

What to Expect in the Last Days and Hours of Life

Information for patients and their caregivers



About dying

Dying, like living, is a different experience for everyone. However, there are some common things that may happen to your body and to your emotions. Knowing what they are can help you cope.

Knowing that you or your loved one is close to dying can be emotional. Knowing what you can expect to see, feel, and do can give you some comfort and peace of mind.

This booklet will tell you about the changes you might go through. It will also provide suggestions for how your caregiver, friend or family member can help.

You can read the booklet all at once or just read the parts that you need. Remember, you might not see or experience all of the changes listed in this booklet. Please speak to your health care team if you have any questions or concerns.

Your health care team is here to support and help you.

“What lies behind us and what lies before us are tiny matters compared to what lies within us.”

Ralph Waldo Emerson

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How can I expect my body to change?

Here are some common physical changes you can expect as you near death. You may experience some but not all of them.

Your health care team may stop checking blood pressure, pulse and temperature as this information will not change the plan of care.

Pain and discomfort

For the patient: What can I expect?

- You may feel pain. Your health care team will control it the best they can.
- You may find it hard to swallow. If this happens, your healthcare team will give you your medicine in other ways.
- A small pump may be used to give pain medicine
- Your arms or legs may become swollen. This could become uncomfortable.

For the caregiver: What can I do to help?

- You might not be sure if your loved one feels pain if they cannot speak. Talk to the healthcare team. They can check for signs of pain, such as:
 - frowning
 - moaning
 - moving around
 - pulling away when touched
- If you think your loved one is in pain, explain what you see to the nurse.
- Ask the health care team about ways to reduce pain (heat/cold massage or relaxation therapy).
- Your loved one might have swollen arms or legs from extra fluid. You can help by keeping their arms and legs raised.

Lack of energy

For the patient: What can I expect?

- You may feel like staying in bed all day.
- You might find yourself sleeping more and may have trouble waking up.
- Your body might feel very weak.
- You might have less energy to talk.

For the caregiver: What can I do to help?

- Sit with them and hold their hand
- Your loved one may be able to hear you even if it looks like they is sleeping. Speak to them as if they can hear you. Share news, plans, stories and feelings.
- Reduce loud noises.
- You can choose to softly play some of their favourite music.

Changes to eyes and vision

For the patient: What can I expect?

- You may feel like you have a harder time focusing or seeing clearly.
- Your eyes may stay open while you are sleeping which can make them feel dry.

For the caregiver: What can I do to help?

- The nurse or pharmacist can show you how to give your loved one eye drops. This will keep their eyes moist.
- Know that it is normal for their eyes to be a little open, even when sleeping.

Lack of hunger and thirst

For the patient: What can I expect?

- You may no longer feel the need to eat or drink. This is normal.
- If you do eat a little, you might find that food and fluid do not increase your energy, your weight, or your strength.
- Your mouth may become dry.

For the caregiver: What can I do to help?

- If your loved one is awake, alert and able to swallow, you can offer them ice chips. Raise the head of the bed before you feed them the ice chips. Stop right away if you hear them coughing.
- If their mouth is dry, you can use swabs and moisture sprays.
- **Do not feed or give fluids to the person you are caring for when they are drowsy or sleepy.** It may go to into their lungs and cause them to choke.
- **Intravenous fluids may or may not help at this time.** Speak with your health care team to find out what is best for your loved one.

Temperature and skin changes

For the patient: What can I expect?

- Your skin may feel warm.
- As your blood circulation slows, your skin will begin to look and feel different. It may also feel cold.

For the caregiver: What can I do to help?

- Understand that these changes to temperature and skin are normal.
- Add or remove blankets to make your loved one feel more comfortable.

Changes to breathing

For the patient: What can I expect?

- Sometimes you might start breathing more quickly and not as deeply.
- You might stop breathing for short periods of time. These periods will get longer as you near death.
- You may start making noises from your throat. This might happen because there is too much saliva in your throat. This could also happen when the muscles in your tongue and jaw begin to relax.
- You might feel your mouth become drier as you start to breathe more from your mouth.
- Your nurse can give you some oxygen if it gives you comfort.
- Your nurse can give you medicine to help dry up any fluid in your chest or throat.
- Suctioning is not used often. It is only used when it is needed.

For the caregiver: What can I do to help?

- If it is comfortable for your loved one, keep the bed flat and turn them on their side. This will help to drain extra saliva.
- Help them with mouth care. For example, use mouth sponges to keep their mouth moist or use a moisture spray as directed by your health care team.

Changes to bladder and bowel function

For the patient: What can I expect?

- As your muscles begin to relax, you might lose some control of your bladder and/or bowel.
- You might urinate less. Your urine may become darker as your kidney function slows down.
- Your nurse may offer you disposable underwear. This will keep you more comfortable. Your nurse might also put a catheter in you. A catheter is a tube gently placed in your bladder to help drain your urine.

For the caregiver: What can I do to help?

- Tell the nurse if you think your loved one needs to urinate or have a bowel movement.

Confusion and restlessness

For the patient: What can I expect?

- You may start to feel confused. This can be caused by changes in your body.
- You may find it hard to recognize family and friends.
- You may start to see things that are not there.
- You might feel restless. You might try to get out of bed.
- Your nurse can give you medicine to help you feel calmer.

For the caregiver: What can I do to help?

- Gently remind your loved one what your name is and who you are.
- Speak softly, clearly and in short sentences.
- Keep a clock and calendar in the room.
- If they see something that is not there comfort them if they are upset. You can try to gently change the topic.

“What we once enjoyed and deeply loved we can never lose, for all that we love deeply becomes a part of us.”

Helen Keller

How can I expect my emotions to change?

It is common to have changing emotions as you or a loved one nears death. Some examples of the emotions you or your friends and family might feel are:

- anxiety
- fear
- anger
- sadness
- guilt
- embarrassment
- a feeling of loss
- feeling like you want to be alone

It is normal to feel one or all of these emotions.

Here are some things that you and your caregivers can do to help each other feel better:

- Share your feelings with each other.
- Share stories and memories.
- If you find it hard to talk to your family, you can talk to a health care provider or spiritual care provider.
- Bring familiar things from home for comfort. For example, you can bring blankets, photos and music.
- Relaxation therapy or breathing exercises may help calm you.
- At this time, just being beside and touching your loved one can be more important than words.

If you feel like you need more help with your emotions, please talk to your health care team. They can tell you about hospital and community supports available to you.

For the caregiver

How should I take care of myself?

It can be hard on your body and emotions to care for someone who is dying. In order to better care for your loved one, you must also care for yourself.

Here is a list of things you can do to care for yourself:

- Try to get enough sleep and eat a well balanced diet.
- Ask for and accept help from family and friends.
- Take breaks when you feel overwhelmed or uncomfortable.
- Take a break and do something you enjoy.

- Understand that it is normal to have changing emotions.
- Ask for a visit from someone from spiritual care or your faith community.
- If you have any questions for the healthcare team, write them down. This will help you remember to ask them when you see them.

How will I know when death is nearing?

As death nears, your loved one will no longer respond to your voice or touch. You can still talk to them as if they can hear you. They may still be able to understand what you say or recognize your voice.

Moaning is common in the last days of life. If your loved one is moaning, it could mean they are in pain but this is rare. It could also mean the muscles in their jaw are relaxed.

As they near death, your loved one may stop breathing for several seconds. This is normal and causes no distress to your loved one.

No one can predict exactly when death will occur. Your healthcare team can inform you about the changes they are noticing.

How will I know my loved one has died?

Your loved one has died when they are no longer breathing. They will have no heartbeat and no response to voice or touch. Their eyelids may be slightly open. Their jaw will be relaxed.

Your loved one's body will remain in the hospital until the funeral home picks them up. The doctor will complete a certificate of death. This certificate will go with the body to the funeral home. The funeral home will provide you with copies of the death certificate.

“Change is a natural part of life. We live. We grow. We die. We continue to live until our last breath.”

G. M.

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