

Eating and drinking in dementia

A guide for families and carers

This leaflet advises you on how you can help someone with dementia to overcome problems with eating and drinking. If you have any further questions, please speak to a doctor or nurse caring for your friend or relative.

Many people with dementia have problems with eating and drinking. Food plays a very important part in our lives, so it can be upsetting to see someone we love lose interest in food and lose weight as a consequence.

This leaflet gives some practical tips on helping someone with dementia to eat and drink. It also discusses some of the alternatives.

Why does this happen?

Some of the most common reasons why people with dementia may stop eating or drinking and some ways that you can help are described below.

People with dementia may:	What can help?
<p>Lose their sense of time and forget about meal times.</p> <p>Have difficulties connecting feelings of hunger with eating. They may forget to eat even when food is placed in front of them.</p> <p>Be suspicious about food.</p>	<ul style="list-style-type: none"> • Helping them to eat will prompt and remind them to start eating. Often, once a person starts eating they find it easier to continue. • Gently placing your hand over their's to help guide the fork or spoon to their mouth can be helpful. • Choose easy-to-eat meals. • Offer reassurance.
<p>Become distracted, especially in a busy ward or at a table with lots of people sitting around it.</p> <p>Find it difficult to sit down to a meal and may pace around.</p>	<ul style="list-style-type: none"> • Try 'finger foods' that can be carried around, such as sandwiches, cheese portions, fruits like bananas or grapes, or cake bars. • Carry drinks in cartons or bottles, as these are easier to carry around • Keep mealtimes quiet and calm – avoid having the television or radio on. • Remind your friend or relative when meals are due and try to maintain routine.

People with dementia may:	What can help?
Find it hard to use a knife and fork and may stop eating because it is physically difficult.	<ul style="list-style-type: none"> • Try foods that can be eaten by hand – some manage better when feeding themselves in this way. • Specially adapted utensils are available from occupational therapy, including cutlery, non-slip mats, high-sided plates or guards and two-handed or spouted cups. These can make it easier to eat and can help to maintain your friend/relative's independence.
Have problems with chewing and swallowing. They may keep food in their mouths without swallowing. Swallowing may become difficult and they may cough or choke when eating.	<ul style="list-style-type: none"> • Soft, smooth foods are easier to swallow. If swallowing is a problem, ask for a speech and language therapist to assess your friend/relative and advise on next steps. • Use safe feeding techniques such as ensuring upright positioning and a slow pace of feeding. • Try giving verbal prompts to swallow and clear their mouth if this helps them. • Assist with oral care after meals if there is food residue left behind. Assistance may include the use of oral care sponges or brushing teeth.
Find that some of the medications used can cause a dry mouth or constipation, and therefore be discouraged from eating.	<ul style="list-style-type: none"> • Encouraging regular nourishing drinks can help ease a dry mouth and prevent constipation. • If appetite is poor, avoid high fibre foods, as these can make someone feel full. • Using gravy and sauces can make food easier to swallow.
Experience altered sense of taste and changes in food preferences.	<ul style="list-style-type: none"> • Offer a variety of foods. • Try intensely flavoured foods including sweet flavours and condiments.

I am worried that my friend/relative with dementia is losing weight – what can I do?

The dietitian can give you practical advice and written information on how to improve the diet of someone who has a small appetite.

There are also a variety of supplement drinks available on prescription from the doctor or dietitian looking after your relative/friend in the hospital or at home. These have extra energy,

protein, vitamins and minerals added to them and can help to provide extra nutrition when appetite is poor.

Sample packs are available from the dietitian and these can help you find out which flavours are preferred. You can also buy supplement drinks such as Build-up and Complan in the chemist. Other useful drinks such as Nurishment and Nutrament can also be bought in many supermarkets.

My friend/relative has stopped eating - what now?

In the advanced stages of dementia, eating and drinking may stop altogether. There may also be a risk of choking when trying to swallow. Offering food and drink is an important way of showing care and concern for someone and it can be distressing when this is no longer safe or possible. In cases where your friend or relative is close to the end of their life, our priority will be to make them comfortable. The decision may therefore be made to continue offering food and drinks, even though the risk of aspiration (food or drinks entering the airway) can contribute towards cause of death.

Won't they starve to death?

In the last stages of life it is part of the natural process of dying that a person stops eating and drinking. Feeding a person by tube will not help them to live longer and may make them more uncomfortable. They are more likely to need to urinate and move their bowels, this means that they would need to be moved more often or have a catheter inserted. For those who are dying, the time comes when it might be more compassionate and caring to allow the natural dying process take its course in a peaceful and dignified way.

Won't they be hungry or thirsty?

We have found that people at the end of their life often don't feel hungry or thirsty. You can still offer food and drink, but you shouldn't put pressure on the patient to eat or drink if they don't want to. Respectful and dignified care is the priority at this stage. Instead, those caring for the person with dementia can concentrate on keeping their mouth clean and fresh by offering regular mouth care.

What is tube feeding?

There are two types of feeding tube, a **nasogastric tube** and a **percutaneous endoscopic gastrostomy (PEG) tube**. These tubes are used to give a liquid feed that is very similar to the supplement drinks. A feeding pump is used to slowly drip the feed into the stomach.

- **Nasogastric tube feeding:** A nasogastric tube is a thin tube which is passed through the nose down into the stomach. Inserting the tube can be uncomfortable, but the discomfort usually (although not always) passes. Nasogastric tubes are not ideal for long-term use as they can cause irritation in the nasal passages. They are not used for restless and agitated patients as there is a risk of the tube becoming dislodged, which may result in the feed passing into the lungs, causing choking and pneumonia. This is called aspiration.
- **PEG feeding:** A PEG tube is passed directly into the stomach through the stomach wall. This is done using a local anaesthetic and under sedation. It is more comfortable than a

nasogastric tube and can be left in place long-term. It is important that a person is fit enough to go through this procedure – many patients with advanced dementia are not well enough and there is a risk that they may become even more unwell. Sometimes, the PEG may cause infection and soreness around the tube site, and research shows that feeding someone using a PEG does not prevent aspiration (where food can pass into the lungs). A big review of the evidence reported that PEG feeding in end-stage dementia does not prolong or improve quality of life (Sampson et al. (2009), 'Enteral tube feeding for older people with advanced dementia', *The Cochrane Library*, Issue 4)

Making the decision

At this point, the person with dementia is not usually able to decide for themselves whether they want to be fed by tube. All decisions about feeding are made with the help of relatives and carers. If a patient has previously made a written statement (sometimes called an advance directive) stating they do not wish to be fed by a tube, these wishes are respected.

If it is unclear if tube feeding would benefit the patient, it may be tried for a period of time. Patients will not be tube fed if the team caring for them feel it would do more harm than good.

Please talk to the medical team looking after your relative/friend if you have any questions or concerns.

Contact us

If you have any questions or concerns about eating and drinking difficulties in dementia, please discuss these with the medical team, or the Dementia and Delirium Lead, Dr Mark Kinirons on 020 7188 2519.

The team will be able to refer your friend or relative to the Dietitian or Speech and Language Therapist as appropriate.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' t: 020 7188 8803 at Guy's e: pals@gstt.nhs.uk

Leaflet number: 2300/VER3

Date published: August 2014

Review date: August 2017

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