

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 intended as 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 sequence. Some symptoms may lessen at the end of life and some may become worse.

This booklet is not intended to replace advice given by the health care team member, such as a nurse, physician, clergy, social worker, pharmacist or CCAC Care Coordinator.

You the Caregiver

In order to prepare for what is ahead, it's important to discuss 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 a dying loved one can leave you emotionally and physically exhausted.

You may find that normal family routines are disrupted. Your ability to concentrate may also be affected.

Guilt, anger, frustration and/or sadness are common feelings and are normal responses to the events you're experiencing.



Share your concerns and fears with your family, friends and health care providers; these people can offer you support and information about services available to help.

Caring for a loved one at the end of life can be emotionally and physically challenging.

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

- Ask for help when you need it.
- Maintain reasonable expectations of yourself.
- Give yourself permission to feel the way you are feeling.
- Take breaks, eat properly and rest at regular intervals to help you cope during this difficult time.
- Seek medical attention for your own health care needs.

You are a very important part of the care team. Every team member needs to stay well in order to contribute their unique strengths and abilities.

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 to them 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.
- Lubricate 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 comforting in the process of "letting go".
- Reminisce about the past.

What are the signs of approaching death?

The signs and symptoms discussed below will not be present in everyone, but 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 unexplained reasons, some people's condition may improve for a short period of time.

Social and Emotional

- Some people may enter a withdrawal phase, losing interest in people and events.
- The dying person may be experiencing many

different emotional states such as guilt, anger, frustration, helplessness and/or sadness.

- Some individuals fear being abandoned or becoming a burden to those caring for them.
- In some cases they may have concerns about losing their dignity and control as death approaches.
- Expressing emotions such as tears are a natural way to show feelings.

Spiritual

- People vary greatly in their spiritual and/or religious beliefs and needs. Clergy and/or spiritual advisors can provide compassionate support to you and your family.
- The use of rituals, religious rites or sacraments may provide comfort at this time. Let the health care team know what the
- individual's beliefs and values are and if you wish, they can provide assistance in accessing spiritual support.
- Discuss with your health care team any cultural or religious customs important to your loved one to be followed at present, 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.

- Responsiveness and awareness may decrease. They may or may not be conscious.
- At times, your loved one may become restless. They may reach out to unseen objects, pull at bedclothes or try to get out of bed. This can occur for many reasons such as a decrease in oxygen to the brain, medications or changes in their condition. 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 may increase their discomfort.
- 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 do not give fluids/food as they may be at risk of choking.

Sleeping

- Some people may sleep for long periods of time 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 irregular, shallow breathing and/or brief periods when breathing may stop. These breathing patterns are normal and indicate the natural progression towards death.
- Individuals who are short of breath may find it beneficial to have the head of the bed elevated manually or with pillows. A gentle fan across the cheeks may also be helpful. Medications can be given to reduce the symptom of breathlessness and reduce anxiety.
- Noisy breathing or gurgling may develop. This happens due to muscle weakness; the person is no longer able to swallow their saliva and fluid collects in their throat. This is not painful for the individual but may distress family members. Suctioning is not recommended.

Elimination

- Bladder and bowel function will decrease as food and fluid intake decreases. Urine and stool may also change in colour, be passed less frequently and in smaller amounts. Other factors such as immobility and medication may contribute to this.
- The person may lose control of their bladder and bowel function as the muscles begin to relax. It may be necessary to use an incontinence brief or a bladder catheter. 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, particularly in the arms and legs.
- The body may become purplish (mottled) caused by the circulation of 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

Some symptoms may require interventions by your health care team. You should 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

Maintain a calm environment, 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 bladder and/or bowel contents.
- The jaw may relax, leaving the mouth slightly open. Fluid may ooze from the mouth.

After death has occurred:

- If this is an expected death and your loved one does not want resuscitation do not call 911. This is not a medical emergency. Calling 911 could mean that attempts at resuscitation and transfer to the hospital could be initiated. Call your nursing provider.
- 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 bereavement support services available for you and your family.

Before the Funeral

When you meet with the funeral director, you will need the following information regarding 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

The Police recommend that you have a friend or neighbour keep a watchful eye on your home during the time you are away and involved with the funeral events. Your home is vulnerable when others know that you will not be there.

Compassionate Care Benefits

At this difficult time, the demands of caring for a dying loved one can jeopardize both your job and the financial security of your family. You are entitled to 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 <http://www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml>

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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Funded in part by:



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