
When Someone is Dying... in the Community

What can I expect?
What can I do?



The Palliative Approach to Care aims to relieve suffering and improve the quality of living and dying.

Although it is impossible to totally prepare for a death, knowing what to expect can make it easier.

This guide may be helpful in preparing you to understand this final stage of life.

It contains some helpful information about what to expect at the end of life and may add to what your health care team has already discussed with you.

Dying is a natural process as the body begins shutting down. The following physical and emotional signs of approaching death are described to help you understand what may happen. Not all signs and symptoms will occur with every person, nor will they occur in any particular order. Some symptoms may lessen at end of life, or they may become worse, interfering with the comfort of your loved one.

We hope this guide will help you to understand and to attend to your loved one's changing needs and to ease any fears or worries you may have. If you have any questions or concerns about this information, please speak to your health care team.

Remember to write down any questions you may have for discussion with your health care team.

Social & Emotional Responses to Approaching Death

- The person dying and their caregivers may be experiencing different emotions such as guilt, anger, frustration, helplessness or sadness. Tears may be a common and natural expression to the events you are experiencing.
- Some people 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 they approach death. Reassure them that they will be cared for.
- As death approaches, the person becomes quieter and less interested in their surroundings. They may become withdrawn and confused about time and place.
- Vision-like experiences may occur. The person may see or speak to people not visible to you. Try not to explain away what the person says. Be supportive by listening to the person. If they are distressed by this experience, gently remind them who is with them. Speak to your health care team about your observations and concerns.
- Goodbyes are appropriate. Both the person dying and their family and friends may find comfort in this process of “letting go”. Those who have not visited in a while may not be aware of how much has changed in the dying person. If possible, you may choose to update visitors before their visit and set a time limit for the visit.
- A dying person usually does not suddenly change during this time; a person will most often die as they lived. For example, you may be disappointed if you’re hoping for a mellowing, or opening up of someone who has always been very quiet and private.

Children

Children can sense when adults are sad or worried, even if you try to hide it. Children understand and cope with dying and death differently, depending on their age. For some children, what they imagine in their minds may be worse than what is real. Your health care team can offer you advice on how to support children, at this time.

Spirituality

- People vary greatly in their spiritual and/or religious beliefs and needs. During this time, clergy or a spiritual advisor can provide compassionate spiritual support to you and your family. You may ask your health care team for assistance in accessing spiritual support.
- The use of rituals, religious rites or sacraments may provide comfort. If you or your loved ones have any cultural or religious needs or customs related to death and dying, please let your health care team know.
- If the person is struggling with unanswered questions, it may be helpful to seek assistance, as these struggles may heighten physical suffering.
- This is a difficult time, and we are often hardest on ourselves. You are doing the very best that any person could do if they were in your place. Supporting a loved one at end of life requires courage. As difficult as this time is, it can offer great benefits.

Being Present and Connected

- A calming effect may be achieved by sitting quietly at the bedside. You could try holding their hand, playing soothing music, placing a cool cloth to their forehead or reading something comforting.
- It's natural to be concerned about the right things to say or do. But unless the person asks to be left alone, just being there may be the right thing to do.
- If you are providing care, talk to your loved one and let them know what you will be doing.
- Allow your loved one to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen; you are not expected to have all the answers.
- Don't isolate your loved one from life. Talk to them about what is going on with family members, other points of interest for them. They may prefer to be included in these discussions.
- Allow opportunities for some one-on-one time if there are multiple visitors.
- Be willing to reminisce about your loved one's life. Remember things you laughed about.
- It can be a comfort to your loved one to hear your voice. Don't be afraid to talk with your loved one about memories. Reassure them that it's okay to go.
- If your loved one has a special friend from the neighborhood, give them an opportunity to say "goodbye".

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 does not need nourishment. People commonly feel it is necessary to encourage the person to eat in the hope of sustaining life. Food and fluid may actually cause discomfort.

- The person may ask for ice chips, popsicles, ice cream or some other food of choice. Do not be surprised if only a mouthful or two is taken.
- Provide foods only when the person states they are hungry or thirsty.
- Stop feeding the person if they are coughing on food/fluid, holding food/fluid in their mouth and/or are very sleepy or seem unable to swallow safely.
- Allow the person to refuse all food and fluids.
- At end-of-life, intravenous fluid replacement is not usually recommended.
- Frequent mouth care is essential, as it provides moisture and comfort. Use a lip moisturizer to protect the lips.

Elimination

Urine output and bowel function will decrease as food and fluid intake decrease. Urine and stool may also change colour or 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 bladder or bowel function as the muscles begin to relax. In this instance, it may be necessary to use an incontinence brief or a bladder catheter. Any questions about the management of these symptoms should be directed to your health care team.

Sleeping

People tend to sleep more as their illness progresses. It may become more difficult to wake the person. As death nears, the person may become unresponsive. At times like this, bring a book to read or a small project to do to keep yourself occupied. Remember, they tire easily now; plan for rest periods between activities or visitors. It is okay to restrict visitors.

Restlessness and Confusion

Confusion as to time, place and recognition of people is common. This may include members of the family and close friends. At times, the person may become restless, seeing or hearing things that are not there, e.g., reaching out to unseen objects, pulling at bedclothes, or trying to get out of bed. This may occur for many reasons: a physical change related to the disease process, a medication effect, or it may be that they are struggling emotionally or spiritually. It would be helpful to discuss these changes with your health care team.

Breathing

Regular breathing patterns may change. You may notice irregular, shallow breathing or perhaps periods lasting 20 to 60 seconds when breathing may stop and start again. These changes are generally not due to a lack of oxygen. Be aware that these changes do not cause discomfort in your loved one.

Breathing Changes

Depending on the diagnosis, your loved one may develop shortness of breath at this stage. Supplemental oxygen is of less value at end-of-life.

- There are medications which may be helpful for these symptoms.
- Persons suffering with breathlessness may find it beneficial to have the head of the bed elevated (pillows can be used) and to be in a cool, calm environment.
- A gentle breeze across the cheeks can help with shortness of breath.

Noisy breathing or gurgling may develop. This happens due to muscle weakness; the person is no longer able to swallow their saliva at this stage. This noise often distresses family members, but it is not a cause of discomfort for the dying person.

- If there is concern that your loved one is uncomfortable, doctors can prescribe medications which may be helpful for these symptoms.
- Deep suctioning can cause discomfort and may not help stop the noise. It may make the secretions worse and may cause gagging and vomiting.
- Turning your loved one on their side may help saliva to drain naturally from the mouth.

Skin

As your loved one nears the end of life, you may notice their skin begins to change colour and their arms and legs become cooler.

The underside of their body may become purplish and mottled.

The circulation of blood is slowing down. A person nearing end of life, however, is probably unaware of these changes and would not likely feel cold. Please do not use a hot water bottle or a heating pad; these items are dangerous and can cause burns. Light blankets may be used.

When to Call the Nurse

Some symptoms may become worse at end of life and interfere with the comfort of your loved one. You should call the nurse if you are concerned that the person is:

- in pain
- anxious and/or increasingly restless
- feeling more short of breath
- experiencing frequent muscle twitching
- holding food / fluid in their mouth

Maintaining a calm environment, providing reassurance and remaining at the bedside until the nurse arrives will provide safety and support to your loved one.

Practical Issues

- If your loved one can no longer communicate, or is no longer capable of making treatment decisions, the Substitute Decision Maker assumes responsibility for ensuring the person's wishes at end of life are honoured.
- Ask about Compassionate Care benefits (see back page) if you are going to need time off work.
- It is helpful if you and your family discuss end-of-life rituals and funeral plans, prior to the death. This will prevent you from having to make major decisions at a very emotional time. It is important to share these plans with your health care team.
- Everyone is encouraged to discuss their wishes, with respect to organ donation, long before they die. If interested, please discuss with your health care team.

How will I know death has occurred?

Even though death is expected, you may not be prepared for the actual moment it occurs. At the time of death:

- There will be no response, no breathing & no pulse
- Eyes will be fixed in one direction
- Mouth may be open
- Eyelids may be opened or closed
- There may be loss of control of the bladder or bowel
- *There will be no pain*

You may have many reactions to the moment of death of your loved one. It is normal to feel shocked, to cry, to sit quietly or even to feel relieved for your loved one.

After Death has Occurred

If this is an expected death, do not call 911. Call your nursing agency to notify your nurse or nurse on call. Your nurse will make a visit to formally pronounce your loved one's death.

Do spend as much time as needed with your loved one.

When you are ready, the funeral home you have chosen will need to be called. The nurse will leave a copy of the Expected Death in the Home form and partial Medical Certificate of Death in the home for the Funeral Director to take when they pick up the body.

If you have health care professionals involved in the care of the dying person, they should be notified of the death. They are available to provide you with emotional and bereavement supports.

Your health care team can also suggest the safe, responsible way of storing and disposing of medication and equipment, but it is the family's responsibility to do so. Contact your care coordinator or health care team for no cost pick-up of the **Symptom Response Kit** medications.

Caring for Yourself

You are an important part of the team caring for your loved one. Each team member needs to stay well to contribute their unique strengths and abilities.

Caring for a loved one, at end of life, can be challenging. Normal family routines will be disrupted. You may feel you have lost the ability to focus on anything. You may sometimes wish for things to be over because of the uncertainty, helplessness, emotional and physical exhaustion you may be experiencing. This is completely normal.

A dying person may find great comfort in knowing that you are taking care of yourself. Take time for breaks. Eat simple nutritious meals and snacks. Go for a walk outside and rest at regular intervals. These will help you to cope during this difficult period.

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

- Ask for help when you need it
- Accept offers of help and support from friends and relatives
- Maintain reasonable expectations of yourself
- Give yourself permission to feel the way you're feeling

**There is some mystery to death and dying.
We may not know all the answers to your questions,
but we will be here to help.**

Compassionate Care Benefits

The demands of caring for a gravely ill family member may jeopardize 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 may:

- Contact your Human Resources department for assistance
- Go to your Service Canada Centre
- Call **1-800-206-7218** (TTY: 1-800-529-3742)
- Go online to:
www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml

Grief & Loss Resources:

- Bereaved Families of Ontario - <http://bereavedfamilies.net/>
- Caredove - <https://www.caredove.com/wwihpc>
- My Grief - <http://www.mygrief.ca/>

General Caregiving Resources:

- Canadian Virtual Hospice:
http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx



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