

End of Life

Information for Caregivers



Version 1: March 2024

This guide is for people who are preparing for the death of a family member, partner or friend. This is a difficult time for you. Take your time reading it. There is a lot of information to cover and it may be difficult to read some of the sections. Refer to the Table of Contents and start with the sections that are most important for you right now.

You may want to make notes about:

- things you need to do
- the decisions you need to make
- questions you would like to ask:
 - your doctor
 - the other members of your healthcare team
 - your lawyer
 - family and friends

Your healthcare team is here to help you. Be sure that you ask about anything that is on your mind.

At the end of the guide, we have included a resources section with links to websites you may find helpful.

IMPORTANT: This guide does not take the place of the advice of your healthcare team.

This guide was created by the Huron Perth Healthcare Alliance (HPHA) End of Life Working Group.

Contents

Changes to Expect Near Death

Physical Changes	5
Breathing Patterns	5
Eating & Drinking	6
Gurgling in the Throat	6
Loss of Bowel or Bladder Control	7
Mouth Care	7
Nose Care.....	7
Eye Care	8
Pain	8
Restlessness and Agitation..	8
Weakness and Sleepiness...	9
Emotional Changes	10
Spiritual Changes	12
Psychological Changes.....	13

Information for Caregivers

Taking Care of Yourself	15
Self-Care.....	15
Say What You Need to Say .	16
Children	16
Pets.....	17
Organ & Tissue Donation.....	18

Death

Giving Permission	20
The Moment of Death	20
After Death	21
Death in Hospital.....	21
Autopsy	22
Burial.....	22
Cremation.....	22
Grief.....	23
Practical Considerations	24
Resources.....	25

Changes to Expect Near Death

In this section, you will learn about:

- Physical Changes
- Emotional Changes
- Spiritual Changes
- Psychological Changes

Changes to Expect Near Death

As serious illness progresses or as the body weakens with age (which may include multiple diseases), changes are common. These changes can affect how a person's body functions, how they think, communicate and behave. 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 that people understand what is happening, the better they will be able to cope with these changes and be present with their loved one.

Although all dying people do not experience the same symptoms, it is helpful to know some of the common ones. We've organized these changes into the following categories: Physical, Emotional, Spiritual, and Psychological.

Physical Changes

Changes that occur in the body are a normal part of the dying process.

Breathing Patterns

As we die, we get weaker and our breathing patterns change. There may be short periods when the dying person stops breathing and when the time between breaths may get longer. It can seem to others like the dying person is gasping. Sometimes, breathing becomes deeper, more rapid or irregular. Oxygen will not help in any of these

situations. The dying person will not be aware of these changes or be upset by them. Still, such changes can be distressing to watch.

Eating & Drinking

Near death, dying people may not eat or drink very much, if anything at all. At this time, eating or drinking could also cause discomfort and swallowing can be difficult. With guidance from the healthcare team, if the 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 they cough or have trouble breathing. It may be helpful to know that 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. This is also a reason why an intravenous (IV) is usually not started near death because the body cannot use the fluid properly. However, an IV will be used if the dying person has a symptom that IV fluid might help.

Gurgling in the Throat

Very near death (a day or two to a few hours before) the dying person might gurgle or make snoring-like sounds. These noises are caused by small amounts of mucus in the throat, the jaw dropping back or the tongue moving back due to the relaxation of jaw and throat muscles. Sometimes, you may hear a soft, short moaning sound with each breath out. These changes will not cause suffocation or death from a blocked airway. A nurse may turn the dying person on their side, with their head slightly raised, making sure that pillows are placed all along their back to support this position. Staying in this position will often stop the sounds.

Loss of Bowel or Bladder Control

Dying people may lose control of their bladder and bowels; this is called incontinence. Incontinence is common and happens when the muscles relax. As death approaches, the dying person may not need to urinate as often. Urine may become tea-coloured and strong smelling. This is caused by drinking less fluid and the decrease in blood circulation through the kidneys.

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. You can use a sponge-tipped swab to clean and freshen the lining of the mouth, the gums, and the tongue. The dying person may bite on the swab when it first goes into their mouth. This is normal. If this happens you should hold onto the stick. After a few moments the biting will stop. The mouth should be cared for at least every few hours. Your healthcare team can tell you the products to use and what to do.

Nose Care

The nose can become dry and uncomfortable. Nostrils can be moistened with a water-based gel which will be provided at the hospital. If the person is dying at home, the water-based gel can be bought at a pharmacy without a prescription.

Eye Care

Eye drops, such as artificial tears, will help soothe dry eyes. While in hospital, the drops will be provided. Your nurse can show you how to use the eye drops. If the person is dying at home, drops can be bought at a pharmacy without a prescription.

Pain

Usually, pain does not get worse near death. As the body changes and the dying person becomes sleepier and moves less, they may have less pain. 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. Some facial and body movements might be a sign of pain and that more pain medication is needed. Ask your healthcare team if you have any questions about controlling pain.

Restlessness and Agitation

Sometimes dying people become very restless or agitated. This may present as restless and repetitive motions, such as pulling at bed sheets or clothing. Such motions can be caused by changes in the body or by medications given. You should not interfere with or try to restrain such motions but should notify a member of the healthcare team if this is happening.

Some things you can do to help with restlessness and agitation are:

- Speaking in a calm, quiet voice to the dying person while lightly massaging their forehead.
- Reading aloud, or playing some soothing music may help with

their agitation.

- Talking about a favourite place the person enjoyed, or a favourite memory.
- Trying to not have too 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 additional restlessness. When a dying person is restless or agitated, one person speaking at a time is best.
- Watching how a dying person responds to touch and sounds. Sometimes touching an agitated person makes them uncomfortable.

Weakness and Sleepiness

Over time, it is common to spend increased time in bed and to sleep for longer periods of the day. In the last few days of life some people can change quickly from being reasonably independent to sleeping all of the time. Sometimes this change happens over just a few hours.

You do not need to be quiet around the dying person. You can speak with a normal voice. However, very loud noises should be avoided, as these may be startling and disturbing. Talk to the dying person as if they can hear everything. They may be too weak to respond or may not be able to speak, but often will still be able to hear and understand what is being said.

As time of dying comes very close, the dying person's hands, arms, feet or legs may become cooler and the colour of their skin may change. The underside of their body may become darker and the

skin can look purplish. 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. You can keep them warm with a blanket. Their eyes may be open and not blinking at this time.

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. This is often an indication that death is likely to occur within the next 24 hours.

Emotional Changes

The dying person can suffer emotional pain as they anticipate their death. So can family and friends of the dying person. Emotional pain may even be more intense and harder to cope with than the physical realities of death. Emotional pain is personal and unique to the person who experiences it.

One or more of the following is often a source of such pain:

- fear of dying or of the unknown
- guilt about specific events or relationships
- sadness about separating from one's family and friends
- sense of helplessness and loss
- diminished sense of self-worth
- disappointment over failed treatment leading to hopelessness
- worry, anxiety, nervousness, or panic
- difficulty making plans
- anger or frustration

Acknowledging these pain points and working through these can be beneficial to our health and well-being.

In difficult times compassionate acts may take on extra significance. These can become ways of ordering and calming the feelings that arise. They can also provide a way to express the love you may hold for the dying person. You might consider doing some of these things with them:

- sitting while gentle music plays in the background
- quietly humming or singing a song
- reading a favourite story, scripture or poem
- reading cards or notes sent by family and friends
- holding or stroking their hand or arm
- brushing their hair or wiping their face
- giving mouth care or giving small sips of water or ice chips (with guidance from the healthcare team)
- rubbing their feet or legs
- reminding them that they are loved and will be remembered
- thanking them for the ways they have touched your life

Such activities are comforting not only for the dying person, but also for us. They calm the feelings of helplessness and uselessness that arise as the person grows weaker and perhaps less alert. They provide avenues for us to express what the person means to us.

Spiritual Changes

Most of us spend much of our lives avoiding thinking about death. Now, perhaps for the first time, the dying person may begin to evaluate their life and think seriously about death and dying. They may worry whether their life has made a difference. There may be feelings of guilt about things left undone or sadness about leaving family and friends. They may be afraid of what comes after death. Most people have these concerns, whether the person is religious or not, it is a normal part of the human experience. What makes such issues spiritual is that they raise questions about the meaning of life – life in general and their life in particular.

If you belong to a spiritual or religious tradition, you may be able to find rituals in the tradition that highlight the significance of your experience and offer comfort to you and the dying person. For assistance in arranging for such rituals, contact your spiritual/religious leader or let your healthcare team know. We will help arrange spiritual/religious support.

While dying, some people see or speak with those who have already died or who are not physically in the room. These experiences are comforting. 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. Try to feel comfortable affirming the dying person's experiences. If the visions are frightening ask your healthcare team for suggestions about how to comfort the dying person.

Psychological Changes

While dying, most 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. Doing so helps provide a comforting and calm environment.

As well, dying people may seem to be confused about time, place and the identity of people, including close and familiar people. Family, friends and caregivers should clearly identify themselves by name before they speak. When speaking, speak softly, clearly, and truthfully. When doing something to them explain the reason for what you're doing. For example, you might say, "It is time to adjust the pillow behind you. You need this so that the pain won't come back."

Information for Caregivers

In this section, you will learn about:

- Taking Care of Yourself
- Children
- Pets
- Organ and Tissue Donation

Taking Care of Yourself

Death can be seen as an end to suffering. It can also be seen as a time of reflection and healing. Most caregivers/family members get to a point where they want the dying process to end. This may cause feelings of guilt. 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.

Self-Care

- 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, 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.
- Try to get some rest and sleep.
- Ask the healthcare team about any questions, concerns or fears that come to mind.
- You may have mixed feelings: peace, relief and terrible sadness. Tears are important. You do not need to hide your tears or apologize for them. Tears are a sign of love and show the dying person they have affected your life in a meaningful way.

Say What You Need to Say

When you feel you are ready, think about how you will say goodbye. Take time to talk to the dying person 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

It is natural to try to protect children. However, like adults, being prepared for what they will experience is generally comforting for everyone. Consider that children may imagine dying as being worse than what they will see at the dying person's bedside and that they will likely already sense that something distressing is happening. Including children and teenagers in some conversations about the dying person can help them know there is a reason for the distress and helps them to not feel isolated and alone during such a difficult time.

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. Involve your children as much as they wish. If they want to visit the dying person, let them know what to expect. Tell them about the hospital and how the person will look. If you don't know what to say to your child, ask a member of your healthcare team if they have experience in this area and can help.

Generally, 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.

You can further help children and teenagers by:

- Trying to keep daily schedules and routines.
- Telling your child's school so that teachers and counsellors can be supportive.
- Remembering that children often grieve in small, short periods of intense grief followed by play and regular activity.
- Remembering that children may revisit their grief. This is normal and healthy.
- Reinforcing the three Cs:
 - "Someone will be there to **care** for you after the death."
 - "The disease is not **contagious**."
 - "You did not **cause** the illness."

Pets

It may be comforting for the dying person to have the family pet nearby. If they would like to see a pet, check with your healthcare team to see if you can arrange a visit. You may be so busy caring for the dying person that you don't have enough time to care for their pet or yours. Ask friends to help with pet care or check into local pet care services. If the pet is a dog you can contact [Elder Dog](#), a national, community-based, non-profit organization with a mission to assist and support older adults in the care and well-being of their canine companions. Visit: www.elderdog.ca

Organ & Tissue Donation

Ontario Health (Trillium Gift of Life Network) is responsible for delivering and coordinating organ and tissue donation and transplantation services across the province. All patients at high risk of death at HPHA are referred to the Trillium Gift of Life Network. The dying person may or may not be an eligible donor, and they may or may not be registered as a donor. Discussing donation with the dying person, with family, and with staff can help with unsure expectations at the time of the individual's passing. For many, donation is a meaningful way to leave a legacy.

Death

In this section, you will learn about:

- Giving Permission
- The Moment of Death
- After Death
- Grief
- Practical Considerations
- Resources

Giving Permission

A dying person may try to hold on, to be sure that those who are left behind will be all right. Family and friends are encouraged to tell the dying person that it is all right to let go, if they are ready. This might bring much needed peace. It may be helpful to hold hands and say everything you need to say. There are moments too, when a person seems ready to die but stays with us much longer than expected. This can simply mean the organs are slower shutting down. Sometimes, the body seems to have a mind of its own; this is why it's difficult to say when someone will die.

You may wish to be with the dying person when they take their last breath, but there are times when it seems the individual may be waiting to die alone. Each time you leave the room say goodbye as though you may never see the person again.

The Moment of Death

When people die, their breathing and heart beat 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 though you may wish for your nurse to attend. The body does not have to be moved until family and friends are ready. You may want to take time to reflect, say a few words, touch the person's body, or say some final

goodbyes. Others may not want these things. You can take as much time as you need to say goodbye. 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.

After Death

Death in Hospital

If you have specific personal, familial, cultural or religious traditions related to the process of dying, please speak to the healthcare team so that these can be accommodated.

When a death occurs in a hospital and plans are in place, your healthcare team will call a doctor to complete the death certificate. A nurse or doctor will ask your family about funeral plans. If plans have been made, the family should call the funeral home. Your healthcare team can help with this. If plans have not been made, a funeral home must be chosen as soon as possible.

It is realistic to spend some time (an hour or more) with the recently deceased person. Eventually, family should collect belongings and take them home as they are able. Sometimes people want to place special articles or mementos with the person's body. It may be best to bring these remembrances to the funeral home to avoid losing these items when the individual's body is transported. If cremation is going to occur, family members who want to say goodbye should be given the opportunity to view the body before it is moved.

Autopsy

Typically, when people die of an advanced illness an autopsy is not required. Talk with your healthcare team about what an autopsy involves and whether one is recommended.

Burial

There are two kinds of burials. The most common is an in-ground burial. Another, more expensive kind of burial, involves placing the casket in a building, or mausoleum, above or just below the ground.

Cemetery costs vary. Ask for a written statement listing all costs before finalizing the purchase.

Cremation

A funeral home or crematorium can help you with cremation plans. You can use any kind of container, such as an urn, to hold the ashes. Often people choose a container with a special meaning. You can choose to have ashes buried. Some family members choose to keep the urn in their home. Others choose to share the ashes among family members.

There are no legal restrictions about scattering ashes in a body of water, or in the wild. But the scattering of ashes on land is subject to property laws—check your municipal bylaws.

If the dying person chooses to be cremated, there is no rush to hold a funeral.

Grief

Grief is a natural process that accompanies loss. Loss may be experienced at various stages throughout illness, as well as after death. Most of us need time to work through the pain that comes from loss. Some have described this process like going on a journey without a map; there is no set way that grief is experienced and there are many ways to react. Know that your friends and family will all grieve in their own way. This is normal and okay. The strong emotions you are struggling with; sadness, anger, fear, guilt, etc., will usually lessen over time.

After the person has died, allow yourself to mourn. Mourning may involve crying, sharing memories and stories, having time alone, making a scrapbook or engaging in other meaningful activities. You may want to avoid doing things you shared with them, or may think about how to do these things differently as you learn to journey without them after death in story and memory. Mourning is different for everyone. There is no set time limit on grief. Grief comes and goes in waves and when we least expect it.

It may be helpful to know that your grief is unique, and that family and friends may grieve differently. There is no right or wrong way to grieve. You can also expect to feel a wide range of emotions and may even feel numb at times and want to shut down as a way to cope with and process your loss. Try to be patient with yourself, considering your emotional and physical limits during this time. Surround yourself with a supportive network of family and friends. Make use of rituals like funerals, memorials and doing meaningful things like lighting a candle or setting up a special picture of your loved one. These things

honour the memory of the person who has died and help us feel connected to them in new ways.

Spending time 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 healthcare team. While many of us prefer to keep our feelings private, it is important to have a few people with whom you can share how grief is affecting you. Bereavement resources and support groups are available. Some of these are listed at the end of this guide.

Practical Considerations

The paperwork associated with a 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 can provide copies of the death certificate; ask for at least five copies.

In addition to your lawyer, the [province of Ontario's website](https://www.ontario.ca/page/what-do-when-someone-dies) can help you with answers to common questions about what to do, and what support is available, when a person dies. You can visit the site at **www.ontario.ca/page/what-do-when-someone-dies**.

You may also need to:

- transfer the ownership of any vehicles
- cancel the person's health card after final billing is complete
- 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

Resources

Hopefully this guide 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 review the resources listed below. We wish you strength and peace as you journey through this difficult time.

[Advance Care Planning](#): Detailed information on planning for death.
Visit: advancecareplanning.ca

[Canadian Virtual Hospice](#): Information and support for palliative care, caregiving and loss and grief for patients, family members, and health professionals. It includes numerous links to helpful services including **[MyGrief.ca](#)** and an “Ask a Professional” service, which allows you to privately ask a palliative care health professional your own questions about death, dying and palliative care.

Visit: virtualhospice.ca

[Financial Consumer Agency of Canada](#): Preparing financially for your death or the death of a spouse or partner.

Visit: **www.canada.ca/en/financial-consumer-agency.html**

[Ontario Caregiver Organization](#): Supporting caregivers with its free direct-to-caregiver programs and services, including 1:1 and group peer support, caregiver coaching, educational resources, a 24/7 helpline and more. Visit: **www.ontariocaregiver.ca**

[Service Canada](#): Pensions, benefits and personal finances following a death. Visit: **www.servicecanada.gc.ca**; or you may wish to call 1-800-622-6232.

[SouthWesthealthline.ca: Bereavement Support – South West](#). Local bereavement programs that provide emotional support, problem-solving assistance, information, and guidance for people who have recently lost someone. Included are counselling programs and mutual support groups for widows and widowers, children who have lost a parent, parents who have lost a child, and other people who are grieving.

Visit: **www.southwesthealthline.ca/listServices.aspx?id=10162**

[Caregivershuronperth.ca](#): Caregiver Resources for Huron Perth area. Designed by a team of caregivers and healthcare providers across Huron and Perth counties to help caregivers find local services, programs and resources.

Visit: **www.caregivershuronperth.ca/Services/Caregivers**

[KidsGrief.ca](http://www.kidsgrief.ca): Helps parents support their children when someone in their life is dying or has died. Visit: **www.kidsgrief.ca**

[YouthGrief.ca](http://www.youthgrief.ca): Developed by grieving youth, for grieving youth. Sharing wisdom, experiences and advice from more than 30 young people who've been there, and know what it's like to grieve when someone you care about has died. Visit: **www.youthgrief.ca**

[CaringTogether.life](http://www.caringtogether.life): A free platform designed to educate, support and empower parents caring for a seriously ill child and those who are experiencing pregnancy or infant loss. Developed by families and pediatric healthcare providers. Visit: **www.caringtogether.life**

Resources used to create this guide include:

- Canadian Virtual Hospice
- MyGrief.ca
- *Preparing for Death and Dying: A Guide for People with Life-Limiting Illness, Their Families and Friends*. Nova Scotia Health Authority.
- *How Do I Know that Death is Near? & End-of-Life Care Behavioural Health Program*. Hamilton Health Sciences.
- *Information for Patients and Families When the End is Near*. Joseph Brant Hospital