What You Need To Know

Physical and Emotional Considerations

Health PEI

One Island Health System

Provincial Integrated Palliative Care Program

☑ **Patient & Family Approved**

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This information does not take the place of the care and advice of your care team.

Talk to your care team about your questions and concerns.

Health PEI would like to acknowledge the Nova Scotia Health Authority for the development of this booklet in collaboration with Cancer Care Nova Scotia and other community partners. Health PEI has adapted the booklet.

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Important Phone Numbers

Family Physician / Nurse Practitioner:

Care Team:

Care Team, after hours: – Home Care Support (check with area regarding after hours) - Paramedics Providing After Hours Care at Home

Proxy/Substitute Decision Maker:

Clergy or Spiritual Advisor:

Funeral Home:

Lawyer:

Executor:

Bank:

Palliative Care Registration #:

Other:

Changes to Expect Near Death

Physical Changes

This information may be difficult to read, but many people find it helpful to know what they themselves or their family members may experience as they near death. For family members, having this information can better prepare them to care for, or be with someone near death.

Changes that happen as a person dies will vary from person to person. These changes are usually more difficult for others to watch than for the person to experience. The more you understand about what is happening, the better you will be able to cope with these changes. Although all dying people do not have the same signs or symptoms, it is helpful to know some of the common ones. These changes are a normal part of the dying process, and knowing what to expect can help you deal with your fears and concerns. It is important to share your fears and concerns with family members, close friends, and your care team.

Weakness and Sleepiness

As your illness progresses, you may feel weaker and much more tired. These changes usually happen over a few days but can sometimes happen very quickly, even within a few hours. At a certain point, you may be spending all of your time in bed. If you are being cared for at home, having a hospital-style bed will be helpful. Your Home Care team can help with this.

Eating and Drinking

As death nears, it is natural that the dying person may not eat or drink very much, if anything at all. At this stage, food or water will not keep a person alive longer. When the body's systems slow down, it is hard for the body to manage food and water, and eating or drinking can cause discomfort.

> "I cannot express fully enough how important it is for patients and families to know of absolutely any and everything that may happen when the patient is nearing the end of their struggle. We were well informed about things but, there were a lot of things that happened that we certainly were not prepared for."
>
> **- Family caregiver**

Caregiver's Note: If you are caring for a dying person at home and they have symptoms that you are not prepared for, or feel you are unable to cope with, call for help or reassurance. Your first calls should be to the people at the contact numbers your care team gave you. If you are unable to contact them, you may want to call 811 or if the patient is part of the Integrated Palliative Care Program, you can call 911 and you will be forwarded to EMS dispatch. Paramedics will be dispatched and may be able to help manage symptoms at home.

This service is available to all palliative patients enrolled in the Provincial Integrated Palliative Care Program. Enrollment in the program helps paramedics provide support that is in line with the plan you developed with your care team.

Breathing Patterns

As we die, we get weaker and our breathing patterns change. The dying person will not be aware of these breathing changes and will not be upset by them. Still, such changes may be distressing for others to witness.

There may be periods when the dying person stops breathing. This can occur for a few seconds up to 45 seconds between breaths. During these periods the breathing can get noisier and deeper. It may seem to others like the dying person is struggling. However, this is not usually the case. At other times breathing becomes deeper, more rapid, or irregular. Oxygen will not help in any of these situations.

Caregiver's Note: To increase comfort, you may place the person partly on their side, supported with pillows along the whole length of their body. Special soft, long body pillows are available at most department stores and can be very useful at this stage. It is a good idea for caregivers to change the person's position every six to eight hours. Small and gentle changes to position can be helpful. A dying person may seem to be in a light sleep all of the time or may be more awake at night. Family and friends should plan to spend time during the periods when the person seems most alert or awake.

Family and friends do not need to be quiet around a dying person. They should speak with normal voices. However, very loud noises should be avoided, as these may startle and disturb the dying person, causing some distress. Family and friends should talk to the dying person as if they can hear everything. The person may be too weak to respond or may not be able to speak, but they may still be able to hear and understand what family and friends say.

> "There are humorous times, and people need to know it can be okay to laugh, even during a stressful time."
>
> **- Family caregiver**

Loss of Bowel or Bladder Control

Dying people will lose control of their bladder and bowels; this is called incontinence. Incontinence is common and happens when the muscles relax. The best way to care for a dying person who is incontinent is to keep them clean and dry. Checking them often will prevent skin problems like rashes and infections. A plastic mattress cover and incontinence pads will protect the mattress from being soiled.

You can eliminate trips to the toilet by using disposable absorbent undergarments or by asking to have a catheter inserted. There may be some discomfort when the catheter is inserted, but there is usually no pain once it is in place.

Caregiver's Note: For people who are sleepy or cannot swallow properly, food and water can get into the lungs, causing coughing and gagging. This can lead to congestion and pneumonia. Ask your care team how to safely give a dying person food or water.

If a dying person wants water, raise the head of the bed a little and feed them ice chips or give them small amounts of water using a straw or a cup with a spout. Stop right away if the dying person coughs or cannot manage the fluids.

An intravenous (IV) is usually not started near death because the body cannot use the fluid properly. An IV can cause increased fluid in the lungs, and cause the dying person to suffer.

As death approaches, the dying person may not need to urinate as often. Urine may become tea-colored and strong smelling. This is caused by drinking less fluid and the decrease in circulation through the kidneys.

Restlessness and Agitation

Sometimes dying people become very restless or agitated. This may be a sign of delirium. Dying people may make restless and repetitive motions, such as pulling at bed linen or clothing. Such motions can be caused by changes in the body or by some medications.

Caregivers should not interfere with or try to restrain such motions but should notify a member of the care team if there is a change.

To calm a dying person, caregivers should speak in a quiet, natural way, lightly massage the forehead, read aloud, or play some soothing music. It may also be soothing to talk about a favorite place the person enjoyed, or a favorite memory. Try not to have many conversations in the room at once or conversations while music or the TV is on. This may create too much sound and may cause restlessness. When a dying person is restless or agitated, one person speaking at a time is best. Also, sometimes touching an agitated person makes them uncomfortable. When a dying person is restless or agitated, caregivers should watch to see how they respond to touch and sounds. Leaving a nightlight on can be comforting.

Medication can be helpful in easing restlessness when other things do not work. The doctor may prescribe medications for this. Ask the care team if you have any questions about how to calm a dying person who is agitated.

Congestion

Very near death (a few days or a few hours before) the dying person might gurgle or make snoring-like sounds. These noises are caused by several things: small amounts of mucus in the throat and lungs because the person is not able to cough or clear secretions any longer.

Caregivers can help the person by turning them on their side, with their head slightly raised. This is a way to mobilize the secretions when a person is too weak to cough or clear.

Sometimes the doctor will order medication to reduce secretions. Oxygen will not help with this problem. Suction machines are needed only in rare cases, as they may cause distress and discomfort and are ineffective as secretions will return.

Mouth Care

Dying people breathe through their mouths and take in very little fluid, which can make the lining of the mouth and tongue dry and uncomfortable. Frequent mouth care will help. Mouth care with water and a sponge tipped swab is all you need. Lip balm will protect the lips.

Caregiver's Note: You can use these products and a sponge-tipped swab to clean and freshen the lining of the mouth, the gums, and the tongue. Sometimes the dying person may bite on the swab when it first goes into their mouth. This is normal. If this happens, the caregiver should hold onto the stick; after a few moments, the dying person will stop biting.

Mouth care should be done regularly. Your care team can help you with frequency.

Nose Care

The nose can become dry and uncomfortable. Nostrils can be moistened with a water-based gel, which you can buy at a pharmacy without a prescription.

Eye Care

Eye drops, such as artificial tears, will help soothe dry eyes. You can buy these drops at a pharmacy without a prescription.

Pain

Usually, pain does not get worse near death. As the body changes and you become sleepier and move less, you may have less pain. Your doctor may need to adjust medications because of these changes.

Caregivers should not stop giving pain medications to the dying person. The person will still need to continue their regular pain medications.

If a dying person cannot swallow, the doctor may change the way the pain medications are given. Caregivers may be asked to give pain medications by mouth, by putting the medication against the lining of the mouth, or under the tongue. Sometimes pain medications are given in a way that uses fewer needles, with a special infusion set called a butterfly.

Sometimes a person who is dying will moan when they are moved from side to side or when they breathe out. This does not necessarily mean they are in pain. Frowning and grimacing are signs that the person may require medication adjustment.

Ask the care team if you have any questions about controlling pain.

Very Near the Time of Death

As time of dying comes very close, the dying person's hands, arms, feet, or legs may become cooler and the color of their skin may change. This is a normal sign that the circulation of blood is decreasing to the body's limbs and is being reserved for the most vital organs.

Sometimes, a dying person who is unresponsive may suddenly become more alert as death approaches. This can last for minutes or for hours, before they become very sleepy and then unresponsive again.

> "It is good to be prepared…
> like the physical changes. I wasn't expecting
> some of those and wish I knew,
> so it wasn't a shock."
>
> **- Family caregiver**

Emotional, Spiritual, and Mental Changes

Disorientation

Dying people may seem to be confused about time, place, and the identity of people, including close and familiar people.

Family, friends, and care caregivers should speak softly, clearly, and truthfully when they need to say something important. They should explain the reason for what they are doing. For example, they might say, "It is time for your pain pill. You need this so that the pain won't come back."

Giving Permission

A dying person may try to hold on, to be sure that those who are going to be left behind will be all right. Family and friends may be encouraged to tell you that it is all right to let go, whenever you are ready. This might bring you much needed spiritual peace. As difficult as saying it is all right to let go may be, it is one of the greatest gifts you can be given at this time.

It may be helpful to lie in bed together, hold hands and say everything you need to say. Tears are a normal part of saying goodbye. Do not hide or apologize for your tears. Tears can express love.

Family and friends should not feel guilty about not being present at the moment of death. Some people may have waited for a moment alone to die.

> "When you feel you are ready, consider how you will say goodbye… your survivors will cherish forever your heartfelt goodbyes."
>
> **- Dr. Alan D. Wolfelt,** ***author and grief counselor***

Spiritual Pain

Many of us are afraid to die. We worry whether our lives have made a difference. We may feel guilty about some things we have done. We may feel sad about leaving family and friends. We may be afraid of what comes after death. Most people have such concerns, whether they are religious or not; it is a normal part of the human experience. Family and friends can help remind you of the ways you have made a difference in their lives and how you will be remembered.

Withdrawal

While dying, some people begin to withdraw from their friends and family. For example, a person who was very involved in the community may want only one person or a select few people with whom they feel close at their bedside. It's important for family and friends to respect these wishes, as doing so helps provide a comforting and calm environment.

Visions

While dying, some people see or speak with those who have already died or who are not physically in the room. Dying people generally find these experiences comforting.

Caregiver's Note: While you cannot see what the dying person sees, this does not mean that the vision is not, in some sense, real for that person. You should feel comfortable affirming the person's experiences.

If the visions are frightening, ask your care team for suggestions about how to comfort the dying person.

The Moment of Death

Although family members may be prepared for the dying process, they may not be prepared for the actual moment of death. It may be helpful for family members to think about and discuss what they would do if they were present at the moment of death.

When people die, their breathing and heartbeat will stop. The person will not respond to stimulation. The eyelids will be slightly open, and the eyes will seem fixed on a certain spot. There will be no blinking. The jaw will be relaxed and the mouth slightly open. The bladder and bowel may release.

Sometimes the process is so gradual that family and friends are not really sure for a while that the person has died. There is no need to contact anyone immediately, even the doctor. The body does not have to be moved until family and friends are ready. Family and friends can take as much time as they need to say goodbye. They may want to think about whether they would like to be present when the body is removed from the room.

No matter how much you prepare for this moment, death, like birth, arrives in its own time and in its own way. The experience of dying is different for every person and for every family.

Place of Death

When an expected death happens in the hospital, home, nursing home, or palliative care units on PEI, there is no need to call a doctor. The pronouncing of death can be delegated to nurses, paramedics, or a family member.

In PEI, when a death is anticipated to happen at home, we fill out a form called (EDITH – Expected Death In The Home). This avoids the need to have the ambulance and coroner involved. If a person dies at home but the death is not formally planned for, the coroner will need to be called. This can be distressing for friends and family.

A death certificate is needed for every death – there is a section to be completed by the funeral home or care team, and a separate section to be completed by a doctor.

A “Statement of Death” is issued by the Funeral Home.

Autopsy

Typically, when people die of an advanced illness an autopsy is not required.

More Information for Caregivers

The end of a life is a time when families often come together and reflect on the life they have shared. In its way, it can sometimes be as special as when a new life enters the world.

As death nears, it can be a time of fear. But death can be seen as an end to suffering; and it can be seen as a time of reflection and healing. Most family members get to a point where they want the dying process to end, and this may cause feelings of guilt. But wishing for the end is a perfectly normal reaction, and to a great extent it is felt because of the love we have for the person.

> "Guilt is perhaps the most painful companion of death."
>
> **- Dr. Elisabeth Kübler-Ross,**
> ***a psychiatrist and palliative care pioneer***

Taking Care of Yourself

- During stressful times we may lose our appetite, but it is important to try to eat well. We may also drink more coffee and tea, but we should try to drink water too.
- Take time to go outside. If you cannot go outside, be sure to move around, such as by walking up and down the hall doing some form of exercise, or just stretch your legs. Activity and fresh air help to relieve stress.
- Surround yourself with supportive friends and let them help you.

- Use caution if relying on substances to cope. Talk to your care team if you are using alcohol, sedatives, or tranquilizers.
- Try to get some rest and sleep.
- Ask your care team about any questions, concerns, or fears that come to mind.

You may have mixed feelings; such as a sense of peace, relief, or terrible sadness. Tears are important. You do not need to hide your tears or apologize for them. They are a sign of love and show your dying family member that they have affected your life in a meaningful way.

Say What You Need to Say

As your family member's death comes closer, there may be an opportunity for both of you to have the special privilege of saying goodbye. When you feel you are ready, think about how you will say goodbye. Take time to talk to your family member to see if there is anyone they would like to see or talk with. Other ways of saying goodbye include writing letters, making videos, and passing along keepsakes.

Children

Children have great imaginations, and often what they imagine about dying is worse than what they will see at their family member's bedside. Remember that children and teenagers are known to overhear everything. They will sense something upsetting is happening, and if not told, they might invent a reason for the family's distress. They will likely feel isolated and alone if they are not included in important conversations. Young children may fear the loss of others close to them and often may need to be reminded that other family members are not sick and will be with them for a long time.

Children and teenagers grieve differently from adults and often take breaks from grief by playing or going out with friends. This does not mean that they lack compassion or do not understand. They may just need time away from grief and some space away from what is happening.

It is natural to try to protect children. However, their being prepared for what they will see is generally comforting for everyone. Children may misinterpret phrases like “God is taking grandma” or “we lost grandpa” or suggesting that death is like sleeping. Your care team can help you prepare children and youth and help you answer questions they may have.

Website for the resource Child and Teen Grief is:

https://www.princeedwardisland.ca/en/information/health-pei/palliative-care-program

It may be comforting for your family member to have the family pet nearby. If your family member is in the hospital and would like to see a pet, check with the nursing staff to see if you can arrange a visit.

Grief

Grief is a natural process that accompanies loss. Loss may be experienced at various stages throughout illness, as well as after death.

Grief affects all aspects of life, and you may need support. It’s important to express your grief. You will need time to work through the pain that comes from loss. Though grief is a process, it can be like going on a journey without a map. There is no set way that grief is experienced.

Allow yourself to mourn. Mourning may involve crying, sharing memories and stories, having time alone, making a scrapbook, avoiding activities you shared with the person, or developing ways to remember. Mourning is different for everyone. Very good online resources to help with grieving for adults and children are: **Kidsgrief.ca, Mygrief.ca,** and **Virtualhospice.ca.**

> "People are three dimensional, and are not all good or all bad. Sometimes we can remember the bad stuff and we should not feel guilty about having those memories."
>
> **- Family caregiver**

Your grief is unique. Sometimes we compare our experience of loss with that of others. Family members or friends may be grieving differently, and this can make us think we are doing it "wrong." Two common grieving modes are to want quiet time for reflection and the need to keep busy. Remember, no one can tell you how to grieve. Grief is something we all need to address in our own way, in our own time.

Expect to feel a wide range of emotions. We usually link grief with sadness. But grief can also involve a lot of mixed feelings, like anger, guilt, relief, loneliness, anxiety, love, disbelief, and many more.

You may feel numb. At times, you may have no feelings. This is a natural reaction to emotional pain. We can "shut down" temporarily as a way to process loss and grief.

Be patient about your physical and emotional limits. Grieving can affect our energy levels, both physically and emotionally. We may find it difficult to do everyday tasks and duties that we used to perform easily. Be patient with yourself and know that it is okay to set limits for what you can and cannot do.

Maintain a network of support. This can mean emotional support, but may also mean getting support for practical things, like taking care of meals, shopping, child care, or household maintenance. "Support" may also mean just being with people and not talking about your grief.

Make use of rituals. Funerals and memorials are types of rituals that can support your grief. You may also find other rituals comforting, such a lighting a candle, setting an extra place at the table, or touching a special picture or item that belonged to your family member.

Embrace your spirituality. Many people struggle with big questions when faced with death. Allow for these struggles and questions, even though they may not have solutions. Religious and cultural traditions can be a comfort and support. You may question your beliefs. When something painful happens in our lives, we may ask, "What does this mean for me?" and "Who am I?"

So often, our identity as a parent, sibling, son, daughter, grandchild, spouse, partner, or friend shifts when someone we love dies. You may feel shaken, lost, and that life has lost its meaning. This is a normal reaction. Give yourself permission to feel these things, and share your concerns with others.

Treasure your memories by finding ways you can regularly remember your family member. For a while, memories, even happy ones, may be quite painful. When you're ready, writing down or telling stories to people who knew your family member can be very healing; it is a way of celebrating the connection you shared.

There is no time limit on grief. Sometimes we get strong messages that we should be "over" a loss by a specific time. This is unrealistic. Grief is not a straight line on which we move from the pain of loss to the comfort of being fully healed. It ebbs and flows, comes in waves, often when we least expect it. It can sneak up on us; it can surprise us as we turn a corner. Know that grief shifts and changes over time, but there is no set time frame for grieving.

> "The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again, but you will never be the same. Nor should you be the same, nor would you want to."
>
> **- Dr. Elisabeth Kübler-Ross,**
> ***a psychiatrist and palliative care pioneer***

Connecting with people who understand what you are going through is one of the best ways to support yourself. Talk about your grief with caring friends, relatives, or your care team. While many of us prefer to keep our feelings private, it is important to have a few people with whom to share how grief is affecting you.

Some people say grief feels like having a large burn and every time the wind blows it hurts. Some say it feels like you are walking through a thick fog or watching yourself in a bad movie. Others feel nothing or feel numb. Whatever your experience of grief is, remember to be patient, with your grief and with yourself. Getting though a period of grief can take longer than you think it should. And, be patient with others – they generally mean well.

> "Everyone grieves in different ways. For some, it could take longer or shorter. I do know it never disappears. An ember still smolders inside me. Most days, I don't notice it, but, out of the blue, it'll flare to life."
>
> **- Maria V. Snyder,**
> ***American Author***

Planning Ahead

The paperwork associated with death can feel overwhelming. To complete the paperwork, the executor will need two documents: the will naming the executor and the death certificate. The funeral home will provide you with a Statement of death; ask for at least five copies.

In addition to your lawyer, there are other contacts that can help you:

- **Service Canada:**
  visit **http:www.servicecanada.gc.ca**,
  or call 1-800-622-6232

In addition to following the instructions in the will and managing a variety of financial matters, here are some of the things the executor will need to do:

- Transfer the ownership of any vehicles; visit Access PEI
- Cancel the person's health card; call Access PEI
- Redirect mail; contact Canada Post by visiting your local post office
- Cancel any credit cards and pay any outstanding balance. It is important to check to see if there is life insurance attached to the card; if there is, this insurance should look after any outstanding balance.
- Cancel newspaper and magazine subscriptions, cable TV, and internet services.
- Advise the landlord of death, if the person was renting a property.

> "We had no idea what to do when our father died; the Social Worker was very helpful."
>
> **- Family caregiver**

To Learn More

Hopefully, this booklet has answered some of your questions and brought to mind conversations you need to have and plans that need to be made. For more information, you may want to contact the following services:

- Health PEI ACP **(www.healthpei.ca/advancecareplanning)** provides detailed information
- Canadian Virtual Hospice **(virtualhospice.ca)** provides a wide variety of information on and support for palliative care, care giving and loss and grief for patients, family members, and health professionals. It includes an "Ask a Professional" service, which allows you to privately ask a palliative care professional your own questions about death, dying, and palliative care.
- Hospice Associations on PEI
- Community Legal Information Association of PEI (**www.cliapei.ca**)
- Service Canada (**http://www.servicecanada.gc.ca**; or call 1-800-622-6232) provides a variety of information about dealing with pensions, benefits, and personal finances following a death.
- Provincial Integrated Palliative Care Centre

  Phone: 902-368-4781

  Email: palliativeadmin@ihis.org
- Access PEI **www.princeedwardisland.ca/en/information/transportation-infrastructure-and-energy/access-pei-locations**

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