

Information on changes in eating and drinking for people with advanced dementia and those moving towards the end of their lives.

A guide for family, carers and friends.




This information provides a guide on how you can help a friend or relative with dementia in the advanced stages if they are having increasing difficulties with eating, drinking and swallowing. It gives some practical tips on supporting your relative or friend to eat and drink. It also considers some of the choices that may need to be discussed as their dementia progresses.

As dementia develops, many people have difficulty with eating, drinking and swallowing. Because food plays such an important part in our lives, it can be upsetting and distressing for us to see someone that we love lose interest in food and begin to lose weight.

If you are looking after someone with dementia, you may find it useful to understand what to expect and what can be done to help. If you are not ready to read the information at this moment, you can come back to it at any time.

Why does somebody with advanced dementia have difficulty eating, drinking or swallowing?

Some of the most common reasons why people with dementia may stop eating, drinking or swallowing and what you can do to help are described below.

Your relative or friend with dementia may:	What can be done to help?
<p>Have difficulty with chewing or swallowing food.</p> <p>Store food in their mouths.</p> <p>Try to eat non-food items that they are able to reach in the room for example tissues or paper.</p> <p>Have a change in food choices or have more interest in sweeter tastes or different flavours.</p> <p>Losing interest in food.</p> <p>Becoming suspicious of food.</p> <p>Be unable to recognise food or connecting with feelings of hunger</p>	<p>Soft, smooth foods are usually easier to swallow. Using gravy and sauces can also make food easier to eat.</p> <p>The person caring for your relative or friend can offer mouth care after meals, to clear any food that is left behind.</p> <p>Encourage them to have a drink or something to eat instead if they are placing non-food items in their mouth. Move non-food items out of reach.</p> <p>Sometimes changing from sweet to savoury flavours every few teaspoons can help your relative or friend to eat a little more.</p> <p>Making a note of what they like eating or foods they dislike, helps to make better food choices.</p> <p>Offer reassurance using a calm and gentle voice.</p>
	<p>The right environment can help to stimulate people to recognise food, and so eat and drink. If possible encourage the person with dementia to sit at a table, use stimulating smells and appealing photographs of dishes to engage the person in meal choices. People with dementia cannot always see white food on a white plate or water in a clear glass. Use coloured cutlery and crockery to contrast with food and drink. Make food more appealing by using food of contrasting colours. Use warming plates to prevent food from cooling too quickly. Avoid noisy, distracting environments to focus on eating.</p>

Your relative or friend with dementia may:	What can be done to help?
<p>Decline drinks</p> <p>Remember to drink or be able to recognise feelings of thirst</p>	<p>Try different flavours of drinks from a teaspoon. See if they will have more of a favourite flavour. "Little and often" helps to encourage small amounts to be drunk.</p> <p>Remind them it is time for a drink in a calm and reassuring voice. Encourage them to hold the cup with you. Encourage sips of drinks throughout the day. Avoid using clear containers that can be difficult for the person with dementia to see.</p>
<p>Cough, choke or become chesty when eating or drinking if the ability to swallow becomes weaker</p>	<p>Help your friend or relative to eat, offering food on a teaspoon at a slow pace. Encourage them to eat small amounts as often as they are able or want to.</p> <p>It is safer for the person with dementia to sit as upright as they are comfortably able to when eating, drinking or taking medication.</p> <p>Using a thickener to make drinks a thicker consistency may help them to be swallowed more easily, but this would only be according to the advice from a Speech and Language Therapist.</p>
<p>Have difficulty swallowing tablets</p> <p>Have a dry mouth</p> <p>Be taking medication that may cause a dry mouth or constipation</p>	<p>Medicine can often be given in a different way, in a syrup or liquid form or through a patch stuck to the skin. Some tablets can be taken alongside food to help them be swallowed.</p> <p>Try regular mouth care using a soft toothbrush dipped in water, tonic water or pineapple juice which can help to make their mouth feel less dry. Gently moistening the mouth or applying lip salve will give comfort. Speech and Language Therapy advice or medical advice may be helpful.</p> <p>Offer small sips of nutritious drinks frequently and stewed fruits or pureed vegetables that are high in fibre may help to ease constipation</p>

<p>Have a sore mouth</p>	<p>Offer drinks that are not too warm or too cool can help to soothe the mouth. Carers can check to see if there are any dental problems or infections in the mouth that need treatment and may refer on to the doctor/dentist.</p>
<p>Your relative or friend with dementia may:</p>	<p>What can be done to help?</p>
<p>Be too drowsy or sleepy to eat or drink</p> <p>Become easily distracted</p> <p>Become upset , tearful or angry and refusing food or drinks offered</p> <p>Want to eat or drink something outside of normal mealtimes.</p>	<p>If they are asleep or drowsy it is important to wait until they have become more awake before trying food or drinks</p> <p>Turning off the television or radio and keeping the room quiet can be more relaxing and help the person with dementia to focus on eating or drinking</p> <p>Calmly prompting them it is time to eat and reminding them to swallow can help You can still offer food and drink but shouldn't put any pressure on the person with dementia to eat and drink if they don't want to. Respect is a priority at this stage.</p> <p>Be flexible and prepared to offer food and drinks at different times.</p>



End of Life



My friend/relative has stopped eating altogether.

So what happens now?

In the later stages of dementia eating and drinking sometimes stops altogether and there may be a risk of choking when trying to swallow or chest infections developing. In cases where your friend or relative is close to the end of their life our priority is to keep them comfortable and to avoid distress

As a carer you may feel anxious or upset that your relative no longer enjoys food. Although this can be hard to accept, it is important that you don't force them to eat and, towards the end of their life, it is okay if they don't.



You may find that you can offer love and support to your relative in a different way by giving them some reassurance and gentle words or by holding or stroking their hand if they don't feel like eating.

Those caring for your friend or family member can concentrate on offering regular mouth care to keep their mouth clean and fresh.

Will they be hungry or thirsty?

We have found that people at the end of life stage often don't feel hungry or thirsty. When someone starts to die, their body no longer has the same need for food and drink as before. The body's metabolism slows down and the body can't digest the food so well or take up the goodness from it. People with dementia at the end of their lives stop drinking, and although their mouth may look dry, it's not a sign that they are dehydrated.

Will they starve to death?

In the last stages of life part of the natural process of dying is that a person stops eating or drinking.

What is tube feeding?

There are 2 types of tube feeding. A nasogastric tube and a PEG (percutaneous endoscopic gastrostomy). Both of these types of tubes slowly drip a liquid feed (similar to a supplement drink) into the stomach. A review of the evidence shows that tube feeding also carries a risk of chest infections developing as the liquid feed can enter the airway. Nasogastric tubes can be uncomfortable and inappropriate if someone is agitated or restless.

Do they need feeding through a tube?

Feeding a person through a tube when they are approaching the end of their life will not help them to live longer and may make them more uncomfortable. It may be more compassionate and caring to allow the natural dying process to take its course in a peaceful and dignified way.

The published evidence is that tube feeding started in advanced dementia does not improve nutrition and is often associated with more frequent chest infections.

Tube feeding appears to be uncomfortable for many, especially nasogastric feeding, where the tube is often pulled out by the person with dementia.

Most health professionals believe that tube feeding at this stage is not beneficial as the risks outweigh the benefits.

Tube feeding appears only to be of benefit if done at a stage of dementia when the person is still aware of people around them and able to interact, and has not already lost a significant amount of body weight. Examples would include swallowing difficulties due to a stroke in vascular dementia, or people with dementia associated with Down's syndrome.

How can my relative or friend make their wishes known if they are unable to talk about or understand the choices?

Often at this time, the person with dementia is no longer able to make decisions themselves about continuing with eating and drinking, or considering being fed by a tube.

We want the person with dementia to be involved in their care so the earlier that they are able to think about some of the issues that may affect them the more they can express their thoughts and opinions.

If your relative has previously made a written statement or an advanced care plan, stating that they do not wish to be fed by a tube, these wishes are respected.

I feel worried about how to decide what is best for my friend/relative if eating and drinking becomes a problem for them

All decisions about feeding are made by the medical team caring for the person with dementia. The professionals involved are bound to act legally in a person's 'best interests' as described in the Mental Capacity Act. They will make a decision about feeding by weighing up the benefits and burdens of any treatment. They will take into account the person with dementia's previous wishes, if known, and consult with families.

If it is unclear whether tube feeding would benefit your friend/family member, the team caring for them will consider the options and will not advise tube feeding for them if they feel it will do more harm than good.

Continuing to offer your friend or relative food and drinks is an important way of showing care, a decision may therefore be made to continue to offer food and drinks and accept the risk of choking or chest infections developing as a result of food or drinks entering the airway as the most dignified choice. Decisions should always be discussed and clarified, and close liaison with a Speech and Language Therapist would be beneficial.

If you have any further questions please speak to a doctor, nurse or member of the team caring for your relative.

Developed by the Dementia End of Life Practice Development Team

www.dementiaeolp.org.uk

With special thanks to:

Alzheimer's Society (UK): Useful Alzheimer's UK fact sheets www.alzheimers.org.uk

Macmillan.org.uk/carers: Marie Curie End of Life: a guide. A booklet for people in the final stages of life and their carers

Guys and St Thomas NHS Trust: www.guysandstthomas.nhs.uk/resources/patient-information/acute/eating-and-drinking-dementia

Department of Health. End of life care strategy – promoting high quality care for adults at the end of life. July 2008.

Speech and Language Therapists "Speech and language therapy provision for people with dementia" (2005) RCSLT Position Paper, RCSLT: London.

Royal College of Physicians (2010) *Oral Feeding Difficulties and Dilemmas: particularly towards the end of life*. Royal College of Physicians & British Society of Gastroenterology, London.

Local Speech and Language Therapy teams