

815.2 PALLIATIVE FEEDING FOR COMFORT GUIDELINES

1. Introduction

Nutrition is a key priority for healthcare organisations and providing oral intake of food/drink is often an important issue for carers. Managing the risks of oral intake for patients with eating and swallowing problems is important in terms of safety, but can be a challenging ethical dilemma for healthcare professionals and carers (Hansen 2013).

Some patients will present with oral or pharyngeal stage swallowing difficulties (dysphagia) and can be at risk of choking or aspiration. Other patients can lose interest in food at the end stage of life and those with end stage dementia may lose the ability to recognise food (Evans and Best 2015).

The risk of malnutrition and dehydration needs to be assessed in all patients. Healthcare professionals have a duty to provide appropriate nutrition and hydration for patients in their care (NMC 2015, GMC 2010). This document gives advice and guidance on decision making regarding nutrition and hydration in patients who are no longer able to tolerate enough oral food and fluid to meet their nutritional requirements. The Department of Health (2014) states that all staff in contact with patients should be trained in the appropriate use of hydration at the end of life and how to discuss this with patients, their relatives and carers.

Deciding whether to introduce artificial nutrition and hydration (ANH) or to continue to allow food and drink orally once a swallow becomes unsafe, can be challenging for professionals, patients and carers (Chaklader 2012). Professionals need to work together to ensure the risks and benefits of eating and drinking are considered for each individual person to optimise their quality of life. This co-ordinated approach, particularly towards the end of life, is essential for patients with chronic progressive conditions, to ensure consistent and smooth transfer of care between acute and community settings (BGS 2012).

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).

'Comfort' or 'risk' feeding are terms used to describe continuation of careful hand feeding when ANH is not appropriate, while acknowledging there are risks in doing so (e.g. aspiration), and minimising these risks as much as possible. It is generally accepted that such patients will be in the palliative stage of their care. 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 and for many patients this phase is the last year of a person's life, not just the last weeks and days. In Buckinghamshire Healthcare NHS Trust (BHT) this is supported with a Palliative Care Plan which allows for planning and support so that people have more choice about their care during their last months and can make decisions about their preferred place of death. Thus, this document and the accompanying plan will be known as "Palliative Feeding for Comfort". 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. Typically, prescribed nutritional products are unlikely to be indicated when someone is nearing the end of his or her life.

2. Definition of Terms

Term	Definition
Artificial nutrition or hydration	Giving an individual nutrition and fluids by another means instead of by mouth.
Aspiration	Where food or drink passes the vocal folds and enters the lungs.
Aspiration pneumonia	An infection in the lungs caused by food, fluid, saliva containing bacteria, or vomit entering the lungs.
Bolus	The substance which is being swallowed, e.g. mouthful of food or drink.
Mental capacity	Having the cognitive ability to make your own decisions.
Careful hand feeding	Where the individual is fed by the care giver or given hand-over-hand support to eat and drink. A skilled approach which recognises the vulnerability of dependent individuals.
Cognitive feeding issues	Where behaviours associated with deteriorating cognition or mental function impact on eating and drinking.
LPA	Lasting Power of Attorney
MDT	Multidisciplinary team
Purée diet	National descriptor for smooth sieved food.
Risk feeding	Where an individual continues to eat and drink in spite of the risk of food and fluid entering the lungs.
SLT	Speech and Language Therapist / Speech and Language Therapy

3. Purpose and Scope of Guidelines

This document will guide healthcare professionals through the decision making process, encompassing patient choice, involving carers and ensuring clear documentation of the decision reached.

It also addresses capacity, ethics and quality of life issues, providing the MDT with a patient centred framework to facilitate decision making regarding nutritional management (RCP 2010).

The best current practice in the management of people with dementia is 'person centred dementia care' (Harwood 2014). The palliative feeding for comfort process ensures that all aspects of care and potential outcomes are considered. This approach should result in a patient centred decision which is made with serious thought and over a reasonable time frame. This approach is also appropriate for other patients with life-limiting conditions where their prognosis is less than a year and swallowing or feeding is an issue, e.g. chronic obstructive pulmonary disease (COPD), multiple complex diagnoses.

Palliative feeding for comfort should be considered in the following situations:

- A patient is deemed unsafe to eat and drink and is found to be unsuitable for ANH.
- A patient has capacity, understands fully the high risks of aspiration of oral intake but chooses to continue to eat and drink consistencies which present a greater risk of aspiration.

The [Palliative Feeding for Comfort Plan](#) (see Appendix 1) outlines the reasons why a person may be a candidate for comfort feeding and also considers the patient's capacity to make a decision regarding their nutritional management.

These guidelines can be initiated in the community or during an acute admission.

Discussion with the patient, family/carers and healthcare professionals at every stage of the process is essential. A co-ordinated approach is essential to ensure consistent transfer of care between acute and community settings.

4. Palliative Feeding for Comfort Process

This document has been produced to guide the MDT to start the process as quickly as possible. Waiting for review by SLT should not stop initiation of the process. Referral to SLT can be made at any point in the process and in some cases a formal swallowing assessment may be required before a decision can be made.

Wherever possible 'nil by mouth' status should be avoided but diet and texture modification may continue to be appropriate in an attempt to reduce risk or to alleviate symptoms such as coughing.

It is essential that initiation of the [Palliative Comfort Feeding Plan](#) is preceded by detailed information gathering to establish:

- The nature of the patient's dysphagia.
- The patient's diagnosis.
- The patient's prognosis.
- The patient's eating and drinking baseline.
- Whether the patient's clinical picture is transient and reversible in nature or unlikely to improve even with treatment.
- How future management will impact on the patient's quality of life.

In the acute setting, if the patient's dysphagia is transient, a defined period of tube feeding (usually nasogastric feeding), with clear, agreed objectives may be appropriate, with regular review to assess the outcome, e.g. for 7 - 10 days to allow for treatment of a reversible condition. In this instance, the time frame for tube feeding and the proposed feeding tube removal date should be documented. Short term tube feeding in the community is unlikely to be possible.

In the community the focus is on making people as comfortable as possible. This process allows care staff to implement modified diet and fluids to prevent symptoms such as coughing and choking straight away. Telephone support is available from the SLT department and a formal assessment can be arranged where required. In some cases the modifications may be necessary to prevent discomfort as the patient is dying; in some cases the dysphagia may be transient during a period of ill-health and the SLT may be required to review the patient to upgrade the diet and fluids again once the patient has improved.

5. Mental Capacity

The Mental Capacity Act (MCA) 2005 provides a statutory framework for people who lack the capacity to make decisions for themselves in connection with their care or treatment. The layout of the [Palliative Feeding for Comfort](#) form ensures that, if completed in full, capacity assessments will have been undertaken in accordance with the Act. The MCA is time and decision specific so any new decision requires a separate capacity assessment and capacity should be reviewed regularly as it does change over time.

All practitioners must adhere to the MCA and its statutory Code of Practice. It is enshrined in law that everyone is assumed to have mental capacity to make decisions for themselves. When capacity to consent is in doubt, or variable, or for patients who lack the mental capacity to make decisions for themselves, efforts should be made to find out if the patient has made an Advanced Statement/Directive. Mental capacity may need to be assessed on multiple occasions if the patient's cognitive function fluctuates or is difficult to assess. A second opinion can be requested from other clinicians, Medicine for Older People chaplains, the Mental Health Team or other professionals who are trained in assessing mental capacity.

Communication with family members/carers is **key** to the process, as is completion of the [Palliative Feeding for Comfort](#) documentation. Under English law, relatives without a valid and applicable LPA cannot consent on the patient's behalf, but due regard should be paid to all their views about the patient's prior beliefs, values and wishes. If there is significant disagreement, an independent second opinion should be sought. **The consultant or GP should make the ultimate decision** about palliative feeding for comfort and the process must be endorsed by their signature to demonstrate that the relevant MDT discussions have taken place and adequate information has been shared with the patient/family.

6. Ongoing Management

Appropriate nursing handover should take place to ensure that risk is acknowledged and minimised with scrupulous oral care and optimum seating position and that, where required, careful hand feeding is offered. In an acute setting it is also essential to inform the relevant physiotherapist so that chest intervention for that patient can be discussed with the medical team. It is also expected that SLT will monitor the patient on a weekly basis until discharge.

For patients who are nearing the end of life and where a decision has been made for palliative feeding for comfort, the responsible medical team should consider what treatment escalation should occur in the event of a deterioration in the patient's condition. For example, if the patient develops aspiration pneumonia while still in hospital, is the plan for IV or oral antibiotics or symptomatic management? For patients who lack capacity for the relevant decisions, the MCA must be adhered to and any resulting anticipatory treatment plan is advisory only, with each best interest decision being made at the time it is needed. This plan must be documented in the notes and in the advance treatment plan. Any anticipatory care plan must be communicated to the patient's GP.

For patients assessed to be in their final hours or days of life, in addition to decision making about palliative comfort feeding, an individualised plan of care should be developed to include symptom control, psychological, social and spiritual support for the patient and family (Leadership Alliance for the Care of Dying People; One chance to get it right – improving people's experience of care in the last few days and hours of life. 2014).

7. Discharge Process

All team members need to work closely together to ensure that the palliative comfort feeding plan is appropriately documented in the patient's discharge summary. If the patient is being discharged from hospital with the expectation of deterioration in their condition in the near future, consideration should be given to an anticipatory treatment plan for the community, i.e. hospital readmission or care at home (including care within a care home). This information should be included in the hospital discharge summary. The [Palliative Feeding for Comfort](#) form and plan should be attached to the discharge documentation. This forms a crucial stage in the process, allowing the patient to leave the acute setting with a clear plan in place informing future management.

A letter should be sent to the GP, with guidance and information leaflets sent to the patient's carers/care home.

It is good practice to make a referral to the relevant community teams for every patient with a palliative feeding for comfort plan in place. This enables:

- Support of the patient and those around them, in their own environment, by staff who are aware of the palliative feeding for comfort plan.
- Cohesive care of community patients.
- Collaboration with GP practices.

8. Training and Monitoring

Training will be provided through multiple channels, including the Nutrition Study Day, Palliative Care study days and Trust induction programme.

9. Audit

In August 2018 a multi-disciplinary group met and agreed minor changes to the documentation following feedback collected during the first year of implementation. An audit was completed including a Survey Monkey questionnaire to staff. No significant changes were suggested but there remained some inconsistent practice and further training and education is required. An action plan will be developed following this audit.

10. References

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[Appendix 1 Palliative Feeding for Comfort Pathway](#)

[Appendix 2 Palliative Feeding for Comfort Case Examples](#)

[Appendix 3 Palliative Comfort Feeding: Information for Professionals](#)

[Appendix 4 Palliative Feeding for Comfort Guide for Relatives and Carers](#)

[Appendix 5 Top 10 Tips – Caring for Someone with Swallowing Difficulties](#)

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Buckinghamshire Healthcare NHS Trust/Buckinghamshire Clinical Commissioning Group	

Appendix 1

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

Name
DOB
Hospital No:
NHS No:

Date of commencement: _____

The above named patient is at high risk of food and fluids entering his/her lungs (aspiration) and may not be meeting his/her nutritional/hydration needs orally as a result of a poor swallow or cognitive feeding difficulties. 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 can/cannot (delete as appropriate) 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 thin fluid <input type="checkbox"/>	Teaspoons Level 2 mildly thick (stage 1 fluid) <input type="checkbox"/>
Sips thin fluid <input type="checkbox"/>	Sips Level 2 mildly thick (stage 1 fluid) <input type="checkbox"/>
Chilled puree <input type="checkbox"/>	Hot puree <input type="checkbox"/>
Other;	
3B Feeding Plan for reduced oral intake: <input type="checkbox"/>	

(Date for review of decision to comfort feed (if required):

(Date referred to Speech & Language Therapist (if required):

Decision authorised by (signature/name of consultant/GP):

Prompt: Is a Treatment Escalation Plan/Palliative Care Plan appropriate/in place?

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

Refer to SLT for swallowing assessment

Yes

No

- In the acute setting consider nasogastric feeding 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.
- In the community, if not for hospital admission start Feeding Plan while waiting for SLT.
- 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.
- Consider Treatment Escalation Plan

Communicate decision and feeding plan across healthcare settings with Palliative Feeding for Comfort Document

STEP 3: Implement Feeding Plan

3A. (Emergency) Oral Feeding Plan for patients with dysphagia on the Palliative Feeding for Comfort Pathway

<u>Acute</u>	<u>Community</u>
<ul style="list-style-type: none">• Patient is alert and respiratory status is stable.• Commence teaspoons, then sips, of water. If coughing on water, thicken to Level 2 mildly thick (Stage 1) (2 scoops of Resource[®] ThickenUp[®] Clear per 200 ml).• Commence teaspoons chilled puree, e.g. yoghurt, fruit puree, mousse.	<ul style="list-style-type: none">• Patient is to remain in the community.• Continue thin fluids; if coughing on water thicken to Level 2 mildly thick (Stage 1) (2 scoops Resource[®] ThickenUp[®] Clear per 200 ml).• Hot puree. Restrict to chilled puree if coughing on hot puree.
<ul style="list-style-type: none">• 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

<ul style="list-style-type: none">• 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 things which have more flavour like curry• Go with food preferences, don't worry about sticking with conventional foods or mealtimes• Be led by patients, don't force feed

Appendix 2: Palliative Feeding for Comfort Case Examples

- Mary is 80 years of age and lives in a care home. She has a background of dementia. She usually eats and drinks well but is being treated for a urinary tract infection (UTI) and has started to cough on fluids. Mary does not have capacity and staff implemented a Palliative Feeding for Comfort decision, using thickened fluids to Level 2 moderately thick fluids as this prevented the coughing on thin fluids. They contacted the local SLT department to talk through their decision, discussed the plan with her husband and documented the decision in the care plan. Two weeks later SLT contacted the care home. Mary was considerably better and no longer required the thickened fluids. The decision was reversed; Mary has been kept comfortable and potentially avoided a hospital admission with pneumonia.
- Samuel has been admitted to the acute hospital with an infection, but his chest sounds clear. He has a background of dementia. Staff would like his swallowing assessed but it is 6 p.m. and the SLT is not available. Samuel is calling out for a drink and staff want to keep him safe, but comfortable. His capacity is assessed and a Palliative Comfort Feeding decision is made, communicated with his daughter and documented. Teaspoons of water cause some coughing, but he is managing teaspoons of Level 2 moderately thick fluids and a little ice cream. Samuel feels more comfortable and his daughter is much happier. A message has been left on the SLT answer machine for review first thing in the morning.
- Jack lives at home and his care team are aware that he is in the palliative stage of his end stage chronic obstructive pulmonary disease (COPD). Jack and his wife are very keen that he remains at home when he reaches end of life. Jack suddenly deteriorates and is choking when he drinks but really doesn't want to go into hospital. Jack's district nurse completes a capacity assessment. He has capacity and she explains that a Palliative Comfort Feeding decision can be implemented and an emergency prescription for a fluid thickener organised. The thickener enables Jack to manage sips of fluid during his last few days at home.
- Bob has been admitted to hospital with a UTI. He has a background of cancer but, in terms of eating and drinking, usually manages normal diet and thin fluids. In hospital he is coughing on thin fluids and taking very little food which is way off his normal baseline. Despite his diagnosis of cancer, the UTI is treatable and the medical team decide to discuss with Bob a nasogastric feeding tube for a defined period of time of 10 - 14 days to allow him to recover from the UTI and return to his baseline. The pathway shows that a Palliative Feeding for Comfort decision is not appropriate.
- Martha lives in a residential home. She has had dementia for many years. She has not had a chest infection and does not cough and choke when eating and drinking, but she has started to hold food in her mouth and doesn't initiate swallowing. Staff at the care home use the (Emergency) Feeding Plan (3B) for patients with reduced oral intake. They find that the best strategy is to give Martha a napkin and encourage her to dab her mouth with the napkin, she needs full assistance for her feeding but can manage this and it triggers a swallow. She still isn't taking very much but likes a portion of ice cream between meals.

Appendix 3: Palliative Comfort Feeding: Information for Professionals

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.

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Palliative Feeding for Comfort; Information for Professionals

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.'

Safe & compassionate care,

every time



Buckinghamshire Healthcare
NHS Trust

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

Safe & compassionate care,

every time

Introduction

This guide provides practical guidance on 'comfort feeding' to help reduce risks of infection 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 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 the person's best interests, or the person themselves may have 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 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:

- 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 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 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 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?pageld=2055>
- 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 - Mouth care

Good mouth care (such as brushing teeth, rinsing mouth with mouthwash if able) can help reduce the risk of a chest infection by reducing the amount of bacteria in the mouth to improve 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/vac/>

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 person's 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, 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 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 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".

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 are 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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Author: Debbie Begent/Liz Pryke
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TOP 10 TIPS – CARING FOR SOMEONE WITH SWALLOWING DIFFICULTIES

- 1.) Help the person to sit upright and ensure that they are awake
- 2.) Always stay with the person when they are eating
- 3.) The person may need modified texture diet, i.e. pureed food/thickened fluids
- 4.) Promote independence by supporting the person to feed themselves if able
- 5.) Make sure the person has swallowed before offering more food or drink
- 6.) Offer food and fluids little and often and provide regular mouth care
- 7.) If coughing or choking causes the person distress – STOP and try again later
- 8.) Talk to the Medical Team about liquid, soluble or dispersible medication
- 9.) Presentation is important – ensure food looks as appetising as possible
- 10.) Give choice – try different flavours and be aware of food preferences