

Eating and drinking in the last months and weeks of life

Information for patients, relatives and carers

This leaflet aims to answer common questions about appetite, weight loss and having fluids via a drip or feeding via a tube, if you, or the person you are close to, are in the last months or weeks of life.

Why do people eat and drink less as they near the end of life?

Many people with serious illnesses lose their appetite and stop feeling thirsty as they become less well. Sometimes there is an obvious cause such as feeling sick or having a sore mouth. However, very often the illness itself causes the loss of appetite or thirst.

As the body weakens, it works less well and needs less fluids and food. Many cancers and some other illnesses make the body produce chemicals which break down muscle and fat faster than usual. These chemicals also 'trick' the part of the brain that controls appetite into thinking that the person is full after only a few mouthfuls or even after no food at all. These chemical changes will only go away if the underlying illness is successfully treated but often that is not possible.

Some people experience swallowing difficulties (dysphagia) as a symptom of their condition, for example, in Parkinson's disease or dementia. In these cases, swallow function is likely to get worse as a natural progression of the condition and this will impact their ability to eat and drink.

It is important to remember that it is the illness which is making body systems fail, not the lack of fluid or food. It can be hard to accept a person's lack of interest in food and drink as it may be a physical sign that they are not going to get better and are likely approaching the end of their life. Nevertheless, you can still support your loved one by offering them food and drink for pleasure and comfort - there are some tips that you may find helpful at the end of this leaflet. It may also help to talk to the healthcare professional team looking after you if you are finding it difficult.

What will happen without eating or drinking?

In advanced illness people can start to lose weight even when their appetite is still fairly normal because the body is no longer able to use the nutrients from food properly. The appetite naturally reduces as it realises it can no longer cope with food or fluids. People with advanced illnesses may live for several days or weeks after they stop eating and drinking but it is extremely unlikely they will feel hungry or thirsty.

How can I help a dry mouth?

A dry mouth is a common problem at any stage of illness and this feeling is quite different from feeling thirsty. Medicines such as saliva sprays, gels and chewing gum may be helpful in relieving a dry mouth, as can using mouth care sponges dipped in water (or a favourite drink).

To stop a dry mouth developing in the first place it is important to remember to brush your teeth twice a day with a toothbrush and consider using a mouthwash too. This is particularly important if someone has no teeth.

What about fluid or food via a 'tube' or 'drip'?

Sometimes fluid given via a drip may help but these treatments need to be regularly reviewed. In the last few days or hours of life the body often cannot handle fluid appropriately, so giving drips can sometimes cause side effects, such as 'chestiness' or noisy breathing, as well as swelling of the arms or legs.

Feeding into a vein is very rarely done. When it is, it is for short periods of time in an illness where the person is expected to recover. It is not helpful for people with advanced illnesses where recovery is unlikely and it can, in some situations, cause harm.

Feeding via a tube through the nose into the stomach (nasogastric tube) or directly through a hole into the stomach (gastrostomy) is possible for some people who have an appetite but are not able to eat properly. Again, this is only done in specific circumstances and is not helpful to people with advanced illnesses where recovery is unlikely.

We know from research that neither fluid drips nor tube feeding will make people with advanced cancer or other advanced illness put on weight or live any longer. For most people with only days or hours to live, their body systems are shutting down and they are unable to utilise any food or fluid that is given to them. We know that they do not experience thirst or hunger.

What will happen if I am already fed by tube? Will this be stopped?

As someone becomes less well, their appetite reduces and their body becomes unable to process food. Complications such as regurgitation (food rising up from the stomach and into the mouth), sickness and food spilling over into the lungs (aspiration) can occur. At this point decisions may be made about whether tube feeding should continue.

Of course, if you are able to make your own decisions you have the right at any time to say that you want to stop being fed through the tube.

If you become too ill to make that decision, the healthcare professionals looking after you will make a careful assessment and discuss with those close to you what the right thing to do is. The ultimate responsibility for decisions about starting and stopping tube feeding rests with the senior doctor who is caring for you or your loved one.

Remember, no decision is final and any decision that is made can always be reviewed. The medical team looking after you will always monitor the situation and discuss it on a regular basis.

Are there any medications that can help with appetite or weight gain?

Some medications, such as steroids and progestogens, can help boost appetite but often the effect is only temporary. These treatments can also have side effects so your medical team will advise whether or not they are appropriate for you.

Tips to support eating and drinking if you or someone close to you is unwell

- Try small meals or snacks spread out over the day rather than large meals
- Don't worry too much about balanced meals, eat what you feel like having
- It might be helpful to talk to our dietitian about different sorts of meals and foods. The dietitian may recommend food supplements such as Ensure[®] and Fortisip[®] which you can get on prescription
- A favourite drink can be frozen as an ice lolly or ice chips - this can be easier to suck on than trying to drink liquids
- If you want to continue drinking liquids, often just a few sips at a time is all that is wanted. The discomfort and risks associated with eating and drinking can sometimes be reduced by changing the texture (thickness/runniness) of food and fluids and using other strategies such as supporting people to sit upright and get out of bed for meals if it is comfortable and safe for them. Our speech and language therapists can advise on this so please ask the doctors and nurses looking after you or your loved one to refer you for advice
- Trying to feed someone who is not swallowing can be harmful and can feel like an added pressure to someone who is already unwell. Offer food and drink at regular intervals but stop if they are too drowsy, not opening their mouth in response to the cup or spoon, or not swallowing or emptying their mouth. Try and clean their mouth at the end of a meal in case any residues are left
- Consider discussing eating and drinking with the person who is unwell, acknowledge that you support them with their wishes and be guided by them on what they wish to eat and drink
- Gentle exercise can help slow muscle loss; a physiotherapist can advise you further

How we can help

This is likely to be a difficult time for you and your loved ones. Nurses, doctors and other staff are there to help you work through your worries and concerns and to offer you care and support. Please talk to us if there is anything on your mind.

Additional information and support

Chaplaincy service

The chaplaincy team is made up Anglican, Jewish, Muslim, and Roman Catholic chaplains, and has contacts in the community to provide for the needs of other religious communities. The team is happy to make contact with and arrange a visit by a representative of a community known personally to the patient or those who are close to them.

We offer confidential religious, spiritual and pastoral care to all patients and visitors between 09.00 and 17.00 with a 24/7 urgent out-of-hours on-call service. To request a visit, speak to a member of your care team and ask them to contact the on-call chaplain. Patients can also call directly on **020 3312 1508** where you can leave a message but please be aware you may not receive a response until the next working day.

Interpreting services

Discussions and decisions about treatment options can be challenging, especially if English is not your first language or if you don't have good support networks. If you need a language or British Sign Language interpreter please let your care team know and they will organise this for you.

Patient advice and liaison service

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:

imperial.communications@nhs.net

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Trust-wide
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