

What to expect towards the end of life

A guide for caregivers

When someone that you care about is at the end of life, it is a challenging time, full of complicated emotions and concerns. As a caregiver, you may have many questions or feel uncertain about how best to meet their needs. These concerns are a natural part of caring for someone approaching death. Knowing what to expect in the last days and hours of life can help you feel better prepared.

This guide will help you understand and attend to the changing needs of the person you are caring for. If you have any questions about this information, please speak to the doctor or nurse.



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Physical changes and needs

At the end of life, a person's body goes through many physical changes. These changes usually happen over a few days, but sometimes can happen quickly over a few hours. A person can go from looking stable to looking as though they have only hours to live. These changes may be stressful or upsetting, but they are the normal process of dying. They are not usually medical emergencies.

These physical changes are described in the following sections, along with tips on how you can help to keep the person you are caring for as comfortable as possible.

Eating and drinking

Why are they eating and drinking less?

At the end of life, people generally do not feel hungry or thirsty because the body's systems have slowed down. The body loses its ability to use food and fluids, and does not benefit from the nutrients. At this time, they will eat or drink very little, if at all. This is normal.

If they do not want to eat or drink, it is important to respect their wishes. It is natural to want to feed someone who is ill, but feeding a dying person will not ease their suffering and will not extend life. In fact, food or drink can make a dying person feel sick and uncomfortable.

Important Notes

- Be careful not to force them to eat or drink.
- If they cough or have trouble breathing during feeding, stop immediately.
- **Do not feed them if they are very sleepy or cannot swallow properly.** Food and water can get into their lungs and can lead to congestion and pneumonia.
- Don't be alarmed if their urine is dark in colour. As a person drinks less, urine becomes more concentrated and darker.

How can I help with eating?

It's okay to focus on enjoyment rather than nutrition. It can be normal for a person to feel full after only a few bites of food.

- Make sure the person is alert and sitting up before offering food, as shown in the picture.
- Offer soft foods the person might like.
- Offer just small amounts at a time and stop if the person seems full.
- If they cough or have trouble breathing during feeding, stop immediately.



How can I help with drinking?

It's okay to offer fluids. First, raise their head off the pillow slightly to prevent gagging. Then, offer fluid in one or more of the following ways:

- Give a couple of sips of water from a syringe or baby cup with a spout.
- place a couple of ice chips in their mouth.
- offer a sponge swab (see picture) dipped in water for them to suck.
 - Home care can provide these to you. The person you are caring for may bite down on the sponge. This is a normal reaction. Continue to hold onto the stick. After a few moments, they will let go.



What about using intravenous feeding (IV)?

Many caregivers ask about intravenous (or IV) feeding. In IV feeding, a doctor or nurse inserts a needle into a person's arm and fluids are given directly through the vein. These fluids are usually water with salt added. We tend to not recommend the use of IV feeding. IV fluids do not provide much nutrition and may cause discomfort.

Pain

What are the signs of discomfort?

Pain does not usually get worse at the end of life. In fact, a person may experience less pain as they become sleepier and move less.

Even when people are not able to talk, they can usually show us with their bodies when they are experiencing discomfort or pain. Look for signs like:

- tensing of the face, hands or body
- clenching of the teeth.

Your health care team will monitor closely for these signs as well.

Are they in pain when they moan?

You may hear the person moan. Moaning happens most often as a dying person breathes out or when they are moved from side to side. This kind of moaning is not necessarily caused by pain. It may be caused by a change in breathing. This is explained in more detail on page 8 in the section called, *Changes in breathing*

Will the doctor change their pain medication?

If pain medication is being used, the doctor or nurse practitioner may change the dose or how the medication is given as a person's condition changes.

For example, if they can no longer swallow, some pain medications can be provided through a pain pump or injection. If you think that the pain medication needs to be changed, contact the doctor or nurse.

Restlessness, agitation and disorientation

At the end of life, people can become very fidgety, restless or disoriented. Occasionally, people may feel frightened or threatened. It is also common for people near death to believe that they see things that may not be physically there, such as animals or people who have died. They may appear confused or appear angry, and may not recognize familiar faces. Confusion and personality changes at the end of life can be normal and are not signs the person you are caring for feels differently about you.

How can I help with their confusion or restlessness?

- Identify yourself by name and speak clearly.
- Try calming activities like holding hands, playing quiet music or reading softly to them.
- They may become more agitated if left alone. Ask whether they would like to have familiar faces around more often. It can be challenging to provide this additional care. Talk to the care team about resources that may be available, such as hospice volunteers and personal support workers.
- Try not to argue, correct or contradict what they say.
- Minimize confusion. Try to have only one conversation at a time. Keep noise and chaos to a minimum.
- The person you are caring for may no longer like or enjoy things that they used to. You may have to try different strategies to see what helps to calm them. Talk to the care team if you need advice on things to try.

- Some people may get their days and nights mixed up. It can be helpful to keep the room bright during the daytime and dark at nighttime.
- Talk to a member of the care team if you are concerned. The doctor or nurse can arrange for medication to help.

Mouth, nose and eye care

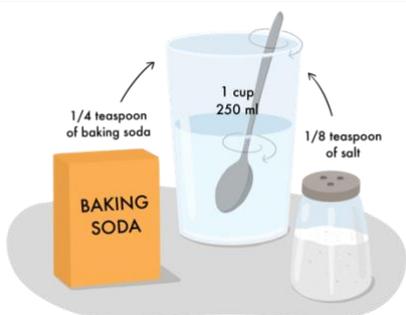
Near the end of life, the tongue, lips, nose and eyes can feel dry and uncomfortable. You may find the person you are caring for often breathes through their mouth. This can make dryness worse. Frequent mouth, nose and eye care will help ease the dryness and discomfort.

How can I help with mouth, nose and eye care?

- Frequently clean and freshen the lining inside the mouth. You can use water or a solution made of salt, water and baking soda as described below.

Solution for dry mouth

1. Mix together
 - 1 cup (250mL) water
 - 1/8 teaspoon of salt
 - 1/4 teaspoon of baking soda
2. Moisten a mouth-care sponge (supplied by the home care team) with the solution and use the sponge to clean and freshen the inside of the mouth, the gums and the tongue. The nurse can show you how to do this.
3. They may bite down on the sponge. This is a normal reaction. Continue to hold onto the stick. After a few moments they will let go.
4. Make a fresh batch each day.



1/4 teaspoon of baking soda

1 cup 250 ml

1/8 teaspoon of salt

- Avoid using mouthwash that contains alcohol. It can increase dryness.
- Use lip balm to protect the lips.
 - **Important:** If the person you are caring for is using oxygen, do not use petroleum jelly (such as Vaseline) on the lips.



- If their nose becomes dry, you can moisten the nostrils with a water-based gel (such as Secaris). You can buy this at a pharmacy without a prescription. Water-based gels can be used safely with oxygen.
- If needed, you can moisten the eyes with artificial tears 3 or 4 times per day. The nurse will show you how. You can buy artificial tears without a prescription at a pharmacy.



Weakness and sleepiness

People at the end of life may feel very weak and tired. They tend to sleep more as their illness progresses. At this time, it is common for them to:

- spend all their time in bed
- appear to be drowsy or in a light sleep most or all the time
- be hard to wake up
- talk very little or not at all.

Is the pain medication making them drowsy?

If the person is drowsy and sleeping a lot, you may be concerned that they are getting too much pain medication. In general, pain relief relaxes the body and allows the patient to sleep more restfully. Talk to the doctor or nurse if you are concerned about possible side effects of the pain medication.

Can they hear me?

In some cases, the person may be in a coma or sleep-like state. They will not be able to respond to talking or touch the way that they usually would. We do not know how much people can hear or how much they understand, but it is likely they continue to hear and understand some things. They likely still recognize and get comfort from your voice. If it feels right for you, continue to talk to and touch them to provide comfort.

How can I help when they are weak and sleepy?

- Change their position in the bed every 6 to 8 hours, switching between the positions they find most comfortable. Regularly changing position helps to reduce discomfort and prevents bed sores from developing. The picture on the next page, shows two positions that we have found to be the best. The nurse or support worker will show you how to do this.

Comfortable positions

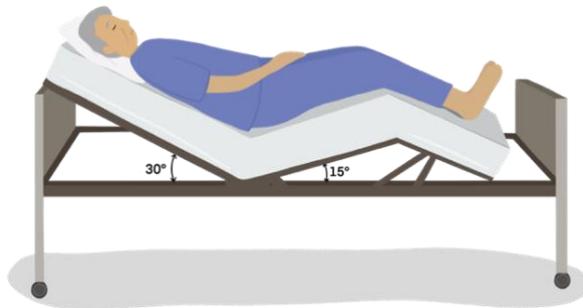
Turned partly to the side

This position is helpful when a person is congested. To keep them from rolling onto their back, use pillows to support the whole length of the back.



Flat on the back with the head and legs slightly elevated

Raise the head about 30 degrees. Do not raise the head too much so they don't slide down in bed. The resulting friction can cause bed sores. The legs should be raised about 15 degrees. Ask a nurse how best to position them and adjust the bed.



- The nurse may recommend a special mattress to help treat or prevent bed sores.
- Eliminate trips to the toilet by using disposable absorbent underwear. In some situations, a catheter might be placed into the person's bladder and attached to a bag to drain their urine. There may be some discomfort when the catheter is inserted, but there is usually no pain once it is in place.
- You may talk to the person you are caring for as if they can hear everything. Say everything you want to say. You can continue to be affectionate and reassure them that you are close by, if this feels right for you.

Changes in breathing

How may their breathing patterns change?

As the person you are caring for gets weaker, you may notice their regular breathing patterns change. Their breathing may:

- speed up
- sound shallower or deeper
- become irregular.

Generally, these changes are not because they are not getting enough oxygen. If you have any concerns about changes in breathing patterns, please discuss them with the health care team.

Just before death, their breathing will slow down. There may be gaps that last as long as 20 or 30 seconds between breaths. Their breathing may sound like gasping. This pattern of breathing can last for hours or days. They will not be aware of these changes or be in any distress.

Why is their breathing noisy?

When a person is in a coma or an extremely drowsy state, their breathing often sounds congested or like snoring. There may also be a soft, short moaning sound with each breath. These noises are caused by a small amount of mucus or phlegm in the throat that builds up when a person is not conscious enough to cough.

This change in breathing tends to occur anywhere from a few days to a few hours before a person dies. Although the sounds may be difficult to listen to, the person will not be in any distress and will not choke on the mucus or phlegm. Oxygen will not help reduce or stop the noise.

Sometimes, caregivers ask about using a suction machine to remove mucus. We generally do not recommend using these machines because the hose can cause the person to gag and vomit.

If you are concerned the person you are caring for is uncomfortable, the doctor or nurse practitioner can prescribe medicine to help.

How can I help with noisy breathing?

You can help to reduce or stop noisy breathing by positioning them in the fetal position on a flat bed. Pillows are very useful to support the back and prevent them from rolling over.

Looking after yourself

The end of a person's life can be a time of worry and stress. Throughout the course of their illness, you have likely faced many challenges, not only from providing care but also from dealing with your own grief and emotions.

As their death approaches, you may experience a variety of feelings, including fear, worry, sorrow, comfort, peace and relief. You may also feel that the person you are caring for is nearing the end of suffering. All these feelings are normal.

As a caregiver, you may be emotionally and physically exhausted. You may also be taking care of grieving children, or other family members and friends. As important as it is for you to look after others, you also need to care for yourself. Looking after yourself will help you to be a better caregiver for the people around you.

If you would benefit from additional emotional support, please let the doctor or nurse know. We will help to look into things such as counselling services. Your primary care provider (such as a family doctor or primary care nurse practitioner) can also help to support you now and in the future.

In some situations, the health care team may be able to provide additional practical services to allow you time to take a break, such as increased personal support worker hours or hospice volunteers. Please talk to the team if you are starting to feel overwhelmed.

How can I look after myself?



- Remember to eat regularly and drink plenty of fluids to stay hydrated.
- Try to get some sleep. By allowing yourself enough time to rest, you will be better able to help the person you are caring for and keep yourself healthy during this time.
- Try to take time for yourself. Taking time for a shower or bath, a quiet walk, meditation or prayer can help.

- If possible, surround yourself with supportive friends and relatives. Ask for help when you need it. People can be eager to help during this difficult time. Say yes to offers of help with meals, housework, child care, grocery shopping, driving or sitting with the dying person while you take a break. Talk to your health care team about resources that might be available to support you.
- Discuss your fears and worries with the health care team. If you need help coping with grief, talk to someone such as your family doctor or palliative care doctor about resources that may be available to you.

Very near the time of death

What happens when the person is close to dying?

As death nears, the person's eyes may stay open without blinking. There may be long pauses between breaths.

You may also notice some skin changes, which occur as blood circulation slows. These changes may be that:

- their skin becomes blue or blotchy
- the underside of their body darkens
- their skin around the mouth appears bluish grey.
- their face becomes pale
- their nose, ears, hands, arms, feet and legs feel cool to the touch
- their fingertips darken.

At this time, the nurse may stop taking the person's blood pressure and pulse. These are less critical when a person is close to death.

Occasionally, someone who is unresponsive may suddenly become more alert or have a surge in energy. For a short period of time, they may be talkative or more interested in food or visitors. If this temporary change occurs, they are not in any distress.

How can I help them near the time of death?

- Keep them at a comfortable temperature.
 - If they feel warm, soak a cloth or towel in cool water and lay it on their forehead or chest for cooling.
 - If they feel cold, use blankets to keep them warm.
- Avoid loud noises that may startle and disturb the person you are caring for, causing distress. Speaking at a normal level is fine.
- If it feels right to you, you may want to:
 - reassure them that it is okay to die
 - let them know how much they mean to you
 - say "I love you".

When they die

When someone dies at home, often there will be no nurse, doctor or personal support worker with you. You may be alone with the person who has died.

How will I know death has happened?

You will know that the person has died because:

- they will not be breathing
- their eyelids may be slightly open and will not blink
- their pupils will be bigger
- their eyes will be fixed on a certain spot
- their jaw will relax and their mouth will be slightly open
- they may urinate or have a bowel movement.



How long can a deceased person be kept at home?

You can spend as much time as you wish. You may prefer to keep the person's body with you for a few hours or overnight. You may prefer to have their body removed sooner. Either is fine. There are no legal reasons to remove someone's body immediately. Let the palliative care doctor or nurse practitioner know what you would prefer when you call.

As time passes after a death, physical changes occur in the body that makes it difficult to change the person's position. If you do decide to keep the person's body at home for a period of time, you may try to close their eyelids and move them onto their back. It is normal that their eyes may not close.

A farewell gesture such as a hug, a kiss or some words can help you honour the moment and say goodbye.

When should I call the funeral home?

After the doctor or nurse practitioner has arrived and filled out the necessary forms, you can call the funeral home. You are encouraged to make arrangements with the funeral home before the person dies, but this is not required.

When should I call the palliative care physician?

If the person you are caring for dies:

- **Between 7:00 a.m. and midnight**, call the palliative care doctor to arrange a time for them to come to your home.
- **After midnight**, please wait until 7:00 a.m. to contact us. Our palliative care team is available around the clock for urgent support, but they need to focus on patients who need emergency care.

If you require special arrangements for religious or cultural reasons, please speak to the palliative care doctor before the very end of life.

You do not need to call 911 or police.

If 911 is called, be sure to have the Do Not Resuscitate (DNR) form on hand if you have one. This form will alert authorities not to start cardiopulmonary resuscitation (CPR).

How can I support the work of the Temmy Latner Centre?

Funeral homes often ask families if there is a charity they wish to support with memorial donations. You may wish to discuss this matter with the person you are caring for and any other caregivers before they die. Often, people select a charity that has had great meaning to them over the course of their lifetime or their illness.

We would be honoured if you choose to direct donations in support of the Temmy Latner Centre for Palliative Care. Directing memorial donations to the Temmy Latner Centre will help us continue to provide the best possible palliative care, conduct leading-edge research and deliver valuable education to thousands of students and practicing health care professionals.

If you would like to make an online donation, please visit our website at www.tlcpc.org. For cheque donations, please make cheques payable to Sinai Health Foundation with Temmy Latner Centre for Palliative Care on the memo line. Mail to: 522 University Avenue, Suite 1001, Toronto, ON, M5G 1W7. For more information, please call 416-586-8203 or email foundation.msh@sinaihealthfoundation.ca.

**If you have questions or concerns at any time,
please speak to the doctor or nurse.**
