



PalAssist

Palliative care support & advice

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'They've stopped eating and drinking'

Information for the carers and loved ones of someone with a life-limiting illness.

It is common for people with advanced disease or for those who are approaching the end of life to not want to eat or drink. Family and friends may worry about this. This information sheet explains why appetite and thirst can decline, what to expect and what may help.

Why do they not want to eat?

Eating and drinking is a normal part of life and is essential for sustaining our bodily functions. It's normal for the nutrition and fluids our body needs and is a social and emotional part of being human. It can be confronting when you are close to a person whose hunger and thirst is declining at the end of life.

We know from research that the body's needs change in advanced illness. For example, the person may be unable to absorb nutrients in the gut. This can leave them with a feeling of fullness, plus a risk of vomiting and inhalation. As their body changes, so too must our expectations and, in turn, the care they receive.

Will they starve?

Studies show that people who are terminally ill do not experience hunger or thirst in the same way healthy people do. The desire and the need to eat and drink reduces at the end of life^{1,2}. Swallowing and digestion can also be impaired and the person may be drowsy.

It can be unhelpful to push the person to eat or drink. It will not improve their quality of life, increase their weight or extend their life. It may increase their discomfort, cause nausea or vomiting, or the food or drink may go down the wrong way and into their lungs. Not wanting to eat or drink is a symptom of the end of life, not a cause of it³.

Should they have a drip?

No, this doesn't help. Studies show that using artificial feeding options will not increase comfort, quality of life or life expectancy. These options include putting in an intravenous drip or a tube into the stomach. These are used for people who are temporarily unable to eat or drink. They are not usually helpful for people nearing the end of life.

What can I do?

If the person is awake, and still eating and drinking a little:

- You can offer tasters of their favourite food or drink, even just one or two small mouthfuls may be enough. Little and often during the day is best.
- Thicker soups may be easier to manage – trial delivering it with a spoon or in a cup and avoid foods that need a lot of chewing. Talking to a speech pathologist can help with finding the safest and most comfortable option.
- You can use small chips of ice to freshen the mouth and introduce a pleasant taste. You can use cordial, an icy pole, fruit juice, or even try freezing their favourite tippie. Use small chips to prevent too much fluid in the mouth, which may spill into the lungs.

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We're here, and we care.

If they are sleepy, drowsy, unconscious, or not taking anything by mouth:

- Use oral sponge sticks dipped in something they like to freshen the mouth and introduce a pleasant taste.
- Gently clean their teeth by placing their head to one side. Use a soft-bristled toothbrush and a small dot of toothpaste. Place a facecloth gently inside the cheek to absorb any fluid or froth, if necessary.
- You can also use a gloved finger to apply a little toothpaste to the teeth.
- You can gently cleanse and moisturize the tongue if the person is mouth breathing. Use a moistened sponge stick, gloved finger, or soft toothbrush to do this.

What if they choke, cough or splutter?

Sometimes, the swallowing reflex can slow down. This means that bits of food or fluid have gone down the wrong way and cause a cough. By giving small amounts of food or fluid and checking how this goes, you will be minimising any risk.

Ask to talk with a speech pathologist who can help with changing (thickening) the consistency or texture of their food. Try to have them sitting up while eating or drinking. Try not to worry if they do cough. It may be a sign they are becoming weaker and you need to change what you are doing as their condition changes. Reassure them and talk to care staff if you are worried or unsure of what to do.

When someone refuses to eat or drink

An ill person has the right to say that they want to stop eating and drinking. If they have been receiving nutrition via a feeding tube, they have the right to choose to have it removed. They can also record this decision ahead of becoming incapacitated. The care team will carry out ongoing assessments, talk through this with you and provide information and support.

Are there any medicines that can help?

Each person's situation is individual, so the care team will suggest tailored options. There are some short-term medicines that can temporarily increase appetite if the person is still able to eat or drink, though this medicine is not suitable for everyone. There are other medications that can help with secretions.

Just ask

If you're unsure about anything, you can ask your lead nurse, speech pathologist, or doctor and they will talk through options with you. It can be a confusing time; each person and their situation is unique, and no question is too small.

References:

1. Del Rio et al., (2012) Hydration and nutrition at the end of life: a systematic review. *Psycho-Oncology* 21 913-921
2. Smyth, (2016) Meeting the nutritional needs of palliative patients. *Int J. Palliative Nursing* 22(3) 109-110
3. Clark et al., (2017) Declining oral intake towards the end of life: how to talk about it? *Int. J. Palliative Nursing* 23(2) 74-82
3. Van der Riet et al. (2006) Nutrition & hydration at the end of life: a pilot study of the palliative care experience. *J.Law and Medicine* 14 182-198

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