

# Preparing for Death and Dying

**A Guide for People with Life-Limiting Illness,  
Their Families, and Their Friends**

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.

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978-1-55457-661-6, 2nd Edition

This booklet was developed in collaboration with Cancer Care Nova Scotia and other community partners. The Department of Health and Wellness would like to thank the patients, family members, and health professionals who contributed to this publication, the Colchester East Hants Hospice Society for granting permission to adapt their resource, “What to Expect at End of Life,” and the Nova Scotia Health Authority for permission to adapt their resource, “*Palliative Care Tissue, Body and Brain Donation.*”

# Table of Contents



<b>Important Phone Numbers .....</b>	<b>4</b>
<b>Introduction .....</b>	<b>5</b>
<b>What Is Palliative Care? .....</b>	<b>7</b>
<b>What Plans Do I Need to Make? .....</b>	<b>8</b>
Talking with Your Family and Care Team .....	8
What Is an Advance Care Plan? .....	10
Preparing a Personal Directive .....	11
What Is a Do Not Resuscitate Order? .....	13
Emergency Health Services	
Special Patient Program (EHS SPP).....	14
Your Financial Affairs .....	14
Your Emotional and Spiritual Needs .....	15
Tissue, Body, and Brain Donation .....	16
Tissue Donation.....	18
Cornea Donation.....	18
Body Donation .....	19
Brain Donation .....	20
Memorial or Funeral Plans .....	21
Burial .....	23
Cremation.....	23

<b>Helpful Services .....</b>	<b>24</b>
211 Nova Scotia.....	24
811 – Nova Scotia's Tele-care Service .....	24
Caregiver Benefit.....	25
Caregivers Nova Scotia .....	25
Compassionate Care Benefits.....	26
Equipment Needs.....	26
Financial Concerns .....	27
Health Charities and Non-Profit Organizations ...	27
HELP Community Bed Loan Program.....	28
Home Care.....	28
Hospice Societies .....	29
Palliative Home Drug Program .....	29
Services in Languages Other than English .....	30
<b>Changes to Expect Near Death.....</b>	<b>31</b>
Physical Changes .....	31
Breathing Patterns.....	32
Eating and Drinking .....	33
Gurgling in the Throat.....	34
Loss of Bowel or Bladder Control .....	34
Mouth Care.....	35
Nose Care.....	35
Eye Care .....	36
Pain.....	36
Restlessness and Agitation .....	37
Weakness and Sleepiness.....	38
Very Near the Time of Death .....	39
Emotional, Spiritual, and Mental Changes .....	40
Disorientation .....	40
Giving Permission .....	40
Spiritual Pain .....	41
Withdrawal.....	42
Visions .....	42
The Moment of Death.....	42

<b>Place of Death .....</b>	<b>43</b>
Death at Home .....	44
Death in a Nursing Home .....	44
Death in Hospital .....	45
<b>More Information for Caregivers .....</b>	<b>46</b>
Taking Care of Yourself .....	46
Say What You Need to Say .....	47
Children .....	47
Pets.....	48
Grief .....	49
Autopsy .....	53
Practical Considerations .....	53
<b>To Learn More .....</b>	<b>55</b>
<b>References.....</b>	<b>57</b>

# Important Phone Numbers

Family physician:

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Care team, daytime:

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Care team, after hours:

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Substitute/Delegate decision maker:

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Clergy or spiritual advisor:

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Funeral home:

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Lawyer:

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Executor:

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Bank:

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Other numbers:

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If you are part of the EHS Special Patient Program,  
patient ID#: \_\_\_\_\_

# Introduction



This booklet is for people living with an advanced illness, for their families and friends.

Preparing for your death or that of a family member or friend is difficult. This booklet is designed to help you prepare for death and dying. 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, and the questions you would like to ask your doctor, the other members of your care team, your lawyer, family, and friends. Your care team is here to help you. So be sure that you ask about anything that is on your mind.

In this booklet we use the term “caregiver” to refer to family members, friends, or neighbours who care for or help, in any way, a dying person.

We sometimes use the term “family member” to refer to the dying person. But we recognize that not all caregivers are caring for, or helping, their own dying family member. The dying person could be a friend, neighbour, or colleague.

We've chosen to use the terms "caregiver" and "family member" to avoid having to list the variety of people represented by these terms. Keep this in mind when you are reading the booklet.

This booklet has six parts:

- **"What Plans Do I Need to Make?"** describes some of the issues you need to discuss, the decisions to be made, and the plans you need to put in place.
- **"Helpful Services"** outlines a number of services that provide all types of support, from the practical to the emotional.
- **"Changes to Expect Near Death"** reviews the common physical, emotional, mental, and spiritual changes that occur near death. This information may be difficult to read. But many people feel that knowing what to expect helps to prepare them to care for, or just be with, a dying person.
- **"Place of Death"** has information about the things caregivers may need to do, depending on where a death occurs.
- **"More Information for Caregivers"** includes helpful suggestions to prepare for a family member's death and to cope with grief.
- **"To Learn More"** lists websites and telephone numbers that may be helpful.

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*"As a patient, I would need to know this information. If there is something in the booklet people aren't ready to read, they can skip over it."*

– Family caregiver

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# What is Palliative Care?



Palliative care is a type of care that enhances the quality of life of people with a life-limiting illness by preventing and relieving suffering. In addition to helping the patient, palliative care helps a family cope during a family member's illness and death, and during the grief process.

Palliative care is an approach that is helpful early in an illness, not only near death. This type of care provides relief from pain and other symptoms. It includes emotional and spiritual care.

End-of-life care is an important part of palliative care.

It is important to know that palliative care neither hurries nor delays death. Rather, it helps people live as actively as possible until their death.

# What Plans Do I Need to Make?



Many people can help you prepare for death. Your family, friends, clergy or spiritual care provider, lawyer, and care team can support you as you make your plans. Remember, you are not alone. Many people will be willing to help you.

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“By thinking ahead about what could happen—and about how you will deal with problems if they do happen, you can create a better life and a better quality of life for yourself and for the people who love and care about you.”

— Roger C. Bone, an American doctor who wrote extensively about his own experience with terminal cancer

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## Talking with Your Family and Care Team

Your care team is whoever you consider to be important supports in managing your care. The team can be different for each person and can depend on your wishes and needs. It can include your family doctor, nurse, social worker, spiritual advisor, palliative care specialists, family and friends.

It is important to talk with your family and care team about your care wishes when you are dying. Having a

plan will help reduce your worries and your family's worries. A plan will also help your family and care team do their best to respect your wishes. Together, you can talk about and decide where you would prefer to die and what care to have available now and when the time of death is near.

Tell your family and friends the things you want to say. Hug, touch, laugh and cry—all of these things are important to you and your family and friends.

If you want to die at home, it is important to talk with your family, family doctor, and care team to make sure the right supports and plans are in place. For example, a funeral home will need a death certificate to transport your body. If the right plans are in place, your family can call the funeral home directly. The funeral home will call your doctor to complete the death certificate and will arrange the transport of your body. If these plans are not in place before your death, an ambulance may need to come, and this may be distressing for your family.

If you choose to die at home and then change your mind, you can be admitted to a hospital. You need to let your family and doctor know if you want to go to the hospital, so that they can put the right plans in place.

If you choose to die in the hospital and then change your mind, you may be able to return home if the right supports can be arranged. Talk to your family and doctor about the supports and plans that need to be in place for you to return home.

You will need to choose a funeral home. There are differences in the prices of services offered by funeral

homes. The staff from the funeral home will need to meet with you to make arrangements, determine costs, and help you with the paperwork.

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“Be aware that everyone will react differently to your news, just as each terminally ill person reacts differently to his or her own illness. Many will be shocked. Many will cry. Some will refuse to believe it. Some will spring into helpful action.... Many will not know how to respond.”

– Dr. Alan D. Wolfelt, author and grief counselor

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## What Is Advance Care Planning?

Advance Care Planning is a process you can use to

- think about what is important to you concerning healthcare choices
- explore related medical information
- communicate your wishes and values to your family, delegate (substitute decision maker), and healthcare team
- set goals of care
- record your healthcare choices and decisions, in the event you can no longer speak for yourself

For more information about Advance Care Planning, talk to your care team and/or visit [www.advancecareplanning.ca](http://www.advancecareplanning.ca). You may also request a workbook for Advance Care Planning called *Speak Up Nova Scotia*, by calling the Nova Scotia Hospice Palliative Care Association at: 1-902-818-9139.

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“Mom made some plans well in advance of her passing, about a DNR and not having life support. She didn't want us to have to make those decisions.”

– Family caregiver

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## Preparing a Personal Directive

Preparing a personal directive is part of advance care planning. A personal directive allows you to say how health and personal care decisions are to be made for you if you become incapable of making decisions. A personal directive also helps others who will need to make decisions for you. A personal directive only comes into effect if you become mentally or physically incapable of speaking for yourself. If your condition improves so that you can speak for yourself, a personal directive can be withdrawn.

A personal directive is a legal document that allows you to

- name a person you trust (called a delegate) to make health and personal care decisions for you (Your delegate does not need to be a member of your family.)
- write down the decisions that you wish to be made for you

A personal directive includes decisions about

- healthcare, nutrition, and hydration
- where you would like to live and die
- comfort measures and support services

Your personal directive needs to be written, dated, signed by you, and witnessed by an adult. You do not need a lawyer to write a personal directive.

It is important for your family and doctor to know that you have prepared a personal directive. Let them know where you keep your personal directive.

A personal directive does not include financial decisions. To name a person to make financial decisions, you will need to set up an Enduring Power of Attorney document (see page 14).

To learn more about personal directives, read the information on the Department of Justice website: [novascotia.ca/just/pda](http://novascotia.ca/just/pda). On this site you will find links to

- frequently asked questions
- an information booklet
- a brochure about planning for your future
- a brochure about making personal care decisions for a family member
- instructions for creating a personal directive, with a sample form (shows you how to create a personal directive, includes a form you may use, and highlights choices to consider)
- instructions for creating a personal directive, with a sample form, naming a delegate only (shows you how

to fill out a personal directive, when the only thing you want to do is name a person to make decisions for you)

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“Be your own counsel. No one, including your physician, religious counselor, spouse, or friends can understand 100% what you want and need... we can, and should, ask for advice...but ultimately, we should decide.

– Roger C. Bone, an American doctor who wrote extensively about his own experience with terminal cancer

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## What Is a Do Not Resuscitate Order?

A Do Not Resuscitate Order (DNR) is a statement of your preferences, signed by you, your delegate, or a physician, that directs health professionals not to attempt CPR (cardiopulmonary resuscitation) if your heart stops beating and you stop breathing. A DNR is sometimes called “Do Not Attempt Resuscitation” (DNAR) or “Allow Natural Death” (AND).

By having a DNR in place, you will avoid traumatic resuscitation efforts that have little hope for a successful outcome for palliative patients.

It is important to know that when a DNR is in place all other medical care will continue until the time of your death, and you can still call 911 in emergencies.

Your doctor or care team can help you understand more about how to prepare a DNR.

## Emergency Health Services Special Patient Program (EHS SPP)

If your end-of-life care will be at home, you may want to talk to your care team about registering with the EHS SPP. This program allows paramedics to help manage some of your symptoms at home, instead of taking you to the hospital by ambulance. A health care provider will need to enroll you in this program.

Talk to your care team or visit <http://novascotia.ca/dhw/ehs/public.asp>.

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“It was a huge relief to know that the paramedics could help us at home.”

– Family caregiver

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## Your Financial Affairs

It is important to make sure your affairs are in order. Preparing a will and organizing your finances will help your family take care of your estate. If you own your home, talk with your lawyer about the benefits of adding a family member’s name to the deed. Your estate includes pension benefits, insurance policies, and any other income you may have.

It is important to ask someone to act for you in case you become unable to speak or make decisions about your property and finances. This is called giving them



enduring power of attorney. An enduring power of attorney is a special power of attorney document. It states that the authority of the person named to act on your behalf continues, even if you become mentally or physically incompetent.

A will is the only way that you can be sure that you, rather than a court, make decisions about your estate. A will also names the person who will look after your estate. This person is called your executor. If you already have a will, make sure it is up to date. Once your will is ready, it should be put in a secure place. Be sure your executor knows where your will is stored.

For more information, talk with your lawyer, and call the Public Legal Education Society, toll-free at 1-800-665-9779, or visit <http://www.legalinfo.org/>.

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"I helped Mom do her will a couple weeks before she passed away. It gave her comfort knowing it was done.

– Family caregiver

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## Your Emotional and Spiritual Needs

Each person has unique emotional and spiritual needs. Your needs will depend on things like your life history, your support system, and your spiritual and religious beliefs. Your care team will try to help you find the emotional and spiritual support that is right for you.

Think about these questions:

- Would you like to have any rituals performed before or after you die?
- Would you like to have particular objects with you or near you before or after you die?
- Would you like to see or speak with particular family members, friends, or spiritual leaders?
- Would you prefer that certain people not visit you now or near your death?
- Would you like to have clergy or a spiritual advisor at your bedside?

Write down your wishes and discuss them with your family members.

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“Tapping into your spirituality is about becoming more authentically connected to yourself, to God... to whatever gives you the deepest meaning in life. In that respect, everyone is spiritual.”

– Rev. David Maginley,  
Chaplain, QEII Health Sciences Centre

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## Tissue, Body, and Brain Donation

Donating your tissue, body, or brain is a wonderful way to leave a legacy. If you are interested in being a donor you will need to sign your donor card. Your signed Nova Scotia Health card, with the word “Donor” on the front,

gives your legal consent for donation. Because your family must also give consent at the time of your death, be sure to make your wishes known to them now.

In addition to the consent on your health card, you or your family will need to complete the intake forms for the program you want to donate to.

Some palliative patients want to know specifically about **organ** donation. It is very unlikely that a palliative care patient would be eligible for this form of donation. To be an organ donor, a patient must be in an Intensive Care Unit because of a brain injury, and hooked up to a breathing machine (called a ventilator).

You can make things easier for your family by talking about tissue, body, and brain donation now. When your family knows and respects your wish to be a donor, they will feel at ease carrying out your wishes. Indeed, many families find comfort in knowing their family member's final wishes were honoured. And, at a time of sadness, could take comfort in knowing that your donation may help others.

Annually, donation programs host a Gift of Life ceremony to honour donors. The donation program invites families of donors to the Gift of Life ceremony.

To get an MSI Health Card Renewal Form, which contains a section on organ and tissue donation consent, call 1-800-563-8880, or visit <http://novascotia.ca/DHW/msi/docs/MSI-Health-Card-Renewal-Form.pdf>.

## **Tissue Donation**

Palliative patients may be tissue donors. Many tissues can be donated, including corneas, skin, sclera, bones, tendons and ligaments, and heart valves.

Adults under the age of 71 can be possible tissue donors. Screening of tissue donors happens just after death, because there are some conditions that prevent donation.

Open casket funerals are possible after tissue donation. All efforts are made so that there are no visible signs that donation has occurred.

## **Cornea Donation**

The cornea is the clear, round “window” of tissue that lets light enter the front of the eye. It looks like a contact lens.

Many palliative patients are able to donate their corneas, and everyone under age of 71 is a possible donor. Many can take comfort in knowing that they are giving the gift of sight.

If in a nursing home or hospital, make sure the staff members know that you want to donate your tissue or corneas. They will help your family make the proper arrangements.

The following guidelines help families with cornea donation in the case of a home death:

- Corneas may be accepted up to 16 hours after death.
- After you have taken time to say goodbye to the deceased, call locating at the QEII Health Sciences Centre: (902) 473-2220. Ask for an on-call Tissue Bank Specialist.
- Tell the tissue bank specialist the time that death occurred.
- The tissue bank specialist will arrange the transport of your family member for cornea recovery. They will tell you when to expect the transport services.
- After cornea recovery, the tissue bank specialist will arrange to have your family member transported to the funeral home of your choice.

For more information about tissue donation, including cornea donation, call the Regional Tissue Bank, 1-800-314-6515, or visit [www.legacyoflife.ns.ca](http://www.legacyoflife.ns.ca).

## **Body Donation**

This form of donation, operated under the Dalhousie University Human Body Donation Program, helps health-profession students build the knowledge they need for their future careers. The program also supports research.

Start your decision-making process by talking with your family. It is important that they support your decision.

There is no maximum age restriction for the acceptance of body donation to medical science. All donors must be 16 years of age or older.

You and your next of kin will need to complete a Donation Form and a Cremation Form (available at the web address below).

It is important to understand that some donations are not accepted. The final decision is made at the time of death. Family members need to be prepared to make burial or cremation arrangements if your body cannot be donated.

For more information about the Human Body Donation Program, call (902) 494-6850, or visit [www.dal.ca/bodydonation](http://www.dal.ca/bodydonation).

## **Brain Donation**

The Maritime Brain Tissue Bank is a program of the Dalhousie University Faculty of Medicine. The program collects brain tissues for dementia research.

There is no age restriction to donate to the Maritime Brain Tissue Bank.

Brain donors must have an autopsy after death. An autopsy is a medical procedure and takes place at the hospital.

To donate to the Maritime Brain Tissue Bank:

- Before or after death, the donor's next of kin must ask the doctor for an autopsy of the deceased and sign the Consent for Autopsy form.
- The donor's next of kin must add a note on the Consent for Autopsy form indicating the wish to donate to the Maritime Brain Tissue Bank.
- The signed consent form is placed in the patient's chart.

For more information about the Maritime Brain Tissue Bank, call (902) 494-4130, or visit [braintissuebank.dal.ca](http://braintissuebank.dal.ca).

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“The gift that has been given to me says much about our capacity for great compassion and generosity.

– Tissue donation recipient

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## Memorial or Funeral Plans

Memorials and funerals mark the significance of the life that was lived. They honour and remember the person who has died. They help family and friends express their grief and find meaning and purpose in their lives, even in the face of loss.

Traditionally, funerals happen with the body or the ashes of the deceased person present. Memorial services are ceremonies without the presence of the body. Funerals are usually held within days following death; memorial services may take place weeks or months after a death.

Memorials and funerals can bring people who care about one another together in an environment of love and support. They help family and friends to begin to accept the reality that someone important in their life has died. They allow us to say goodbye to the person who has died.

It may be easier for you and your family members to make memorial or funeral plans together. It is helpful to attach a copy of these plans to your will.

You may also want to write or talk about some personal or family history that may help with preparing a service or writing an obituary.

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“Dad very much wanted to go to the funeral home and make his own arrangements.”

– Family caregiver

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Here are some of the questions you may want to think about:

- Do you want a service?
- What type of service do you want?
- Where would you like the service to be held?
- Who would you like to lead the service?
- Are there family members or friends you would like to read, sing, or play an instrument?
- Do you want there to be a visitation?
- Do you want a burial or cremation?
- If you want to be cremated, do you want your ashes buried, scattered, or kept in a special place?
- Do you want an obituary?
- Is there a special reading, prayer, or piece of music you would like?
- Do you want the funeral home to webcast your funeral so that family and friends unable to attend may participate?



## **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**

You must use a funeral home to have a cremation. You can use any kind of container (such as an urn) to hold the ashes. Often people choose a container with a special quality or meaning. Sometimes people like to have a large urn so that, in the future, another person's remains may be placed in it.

You can choose to have your ashes buried. One burial plot can hold three urns.

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 you choose to be cremated, there is no rush to hold a funeral.

# Helpful Services



## **211 Nova Scotia**

It can be challenging to navigate the wide range of community and social services provided by government and non-profit organizations.

211 allows you to easily access over 4,000 community and social services.

By dialing 211 or visiting the Nova Scotia 211 website (<http://ns.211.ca>), you can easily and quickly connect to the social, health, and community services you need, anywhere in the province.

211 is available 24 hours a day, weekdays and weekends.

211 is available in English and French and for the hearing impaired. There are also interpretation services available in over 100 languages.

## **811 – Nova Scotia's Tele-care Service**

811 is Nova Scotia's non-emergency health line, staffed by Registered Nurses.

811 nurses can answer your health-related questions, advise you if you need to see your doctor or go to the Emergency Department, and provide information about services in your area.

811 is available 24 hours a day, weekdays and weekends.

811 provides services in over 125 different languages.

## Caregiver Benefit

This program, run by Continuing Care Nova Scotia, helps low income people who need a lot of care, with a Caregiver Benefit of \$400 a month. To qualify, both the caregiver and the person to receive care will need a home-care assessment. For more information, call Continuing Care, 1-800-225-7225, or visit <http://novascotia.ca/dhw/ccs/caregiver-benefit.asp>.

## Caregivers Nova Scotia

This non-profit group helps people who are caring for family members or friends. The group offers many different kinds of caregiver support, including workshops, phone, and group support. Call toll-free, 1-877-488-7390, or visit <http://caregiversns.org/> to learn more about these services.

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"You can feel really isolated when you are a caregiver, [and] it was helpful for me to have a support service to call."

– Family caregiver

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## Compassionate Care Benefits

This program is part of Employment Insurance. It supports a maximum of twenty six weeks of paid leave from work for people who are caring for a family member who is likely to die within six months. The benefit can be shared amongst family members. After you apply, there is a two-week waiting period before the payments start. The program has a broad view of the term “family member,” which applies to

- a member of the family by blood, marriage, or adoption
- a spouse’s or common-law partner’s family members
- a person who is “like” family, such as a close friend or neighbour

To see if you are eligible or to apply, consult Service Canada’s Employment Insurance Compassionate Care Benefits page ([http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml)), or call 1-800-622-6232.

## Equipment Needs

If you are being cared for at home, you may need some medical equipment to help you feel comfortable. Many people find it helpful to have a higher toilet seat, a bath chair, and a hospital bed. Ask your care team about the equipment that may be most helpful for you and your caregivers, and about where to get what you need.

## Financial Concerns

Being diagnosed with a life-limiting illness can impact your financial situation. If you are concerned about finances, ask your care team about the supports that are available to help you with your expenses.

## Health Charities and Non-Profit Organizations

There are a number of health charities and non-profit groups that provide financial, practical, or emotional support services for patients with certain illnesses.

Examples include

- AIDS Coalition of Nova Scotia
- ALS Society of New Brunswick and Nova Scotia
- Alzheimer Society of Nova Scotia
- Canadian Cancer Society
- Canadian Diabetes Association
- Huntington Society of Canada

Call 211 to ask about organizations that may provide services that would be helpful to you.

## HELP Community Bed Loan Program

Hospital-style beds are available to people for use in their homes. There are no time limits for use of a bed, but there may be a wait to get one. To be eligible you must

- be a resident of Nova Scotia
- have a valid Nova Scotia Health card
- be assessed by a Care Coordinator
- agree to be responsible for the bed while it is in your home

To apply, call Continuing Care, 1-800-225-7225. For more information, visit [novascotia.ca/dhw/ccs/need-help.asp](http://novascotia.ca/dhw/ccs/need-help.asp).

## Home Care

Continuing Care Nova Scotia's Home Care Services can help with your care needs at home. Home Care can provide nursing services, pain and symptom management, physiotherapy, occupational therapy, home support services, respite care, caregiver support, and more. To learn more, call Continuing Care, 1-800-225-7225.

There are a number of private companies across Nova Scotia that offer home-care services. These services vary in price. Look in your phone book under "Home Health Care Services" or "Nurses." Ask your care team about options available in your community.

## Hospice Societies

Hospice societies are non-profit groups that support patients and families in many different ways. Some have volunteers who can support you at home or in the hospital. Others give support over the phone or will work with you to see what kind of support would be helpful.

Ask your care team about your local hospice society and how it may be of help to you.

## Palliative Home Drug Program

The cost of drugs can be difficult to manage for some people who receive end-of-life care at home. This Pharmacare program may be able to help pay for drugs you need to manage symptoms related to end-of-life care.

To access this program you must

- be a resident of Nova Scotia
- have a valid Nova Scotia Health card
- be assessed for eligibility by a palliative care nurse or palliative care doctor
- be receiving end-of-life care at home

Once you are approved for this program, an authorization form is sent to Nova Scotia Pharmacare. Your local pharmacy then bills the Department of Health and Wellness for your drugs.

Talk to your care team about this program or visit <http://novascotia.ca/dhw/pharmacare/palliative-drug-program.asp>.

## Services in Languages Other than English

If your first language is not English, or you are hearing impaired, ask your care team about free interpreter services.

While your family members may be able to translate for you, doing so may be stressful for them. Or your family may not be familiar with all of the medical terms used by the care team. Professional interpreters are familiar with medical terms and are comfortable working within healthcare settings.



# 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 the moment of 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 that people understand what is happening, the better they 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.

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"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

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**Caregivers:** 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, you may need to 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, Nova Scotia's 24-hour nursing line. Or, if the patient is part of the EHS Special Patient Program (see page 14), you can call 911, and you will be forwarded to EHS's ambulance dispatch. Paramedics will be dispatched and may be able to help manage symptoms at home. This service is available to all palliative patients, even if they are not in the Special Patient Program. However, enrolment 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 will be short periods when the dying person stops breathing. Closer to death, the time between breaths may get longer. It may seem to others like the dying person is gasping. At other times breathing becomes deeper, more rapid, or irregular. Oxygen will not help in any of these situations.

It is important to watch your own breathing patterns when you are caring for a dying person. Caregivers sometimes start to breathe in the same pattern as the dying person, but doing so can cause dizziness.

### **Eating and Drinking**

Near death, dying people 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 could cause discomfort.

**Caregivers, 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 has trouble breathing.

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. 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 several things: 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.

Caregivers can help the person by turning them on their side, with their head slightly raised. Caregivers should make sure that pillows are placed all along the person's back to support this position. Staying in this position will often stop the sounds.

Sometimes the doctor will order drugs to reduce secretions. Oxygen will not help with this problem. Suction machines are needed only in rare cases, but they may cause some distress.

## **Loss of Bowel or Bladder Control**

Dying people may lose control of their bladder and even 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 your doctor to insert a catheter. There may be some discomfort when the catheter is inserted, but there is usually no pain once it is in place.

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 circulation through the kidneys.

Caregivers should wear gloves when handling waste or soiled clothing. You can discuss proper disposal of soiled items with your care team.

## **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. Mouth care will help. There are helpful products at the pharmacy to wet the mouth and protect the lips.

**Caregivers:** 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 person will stop biting.

The mouth should be cared for at least every few hours. Your care 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 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 your pharmacy. Your nurse can show you how to use the eye drops.

## **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 drugs because of these changes.

Caregivers should not stop giving pain drugs to the dying person, even if they are not responding verbally. The person may still need their regular pain drugs.

If a dying person cannot swallow, the doctor may change the way the pain drugs are given. Caregivers may be asked to give pain drugs by mouth, by putting the medication against the lining of the mouth or under the tongue. Pain drugs are sometimes given by suppository. And sometimes they 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.

Some facial and body movements might be a sign of pain and that more pain medication is needed.

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

## **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 a drug.

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 favourite place the person enjoyed, or a favourite 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.

Drugs can be helpful in easing restlessness when other things do not work. The doctor may prescribe a drug that can be absorbed under the tongue or at the side of the mouth, or that can be given by injection. This drug will be a mild sedative that will quickly calm and soothe an agitated or restless person. At first, a person may need this drug every half-hour or hour, and it may take several doses before it helps.

Ask the care team if you have any questions about how to calm a dying person who is agitated.

## **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, over 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. (See page 28)

**Caregivers:** 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. 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.



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“There are humorous times, and people need to know it can be okay to laugh, even during a stressful time.”

– Family caregiver

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### **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 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.

Caregivers should keep the person warm with a blanket, but they should not use an electric blanket.

The person’s eyes may be open and not blinking at this time. The nurse does not need to take the person’s blood pressure and pulse, as doing so can be uncomfortable.

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.

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"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

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## **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 caregivers should clearly identify themselves by name before they speak.

Family, friends, and 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.

Some people prefer to die alone. 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.

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"When you feel you are ready, consider how you will say good-bye....your survivors will cherish forever your heartfelt good-byes."

– Dr. Alan D. Wolfelt, author and grief counselor

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## **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.

If you feel that spiritual support would be helpful, your care team can refer you to a religious or spiritual representative.

## **Withdrawal**

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, for 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.

**Caregivers:** 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, 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, or nursing home, practice varies as to whether or not a doctor will need to examine the patient to pronounce death. Ask your care team about their practice.

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

## Death at Home

When an expected death happens at home and plans are in place, there is no emergency. There is no need to call 911. If you want to die at home, it is important to talk with your family, family doctor, and care team to make sure the right supports and plans are in place.

The funeral home will need a death certificate to transport your body. If the right plans are in place, your family can call the funeral home when they are ready. They can take their time; they do not need to do this right away. They may want to call other members of the family at this time.

The funeral home will call your doctor to complete the death certificate and will arrange the transport of your body.

If these plans are not in place before your death, an ambulance may need to come, which may be distressing for your family and friends.

## Death in a Nursing Home

When you move to a nursing home it is important to let your family, family doctor, and care team know about the kind of care you would like when you are dying. Having a plan will help reduce your worries and your family's worries. A plan will also help your family and care team do their best to respect your wishes.

When a death occurs in a nursing home, and plans are in place, staff will call a doctor to complete the death certificate. The staff will support family to say their goodbyes.

If funeral plans are in place, family or staff will call the funeral home. If plans are not in place, family will need to choose a funeral home as soon as possible.

## **Death in Hospital**

When a death occurs in a hospital, and plans are in place, staff 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 or the hospital needs to call the funeral home. If plans have not been made, family will need to choose a funeral home as soon as possible.

Family may stay at the hospital until the funeral home staff come, as long as there is not an urgent need for the room.

Family should collect belongings and take them home.

# 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 this 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.

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“Guilt is perhaps the most painful companion of death.”

– Dr. Elisabeth Kübler-Ross, a psychiatrist and palliative care pioneer

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## 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 health 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: peace, relief, and 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

That your family member's death may be close gives both of you 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.

You may find it helpful to read: *When a Parent is Sick – Helping Parents Explain Serious Illness to Children*, written by Joan Hamilton. This book is available at all public libraries in Nova Scotia.

## **Pets**

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.

You may be so busy caring for your family member that you don't have enough time to care for their pet or yours.

Ask friends to help with pet care; check into local pet care services; or, if the pet is a dog, contact Elder Dog, <http://www.elderdog.ca>, 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.

## 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.

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“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

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**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 of reflection and to 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 as 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.

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“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

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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. Bereavement resources and support groups are available. If you would like more information about grief or think that a support group might be helpful, ask your care team how to contact a local group.

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 through a period of grief can take longer than you think it should. And, be patient with others—they generally mean well.

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“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

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## Autopsy

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

## 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, there are two offices that can help you:

- Service Canada: visit <http://www.servicecanada.gc.ca>, or call 1-800-622-6232
- Access Nova Scotia: visit [novascotia.ca/sns/access](http://novascotia.ca/sns/access), or call 1-800-670-4357

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; call Access Nova Scotia, 1-800-670-4357, or visit [novascotia.ca/sns/access](http://novascotia.ca/sns/access)
- cancel the person's health card; call Access Nova Scotia, 1-800-670-4357, or visit [novascotia.ca/sns/access](http://novascotia.ca/sns/access)
- 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

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

– Family caregiver

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# 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:

- **Access Nova Scotia:** visit <http://novascotia.ca/sns/pdf/ans-vstats-death-what-to-do-when-someone-passes-away-guide.pdf>, for the booklet called: What you have to do after someone has passed away: A guide to the organizations and affairs that should be dealt with following a death.
- **Advance Care Planning** ([advancecareplanning.ca](http://advancecareplanning.ca)) provides detailed information, or call the Nova Scotia Hospice Palliative Care Association, 1-902-818-9139.
- **Canadian Virtual Hospice** ([virtualhospice.ca](http://virtualhospice.ca)) provides a wide variety of information on and support for palliative care, caregiving, 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 health professional your own questions about death, dying, and palliative care.
- **Caregivers Nova Scotia** ([caregiversns.org](http://caregiversns.org)) provides information, support, and education for caregivers. Call (902) 421-7390, or toll-free at 1-877-488-7390.

- **Continuing Care Nova Scotia Home Care Services** can help with your care needs at home. Call 1-800-225-7225.
- **Financial Consumer Agency of Canada** (<http://www.fcac-acfc.gc.ca/Eng/forConsumers/lifeEvents/livingRetirement/Pages/preparin-planifie.aspx>) provides information about preparing financially for your death or the death of a spouse or partner.
- **The Legal Information Society of Nova Scotia** ([legalinfo.org](http://legalinfo.org); or call 902-455-3135) provides information about a wide array of legal matters, including wills and enduring power of attorney.
- **Nova Scotia Hospice Palliative Care Association** ([nshpca.ca](http://nshpca.ca); or call 902-818-9139) provides a wide variety of palliative care information and resources for patients, family members, volunteers, and health professionals.
- **Nova Scotia Department of Justice** ([novascotia.ca/just/pda](http://novascotia.ca/just/pda)) provides detailed information about setting up a personal directive. Or call the Legal Information Society of Nova Scotia, (902) 455-3135.
- **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.

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