

Other ideas that may help:

- Keep asking "What is helpful for my relative / loved one at this time?" There is no single 'right' answer as it depends on each person's individual situation.
- Continue to offer other forms of support e.g., gentle massage, skin care, music and conversation.
- Keep the person company talk to them, read to them, watch films together, play music, or simply sit with them and hold their hand.
- Even when people cannot speak or smile, their need for companionship remains. The person may still draw comfort from your touch or sound of your voice.

Contact details:

- The End of Life Care team, telephone 01623 622515, extension 4570/4571, between Monday and Friday, 9am to 5pm.
- The Speech and Language therapist, telephone 01623 622515, extension 3320.



Further sources of information

NHS Choices: www.nhs.uk/conditions
Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222 **Newark Hospital:** 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this letter or information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PFT@nhs.net

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases.

Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them.

If you require a full list of references for this leaflet, please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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Information for patients, relatives and carers

Eating and drinking at the end of life - last hours/days

Includes information about mouth care and taste for pleasure









End of Life Care

In this information leaflet, the term 'end of life care' refers to the last hours/days of the patient's life. During this time, the focus will be providing care that prioritises comfort and patient choice.

Reduced need for food and drink

Food and drink are so much more than just giving calories, nutrients and fluid. They are important parts of our cultures, our preferences and choices and are central to how we connect, share and show care for each other.

Loss of interest in eating and drinking is a usual part of dying but this can sometimes be hard to accept for the people important to the patient. The nursing team will support the patient to eat and drink for as long as they want and are able to do so. People important to the patient can be involved in supporting the dying person with any food and drink. Please talk to the nursing team about how best you can be involved.

The patient becoming sleepier for longer periods is a natural and expected part of the dying process. When the dying person stops eating and drinking, mouth care should be given more often (every two to four hours or more if needed). Mouth care will be given by healthcare professionals, who will be happy to support and guide you if you wish to help out with mouth care for your relative/loved one. Mouth care is more than just brushing teeth. It is cleaning and moistening all parts of the mouth, teeth (if present) and all of the soft tissues (lips, tongue, cheeks).





Items used in mouth care: Tooth brush and tooth paste

The best brush to use is either the patient's own, or a small headed or child's tooth brush with soft bristles. Non-foaming toothpastes which do not dry the mouth out are available from chemists or dental practices.

Moi-stik

Specialist mouth care sticks are available in the hospital setting and can be used for refreshing and moistening the mouth. They can also be used for giving taste for pleasure. These should never be left to soak in drinks as this weakens the stick and the 'bud' can break off if the patient bites down on it during mouth care and may be a choking risk.

Moutheze

These are rubber-type small brushes used to clean teeth, tongue and soft tissues. They are reusable (for the same patient) and must be rinsed and air dried between each use, so keep upright in a cup like a toothbrush.

Moisturising gel/spray

These are used to help relieve dryness and add moisture to the patient's mouth. The nursing staff will provide the gel and, or spray. The gel can be rubbed on as often as needed. It is important that it is spread around the mouth and lips in a thin coat and not just on the tongue. The spray should be pointed towards the cheeks and not directed at the back of the throat.

Lip balm

Lip balm can be used to prevent and treat dry lips.

As part of mouth care, the nursing team may introduce taste for pleasure. This is where the nurses will discuss the patient's favourite drinks with you and they can use these when giving mouth care (once the mouth has been cleaned). The favourite drink may be a simple cup of tea, nonalcoholic or alcoholic drink, which can be soaked into a moi-stik and then placed on the lips and in the mouth of the patient. This allows a tiny amount of the drink to enter the patient's mouth. The patient may get pleasure from being able to taste their favourite fluid.

The hospital staff can't purchase alcohol, but are happy to include it in taste for pleasure/mouth care once supplied by the people important to the patient. If the patient has had swallowing difficulties much earlier in their illness, then we can contact the Speech and Language therapist for advice and support to make taste for pleasure as easy and comfortable as possible. If you are happy, the nurses can put a sign above the patient's bed saying what their favourite drink is, so that everyone will know what to use after giving mouth care. If the patient was having intravenous fluids (by a drip) before it became clear that they were dying, they may be stopped. This is because giving fluids this way can cause more problems, such as extra fluids in the lungs and throat or swelling in the patient's skin/ limbs. These decisions will be explained to you by the doctors and nurses.

The comfort of your relative/loved one is extremely important to us and, if you have any questions or need advice, please speak to the registered nurse responsible for their care. The End of Life Care team and Speech and Language therapists are also available to help.