

My Loved One is Dying

Patient and Family Information



northern health
the northern way of caring

This information helps you understand what changes are natural and expected when your loved one is dying. Just as this person has been a unique individual all their life, the way they die will be unique too.

Your loved one may experience all or some of the changes described. Changes may occur rapidly or slowly.

Some of the changes you might notice include:

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Changes in Appetite

As your loved one becomes less active, they will feel less hungry and thirsty because their body no longer processes food it used to.

You may notice that your loved one:

- Eats very little.
- May feel unable to eat.
- Is uninterested in food.
- Has difficulty swallowing.

Comfort measures:

- Give them only what they want and are able to manage. A reminder to swallow may be helpful.
- Offer small amounts of their favourite food and fluids.
- Sometimes the most comforting thing we can do is to accept that someone no longer wants to eat, and to not keep offering them food when it is no longer wanted.
- Provide frequent mouth care to keep their mouth moist and clean (a member of the care team can teach you mouth care). Lubricate the lips with ointment.



Changes in Strength

This usually occurs gradually over weeks to months, but it can also happen fairly quickly over days.

You may notice that your loved one:

- Tires more easily and may need to nap more often.
- Becomes exhausted with routine activities.
- Becomes short of breath due to moving or talking.
- Needs help to walk, bathe, dress, or eat.
- Becomes extremely weak and needs to be cared for on a couch or in bed.
- Feels anxious or frustrated by changes in energy or strength.

Comfort measures:

- Set priorities so that strength is saved for activities that are most important.
- Pace activities. Provide periods for rest.
- Organize their bed/sitting area so that they can easily reach all that they need.
- Give reassurance. Loss of independence can be upsetting.



Changes in Level of Awareness

As a person's illness progresses, there is a decrease in alertness and the ability to respond to their surroundings may be affected. Sometimes the person may seem to be confused or hallucinating. Your loved one may experience a different reality, sometimes seeing or hearing people or things that are not physically present. These changes are common and are due to changes in the metabolism of the body and brain.

You may notice that your loved one:

- Becomes restless, excited, or irritable for no apparent reason.
- Is easily distracted and unable to follow simple directions, think clearly, or communicate.
- Is unable to remember things such as familiar people, objects, or events.
- Seems drowsy all the time, has a short attention span, and has periods of confusion.

Comfort measures:

- Sit quietly to provide a comforting presence.
- Continue to listen carefully to what they are saying. Your loved one may be saying or trying to communicate something important.
- Speak in a calm and reassuring voice.
- Speak directly and normally. Your loved one may still experience hearing and touch even though they may appear to be in a deep sleep or unresponsive.
- Soothing music or a gentle massage may ease a restless person.

Changes in Breathing

It is normal for a person dying of a terminal illness to experience several different breathing patterns. This breathing can be distressing to watch, but it can be comforting to know that the person who is unresponsive may not be experiencing distress and may not benefit from oxygen therapy.

You may notice that your loved one:

- Has breathing that can either deep and rapid, or deep and slow with pauses.
- Has irregular or shallow breathing.
- Uses their chest, neck, and upper abdominal muscles to assist breathing, making it appear more labored.
- Has short intervals of not breathing followed by regular and labored breathing.
- Has fluid build up in the back of their throat that may make their breathing sounds wet or congested.

Comfort measures:

- Raise the head or upper body slightly with pillows.
- Position the person on their side to help clear secretions.
- Medication may be given to reduce wet or gurgling breath sounds.
- Suction may be necessary.
- Give mouth care frequently to prevent mouth dryness.

Changes As Death Nears

Changes occur as the body slows down and prepares for the final stages of life. Remember, each situation is different and not all of the signs and symptoms will occur in your loved one. Predictions can be difficult, but time with your loved one will be limited once intake by mouth or urine output stops, and once there are obvious changes in breathing patterns.

You may notice that your loved one:

- Sleeps longer, eventually slipping into a coma, which is a sleep-like state where the person is unable to respond to the world around them.
- Becomes restless, pulling at bed linen and wanting to get up.
- Receives medications for comfort to help settle restlessness.
- Has visions of persons and/or things that you can not see or hear.
- Becomes confused and/or restless.
- Breathes irregularly or more shallowly.
- Does not eat or drink.
- Stops breathing for 10 to 30 seconds or longer.
- Has wet or congested breathing.
- Has cold or bluish hands and feet.
- Has mottled or purplish areas on their extremities.
- Has little urine output or loss of bladder control.
- Does not have bowel movements or may have oozing of stool.
- Develops a fixed stare.

The Moment of Death

No matter what we expect and how much we prepare, the exact moment of death arrives in its own time and in its own way. The experience of dying is different for every person and for every family.

You will notice:

- There will be no response.
- There will be no breathing or pulse.
- The life force and consciousness leave the body.
- There will be no pain.
- The person's eyes may or may not be open. Their jaw may slacken.

Comfort measures for family and friends:

- Allow your tears and feelings to come.
- Breathe deeply.
- Be in physical contact with others: hug, hold hands, link arms, or whatever your custom is.
- Do whatever you feel is comfortable.
- It is important for you to take whatever time you need to say goodbye.
- Give children the opportunity to say goodbye. They generally cope well if they are given adequate support and information about what is happening.

Our goal is that this information helps explain the changes that can occur when someone has a progressive terminal illness and when death is nearing.

If you have any questions or concerns, please speak to your medical team. They are there to help you through this difficult time.

References:

Joseph Brant Memorial Hospital, Burlington, Ont. "My Loved One Is Dying...What Can I Do? What Can I Expect?"

Palliative Care at Home (NH #1857, Feb 2016).

Prince George Hospice Society, Prince George, BC. "What Happens Next".

Regina Palliative Care Inc., Regina, Sask. "Planning For Death At Home."

Victoria Hospice Society, Victoria, BC. "When Death Occurs At Home, Information For Caregivers."



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