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What to Expect in the Last Days of Life: A Guide for Caregivers

The end of a loved one's life 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 your loved one's needs. These questions and 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. We've put together this guide to help you care for yourself and your loved one during your last days and hours together at home. This information will also be useful if you are caring for someone in a hospital, hospice or another institution, like a long-term care home.

We hope that this guide will help you to understand and attend to your loved one's changing needs, and to ease any fears and worries you may have. If you have any questions or concerns about this information, please talk with your doctor or nurse. It's a good idea to write down your questions so that you can remember them the next time you speak with your health-care providers.

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 they happen very quickly and dramatically over the course of a few hours. A person can go from looking quite stable to looking as though they have only hours to live. Sometimes these changes may be stressful or disturbing, but they aren't usually medical emergencies. They are part of the normal process of dying.

These physical changes are described in the following sections, along with some tips on how you can help manage them and keep your loved one as comfortable as possible.

Eating and drinking

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

For these reasons, if your loved one does not want to eat or drink, it's important to respect those wishes. It's 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 nauseated and uncomfortable.

Do not feed your loved one if they are very sleepy or cannot swallow properly. Food and water can get into their lungs, which can cause coughing and gagging, and can lead to congestion and pneumonia.

Many family members ask about intravenous (or IV) feeding. In IV feeding, a doctor or nurse inserts a needle into a person's vein, and fluids are given directly through the vein. These fluids are usually water with salt or sugar added. We tend to not recommend the use of IV feeding, unless the person needs special medications that can be given only in this way. IV fluids do not provide much nutrition and, in our experience, sometimes make the dying process longer.

Ways you can help

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 or a spoonful of crushed Popsicle in the mouth.
- Offer a sponge swab dipped in water for your loved one to suck. Your loved one 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.

Important notes

Be careful not to force fluids or food on your loved one.

If they cough or have trouble breathing during feeding, stop immediately.

Don't be alarmed if their urine is dark in colour. As a person drinks less, urine becomes more concentrated and darker.

Pain

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

If your loved one can't tell you that they are in pain, you can look for body language that signals discomfort, such as a scrunched-up forehead, wincing, flinching, stiffening of the body or clenched teeth.

If pain medication is being used, the dose or the way the medication is given may need to be adjusted as a person's condition changes. For example, if a person can no longer swallow, some pain medications can be provided through an IV or injection. If you think that your loved one's pain medication needs to be adjusted, contact the doctor or nurse.

Sometimes, you may hear your loved one moan. Moaning happens most often as a dying person exhales 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 in the section on changes in breathing.

Ways you can help

Use pain medication as instructed by your doctor or nurse. Call your health-care provider if the medication doesn't seem to be working.

Restlessness, agitation and disorientation

At the end of life, people can often become very fidgety, restless, disoriented or distressed. They may feel frightened or threatened. It is also common for people near death to believe that they see things that are not there, such as animals or people who have died. They may appear confused and may not recognize familiar faces. Try not to feel insulted if your loved one doesn't seem to recognize you. This kind of confusion is normal and is not a sign that they feel differently about you.

Ways you can help

Talk to a member of the health-care team. The doctor or nurse can order medication to help ease distress.

Try to keep the room as quiet and peaceful as possible. Limit visual distractions, such as television and computer screens.

Identify yourself by name, and speak clearly and audibly.

Engage in calming activities like holding hands, playing quiet music or reading softly to your loved one.

Your loved one may become more agitated if left alone. Ask whether they would like to have familiar faces around more often.

Try not to argue or to correct or contradict what they say. This may be upsetting for both of you.

Minimize confusion. Try to conduct only one conversation at a time and keep noise and chaos to a minimum.

Mouth, nose and eye care

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

Ways you can help

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

- Mix together 4 cups (1 litre) of water, ½ teaspoon of salt and 1 teaspoon of baking soda. Make a fresh batch of solution each day.
- Moisten a sponge-tipped swab with the solution and use the swab to clean and freshen the lining of the mouth, the gums and the tongue. Your nurse will show you how to do this.
- Your loved one 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.

Avoid using mouthwash that contains alcohol. It can increase dryness.

Use lip balm to protect the lips.

- **Important note:** If your loved one is using oxygen, do not use petroleum jelly (like Vaseline) on the lips. The petroleum can degrade the washers for the oxygen valves.

Moisten the nostrils with a water-based gel such as Secaris, which you can purchase at a pharmacy without a prescription. Water-based gels can be used safely with oxygen.

Moisten the eyes with artificial tears 3 or 4 times per day. Your nurse can show you how to do this. You can purchase artificial tears without a prescription at a pharmacy.

Weakness and sleepiness

Your loved one may feel very weak and tired. People tend to sleep more as their illness progresses. At this time, it is common for people 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

In some cases, your loved one may be in a coma. Someone is considered to be in a coma when they no longer respond to voice or touch. We don't know whether comatose patients are able to hear people talk to them or if they understand what's going on around them. They may be able to hear at times, so you can continue to talk to and touch your loved one to provide comfort.

If your loved one 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 your doctor or another member of the health-care team if you're concerned about possible effects of the pain medication.

Ways you can help

Help find the most comfortable position in bed. We have found that the two best positions are:

- *turned partly to the side*. This position is helpful when a person is quite congested. To keep your loved one from rolling onto his or her back, use pillows to support the whole length of the back.
- *flat on the back with the head slightly elevated (about 30°)*. Be careful not to raise their head so high that they slide down in bed. The resulting friction can cause bed sores. Ask a nurse how best to position your loved one and adjust the bed.

Change your loved one's 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. Your nurse or support worker will show you how to do this.

Eliminate trips to the toilet by using disposable absorbent undergarments or by asking your doctor or nurse to insert a catheter. There may be some discomfort when the catheter is inserted, but there is usually no pain once it is in place.

Talk to your loved one as if they can hear everything. Say everything you want to say. Continue to be affectionate and reassure the person that you are close by.

Changes in breathing patterns

As your loved one gets weaker, you may notice that their regular breathing patterns change. Breathing may speed up, sound shallow or become irregular. These changes are generally not due to a lack of oxygen.

Just before death, your loved one's breathing will slow down. There may be gaps as long as 20 or 30 seconds between breaths. Inhaling may sound like gasping. This pattern of breathing can last for hours or days. Your loved one will not be aware of this change or be in any distress.

If you have any concerns about changes in breathing patterns, please discuss them with the health-care team.

Ways you can help

You can help to reduce or stop the noise by positioning our loved one on their side in the fetal position on a flat bed. Long body pillows are very useful to support the back and prevent your loved one from rolling over. You can find them at most department stores.

Noisy breathing

When a person is in a coma or an extremely drowsy state, their breathing often sounds gurgly or congested, or like snoring. There may also be a soft, short moaning sound with each breath. These noises result from:

- a small amount of mucus or phlegm in the throat that builds up when a person is not conscious enough to cough
- the nearness of the mucus or phlegm to the vocal cords

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 causing the sound. Oxygen will not help reduce or stop the noise.

Sometimes people ask about using a suction machine to remove mucus. We generally do not recommend using these machines because the hose can cause gagging and vomiting.

If there's concern that the dying person is uncomfortable, doctors can prescribe medicine to help. Please ask a member of your health-care team about this.

Looking after yourself

The end of a loved one's life can be a time of worry and stress for you and your family. Throughout the course of your loved one's illness, it's likely that you have faced many challenges, both in terms of providing care and in 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 your loved one is nearing the end of suffering. All of 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. As important as it is for you to look after your loved ones, you also need to care for yourself. Looking after yourself will help you to be a better caregiver for the people around you. You might also encourage your other family members to take good care of themselves.

What you can do

Remember to eat regularly and drink plenty of water to stay hydrated.

Try to get some sleep. By allowing yourself enough time to rest, you will be better able to help your loved one and keep yourself healthy during this time.

Give yourself permission to take a bit of time for yourself, away from the bedside of your loved one. Taking time for a hot shower or bath, a quiet walk, meditation or prayer can help ease your stress levels and renew your energy.

If possible, surround yourself with supportive friends and relatives. Accept their offers for help and let yourself ask for help with things you need. People are often very 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 short break.

Discuss your fears and worries with your health care team. If you feel you need help coping with your grief, ask your family doctor or nurse for a referral to a support or counselling program.

Very near the time of death

As death nears, a person's eyes may stay open, without blinking. There may be long pauses between breaths. You also may notice some of the following skin changes, which occur as blood circulation slows:

- The skin may become blue and blotchy.
- The underside of the body may darken.
- The skin around the mouth may appear bluish grey.
- The face may be pale.
- The nose, ears, hands, arms, feet and legs may feel cool to the touch.
- The fingertips may darken.

Do not worry if the nurse stops taking your loved one's blood pressure and pulse. These measures 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.

Ways you can help

Keep them comfortably warm if their skin feels cool to the touch.

Avoid very loud noises. They may startle and disturb your loved one, and cause distress. Speaking at a normal level is fine.

Say the things you want to say. Some people find it comforting to express thoughts and feelings at this time, such as:

- reassuring your loved one that it's okay to die
- letting them know how much they mean to you
- saying "I love you"

When your loved one dies

How will I know death has occurred?

You will know that your loved one has died because:

- There will be no breathing, response, or pulse.
- The eyelids may be slightly open and they will not blink.
- Their pupils will be enlarged.
- Their eyes will be fixed on a certain spot.
- Their jaw will relax and their mouth will be slightly open.
- There may be a release from the bowel or bladder.

Do not panic. You do not need to call police or 911.

In the event that 911 is called, be sure to have your Do Not Resuscitate (**DNR**) form on hand if you have one. This form will alert the authorities not to initiate cardiopulmonary resuscitation (CPR).

When should I call the palliative care physician?

If your loved one dies between 7:00 a.m. and midnight, please page your palliative care doctor to arrange a time for them to come to your home. If your loved one dies between midnight and 7:00 a.m., we respectfully request that you wait until the morning to page us. Our palliative care team is available around the clock for urgent support during our care for your loved one, but we need to reserve a short amount of time for rest and emergency patient care.

How long can I keep my deceased loved one at home?

There is no need to hurry - you can spend as much time with your loved one as you wish. You may prefer to keep your deceased loved one with you for a few hours or overnight, or you may prefer to have their body removed sooner. Either is fine. There are no legal reasons to remove your loved one immediately. Let the doctor 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 position. If you do decide to keep your loved one at home for a period of time, close their eyelids and move the person onto their back. 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 has arrived and filled out the necessary forms, you can call the funeral home. You may wish to select and make arrangements with the funeral home before your loved one dies.

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 your loved one and family members before the death. Often, people select a charity or cause 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 in the home and in Mount Sinai Hospital, 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, M5G1W7. For more information, please call 416-586-8203, or email foundation.msh@sinaihealthsystem.ca.

*If you have questions or concerns at any time, please speak to the doctor or nurse,
or visit the Temmy Latner Centre website at www.tlcpc.org*
