St Helena Hospice

YOUR HEALTH

SUPPORTING FAMILY CARERS

What to expect and how to prepare when a loved one is facing terminal illness

St Helena Hospice is here to support you and your family during one of life's most difficult times. We aim to provide practical advice, emotional support, and a safe space to ask questions and share concerns.

Topics we will cover

To explain and understand the available realistic choices for patients and families when diagnosed with a terminal illness.

For this topic, we will be discussing:

- Advance care planning
- Care packages and placements
- Equipment

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 often one of the signs that the person is becoming less well.

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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 specific 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, a patient has the right to say that they want to stop being artificially fed.

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 senior 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
- 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).
- Gentle exercise can help slow up muscle loss; a physiotherapist may be able to advise you further, ask your 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 becoming 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).