Up Clear per 200mls) • Hot puree. Restrict to chilled puree if coughing on hot puree.
• Oral intake is for comfort, stop if patient is too drowsy, or oral intake causes discomfort. • Ensure mouth care is maintained. • Complete 'Palliative Feeding for Comfort Document' and document actions in notes/Heart and Minds Care plan. • Discuss referral with SLT. • Consider referral to Palliative Care.	

3B. Emergency Feeding Plan for Patient with Reduced Oral Intake on the Comfort Feeding Pathway

- Offer food and drink little and often.
- Offer high calorie foods and shakes.
- Consider finger foods if appropriate.
- Offer an empty spoon or dab the mouth with a napkin to stimulate a swallow when holding food in the mouth.
- Do not over-face with large portions
- Increase fluid intake with jelly, water melon.
- Taste may have changed or reduced, try thing which have more flavour like curry.
- Go with food preferences, don't worry about sticking with conventional foods or mealtimes.

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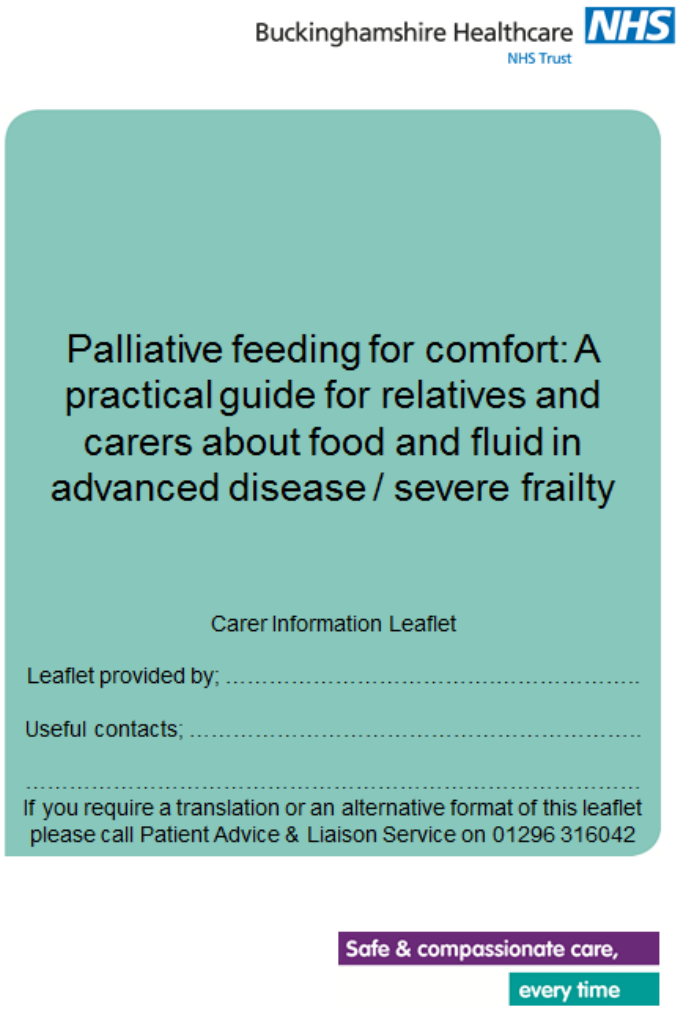
Key Factors

- Dysphagia is not reversible
- For patients in the end stages of life (defined as the last year of life)
- Capacity is documented
- Communication with carers about decision
- Communication from one setting to another
- Focus on comfort by avoiding ‘nil by mouth’ and using modification to alleviate symptoms.
- Guidelines were launched with a training package to acute and community staff.

Carer Leaflet – to guide conversation



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

Carer Information Leaflet

Leaflet provided by; .....

Useful contacts; .....

.....

If you require a translation or an alternative format of this leaflet please call Patient Advice & Liaison Service on 01296 316042

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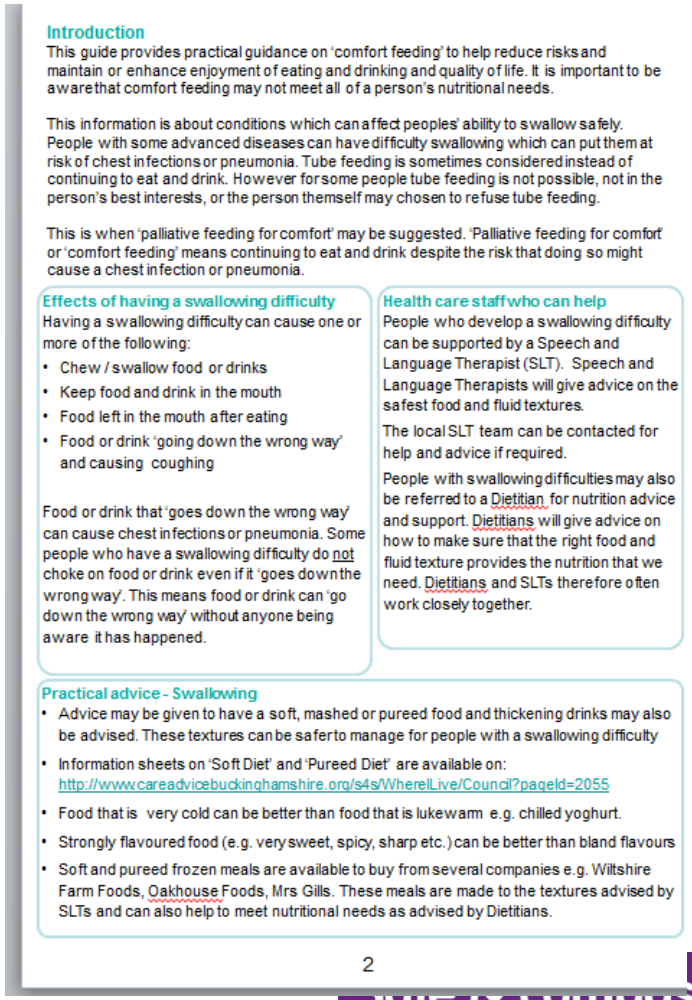

Introduction

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.

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Carer Leaflet

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.bucks formulary.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 is 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.

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NHS Aylesbury Vale Clinical Commissioning Group

NHS Chiltern Clinical Commissioning Group

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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Real Examples

- Lady at care home with progressive neurological disorder, speech and swallow deteriorating. Downgraded to puree and stage 1 by SLT but started coughing with this. Discussion with family, patient and GP around options – PEG vs Palliative Feeding for Comfort. Patient indicated she definitely did not want PEG, family in agreement. Guidelines followed, document signed, this started process of advanced care planning i.e. ceiling of treatment, not for hospital admission. Focus on quality of life, staff all aware of the plan, as well as patient / family.
- Care home had a resident who was receiving end of life care, coughing when eating and drinking, only managing small amounts. They highlighted this to GP and suggested Palliative Feeding for Comfort. GP agreed and prescribed thickener, signed the document on next visit. When I was on a routine visit, staff talked me through it and told me the lady was managing small amounts of puree diet / stage 1, not for hospital admission, oral intake for comfort.

Audit

- Audits planned looking at the implementation and impact of the guidelines. E.g. feedback from care homes, tracking patient cases through the system.
- The guidelines will be adapted and reviewed in 1 year.

Conclusions

- Healthcare professionals are more in tune with the quality of life issues important to patients
- The implementation of risk feeding lacks consistency, can be poorly documented and the quality of communication with carers varies
- Developing a local protocol collaboratively tailors the guidelines to local requirements and improves buy in.
- Consider the whole package; supporting materials, training, audit.

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