

Compassionate Care Benefits

One of the most difficult times for anyone is when a loved one is dying or at risk of death. The demands of caring for a gravely ill family member can jeopardize both your job and the financial security of your family. The Government of Canada believes that, during such times, you should not have to choose between keeping your job and caring for your family.

To apply for Compassionate Care Benefits, you can call **1-800-206-7218** (TTY: 1-800-529-3742) (from the main menu, choose option “2,” and then press “2” to access “types of benefits”) or you can go online to www.servicecanada.gc.ca. and then click on: All Canadians - “Apply for Employment Insurance Benefits.”

To order more brochures, contact:



HPC Consultation Services of
Waterloo • Wellington

519-578-9757 ext 104
or 519 823 2551 ext 2301 or 2335

To download the brochure, go to:

www.hpconnection.ca, Clinical Information

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When Someone is Dying...

What can I expect?
What can I do?



- *Life's Thread* -

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

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

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

Death 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 can happen. Not all these signs and symptoms will occur with every person, nor will they occur in any particular sequence. Some symptoms can lessen at end of life or they can become worse, interfering with the comfort of your loved one.

This brochure is intended only as a guide and may help provide comfort to the dying person and those who care for them. It is not intended to replace advice given by a health care professional, such as a nurse, physician, clergy, social worker, homecare case manager or pharmacist.

Caring for yourself

Caring for a loved one at 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're feeling

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

Please take the time to discuss any questions about this brochure 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
- Eyelids may be opened or closed
- There may be loss of control of the bladder or bowel
- There will be no pain

Even though this is an expected death, you may feel more anxious. It is NOT an emergency.

After death has occurred

Call your nursing agency to notify your nurse or nurse on call of the death. Your nurse will make a visit to formally pronounce your loved one's death.

Do Not Call 911, police or ambulance as this could mean that attempts at resuscitation and transfer to Emergency could be initiated.

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

The funeral home you have chosen will need to be called. You will be asked to sign a form releasing your loved one to the funeral home.

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 assistance and emotional support.

A health care provider 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.

Social & Emotional Responses to Approaching Death

- As death approaches, the person becomes quieter and less interested in their surroundings. He/she may become withdrawn, less sociable and also be confused about time and place.
- The person dying and their caregivers may be going through different emotional states such as guilt, anger, frustration, helplessness or sadness. These are common and normal responses to the events you are experiencing.
- 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 they approach death.
- Tears are a natural expression of one's feelings.
- Vision-like experiences may occur. The person may see or speak to people and places 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 where they are and who is with them.
- Normal family routines may be disrupted and you may feel you have lost the ability to concentrate 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. Taking time for breaks, eating properly and resting at regular intervals will help you cope during this difficult period.

- Goodbyes are appropriate. Both the person dying and their family may find comfort in this process of “letting go”.
- A dying person 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.

Spirituality

- People vary greatly in their spiritual and/or religious beliefs and needs. During this time your member of clergy or spiritual advisor can provide compassionate spiritual support to you and your family. If necessary, you can ask your Health Care provider for assistance in accessing spiritual support.
- The use of rituals, religious rites or sacraments may provide comfort at this time.
- If the person is struggling with unanswered questions, it would be wise to seek assistance. 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 rewards.

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
- choking
- running a fever

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, the Substitute Decision Maker assumes responsibility for ensuring the person’s wishes for end of life are honoured.
- Ask about Compassionate Care benefits if you are going to need time off work. – see back page.
- It is helpful if you and your family discuss funeral plans prior to the death. This will avoid having to make major decisions at a very stressful time.
- Everyone is encouraged to discuss their wishes with respect to organ donation long before they die. If interested, discuss with your Physician.

Physical Signs of Approaching Death cont'd

Breathing

Regular breathing patterns may change. You may notice irregular, shallow breathing or perhaps even brief periods when breathing may stop. These breathing patterns are normal and indicate the natural progression towards death. Depending on the diagnosis, the person you are caring for may develop shortness of breath at this stage.

Sometimes oxygen or compressed air is used to provide symptom relief to a person at end of life. Persons suffering with breathlessness may find it beneficial to have the head of the bed elevated (pillows can be used) and be in a cool, calm environment. A gentle fan across the cheeks can help with shortness of breath. There are medications which can be helpful for these symptoms as it is normal for breathlessness to cause anxiety.

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 not the dying person. Such noises are not a sign of pain.

Skin

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

Being Present and Connected

- 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 can be the right thing to do. Sit with the person; hold their hand.
- A calming effect may be achieved by sitting quietly at the bedside, playing soothing music or reading something comforting.
- If you are providing care, talk to them and let them know what you will be doing.
- Allow them to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen, you aren't expected to have all the answers.
- Don't isolate them from life. Talk to them about what is going on with family members, other points of interest for them. Avoid withholding difficult information. They may prefer to be included in these discussions.
- Be willing to reminisce about their life. Remember things you laughed about.



Physical Signs of Approaching Death

Food and Fluid

Loss of appetite and decrease in thirst are a natural part of the body shutting down. The body cannot use the 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. Do not give fluids/ food if your loved one is unable to swallow. Ask your Healthcare Professional for assistance. Frequent mouth care is essential as it provides moisture and comfort.

Elimination

Urine output and bowel function will decrease as their food and fluid intake decrease. Urine and stool may also change 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 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 Healthcare Professionals.

Sleeping

Sleeping an increased amount of time is common. It may become more difficult to waken the person. As death nears, the person may slip into a coma and become unresponsive. At times like this, bring a book to read or a small project to do to keep you occupied. Remember they tire easily now. Plan for rest periods between activities or visitors. It's okay to restrict visitors.

Restlessness and Confusion

Confusion as to time, place and recognition of people is common. This can include members of the family and close friends. At times the person may become restless. For example: she/he 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 circulation to the brain, changes in their condition or medications. It would be helpful to discuss these changes with a Healthcare Professional.

