



Long Term Care

# What to Expect: When Someone Close to You is Dying

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This information provides compassionate and clear guidance to help you understand what to expect, ensuring you feel supported and informed during this difficult time.



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Continuing Care



As death approaches, changes can occur which will affect how a person's body functions, how they may communicate, think, and also, how they may behave.

## Common changes that may be seen over hours or days:



### Decreasing Energy

Over time, it is common for your loved one to spend more time in bed and sleep for longer periods. In the final days, they may quickly shift from being somewhat independent to sleeping most of the time.



### Emotional Signs

Your loved one may experience various emotions such as sadness, helplessness, anxiety, or fear. They might withdraw and become quieter, and sometimes they may speak to or seem to see people that visitors cannot see. Confusion about time, people, and place is also common.



### Sleeping

It is normal for a person in their final days to spend much of their time sleeping. They may seem uncommunicative and difficult to wake. You can continue to talk to them throughout the dying process. As death nears, they may become unresponsive, but hearing remains until the moment of death.



## **Appetite**

A decrease in appetite and thirst, with little or no desire for food or fluids, is normal at the end of life. This can be hard for family and friends who show love through providing food. However, this is a natural process, and your loved one will not feel hunger or thirst.



## **Medication Concerns**

Trouble swallowing medications is common as the muscles weaken. Some medications and supplements may no longer be beneficial and can be stopped. For necessary medications, alternatives to swallowing can be discussed with the healthcare team. Medications may also be started to ease symptoms at the end of life.



## **Elimination**

With decreased appetite, urine output and bowel function will also decrease. There may be a loss of control over urine and bowels, and changes in urine or stool color.



## **Restlessness**

Changes in oxygen levels, medications, or the declining condition can cause restlessness or agitation. Your loved one may try to get out of bed, pull at linens and clothes, or reach out for objects or people who are not there.



## Confusion and Distress

As the body weakens, so does the brain, leading to confusion that can cause distress. Your loved one may feel frightened or threatened by their surroundings, or act out of character. Reassuring them that they are safe and not alone can help. Sometimes, confusion can bring comfort as they believe they are in a familiar or comforting place. Supporting their perception can be a compassionate approach.



## Breathing

There will be changes in their regular breathing pattern. They may breathe less frequently, take shallow breaths, or have short periods of no breathing. Rapid, shallow, noisy breathing or gurgling sounds may occur. Although this may be hard to hear, these changes do not indicate distress.



## Circulation and Skin Changes

You may notice changes in their skin, which may feel clammy or appear greyish or bluish. Their arms and legs might become cool to the touch, but they are still comfortable as the circulation of blood slows down.



# How Family & Friends Can Help

When someone close to you is nearing the end of their life, family and friends often wonder how they can provide comfort and support.



## **Be Present**

Friends and family may feel uncertain about what to do and say at the bedside of the person who is dying. Being present is usually more important than what is done or said. Continue to visit and do what you normally do. Knowing that those they care about are there and supporting each other may comfort the person who is dying.



## **Express Love and Appreciation**

You may want to talk about the ways you have loved and appreciated your family member. People sometimes structure their goodbyes around five things: I love you for...I thank you for...I forgive you for... Please forgive me for...and Goodbye.



## **Spiritual and Religious Support**

You may wish to have a faith or spiritual leader come to say prayers, or perform rituals or ceremonies which are familiar to your culture, faith, or spiritual path. There may be a Spiritual Care practitioner on staff who can assist you with your request.



## **Provide Comfort**

Reading to the person, gently rubbing lotion into their hands, playing their favorite music, or placing warm blankets on their feet may be ways to provide comfort.



## **Use Soothing Music**

Calm, soothing music may ease restlessness. Reassuring the person that they are not alone and that they are in a safe place can often help



### **Respect Spiritual Wishes**

Respect the dying person's spiritual wishes as much as possible.



### **Honour Their Choices**

Please respect the person's choice if they choose not to eat or drink. Check with staff before offering any food or fluids.



### **Provide Mouth Care**

Provide mouth care along with moistening the mouth and lips. Ask staff for assistance if needed.



### **Gentle Care**

You may want to wipe the person's hands and face with a cool cloth.



### **Talk Calmly**

Talk calmly and naturally to the individual even if there is no response. Your voice may be reassuring, or you may not wish to talk at all. Your quiet presence can mean a lot.



### **Offer Touch**

Touch can be very comforting to some people. You may wish to hold the dying person's hand.

## You Also Have Needs as a Caregiver:

- ▶ Reminisce with your family member and with others.
- ▶ Try to get enough sleep and to move around/walk.
- ▶ Get enough to eat and drink.
- ▶ Ask for a comfortable chair if you are sleeping in the room.
- ▶ It is alright to ask others for support. People want to know what they can do to help.

## Resources:

- ▶ **Engage with Staff:** Family and friends are encouraged to ask questions, make suggestions, and share relevant cultural or spiritual practices that may be important for staff to know.
- ▶ **Individual Grief:** Each individual experiences grief in a unique way. For some, death and grief are very private processes, while others need social support. Spiritual health and social support can be provided.
- ▶ **Palliative Care Approach:** Strengthening a palliative approach to Long Term Care supports the needs of people living with various life-limiting illnesses, including frailty, dementia, end-stage organ disease, and cancer. Resources can be found on their website <https://spaltc.ca>.
- ▶ **Additional Information:** More information can be found on the Canadian Virtual Hospice website, including the articles “When Death is Near” and “Final Weeks and Days: What to Expect” at [www.virtualhospice.ca](http://www.virtualhospice.ca).



# Moment of Death

The moment of death is a profound and personal experience, and it can happen in various ways. Here's what you can expect and how you can respond.



### **Unpredictability**

Death is not always predictable. It can occur suddenly and unexpectedly, or it can be a more gradual process. Sometimes very ill people experience unexplained improvements and live longer than expected.



### **Signs of Death**

At the time of death, there will be no heartbeat and no breathing. The eyes may be closed or remain open.



## **After Death Occurs**



### **Personal Reflections**

You may want to take time to reflect, say a few words, touch or hug the person, or say some final goodbyes. You may prefer not to do any of these things, and that's okay too.

## If Family & Friends are Present

- Consider if there are other family or friends who want to be notified or come to say their final goodbyes.
- Let the healthcare staff know if there are any rituals, practices, or ceremonies needed after death.
- Spend the time needed. Don't feel rushed.

## If Family and Friends are Not Present

- Staff will call the primary contact who could be a family member or friend to inform them.
- If you decide to come, do not feel rushed in arriving quickly. It may be helpful to bring someone with you for support..
- If you decide not to come, the staff will follow the instructions left by the family.



# Grief and Loss

Grief is a natural and personal response to loss. Understanding and managing grief can be challenging, but there are resources to help.

# Support Resources

## MyGrief.ca



A free online tool designed to support you in your grief and loss. It can help you understand and approach the challenges you may be facing and provide support for others as well.



## Online Learning Modules

The website includes modules with content for specific losses, including the death of a spouse, parent, child, and loss due to conditions like dementia, Multiple Sclerosis, Amyotrophic Lateral Sclerosis (ALS), Huntington's, and more.



**Notes:**

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This information was developed by the WRHA Continuing Care Final Days of Care Committee and originally adapted from the Deer Lodge Centre “When a Loved One is Dying in Long Term Care” resource.



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