

Help and advice on nutrition for people living with advanced dementia

Dementia Services

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Information for Patients, Families & Carers

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Introduction

This leaflet will tell you about some problems people living with advanced dementia can have when eating and drinking (nutrition). It gives a few ideas about what may help.

- Problems with nutrition are common for people who live with dementia. These problems can get worse as the disease progresses.
- The person living with dementia can find it hard to tell you know about these problems because of difficulty communicating. It is important that friends and relatives know what to look out for.
- Sometimes swallowing can become a problem. This leaflet will tell you ways this might be managed.
- Please read through this leaflet. If you have questions then please talk to the healthcare professionals looking after your friend or relative.

Common eating problems

- Weight loss is common in people living with dementia.
- Each person's problems with eating will be different. Refusing food can be part of the process in advancing dementia.
- People living with dementia may struggle to recognise food, drink, and objects like knives, forks, plates, and cups.
- People with dementia may not be able to tell you their needs. They may not be able to tell you they are not hungry or do not like the food.
- Some people with advanced dementia may be less physically active so do not feel hungry. Others may pace and walk around a lot which can mean they use up more calories.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

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To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

- Some people may struggle with concentration, co-ordination and eating without extra help. They may have problems focusing on a meal all the way through.
- Pain, medication, mouth problems, constipation and other medical factors can also cause poor appetite. The medical team will check for these.

Managing problems with eating

- Knowing the person is important. Everyone has their own likes and needs. You will have a better idea about your relative's likes and dislikes. Share this information with staff.
- Giving the person small and regular portions of food that they like can help.
- Food tastes may change. It may help to try foods with different colours, smells and textures. They may prefer foods which are sweeter or with stronger tastes.
- Try to keep meal times relaxed. Have plenty of time to eat. If the person refuses a food, offer it to them again after a short while.
- Make sure they are wearing their glasses, hearing aids or dentures for meals.
- Helping with meals can make a big difference to how much they eat. Make the most of good days, or times of day when their appetite is better.
- It can be hard to eat with a knife and fork. You can chop up food so it can be eaten with a spoon or fingers. Try giving them 'easy hold' cutlery to eat with.
- Brightly coloured plates can help the person to see their food more easily.
- Do not refuse dessert if the savoury meal has not been finished. Do not worry about mixing combinations of food, like sweet and savoury.
- It may help to explain what the food is and use pictures. The wards have flash card pictures of menu options.
- Drinking and eating can be a social activity. Eating and drinking together with your relative or friend may help.
- If nutrition has become a worry, speak to a healthcare professional looking after the person.

Managing problems with chewing

- People living with dementia can have problems with chewing and swallowing. They may forget how to chew or they may hold food in their mouth.
- Keeping the person's mouth clean and healthy (oral hygiene) makes food taste better and helps them to chew and swallow. If the mouth is painful then chewing will be uncomfortable and difficult. They may not want to eat.
- Dentures or a plate should be comfortable and fitted properly . 'Denture fixative' can help with this.
- Weight loss can make dentures loose, 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 feeling of thirst changes as people get older. This can mean a person may not know they are thirsty. This also happens in people living with dementia.
- Prompt them to drink throughout the day and at regular intervals.
- The person may not drink big amounts. A 'little and often' approach is helpful.
- Use a clear glass so the person can see what is inside. Or use a brightly coloured cup to draw attention. **You should not give them a beaker to drink from** unless a speech and language therapist has recommended it. This is because drinks can get into the windpipe.
- You can prompt them to drink by placing a cup in their hand and by leaving an appealing drink within reach. Drink with the person as they may copy what you do.
- It is important to know their likes and dislikes to give the right drinks.
- All fluids count, even soup. Offer different drinks, hot and cold.
- Milk based drinks (like hot chocolate, milkshakes, milky coffee, Complan shakes/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, falls and delirium.

Oral nutritional supplements

- If the person is not eating enough food, the doctors will speak to the dietitian. The dietitian may recommend extra snacks and drinks, known as nutritional supplements.
- Oral nutritional supplements come in different flavours and styles. They can come as milkshakes, juice drinks and desserts. These add extra calories and protein to the diet.
- It is best to give these between meals.
- You may need to prompt and encourage them to eat and drink these.
- If the person does not like the supplements, try to think about the way the supplement is presented. Try a different glass, a different flavour, or serve chilled from the fridge.

Getting help when swallowing becomes a problem

- As dementia progresses, swallowing can become difficult (dysphagia). This is because the person's muscles and reflexes do not work properly.
- Memory problems getting worse and changes to behaviour can also affect swallowing. This can be holding food in the mouth, continuous chewing or 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 get a chest infection.

- We will refer your relative to a speech and language therapist if they are having problems with swallowing.
- A speech and language therapist can assess swallowing and give advice on how to manage the problem. They will advise if the person needs thickened fluids and/or modifying the consistency of food. This will help them to swallow.
- We have a menu with different consistency available on the ward. Please ask staff for a copy to help with meal choices.
- Speech and language therapists also give advice on safe feeding. This might include the correct positioning when eating and how quickly the person should eat and drink.

When swallowing becomes unsafe

- When the swallowing function is not working properly, there is a risk that food and drink can go down into the windpipe and 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. Over time a person may lose weight and become dehydrated.
- For some people the speech and language therapists may say that drink of any thickness and food of any consistency is unsafe for the person to eat. This is an 'unsafe swallow'.

Artificial tube feeding:

- Artificial tube feeding is when a tube is inserted and used to give a person nutrients instead of eating and drinking.
- **We only tube feed those living with advanced dementia if the cause of a person's swallowing problem is reversible.**
- If a person is in the later stages of their dementia and swallowing problems are thought to be due to their progressive dementia then tube feeding is not the right choice.
- There is no evidence to suggest it increases life expectancy in those with dementia. It may shorten their life due to complications.
- Tube feeding will not stop the risk of aspiration. This is because there is a chance contents from the stomach can go back up the throat into the windpipes and lungs.
- It can be an invasive and an uncomfortable procedure. Often patients with dementia do not understand why a tube is inserted. They can try to dislodge or remove it, which can be dangerous.
- Tube feeding can take away the enjoyment of eating and drinking.

Managing risk when artificial tube feeding is not advised:

- The medical team will talk about feeding issues with the speech and language therapists, dietitians and other health care professionals. If they think that tube feeding is not a suitable option then they will talk with you about '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 'at risk feeding' has been agreed, we will make a plan to manage this in the most suitable way for the person.
- The speech and language therapist will advise the safest thickness of drinks and consistency of food. This is to try to reduce the chance of aspiration and choking.
- You should:
 - encourage regular mouth care
 - help when eating and drinking
 - make sure the person is eating and drinking upright
 - make sure the person is awake and unrushed
- If the person is struggling then they should rest until recovered.
- Try to think about what the person would have wanted if they could have made their own decisions. This might include how the person would want to keep their quality of life when their health is getting worse.

Later stages of dementia

When a person living with dementia has problems with eating, drinking and swallowing then this may mean that they are reaching the final stages of their condition. As dementia progresses a person may:

- become more frail
- have more frequent falls or infections
- develop problems with swallowing
- 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.

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 their daily routine
- difficulty using the toilet, like constipation
- mouth hygiene

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

How relatives/ carers can help:

- You can fill out a 'Know Me Better' patient summary form. This will let staff know about your relative's food and drink likes/dislikes and eating habits.
- 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 like cakes and drinks.
- Tell the doctor if you feel your relative is in pain or has a problem in their mouth/throat.
- Help to choose meal options. Ask for a menu and find food they would like from the list.
- The hospital menus are on all wards and on the hospital website for patients and relatives/ carers to look at.
- You can fill out a weekly meal planner (see picture) for your relative or friend.
- Try to sit with the person and encourage them to eat and drink. Let staff know what they have had. This should be recorded on the food record chart and fluid chart.
- 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.
- Bring your relative their own clothes to wear, so they can feel more like their usual self. This can help them to eat and drink more.
- Think about what your relative's wishes would have been if they have issues with their swallowing.

Weekly Meal Planner			
Name:	Dietary Requirements:	Red traylid required?	<i>Carers to fill in</i>
S Number:		If yes, please tick <input type="checkbox"/>	
<small>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.</small>			
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: _____	
<small>Patient Experience Team - October 2017</small>			



More information and support

Leicester's Hospitals Dementia Services

0116 258 5652

Admiral Nurse national dementia helpline

It gives specialist dementia support for families.

0800 888 6678

Dementia UK

www.dementiauk.org

The Alzheimer's Society

www.alzheimers.org.uk

Age UK

Gives 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 بلغةٍ 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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