



When Your Loved One is Dying at Home

What can I expect? What can I do?

Although it is impossible to totally prepare for a death it may be easier if you know what to expect.

Hospice Palliative Care aims to relieve suffering and improve the quality of living.

This booklet may help prepare you for this final stage of life.

Death is a natural process. This booklet is a guide to help you comfort the dying person and understand the body's natural process of shutting down. Not all physical and emotional signs of approaching death described will occur with every person, nor will they occur in any particular order. Some symptoms may get better at the end of life and some may become worse.

This booklet should not replace advice given by the health care team, such as a nurse, physician, clergy, social worker, pharmacist or LHIN Care Coordinator.

You the Caregiver

You are a very important part of the care team. Every team member needs to stay well and take care of themselves in order to care for someone else.

To prepare for what is ahead, it's important to talk about the wishes of your loved one, any cultural or religious traditions, funeral planning and who should be called at the time of death.

Caring for someone who is dying can be emotionally and physically exhausting.

Normal family routines may be disrupted. Your ability to think and concentrate may also be affected.

Guilt, anger, frustration, and sadness are common and normal when caring for someone who is dying.

Share your concerns and fears with your family and friends who are often waiting to learn how they can help and provide support. Your health care providers can also offer you support and information about services available to help.

There are many supports and people who can assist you on this journey. You are not alone.

- Be kind to yourself and try to respect your personal limits.
- Ask for help when you need it from family, friends, and your health care team.
- Give yourself permission to feel the way you are feeling.
- Take breaks, eat properly and rest at regular intervals to help you cope.
- Seek medical attention for your own health care needs.

Being Present and Connected

- Sit with them, hold their hand and reassure them you're there.
- Talk calmly and identify yourself by name.
- Speak softly and clearly when you need to communicate something important.
- Talk while you provide care, explaining what you'll be doing.
- Sit at their bedside, play music of their choice, or read aloud something comforting for them.

- Talk to them about what's going on with family members or other points of interest.
- Offer a cool cloth for their forehead if they're warm.
- Moisten their lips to relieve dryness.
- Consider keeping dim lights on.
- Speak to your loved one, remembering their hearing remains until the moment of death.
- Goodbyes are appropriate and can be comforting.
- Talk about shared experiences and memories.

What are the signs of approaching death?

The signs and symptoms discussed below will not happen to everyone. By being aware of them, you can recognize that death may be near and begin to prepare yourself. These signs may be seen over a number of hours or days. It's difficult to predict the amount of time before death will occur. For unknown reasons, some people's condition may improve for a short period.

Social and Emotional

- Some people may enter a phase where they withdraw, losing interest in people and events.
- The dying person may experience many different emotional states such as guilt, anger, frustration, helplessness and/or sadness.
- Expressing emotions, such as tears, are a natural way to show feelings.

- Some people fear being left alone or becoming a burden to those caring for them.
- In some cases, they may worry about losing their dignity and control as death approaches.

Spiritual

- Religious leaders or spiritual advisors can provide compassionate support to you and your family.
- Rituals, religious rites or sacraments may provide comfort at this time. The health care team can help you access spiritual support.
- Discuss with your health care team any cultural or religious customs important to your loved one to be followed now, at the time of death and after death.

Mental Awareness

- The person may see or speak to people not visible to you. Just being present with them may provide the most comfort at the time.
- Confusion about time, people and place is common. This can include family members or close friends.
- The person may not be alert, aware, or able to respond to you. They may or may not be conscious.
- At times, your loved one may become restless. They may reach out to unseen objects, pull at sheets or blankets or try to get out of bed. These are part of the normal changes the body goes through as it is shutting down. You can discuss these changes with a health care professional.

Physical Signs of Approaching Death

Food and Fluid

- Loss of appetite and decrease in thirst are common; the body is beginning to shut down and doesn't need nourishment. Encouraging them to eat or drink when they don't want to, may increase their discomfort and cause distress.
- They may ask for a specific food but may only take a few small mouthfuls.
- Dry mouth is common, so provide frequent mouth care for comfort.
- If they are unable to swallow or if they are not alert, do not give fluids or food as they may be at risk of choking.

Sleeping

- Some people may sleep for long periods and become more difficult to awaken.
- As death nears, the person may slip into a coma and become unresponsive.



Breathing

- Regular breathing patterns may change. You may notice uneven shallow breathing and brief periods when breathing may stop. These breathing patterns are normal and indicate the natural progression towards death.
- People who are short of breath may find it helpful to have a gentle fan blow air across their cheeks. Medications can be given to reduce breathlessness and anxiety.
- Noisy breathing or gurgling may start. This is caused by muscle weakness. The person is no longer able to swallow their saliva and fluid collects in their throat. This is not painful, but may distress family members. Suctioning can cause more harm than good. Laying the person on their side may allow secretions to drain out.

Elimination

- The amount of urine (pee) and stool (poo) will decrease as the person eats and drinks less. Urine and stool may also change in colour, and will pass less often and in smaller amounts. Other factors such as staying in bed, moving very little, and medication may play a part in this.
- The person may lose control of their urine and stool as muscles begin to relax. They may need to use an incontinence brief or a bladder catheter, which is a tube placed in the bladder to let the urine flow outside the body into a bag.

Any questions about the management of these symptoms can be directed to your health care professional.



Skin

- Skin may become cool, feel clammy and damp, often in the arms and legs.
- Skin might look purple or blue, especially the feet, legs or hands and arms. This colour change is called “mottling” and is caused by the blood slowing down. The person may not be aware of these symptoms and would not likely feel cold. Do not use a hot water bottle or a heating pad. These items can be dangerous at this time and can cause burns. Light blankets may be used.

When to Call the Nurse

Call the nurse if you are concerned that your loved one is:

- In pain
- Anxious and/or increasingly restless
- Feeling more short of breath
- Experiencing frequent muscle twitching
- Choking
- Has an increased temperature

Stay calm. Provide reassurance and stay with your loved one until the nurse arrives.

How Will You Know When Death Has Occurred?

Although death is expected, you may not be prepared for the actual moment it happens.

At the time of death:

- There will be no response, no breathing and no pulse.
- The eyelids may be opened or closed. If open, the eyes will be fixed in one direction.
- There may be a release of urine and stool.
- The jaw may relax, leaving the mouth slightly open. Fluid may ooze from the mouth.

After death has occurred:

- **Call your nursing provider.**
- If this is an expected death and your loved one does not want resuscitation or CPR, do not call 911. This is not a medical emergency. Calling 911 could mean that CPR and transfer to the hospital are started.
- This is a special time for you to express your grief and spend as much time as you need with your loved one. Do not be afraid to touch, hug, kiss or lie down beside your loved one.
- When you're ready, contact the funeral home. The funeral home may wish to speak to a family member.
- Ask the health care team about grief and bereavement support services available for you and your family.

Before the Funeral

When you meet with the funeral home, you will need the following information about your loved one:

- Legal name
- Occupation
- Current address
- Social Insurance Number
- Date and place of birth
- Names and birth places of parents
- Marital status
- Partner's name
- Children's names

Compassionate Care Benefits

At this time, the demands of caring for a dying loved one can put both your job and financial security at risk. You may qualify for Compassionate Care Benefits provided by the Government of Canada.

To apply for Compassionate Care Benefits, you can:

- Contact your Human Resources department for assistance
- Go to your Service Canada Centre
- Call 1-800-206-7218 (TTY: 1-800-529-3742)
- Or go online to <https://www.canada.ca/en/services/benefits/ei/caregiving.html>

Organ and Tissue Donation

Information is available at www.giftoflife.on.ca

Please take time to discuss any question(s) about this brochure with your health care team.

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