

Help and advice on nutrition for people living with advanced dementia

Patient Experience

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Information for Patients, Families & Carers

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Introduction

This leaflet aims to explain some of the issues those living with advanced dementia may have with getting enough food and drink (nutrition). It gives a few ideas about ways that may help.

- Problems with nutrition are common for people who live with dementia. These problems can get worse as the disease progresses and can be worrying for friends and relatives.
- The person living with dementia may have difficulty communicating their difficulties, so it is important that friends and relatives know what to look out for.
- Sometimes swallowing can become a problem, and the management options for this are explained here.
- Please discuss this leaflet with the healthcare professionals looking after your friend or relative.

Common eating problems in those living with dementia

- Weight loss is common in people living with a diagnosis of dementia.
- Each person's difficulties with eating will be unique to them and their situation. Refusing food can be part of the disease process in advancing dementia.
- People living with dementia may struggle to recognise food and drink.
- They may not be able to communicate their needs, such as telling you that they are not hungry or do not like the food.
- Whilst some people may be less physically active so do not feel hungry, others may pace and wander which can mean they use up more calories.

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- Some people may struggle with concentration, co-ordination and eating independently. They may have difficulties focusing on a meal all the way through.
- Pain, medication, mouth problems, constipation and other medical factors can also be potential causes of poor appetite and these should be reviewed by the medical team.

Managing problems with eating

- Knowing the person helps, as everyone has their own preferences and needs. You will have a better idea about your relative's likes and dislikes, so share this with staff.
- Small and regular portions of food that they like often helps.
- Food tastes may change so it may help to try foods with different colours and smells, sweeter or stronger foods may be preferred.
- Try to keep meal times relaxed, allow plenty of time, and if food is refused offer again after a rest.
- If glasses, hearing aids or dentures are worn make sure these are on at mealtimes.
- Prompting and assistance with meals can make a big difference to how much is eaten. Make the most of good days, or times of day when appetite is better.
- If the person is struggling with a knife and fork, chop up food so that it can be eaten with a spoon or fingers.
- Do not refuse dessert if the savoury meal has not been finished, and do not worry about unusual combinations of food.
- It may help to explain what the food is and use pictures - wards have flash card pictures of menu options.
- Drinking and eating can be a social activity, so eating/drinking together may help.
- If nutrition has become a concern, dietitians can give an assessment and advice to help those living with dementia meet their nutritional needs.

Managing problems with chewing

- People living with dementia can have difficulties with chewing and swallowing. They may forget how to chew or they may hold food in their mouth.
- Keeping the mouth clean and healthy (oral hygiene) is important as it improves the taste of food and the ability to chew and swallow. If the mouth is painful then chewing will be uncomfortable and difficult and they may refuse to eat.
- If the person wears dentures or a plate, they should be comfortable and fitted properly ('denture fixative' can help).
- Weight loss can cause dentures to loosen, making it more difficult to eat.
- People living with dementia can get tired easily. Eating soft, moist food that needs little chewing can help.

Managing problems with drinking

- The sensation of thirst changes as people get older, which can mean a person is not aware that they are thirsty. This also happens in people living with dementia.
- Encourage drinking throughout the day and prompt at regular intervals.
- They will usually not drink big volumes, so a “little and often” approach is helpful.
- Use a clear glass so the person can see what is inside, or a brightly coloured cup to draw attention.
- Patients living with dementia may be prompted to drink by placing a cup in their hand, watching others drink, and by leaving an appealing drink within reach.
- It is important to know their likes and dislikes to give appropriate drinks.
- All fluids count, offer a variety of drinks - hot and cold.
- Milk based drinks (e.g. hot chocolate, milkshakes, milky coffee, Complan shakes and soups) are a good way to get extra calories and protein into the diet.
- Dehydration can lead to other problems such as constipation, urinary infections, pressure ulcers and falls.

Oral nutritional supplements

- If the person is finding it difficult to meet their nutritional needs by diet alone then the medical team will talk to the ward dietitian about the need for nutritional supplements.
- Oral nutritional supplements come in a variety of flavours and styles including milkshakes, juice drinks and desserts. These add extra calories and protein to the diet.
- It is often advised these are given between meals to support the nutritional intake from food.
- As with other drinks and food, prompting and encouragement may be needed.
- If the person does not like the supplements, it may help to think about the way the supplement is presented. For example, try a different glass, a different flavour, or serve chilled from the fridge.

Getting help when swallowing becomes a problem

- As dementia progresses, swallowing difficulties (dysphagia) become more common due to the person's muscles and reflexes not working properly.
- Memory problems getting worse and changes to behaviour can also affect swallowing. This can include holding food in the mouth and continuous chewing, as well as forgetting how to swallow.
- In the advanced stages of dementia, some people lose the ability to swallow safely or even to swallow at all.

- When changes in swallowing happen, this can make eating and drinking unsafe. These problems can cause the person to choke on food or develop chest infections.
- If a person is having difficulty with swallowing, a referral to a speech and language therapist can help.
- A speech and language therapist can assess swallowing and give advice on how to manage the problem. This often involves thickening fluids and modifying the consistency of the diet.
- A menu with items which have modified consistency will be available on the ward. Please ask staff for a copy to help with meal choice.
- Speech and language therapists also provide individual advice on safe feeding, including correct positioning and rate of eating/ drinking.

When swallowing becomes unsafe

- When the swallowing function is not working properly, there is a risk that food and drink can go down the wrong way into the windpipe/ lungs .
- If food or drink get into the windpipe and lungs, this is called **aspiration**.
- It may cause coughing, choking, eye watering or going red in the face but there can also be very little signs that aspiration is happening.
- Aspiration can cause serious chest infections such as pneumonia, which may be life threatening. It can also make eating and drinking difficult and over time a person may lose weight and become dehydrated.
- For some people the speech and language therapists will advise that the swallow is unsafe even with changes to the consistency of diet and fluids.

Artificial feeding:

- Artificial or tube feeding would only be appropriate in those living with advanced dementia if the cause of a persons swallowing problem is reversible.
- Tube feeding will not stop the risk of aspiration from stomach (gastric) contents or saliva.
- It can be an invasive and uncomfortable procedure and often patients with dementia do not understand why a tube is inserted and can attempt to dislodge or remove it, which can be dangerous.
- Tube feeding can take away the enjoyment of eating and drinking from a person.
- There is no evidence to suggest it increases life expectancy in those with dementia and it may shorten their life due to complications.
- If a person is in the later stages of their dementia and swallowing problems are felt to be due to their progressive dementia then tube feeding is not appropriate.

Managing risk when artificial feeding is not advised:

- The medical team will discuss feeding issues with the speech and language therapists, dietitians and other health care professionals and if they feel that tube feeding is not appropriate then they will meet and discuss with you a recommendation for 'at risk feeding'
- 'At risk feeding' or 'comfort feeding' is when a decision has been made to continue eating and drinking despite an unsafe swallow.
- If the risk of aspiration is accepted, a plan will be made to manage this.
- The speech and language therapist will advise the safest consistency, to try to reduce the chance of aspiration and choking.
- It is important if a person is at risk of aspiration to encourage regular mouth care, give help when eating and drinking, eat and drink upright, when awake and unrushed.
- If there is any evidence of the person struggling, then they should rest until recovered.
- It is important to consider what the person would have wanted could they have made their own decisions. For many the joy of eating and drinking and quality of life in deteriorating health would have been important.

Later stages of dementia

- As dementia progresses a person may become more frail, have more frequent falls or infections, develop swallowing difficulties, become less mobile, sleep more, eat and talk less.
- Someone in the later stages of dementia who does not have another illness may continue to deteriorate slowly over many months.
- When a person living with dementia develops problems with eating, drinking and swallowing then this may mean that they are reaching the final stages of their condition.

Managing problems with eating during a hospital stay

If a person with dementia needs to come to hospital for another reason, their eating and drinking may be affected by:

- confusion related to illness (delirium).
- illness itself.
- pain.
- being less mobile or bed-bound.
- loss of routine.
- difficulty using the toilet e.g. constipation.
- mouth hygiene.

The medical team will review these issues to identify any problems.

How relatives/ carers can help:

- Complete a “patient summary” form to let staff know about your relative’s likes/ dislikes and routines.
- Bring in their toothbrush, dentures or any other dental equipment.
- Let the nurse and doctor know if your relative has been losing weight at home.
- Bring in their favourite snack food from home - cakes/ drinks etc.
- Tell the doctor if you feel your relative is in pain or has a problem in the mouth/ throat.
- Help to choose meal options. Ask for a menu and find food they would like from the list.
- Copies of the hospital menus are available on all wards and the hospital website for patients and carers to look at.
- A weekly meal planner (shown below) can be made available for carers and family members to complete.
- A patient profile can be completed where carers and relatives can give more information about the person’s food preferences and eating habits.
- If you have time, sit with the person and encourage them to eat and drink. Let staff know what they have had, as this should be recorded on the food record chart and fluid charts.
- Ask for help from nursing staff if your loved one is not sitting fully upright for eating and drinking.
- Encourage your relative to sit out of bed.
- Consider what your relative’s wishes would have been if they have issues with their swallowing.

Weekly Meal Planner

University Hospitals of Leicester NHS Trust

Caring at its best

Name:	Dietary Requirements:	Red tray/lid required?
S Number:		If yes, please tick <input type="checkbox"/>

Please use this planner with the hospital menu to tell us about a patient's food and drink choices. Our catering staff may use this to order meals. A range of menus are available for different dietary needs - please ask ward staff for further details.

Ward _____ Bay _____ Bed _____ or Side Room _____

MONDAY

Breakfast:	Drink:
Lunch:	Drink:
Starter:	
Main:	
Pudding:	
Supper:	Drink:
Starter:	
Main:	
Pudding:	

TUESDAY

Breakfast:	Drink:
Lunch:	Drink:
Starter:	
Main:	
Pudding:	
Supper:	Drink:
Starter:	
Main:	
Pudding:	

WEDNESDAY

Breakfast:	Drink:
Lunch:	Drink:
Starter:	
Main:	
Pudding:	
Supper:	Drink:
Starter:	
Main:	
Pudding:	

THURSDAY

Breakfast:	Drink:
Lunch:	Drink:
Starter:	
Main:	
Pudding:	
Supper:	Drink:
Starter:	
Main:	
Pudding:	

Patient Experience Team – October 2017

Further information and support

- Leicester's hospitals Patient Experience Team: 0116 258 5384
- Admiral Nurse national dementia helpline (provides specialist dementia support for families): 0800 888 6678
- The Alzheimer's Society: www.alzheimers.org.uk
- Dementia UK: www.dementiauk.org
- Age UK (dementia support for Leicester & Leicestershire): 0116 223 7363
<https://www.ageuk.org.uk/leics/our-services/living-with-dementia/dementia-support-service-for-leicester-and-leicestershire/>

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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