

What You Need To Know **Practical Considerations**



Health PEI

One Island Health System

Provincial Integrated Palliative Care Program



Patient & Family Approved

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

**Talk to your care team about your
questions and concerns.**

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**The reverse side of this page
contains important information for
your proxy(ies).**

**Once filled out it can be removed
from this booklet and given to them
for safe keeping.**

Important Proxy Information for

Location of my Health Care Directive:

Location of my will:

Location of my power of attorney papers:

My Funeral Home is:

My Lawyer is:

My Church / Clergy:

Other:

Important Phone Numbers

Family Physician / Nurse Practitioner:

Care Team:

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

Proxy/Substitute Decision Maker:

Clergy or Spiritual Advisor:

Funeral Home:

Lawyer:

Executor:

Bank:

Palliative Care Registration #:

Other:

About This Guide



This practical guide explains what happens at the end of life. It gives information about issues such as choosing where to be looked after, sorting out unfinished business, getting financial help, who can help if you are being cared for at home.

It also includes information for your family and close friends who may be involved in your care, so it is useful for them to read this booklet as well.

You may want to make notes about things you need to do, decisions you need to make, and questions you would like to ask.

Your care team is here to help you. Please be sure to ask about anything that is on your mind.

This booklet has 3 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.
- **“To Learn More”** lists websites and telephone numbers that may be helpful.



“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

What is Palliative Care?

Palliative care is 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. There is evidence that suggests that individuals live better and even longer when they receive palliative care alongside their other health care.

Palliative care encompasses more than just end-of-life 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.

“Their focus was never about why he should have palliative care, it was always about how palliative care services could support him and, by extension, me too. Once we understood that their focus was more about finding comfort for him and less about focusing about his life-limiting illness, the impact was almost immediate.

It is a gift that everyone facing this challenge is deserving of.”

- Family caregiver



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.

“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



Talking with Your Family and Care Team

Your care team is whoever you consider to be important and supports you 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 an “Expected Death in the Home” notification before transporting your body. Your family doctor can fax the form in to the funeral home. If the right plans are in place, your family can call the funeral home directly. The funeral home will arrange the transport of your body, and will obtain the death certificate from your doctor. 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.



“Be aware that everyone will react differently to your news, 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**

What is Advance Care Planning?

Advance Care Planning is a process you can use to:

- think about what is important to you, your values, wishes and preferences concerning your health care.
- explore related medical information
- communicate your values and beliefs to your family, proxy or substitute decision maker, and care team.
- set goals of care
- record your health care choices and decisions, in the event you can no longer speak for yourself on your health care directive.

For more information about Advance Care Planning, talk to your care team and/or visit:

www.advancecareplanningpei.ca



“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

Preparing a Health Care Directive

Preparing a Health Care Directive is part of advance care planning. A Health Care 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 Health Care Directive also helps others who will need to make decisions for you. A Health Care 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 Health Care Directive can be withdrawn.

A Health Care Directive is a legal document that allows you to:

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

A Health Care Directive includes decisions about:

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

Your Health Care Directive needs to be written, dated, and signed by you. You do not need a lawyer to write a Health Care Directive.

It is important for your family and doctor to know that you have prepared a Health Care Directive. Let them know where you keep your Health Care Directive. If you have appointed a proxy, ensure they have a copy.

A Health Care Directive does not include financial decisions. To name a person to make financial decisions you will need to set up a Power of Attorney document.

To learn more about Health Care Directives, read the information on the website below:

www.healthpei.ca/advancecareplanning

On this site you will find links to:

- frequently asked questions
- an information booklet
- Advance Care Planning Workbook
- Health Care Directive form



“Be your own counsel. No one, including family, 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**

What are “Goals of Care”?

Goals of Care is communication between you, yourself and your physician, nurse practitioner or registered nurse and your Proxy(ies) / Substitute Decision Makers to establish a plan of care.

Your care team will work with you to decide which of the following Goals of Care best describe your wishes for your future health care.

R: Medical Care and Interventions, including resuscitation.

M: Medical Care and Interventions, excluding resuscitation.

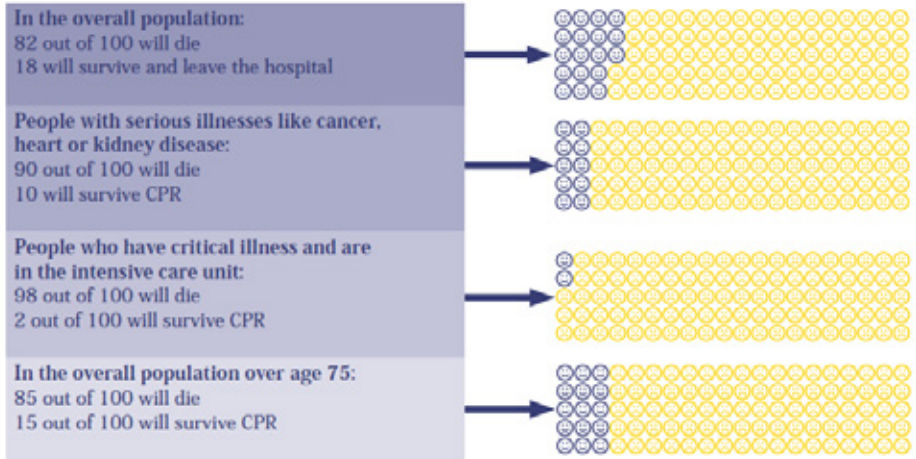
C: Care and Interventions focused on comfort, excluding resuscitation.

A Do Not Resuscitate Order (DNR) is a statement of your preferences, signed by you, your proxy, 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.

How well does CPR work?

How well CPR works depends on the health of the patient. Studies have shown the chance of success with CPR.



What is the chance of survivors going home from hospital?



About $\frac{1}{4}$ will go home independently.

Another $\frac{1}{4}$ will go home but require help at home.

About $\frac{1}{2}$ will need to live in an institution – like a nursing home or rehab centre

What is the chance that survivors will have thinking or communication difficulties?



About $\frac{1}{2}$ will have problems such as memory loss, problems with attention and problems getting things done.

Credit: Carenet

Many people fear that a DNR means that they will not have tests or receive treatment for certain conditions such as pneumonia. It is important to know that when a DNR is in place your preferences for other medical care will continue (e.g. IV antibiotics).

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

Paramedics Providing After Hours Care at Home

Paramedics are a part of our Provincial Integrated Palliative Care Program (PIPCP). When our Home Care offices are closed, paramedics can be called to help with pain and symptom management. This can allow you to stay home rather than being transported to the hospital. This program allows paramedics to help manage some of your symptoms at home, instead of taking you to the hospital by ambulance.

Once you are registered with the Provincial Integrated Palliative Care Program, a health care team will work with you to develop a care plan. Should a paramedic be called to your home after hours they will also follow the same care plan while helping you remain at home. If you are not registered in the program and would like more information please phone (902) 620-3045.

Talk to your care team or visit:

www.princeedwardisland.ca/en/information/health-pei/paramedics-providing-palliative-care-home-program

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

- Family caregiver



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 power of attorney (POA). A power of attorney is a special 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, or call Community Legal Information Association (CLIA) of Prince Edward Island: (www.cliapei.ca).



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

- Family caregiver

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 any particular objects with you or near you before 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 a clergy or a spiritual advisor at your bedside?

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

“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



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 make this decision. Your PEI health card has a spot in the back for a red sticker which implies your wishes to be a donor. 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 ventilator.

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

You can find information on the Health PEI website regarding organ donations.

www.princeedwardisland.ca/en/information/health-and-wellness/organ-and-tissue-donation

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 Substitute Decision Maker (SDM)/Proxy 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

<https://medicine.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 SDM must ask the doctor for an autopsy of the deceased and sign the Consent for Autopsy form.
- The donor's SDM 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 Human Body Donation Program, call 902-494-6950 or visit:

<https://medicine.dal.ca/departments/departments-sites/medical-neuroscience/about/donation-program.html>



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

- Tissue donation recipient

Memorial or Funeral Plans

Memorials and funerals mark the significance of the life that was lived. They honor 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 for your family to be aware of these plans.

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

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

- Family caregiver



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

- Do you want a funeral?
- What type of funeral do you want?
- Where would you like the funeral to be held?
- Who would you like to lead the funeral?
- 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?
- Would you like flowers, or is there something special you would like to wear?
- 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 your chosen funeral home for a written statement listing all costs before finalizing the purchase.

Cremation

A funeral home 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 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 also choose to have your ashes buried.

Some family members choose to keep the urn in their home. Others choose to share the ashes among family members. If you choose to be cremated, there is no rush to hold a funeral. There are some jewelry pieces that can hold ashes. Ask your funeral director.



Helpful Services

811 - PEI's Tele-Care Service

Just dial three numbers **8-1-1**, to access to non-emergency health information and services. Dial **7-1-1 (TTY)**, if you are hearing impaired.

A registered nurse is available, 24/7 to answer your health questions over the phone and to provide reassurance concerning all kinds of general health issues and questions.

Advice and information may include a recommendation to see your doctor or visit your local emergency department. You can also obtain information about health issues and programs/ services available in your community. Calling 811 provides service in over 125 different languages and dialects including for example: Arabic, Cantonese, Farsi, French and Mandarin Chinese.

Compassionate Care Benefits

This program is part of Employment Insurance. It supports a maximum of 26 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 until the day the person dies. 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 neighbor.

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) or call 1-800-622-6232.

Caregiver Benefits and Leave

Through Employment Insurance, you could receive financial assistance of up to 55% of your earnings, to a maximum of \$562 a week. These benefits will help you take time away from work to provide care or support to a critically ill or injured person or someone needing end-of-life care.

As a caregiver, you don't have to be related to or live with the person you care for or support, but they must consider you to be like family.

<https://canada.ca/en/services/benefits/ei/caregiving.html>

CPP Disability - A taxable monthly payment that is available to people who have contributed to CPP and who are not able to work regularly because of a disability.

AccessAbility Supports (*Formerly Disability and Support Program*) - An Assessment will determine how AccessAbility Supports can help meet your individual needs.

Telephone: 1-877-569-0546

www.princeedwardisland.ca/accessability-supports

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:

- Red Cross PEI
- Hospice Association of PEI
- Canadian Cancer Society
- Alzheimer Society of PEI
- ALS Society of Prince Edward Island
- PEI Lung Association
- Heart and Stroke Foundation
- AIDS PEI

Home Care - Provincial Integrated Palliative Care Program

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 Home Care in your area.

There are a number of private companies across PEI 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.

Home Care Office Phone Numbers	Charlottetown	902-368-4790
	Summerside	902-888-8440
	O’Leary	902-859-8730
	Montague	902-838-0786
	Souris	902-687-7096

Hospice on PEI

Hospices on PEI are non-profit groups that support patients and families in many different ways. Hospice on PEI have volunteers who can support you at home or in the hospital and work with you to see what kind of support would be helpful. Hospice on PEI also provides bereavement support to families on PEI.

Ask your care team about your local Hospice on PEI and how it may be of help to you.

Hospices on PEI Office Phone Numbers			
Queens	902-368-4498	East Prince	902-438-4231
West Prince	902-786-3991	Southern Kings	902-838-2269
East Prince	902-438-4231	Eastern Kings	902-215-0286

Palliative Home Drug Program

The cost of drugs can be difficult to manage for some people who receive end-of-life care at home. If you are eligible, this program may be able to help pay for drugs needed to manage symptoms related to palliative and end-of-life care. There is a \$2.00 charge for each prescription.

Eligibility Criteria:

- meet certain physical criteria determined by the palliative nurse
- be a resident of PEI
- have a valid PEI health card
- have agreed to be part of the Provincial Integrated Palliative Care Program
- have agreed the focus of care will be palliative
- do not have a private drug plan
- do not reside in a government nursing home

Once you are approved for this program, an authorization form is sent to Palliative Home Care Drug Program. Your local pharmacy then directly bills Health PEI for the drugs that are covered by this program. Talk to your care team about this program.

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. In addition, 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 health care settings.

To Learn More

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



- Health PEI ACP (www.healthpei.ca/advancecareplanning) provides detailed information
- Canadian Virtual Hospice (virtualhospice.ca) provides a wide variety of information on and support for palliative care, care giving and loss and grief for patients, family members, and health professionals. It includes an “Ask a Professional” service, which allows you to privately ask a palliative care professional your own questions about death, dying, and palliative care.
- Hospice Associations on PEI
- Community Legal Information Association of PEI (www.cliapei.ca)
- Service Canada (www.servicecanada.gc.ca; or call 1-800-622-6232) provides a variety of information about dealing with pensions, benefits, and personal finances following a death.
- Provincial Integrated Palliative Care Centre
Phone: 902-368-4781
Email: palliativeadmin@ihis.org
- Access PEI
www.princeedwardisland.ca/en/information/transportation-infrastructure-and-energy/access-pej-locations



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Notes



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