

# Care for the Dying



Landscape from PEI

## Provincial-Integrated Palliative Care Program Prince Edward Home

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# Care for the Dying

Many physical changes occur during the process of dying that affect the emotional, social, and spiritual aspects of a person's life. There are some signs and symptoms of dying that are observable, although not everyone follows a predictable sequence of events or stages.

Sometimes, the last stages of life can be very stressful for the dying person and those caring for him or her. You may observe changes that are unfamiliar to you. You may have concerns and questions. Learning about the dying process will help.

Remember that each person's dying process is unique. For example, those with a terminal illness, such as advanced cancer, will usually show a steady decline toward death. Those with serious chronic illnesses, however, may have peaks and valleys that sometimes give the impression of recovery.

In this booklet, you will learn about the common symptoms experienced in people who are dying. You may observe none, some, or all of these symptoms in the dying person's last days and hours. You will also learn to anticipate and manage the changes that may occur to help promote the comfort of your loved one.



*Love is the only thing  
we can carry with us when we go.*

– Mary Alcott



# Common Symptoms and What You Can Do

## Loss of Appetite

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As death nears, a person may lose interest in food and drink. The ability to swallow becomes impaired. Loss of appetite and reduced intake are normal parts of dying.

In the early stages of dying, the person may prefer only soft foods and liquids. In the very last stages of life, however, he or she may not want any food or drink. The person may want to suck on ice chips or take a small amount of liquid to wet and freshen the mouth, which can become very dry.

In the last stages of dying, forcing food when the body says “no” may be harmful or painful to the person. Many dying persons will exhibit the clenched jaw sign as a way of saying “no”. Forcing fluids may cause choking, or the person may draw liquid into their lungs, making matters worse.

It is hard for most people to respect the person’s lack of appetite. That’s because many of us equate food with caring. Family members may feel that withholding nutrition is cruel or neglectful. They may worry that they are starving their loved one.

Remember that your loved one is dying from his or her disease, not from starvation. As the physical body dies, the vital organs shut down and nourishment is no longer required to keep them functioning. This is the wisdom of dying, and the body knows exactly what to do.

***What you can do:***

- Talk to the doctor or nurse about the advantages of reducing food and fluid in the last stages of dying.
- Refrain from giving liquids or food unless requested.
- Wet the lips and mouth with a small amount of water, ice chips, or a sponge-tipped swab dipped in water.
- Protect lips from dryness with a protective lip balm.
- Consider removing dentures and bridges, as they may become loose.
- Continue to be a caring and loving presence.



*Live as if you were to die tomorrow.*

*Learn as if you were to live forever.*

– Mahatma Gandhi

## Elimination

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Because the bowel and bladder eventually slow down and do not work as well:

- There is less urine and it is darker in color (tea-colored).  
A catheter may be placed in the bladder as a comfort measure if there is a concern about skin breakdown or inability to empty the bladder.
- Bowel movements become less frequent, but not having one for three to four days could become uncomfortable.  
Discuss this with the palliative care nurse, because medications might be helpful.
- The dying person will usually lose control of bowel and bladder function (incontinence) as muscles in that area begin to relax. This is normal but can be distressing to the dying person and those in attendance.

### *What you can do:*

- Watch for signs of constipation and incontinence and report this to the doctor or nurse.
- Keep affected areas clean and dry. After cleansing, apply a protective barrier cream to prevent skin irritation. This will help maintain the dying person's comfort and dignity.

## Withdrawal

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As the end of life approaches there is a tendency to sleep more. There is less desire to talk. This is the beginning of letting go of life and preparing for death.

Days or hours before death, the dying person becomes less and less responsive and may not awaken when touched or spoken to. This is usually due to extreme weakness and fatigue. The person may become alert and talkative for short periods followed by hours or days of deep sleep and unresponsiveness.

### *What you can do:*

- Plan visits for times when the person is more wakeful and alert.
- Avoid overtiring the person. Limit the number and length of visits.
- Always speak gently, and identify yourself before speaking. Hearing is normally preserved throughout the dying process.
- Use gentle touch, such as holding hands, and provide reassurance. The dying person can feel your touch up until the end.
- Allow time for silence. Remember that you are supporting the dying person to let go.

*The bitterest tears shed over graves  
are for words left unsaid  
and deeds left undone.*

– Harriet Beecher Stowe



## **Confusion, Restlessness, and/or Agitation**

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Restlessness and confusion are common. A dying person may be unable to recognize familiar people or surroundings. They may see things you cannot see, pull at their sheets and clothing, or reach into the air.

As they are dying some people see or speak with people who have already died. People generally find these experiences comforting. Just because you cannot see or hear it does not mean it is not real to your loved one.

### ***What you can do:***

- Speak calmly and gently
- Identify yourself and others in the room to the dying person
- Consider playing calm and soothing music
- Gently touching the person
- Keep the atmosphere quiet and lights dimmed. Try to minimize stimulation
- Do not discount or correct what the dying person is saying
- Medication may be required to manage these symptoms

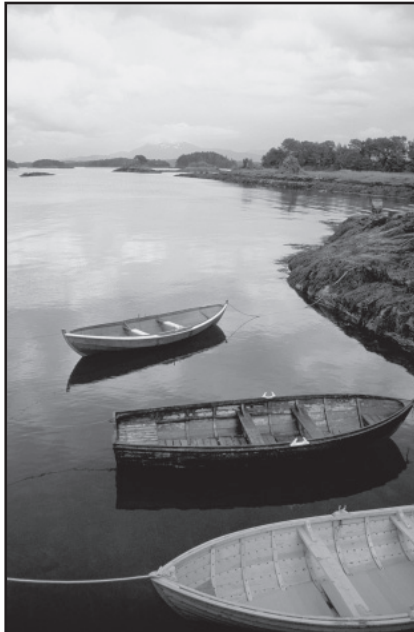
## **Experience Emotional or Spiritual Changes**

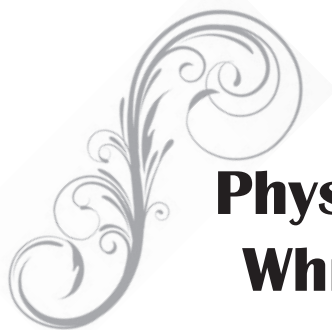
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A dying person may talk about going somewhere, ask to go home, or see and talk to someone that you don't see. This doesn't happen to everyone but when it does remember this is normal and expected.

### ***What you can do:***

- Continue to respond in your usual way
- Realize the dying person may be letting go and saying goodbye
- Accept that things the dying person may say or refer to are not always signs of a problem. This is explained in a book called "Final Gifts" (1993) by Maggie Callahan and Patricia Kelley.
- It may be helpful to have a spiritual leader visit if the person wishes





## Physical Symptoms Which May Occur

Changes that occur as a person dies will vary from one person to the next. Some changes may be unsettling and are usually more difficult for you to watch than for the person to experience. The more family and friends understand what is happening during the dying process, the better you will be able to cope with the situation and manage caring for your loved one at home or in a health care facility.

- Have difficulty swallowing – A dying person may forget to swallow or have difficulty swallowing as weakness increases.
  - Give only small amounts of food or fluids. Too much may cause choking or vomiting.
  - Remind the person to swallow
  - Medications may need to be crushed and given in pudding or yogurt or by an alternate route. Speak to the doctor or nurse about alternate routes.
  
- Have a change in body temperature and color. The person may be hot to the touch or cool as the circulation slows down especially in the arms, hands, legs and feet. The skin may also start to look bluish and patchy in color. This is called mottling or cyanosis. These changes are a normal part of the dying process.

- Use a damp, cool washcloth to forehead.
  - Be alert to signs, such as kicking the blankets off, that the person is getting too hot.
  - Medication may not help to keep the temperature down as the temperature – regulating part of the brain is not working properly and this is what causes the changes in the temperature.
- Changes in breathing. Breathing may become shallow and rapid or slow and labored. As death nears the breathing may become wet and congested sounding. These sounds are due to the pooling of secretions in the throat and the inability (due to weakness) to cough up these secretions. The air passing through these secretions causes this sound. This can be very difficult to see and hear but it very rarely bothers the patient. Moaning as the person breaths in or out may or may not occur. This is normal and does not mean they are in pain. There may be periods where the patient will stop breathing and these can last up to 45 seconds at a time.
- Raise the head of the bed either mechanically or with pillows.
  - Turn the person on their side to use gravity to help drain the secretions. Suctioning rarely helps and can be very disturbing to the patient.
  - Use swabs or a soft cloth to wipe out the mouth.
  - Medications are available to help manage these symptoms. Ask your doctor or nurse about them.



*The world is round and the place which  
may seem like the end may also be the  
beginning.*

– Ivy Baker Priest



## Saying Good-bye

People who are dying often want “permission” to die from those they love. They may need to be assured, quite literally, of four things:

- Things they were once responsible for will be taken care of
- The survivors will be all right without them
- Their life had meaning
- They will be remembered

Saying good-bye is not easy. Yet, it is important for you and the dying person to do so. Take advantage of opportunities when the person is awake and communicative to facilitate the “saying good-bye” process.

Remember that hearing is the last sense to leave. Assume everything you say can be heard and understood, even if the person is not responsive. Never speak about the dying person as if he or she was not in the room.

Usually the amount of stimulation and contact with others that people preferred when they were well is similar to what they desire near the end of life. A dying person may seem to choose the time to die, perhaps when particular people are present or when they are alone.

Realize your limitations. No one is perfect. No one can do everything. Take a break when you need one. Get help when you need it.

Even with all the preparation in the world, it is not easy watching someone you love die. Your decision to be present at the moment of death depends on many things and it is OK to choose to be present, and it is OK not to be there.

No matter how much you think you are ready and prepared for the end, it will still be a shock and you need to understand that this is normal and allow yourself to grieve and cry. Crying is a normal part of grieving for everyone.

### ***At the time of death:***

You will notice that the person's:

- Breathing and heartbeat have stopped
- Eyes are not moving and may be open or closed
- Mouth may fall or remain open as the jaw relaxes
- Skin becomes pale and waxy looking





## **When Death Has Occurred**

It is not necessary to call 911, police or the ambulance. Note the actual time of death, as this is needed for legal purposes.

This is the time to honor any family or cultural rituals.

If you wish, notify any family, friends or spiritual person, which you would like to be present. You may want to collect clothing to send with the funeral home at this time or take them with you when you meet with the funeral director later.

There is no need to call the funeral home right away. Take some time to experience what has happened and to say your good-byes. Sharing stories with family and friends will help in the grieving process.

The final leave-taking can be a difficult time. When you have said your good-byes, it is time to notify the funeral home. When they arrive, if you have selected clothing or special items, these can be given to the funeral home at this time. They will have a stretcher which they will use to transport your loved one. Once the body has been placed on the stretcher they will use a special zippered bag to cover the body for transport. Some people do not wish to be present for this so have a place you can go while the body is being removed.



Funeral plans can be made or confirmed in a meeting with the funeral home later.

Notify the Physician, Home Care Coordinator of the death. Home Care will refer the family for their bereavement service and you can agree or not to participate but we strongly encourage you to take a few of the phone calls so you can express your grief to an experienced bereavement counselor.



Dunes and flowing water in PEI, Canada

## **No Person is Ever Truly Alone**

No person is ever truly alone.  
Those who live no more,  
Whom we loved,  
Echo still within our thoughts,  
Our words, our hearts.  
And what they did  
And who they were  
Becomes a part of all that we are,  
Forever.

*by Richard Fife*



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