

Mouth Care during End of Life Care

Keeping the Mouth Clean, Moist and Comfortable,

RESOURCE FOR PATIENTS, FAMILY AND CARERS



Acknowledgements

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Contents

Introduction	
Why is mouth care important at the end of life?	5
Products used to assist mouth care	8
How to prepare for mouth care	11
Advice and FAQs	15
Things you should not use	
Mouth care poster	17

This resource can be used by the person receiving care, their relatives and those important to them, to help support good mouth care during end-of-life care.

The information included in the resource is not intended to replace any advice from health or social care professionals. We suggest that you consult with a qualified professional about your individual circumstances.

This may be a challenging time for you, there is further support available. You can speak to your doctor or nurse, and you can call the free Marie Curie Support Line on 0800 090 2309.

Introduction

This guide has been created by the Mouth Care Matters in End-of-Life Care Steering Group. It has been developed to help support people during the end of life when a person is dying, and can be used by relatives and those important to the person.

Throughout this resource the term "end of life care" refers to the care provided for a person who is dying. The focus at this time is promoting comfort and will centre around keeping the mouth clean and moist.

The resource refers to the terms "mouth care" and "taste for pleasure". "Mouth care" refers to cleaning the mouth, moistening the mouth and making sure it is comfortable. "Taste for pleasure" is a phrase used to describe having very small amounts of a liquid or taste that a person likes for their enjoyment.

A loss of interest in eating or drinking is normal when someone is dying. Your relative or person important to you will be supported to eat and drink for as long as they would like or are able to. Mouth care and "taste for pleasure" are important during this time and can help bring comfort.

Why is mouth care important at the end of life?

Providing mouth care for the person you care for promotes dignity and comfort.

Saliva helps to keep the mouth moist and comfortable. As people near the end of life, less saliva is often produced. Due to mouth breathing and some medications used to help symptoms, the mouth can become very dry and uncomfortable. The lips may become cracked which can be very sore. Talking, swallowing, eating and drinking may become difficult. Cleaning and cleansing the mouth helps keep the mouth moist, hydrated and comfortable.

You may be concerned and distressed about the condition of the mouth. Halitosis (bad breath) may not be distressing for the person but may cause embarrassment or concern. It may also stop you from wanting to get close to them. These are normal feelings and regular mouth care can make a big difference for you all.

When and how often should mouth care be provided?

Mouth care can be provided at a time that suits the person you care for. If the mouth is very dry you may wish to carry out mouth care or taste for pleasure hourly. However, this depends on what is keeping the person most comfortable and individual circumstances.

If the person you care for is sleeping, you can still carry out gentle mouth care. If the person you care for is unconscious or is unable to cough or swallow it is still important to continue with mouth care. At this stage, use a dry toothbrush with soft bristles or round headed toothbrush to gently sweep around the mouth.

When carrying out any activities including mouth care, it can provide confort to the person you are caring for, if you explain what you are doing. Talk to them whilst you are doing it. Even if the person you care for is in a deep sleep (unconscious) they may be able to hear you or recognise your voice.



"Taste for pleasure" and comfort

Good mouth care and "taste for pleasure" are very important when a person is dying and can help them feel more comfortable.

Many people have swallowing difficulties; "taste for pleasure" is a way of providing comfort in the last days of life. This should be done along with regular mouth care.

"Taste for pleasure" uses the person's preferred drink or taste to moisten their mouth. The preferred liquid or taste can be given using a mouth hydrator (displayed on the photo below) or a soft toothbrush, or a circular brush gently sweeping around the mouth and lips to release some of the liquid.



Image of a mouth hydrator which can moisturise and hydrate the lips, mouth and tongue.

It reduces the risk of choking by applying a slow trickle of water from two drip holes when gently compressed against the lips. Can be used with water and other liquids or tastes (taste for pleasure) to soothe the mouth. Can be used chilled and sucked like a lollypop to soothe a very sore mouth.

Michelle Pearson, a dementia palliative care assistant, describes "taste for pleasure" below:

" I supported a gentleman living with domentia who never tolerated mouthcare. After a conversation about his life, I was told this gentleman loved Ohampagne!! It was worth a try.... it worked :) he had the poshest mouthcare in Derbyshire." Image of a Mouth hydrator being used to soak up liquid from a longstemmed glass, to be used for "taste for pleasure".

Warm liquids such as tea, coffee can be used. Check the temperature of the liquid to make sure it is not too hot before giving to the person.



Images of a glass of clear yellow fluid, glass of red fluid, cup of warm liquid. All of which can be used for "taste for pleasure".

BACK TO CONTENTS



BACK TO CONTENTS

Products used to assist mouth care

Toothbrush

You can continue to use the person's preferred toothbrush; whether it's manual or an electric toothbrush. You can also decide which you feel more comfortable using. For both brushes it is important that the head of the brush is small and that the bristles are soft (see photo below). A toothbrush with a circular head is a good option (see photo below).



Toothpaste

Continue to use the person's preferred toothpaste. For some people at the end of life, the strong mint flavour and foaming nature of many toothpastes caused by an ingredient called sodium lauryl sulphate (SLS) can cause discomfort. Using fluoride toothpaste that is mild mint flavoured, or flavour free, and free of SLS would be a good alternative.



Dry mouth products

These are usually water-based gels or sprays that lubricate the mouth, providing relief from dryness. Some products contain ingredients derived from pigs or milk proteins and may not be suitable for people with a milk allergy, certain cultural beliefs or vegans. This information can be found in the product's ingredients list. Speak to your doctor or nurse for alternatives.



A water-based gel product can form a long-lasting lubricating layer which may help with comfort, speaking, communicating and eating.

Spray directly inside the mouth, on the cheeks, on the floor of the mouth and the tongue. Be careful not to spray towards the back of the throat.

Mouth gels can contain the same naturally occurring proteins that are found in the mouth.

These gels may help with swallowing, and soothe and protect the gums. They are safe to swallow and assist with moisturising a dry mouth and throat.

Use as a saliva substitute and apply to all soft tissues to provide up to seven hours of relief. Apply with a mouth cleanser or circular brush. Can also be used as a denture fixative. Use as a saliva substitute and apply to all soft tissues to provide two to five hours of relief.

This product may contain proteins extracted from milk, not suitable for people with a milk allergy or vegans.

Lip products and care

The lips may become dry and cracked and can be sore and painful.

Apply a water-based gel or beeswax lip balm as needed. Massage onto the lips. Suitable products are available from pharmacies and supermarkets. The use of petroleum jelly should be avoided.



Mouth cleansers

These have soft silicone bristles and can be used to remove secretions, coatings and food residue from the mouth (see photo below). They can also be used to apply dry mouth gels to hydrate the mouth.

The mouth cleanser has silicone bristles and do not detach from the stick.

They can be used for up to 12 hours.

Use a mouth cleanser to moisten the mouth with a water-based gel, apply mouth rinses or water. Effectively removes dry or sticky hard secretions from all areas of the mouth.

How to prepare for giving mouth care and taste for pleasure

It is important to wash your hands thoroughly before and after giving mouth care and "taste for pleasure".

Gather everything you need which will include a toothbrush, toothpaste, mouth cleanser, dry mouth products and lip balm as described above. Use a clean towel to protect the person's clothes you are caring for.

How to provide mouth care

Video link below, from Mouth Care Matters, Health Education England: Carrying out Mouth Care at the end of life: Carrying Out Mouth Care EOL



Tooth brushing

Brush teeth and gums twice a day with a small soft toothbrush and a smear of nonfoaming toothpaste. If the person for whom you are caring for is awake, try and carry out tooth brushing at least twice a day, at a time that suits them best. Take care not to place the brush too far back into the mouth.

If the person for whom you are caring for has difficulty swallowing, use a dry toothbrush

and a small smear of non-foaming toothpaste. Remove any toothpaste from the mouth with a soft toothbrush, circular brush or mouth cleanser.

The act of mouth care can be tiring, it may not be possible to clean the whole mouth in one go. You may need to clean a different part of the mouth each time and allow the person to breath freely without compromising the airway.





Dry mouth care

A dry mouth can feel very uncomfortable and it may be hard for the person you care for to explain that their mouth feels dry. Look out for signs of a dry mouth.

When the mouth is dry, the tongue and lips may stick together or feel rough. Any saliva in the mouth may appear frothy or stringy if the mouth is dry, as opposed to clear and watery in a moist mouth. Hard secretions (crusty dried saliva) may be visible on the roof of the mouth if the mouth is dry.



Image showing a dry tongue

To care for a dry mouth, ensure that any secretions have been removed. This can be done by using a mouth cleanser, circular brush, or toothbrush and a dry mouth gel. If the secretions are very dry and difficult to remove, soften them first by applying dry mouth gel or spray, wait a few minutes and try again. Gently roll the cleanser or circular brush on the secretions, taking care to always move from the back of the mouth towards the lips.

Apply dry mouth gel with a mouth cleanser, circular brush, or small toothbrush. You only need to apply a small pea sized amount of the gel to cover all areas of the mouth.

Apply to the lips, tongue, inside of the cheeks and palate (roof of the mouth). If gel is being applied daily make sure that the mouth is cleaned to remove any build-up of gel. This can be removed by using a soft-headed toothbrush with a rolling motion as detailed above.

Denture care

At the end of life, it is up to the person you are caring for whether they continue to wear their dentures. If they are not worn, it is important to store them in a clean container and ensure they are still cleaned regularly.

If the person you care for chooses to continue wearing their denture, make sure they are removed before cleaning / cleansing and moistening the mouth.

To clean dentures, use a denture brush or different toothbrush to the one you use for mouth care. Use what the person normally uses to clean their dentures. This may be a special denture cleaner or soap and water.

Brush the area of the denture which encounters the roof of the mouth and the bottom gums. Clean dentures over a sink or bowl of water. Rinse thoroughly under cold running water. Place back in the mouth.

Dentures should be removed and rinsed with water after eating.

Aim to take the dentures out before sleeping to help aid comfort.

If the person you care has not worn their dentures for a while, but then wishes to wear them again, it is likely the contour of their gums may have changed. This may cause the dentures to feel very uncomfortable. You may need to seek advice from a member of the dental care team.

How to remove dentures safely



Step 1

Fill a sink or bowl with water. That way, dentures don't break if accidentally dropped.

Step 2

For top (upper) dentures; place your thumb or fingers between the denture and cheek.

Step 3

Press down gently where the denture meets the gums. Try to use even amounts of pressure to loosen them.



Step 4

To remove bottom (lower) dentures, place your thumb and fingers on either side of the denture

Step 5

Rock the dentures gently and lift the bottom denture to loosen.

Storage

Dentures that are not worn; store them in a lidded container to keep safe. They can be stored in water or left dry in the container. To avoid loss of dentures, the denture container can be labelled with the person's name (see photo below for denture pot, denture bath and denture cleaning equipment). If dentures are stored in water, make sure the water is changed daily.



Image showing a denture brush, liquid soap, a lidded denture pot and a denture bath



How to clean a denture animation video link created by Mouth Care Matters, Health Education England: How To Clean a Denture Animation - Mouth Care Matters

Advice and FAQs

Who to contact for mouth care advice

If you have any concerns or need advice about what products to use there are people who can support and help. Try asking the:

- Community or District Nurse
- Hospice and hospital nurses
- · Health care assistants
- Dental teams
- Local pharmacist
- Doctor

Frequently asked questions

What if the person I'm caring for is unconscious?

If the person you care for is in a deep sleep (unconscious) and breathing with their mouth open, carry out mouth care hourly or as often as possible. Gently brush the teeth, gums and tongue to keep the mouth clean, moist, comfortable and free of any sticky stringy saliva.

What if the person I'm caring for cannot open their mouth?

If the person you are caring for is unable to open their mouth, or can only open a small amount, focus your attentions on the areas you are able to access. Providing mouth care and lip care to even small areas will still provide lots of comfort.

What if the person I'm caring for refuses or resists mouth care?

If the person you are caring for resists or refuses mouth care it may be because their mouth is sore. Try and reassure them and give as much mouth care as you can, but do not cause distress. Often applying lip balm or dry mouth products to a small area will provide relief and comfort and the person may then allow you to continue. Sometimes a 'little and often' approach to mouth care is best to help overcome any resistance. Explain what you are doing and why by communicating this to the person.



Things You Should Not Use

Foam sponge mouth swabs

It is strongly recommended not to use foam sponge swabs of any type for mouth care. Their use is banned in Wales and in many organisations across the rest of the UK.

They are not effective in cleaning teeth or removing dental plaque, and there is a risk that the foam head could become detached. This is a serious choking hazard.

A mouth cleanser is a safe replacement for the foam sponge swabs.



Lemon and glycerine swabs

The use of lemon and glycerine swabs is not recommended.

They can worsen a dry mouth.

For people with severe mouth pain / bleeding from the gums at the base of the teeth, or to provide comfort at end of life, a soft toothbrush, circular brush or mouth cleanser is preferable to provide hydration and to keep the mouth moist.

Tap water or water based gel can be used to keep the mouth moist.

Mouth Care During End of Life

Clean, Moist and Comfortable

The person you are caring for should be encouraged to brush teeth and gums twice a day with a small soft toothbrush and a smear of non-foaming toothpaste. Check the mouth/cheeks for food debris.



If the person you care for is unconscious or is unable to cough or swallow it is still important to continue with mouth care. At this stage use a dry toothbrush with soft bristles or a mouth cleanser or circular brush to gently sweep around the mouth. If the person you care for is sleeping, you can still carry out gentle mouth care.

Dentures should be cleaned twice daily, use a denture brush or different toothbrush to the one you use for mouth care. Dentures should be removed at night and stored in a labelled denture pot.



For dry mouth apply dry mouth gels/spray to the inside of the cheeks, tongue, with a Mouth cleanser or circular brush.

Encourage regular sips of water.

Water based lip balm should be applied as required. Lip products are usually water-based gels or beeswax balms.

Mouth care can be given more frequently. hourly or two hourly as necessary, for those people at the end of their life.

Dry mouth gels should be applied to the tongue, inside of the cheeks with a Mouth cleanser or circular brush. Water based lip balm should be applied as required.

"Taste for pleasure" uses the person's preferred drink or taste to moisten their mouth. The preferred liquid can be given using a mouth hydrator. Place the flat edge against the person's top lip, gentle pressure from the lower lip releases some of the liquid. A soft toothbrush or circular brush gently sweeping around the mouth and lips with some of the person's preferred liquid can also be used.

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

This resource aimed at patients, family members and carers has been produced to support the delivery of safe and effective mouth care for adults during end of life care.

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The Nine Quality Standards

This publication has met the nine quality standards of the quality framework for RCN professional publications. For more information, or to request further details on how the nine quality standards have been met in relation to this particular professional publication, please contact publicationsfeedback@rcn.org.uk

Evaluation

The authors would value any feedback you have about this publication. Please contact **publicationsfeedback@rcn.org.uk** clearly stating which publication you are commenting on.

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