

When the need to eat and drink becomes less

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*For relatives and friends - frequently asked
questions about appetite and weight loss*



Why have they stopped eating?

I keep cooking tempting dishes - why do they just push them away?

Many people with serious illnesses such as cancer or heart failure lose their appetite as they become less well. Sometimes there is an obvious cause like feeling sick or having a sore mouth, which medication can help. However, very often the illness itself causes the loss of appetite. It can feel very disheartening when the person you are caring for pushes food away, especially when you have made something they like, but it is important to remember that it is not meant to upset you. They just don't feel like eating and often feel bad about that themselves. It may help to talk to the nurse or doctor about how it makes you both feel.

Why does this happen?

Many cancers and some other illnesses make the body produce chemicals which break down muscle and fat faster than it should. 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 no food at all.

But won't they starve to death if they don't eat?

The answer is no. Changes that occur in the human body during severe illnesses such as advanced cancer or heart failure are completely different from those that happen in healthy people who have been forced to go short of food. 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 food it is given to build itself up. This is why the appetite gets smaller - the body seems to recognise that it can no longer cope with food. Surprisingly, people with advanced illness often live for some time after they have stopped eating completely, although it is one of the more common signs that the person is beginning to get less well.

Are there alternative feeding methods? What about ‘drip’ or ‘tube’ feeding?

We know from research that neither drip nor tube feeding will make most people with advanced cancer put on weight or live any longer.

Feeding via a tube through the nose into the stomach (nasogastric tube) or directly through a hole into the stomach (gastrostomy) is provided for some people who have an appetite but are not able to eat properly, but this is only done in certain circumstances.

Drip-feeding (given into a vein, called TPN or total parenteral nutrition) is done very rarely and usually for just a short time, for example, after some types of bowel surgery. It is not helpful to people with advanced illnesses.

What will happen to someone who is already being fed through a tube? Will their food be stopped?

At any time, an ill person has the right to say that they want to stop being artificially fed and to have the tube removed. If they get less well their appetite may also get smaller, and decisions may then have to be made about whether artificial feeding should be stopped.

If they become too ill to make that decision, the doctors and nurses will make a careful assessment and discuss fully with the patient’s family the right thing to do. The ultimate responsibility for decisions about starting and stopping artificial feeding rests with the doctor caring for the patient.

Sometimes, it can do more harm than good to carry on feeding. The sort of harmful effects that could happen when someone is in the last few days of their life and very weak include regurgitation, sickness and food spilling over into the lungs (‘aspiration’).

Things that may help

- Offer small meals or snacks spread out over the day rather than large meals that can be off-putting.
- Don't worry too much about balanced meals, 'a little of what you fancy does you good'.

You might find it helpful to talk to a dietician about different sorts of meals and foods. Ask the nurse or doctor if this would help.

- Food supplements can be obtained on prescription. These can help if the person you are caring for likes them.
- Alcohol can sometimes help to stimulate appetite and will not usually interfere with medication (but please check first with the doctor or nurse).
- As the ill person becomes weaker, you may notice that food begins to go down the 'wrong way' causing them to cough and splutter. This may be a problem that can be solved by changing the texture of the food and by ensuring as upright a position as possible while eating. It could also be a sign that they are getting less well.

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

Some medications, such as steroids and progestogens, can help boost appetite. Often the effect is only temporary. However, any weight gained in this way is only fat or fluid and not muscle (which is the most useful).

Why have they stopped drinking?

If someone doesn't drink won't they die of dehydration? Isn't fluid even more important than food?

It is normal for people with advanced cancer and other illnesses eventually to stop drinking and to stop feeling thirsty. As the body weakens and the systems start to work less well, there is less need for fluid.

It is important to remember that it is the illness which is making the body systems fail, not a lack of fluid. If someone is very weak and given fluid by mouth it may go down the 'wrong way', making them cough and splutter.

What can I do if they complain that they have a dry mouth?

A dry mouth can be a very common problem at any stage of the illness. Ask the medical or nursing staff about it. This feeling is quite different from feeling thirsty. Medicines such as special saliva sprays, gels and chewing gum may be helpful.

What can I do to help?

If staff feel it is safe to do so, you can carry on offering drinks (as the staff will do when you are not there) but don't be surprised if your relative only wants a few sips at a time. The staff will help you to make sure the drinks are not causing coughing and spluttering.

Some people like to have their favourite drink frozen as an ice-lolly or ice chips - these can be easier to suck on than trying to drink.

When someone is no longer taking drinks from a cup, you can use small sponges dipped in cold water (or the person's favourite drink) to help stop the mouth getting dry. A nurse or other member of staff will be happy to show you how to use these sponges.

Do you ever use drips?

Yes. A drip is the name for fluid, which is usually sterile salt water, given to the patient through a tube that goes in either under the skin or through a vein. Sometimes the doctors and nurses may feel that giving a drip might help and the patient may be admitted onto the ward for this. If a drip is started, it will be reviewed by staff over the next 24 to 48 hours to see if it is helping and also to make sure there are no side effects from it.

However, for most people with only hours or days to live, their body systems are shutting down and thirst is not a problem. Drips often do not help and good mouth care is the most important comfort measure.

Are there any disadvantages to drips?

Yes. In the last few hours or days of life the body cannot handle fluid as efficiently as before - giving drips can sometimes make things worse by overloading the delicate fluid balancing mechanisms of the body. If this happens the person may experience 'chestiness' or noisy breathing, and swelling of the arms or legs, as their body cannot process the fluid from the drip.

Once a decision about a drip has been made, is it final?

No. The doctors and nurses will always monitor the situation and discuss it on a regular basis. The patient always has the right to say they want to have a drip removed.

If the patient is too ill to make that decision, the doctors and nurses will make a careful assessment and have a discussion with the patient's family about the right thing to do.

The ultimate responsibility for decisions about starting and stopping a drip rests with the doctor caring for the patient. Any decision that is made can always be reviewed.

Space for notes:

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Director of Care

Hospiscare, Searle House, Dryden Road, Exeter EX2 5JJ
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