

Eating and drinking decreases as the body is preparing to die. This is one of the hardest things for the family to accept. Assist, but do not force the person to take food or fluids.

Withdrawing is normal. There is less of a need to communicate. The person may have no interest in newspapers or television, begin to withdraw from people and may want to be with just a few people or only one person. It is important that this not be taken personally. The person who is sick may just want as little stimulation as possible.

Levels of awareness and sensory changes are not unusual. The person may:

- not remember things or recognize familiar faces or objects
- be easily distracted and unable to follow simple directions
- be fully awake but non-responsive at times
- speak or claim to have spoken to a person already dead, or claim to see people/places not visible to you

Accept what the person is saying. Avoid explaining or arguing. The experience is real to them. It is normal and common.

Coma - Often before death, people will go into a deep state of unconsciousness called a coma. They may still hear what is said even if they no longer respond. Never assume that your voice cannot be heard.

Hearing is the last sense to be lost.

Where Can I Find More Information?

For more information, start by talking to your doctor, nurse, Home and Community Care Coordinator, spiritual care provider or any other health care provider. A referral to a palliative care nurse or palliative care volunteer team can be made by anyone, including the person that is ill, a family member, a spiritual care provider, a physician or any other health care provider.

You may also refer to the *Preparing for the Journey: Caring for Indigenous People who are Seriously Ill* resource manual available for free download on the CERAH website: <https://cerah.lakeheadu.ca/resources/indigenous-health/>

This brochure was originally created by: Improving End-of-Life Care in First Nations Communities (EOLFN). Additional resources available on the project website: eolfn.lakeheadu.ca



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Caring for Someone with a Serious Illness: What to Expect



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The individual's personal care needs may change. You may be able to help them with:

- Getting in and out of bed, walking around the home
- Personal care (assisting them in going to the bathroom, helping with bathing and personal grooming)
- Feeding and nutrition

Some things that may make the person more comfortable:

- Keep hair clean and combed
- Gently rub the back and skin with lotion to increase blood circulation. Keep skin folds and creases clean and dry
- Adapt clothing to make care easier for the person who is sick and for others
- Keep the mouth moist with water, ice chips, popsicles or mouth swabs. Moisten lips with petroleum jelly (Vaseline®) to avoid dryness and cracking
- Change the person's position in bed and use pillows and extra padding on the bed to avoid bed sores
- Keep the bed clean, dry and comfortable and use fitted bottom sheets

Understanding Pain

Pain is a common experience for people facing a terminal illness. It can be recognized in things like tensing muscles, sweating or facial expressions, or it can appear to be nonexistent. It may come and go or it may be constant and unlikely to go away. As you care for the person, keep the following in mind:

- Visit with them first before you provide care. Recall the day's events to establish a caring relationship.
- Be sensitive to what they are feeling.
- Offer reassurance and encouragement. Loss of independence can be upsetting for them.
- Ask how you can help with bathing or grooming.
- Involve them in decisions about their care.
- Ensure privacy by closing the door.
- Remove used bed pans from sight when not in use.
- Provide them with a bell, chimes or something else to tap on so that they can call you to help if they need to.

No matter what type of illness, there are common signs present when someone is nearing death. For some, this process may take weeks; for others, only a few days or hours.

Activity decreases. They may speak and move less, may spend more time sleeping and may be harder to wake. Help by sitting with the person, holding their hand and speaking softly and naturally.

Losing control of urine and bowel movements can be a problem when death is very near. The amount of urine will decrease and the urine become darker as death nears. Absorbent pads can be placed under the person for more comfort and cleanliness, or a urinary catheter may be required.

Bodily changes may occur such as:

Body temperature may go down so they may feel cold to the touch.

Blood pressure may gradually lower and blood flow to the hands and feet will decrease.

Skin color and fingernail beds may change from normal pinkish to a duller, darker, greyish tone.

Breathing rate may change to several rapid breaths followed by short periods of no breathing.

Coughing may increase as the body's fluids begin to build up in the lungs. This can cause **congestion** and a gurgling sound that may be upsetting to others, but it is not an indication that the person is in pain or suffering.

