

# Advance Care Planning Workbook

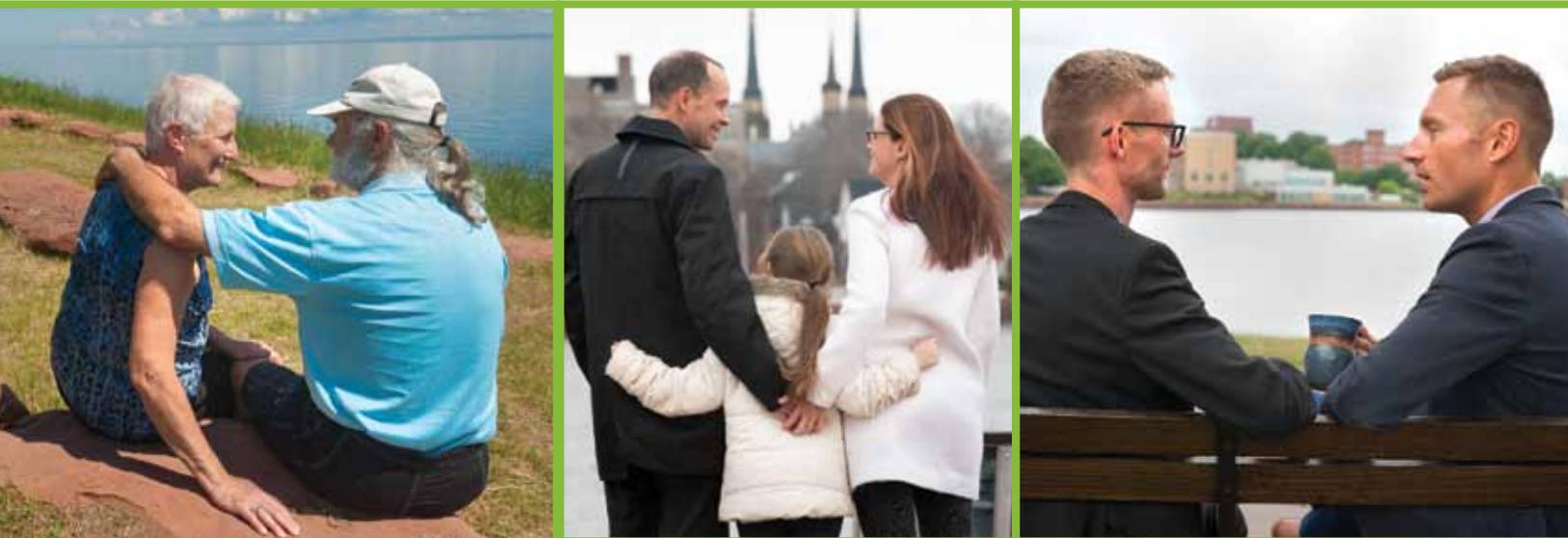
## Prince Edward Island Edition

It's about conversations.

It's about decisions.

It's how we care for each other.

It's about having a say in your health care.



**Health PEI**  
One Island Health System

**Speak Up**  
Start the conversation  
about end-of-life care

[www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning)  
[www.advancecareplanningpei.ca](http://www.advancecareplanningpei.ca) 

For more information about advance care planning, please visit Health PEI website at:

[www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning)

[www.advancecareplanningpei.ca](http://www.advancecareplanningpei.ca)

e-mail: [healthinput@gov.pe.ca](mailto:healthinput@gov.pe.ca)

or the Speak Up National website at:

[www.advancecareplanning.ca](http://www.advancecareplanning.ca)

e-mail: [info@advancecareplanning.ca](mailto:info@advancecareplanning.ca)

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Health PEI is the agency responsible for the provision of health services on Prince Edward Island and leads the Advance Care Planning process for the province. This agency, among other things, works to raise awareness of the importance of ACP for all Islanders and health care providers through education, public engagement and partnerships.

The information provided within this workbook is included as a public service and for general reference only. Every effort is made to ensure the accuracy of the information found here. However, this information is not considered legal, medical or financial advice and does not replace the specific medical, legal or financial advice that you may receive or the need for such advice. If you have questions about your health or about medical issues in general, speak with a health care professional. If you have questions about your or someone else's legal rights, speak with a lawyer or contact a community legal clinic.

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# Making an Advance Care Plan

Advance Care Planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes and to let others know your future health and personal care preferences in the event that a health care provider determines you are not capable to either make and/or communicate your own health care choices. This workbook provides an introduction to advance care planning and tips for having conversations with others about your wishes for future care should you not be able to speak for yourself. It also includes information about making a plan and provides you with a link to the **Health PEI Health Care Directive** form to document your wishes.

In Prince Edward Island, the *Consent to Treatment and Health Care Directives Act* sets out the law around how health care decisions are made on your behalf in the event you are incapable of making those decisions yourself. It describes how you can appoint a person(s) to make decisions for you (the legal term for this person is a “Proxy”) and how decisions regarding your care and treatment are made in the event you have not appointed a Proxy. Appointing a Proxy is done by way of a Health Care Directive, a legally binding document that expresses your wishes for your care and treatment, which can be prepared as part of your Advance Care Plan. The following pages explain the advance care planning process in Prince Edward Island and are intended to provide some information on relevant tools and resources. You can use the workbook to help get the conversation started with a family member or friend or to express your wishes about future care.

## Notes:

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Advance Care Planning means thinking about your values and wishes for future health care and treatment and sharing your wishes with others. The Advance Care Plan resulting from this process is a tool that will inform your family, friends or other trusted individuals about what is important to you and give them the confidence to make decisions for you in the event you are unable to make them yourself. It can include discussions with your health care providers to ensure that you have accurate medical information on which to make decisions or to express wishes about future care and treatment.

## You can use this workbook to get the conversation started.

You may never need your Advance Care Plan – but if you do, you will be glad that you have had these conversations. It is a way to make sure that your voice is heard when you cannot speak for yourself.

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# Why plan for future care?

## Life can take many twists and turns. Imagine:

*One day, without any warning, you find yourself in a hospital with a life-threatening illness or on account of an accident. You are unable to speak for yourself—you do not recognize your family or friends. Your doctors do not feel that you will leave the hospital. Do you want to be kept alive using machines? Does anyone know your wishes? Who will make decisions for you?*

*Your mother has slipped into a coma, and you and your siblings need to make some decisions about her medical care. Which one of you will make those decisions? How do you know if they are the right choices for your mother?*

*Your father is becoming increasingly frail as he ages. His condition seems to change every day, and he's been making regular trips to the hospital. What would happen if he couldn't make decisions for himself during the next hospital visit? Would you be able to make decisions for him based on his wishes? Would you know what to say?*

*You are at the beginning stages of Alzheimer's and you know that at some point you will not be able to recognize people or make your own decisions. How will you make your wishes known? Who will make decisions for you? How will your voice be heard?*

An Advance Care Plan is more than a document outlining your wishes for future care. It's the conversations that you have with family and friends, especially your Proxy (if you have named one in a legally binding Health Care Directive), or with family and friends who may be called upon to be your Substitute Decision-Maker (the person who will speak for you) if a Proxy has not been named in a Health Care Directive. It may also include preparing a written Advance Care Plan, creating a Health Care Directive, and may even involve talking with health care providers and financial and legal professionals.

Having these conversations and making a plan are ways to give your Proxy(ies)/Substitute Decision-Maker(s) the confidence to make decisions on your behalf. It is how we care for each other.

Advance Care Planning is a process, not just a document. Results of the process can include the preparation of a Health Care Directive that expresses your wishes for future care and treatment or names a Proxy(ies)or both.

Remember, this plan will only be used if you are not capable of speaking for yourself and you can change it at any time as long as you are mentally capable.

The choices you make at the end-of-life—for yourself and others—are important. Make sure that your voice is heard and respected. Think about what you would want and start the conversation with others about your end-of-life care and treatment.

# What is a Health Care Directive?

A Health Care Directive is a legally binding document in which you explain, in writing, your wishes about health care and treatment in case a health care provider has determined you are not capable to either make and/or communicate their own health care choices. Everyone is presumed to be capable of making a Health Care Directive. In your directive, you can appoint another person or persons, called a Proxy or Proxies, to make decisions relating to your health care and treatment for you when you are not capable to either make and/or communicate them yourself. A Proxy(ies) must be at least sixteen (16) years of age to consent to their appointment. A Health Care Directive needs to be in writing, and be dated and signed in order to be valid. A Health Care Directive never takes priority over a capable person's consent.

Your Health Care Directive may be very detailed about what care and treatment you want or don't want, or may be a general outline of your values, beliefs and wishes about care and treatment, without details. Your Health Care Directive must be taken into consideration by your Proxy(ies) or Substitute Decision-Maker(s) in the decisions to be made about your care and treatment when a health care provider has determined that you're not capable of doing this yourself.

**A Health Care Directive in Prince Edward Island may include some or all of the following:**

- your appointment of a person or persons as Proxy(ies) to make health care decisions for you when you are unable to make or communicate them yourself;
- what care, treatments, procedures and/or medications you want, don't want, or would like to have stopped;
- when you would like to die a natural death and receive only the care necessary to reduce pain and suffering;
- your statement that specifies an event or circumstances when your health care directive takes effect;
- any other instructions you have concerning your health care or treatment.

**Notes:**

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A health care provider must decide if you are capable of making your own health care decisions. If you are not capable of making your own health care decisions, your Proxy(ies) will be asked to speak on your behalf and the wishes expressed in your Health Care Directive will be taken into consideration provided they are consistent with the ethical standards of the health care provider responsible for your care and treatment. It helps to let others know that you have prepared a Health Care Directive—your family, friends, clergy, lawyer, doctor or other health care provider(s). You may want to discuss your decisions with them and provide them with a copy of your Health Care Directive, especially your Proxy(ies) (if you have named one in a legally binding Health Care Directive), or with family and friends who may be called upon to be your Substitute Decision-Maker (the person who will speak for you) if a Proxy(ies) has not been named in a Health Care Directive.

**Remember, your Health Care Directive will only be used if a health care provider has determined that you are not capable to either make and/or communicate your own health care choices. Remember, you can also change your wishes and your Proxy(ies) at any time.**

You may never need to use your Health Care Directive—but if you do, you'll be glad that you have engaged in Advance Care Planning conversations and that decisions regarding your care and treatment are being made with your values, beliefs and wishes in mind.



# Let's get started

## Making an advance care plan

Advance care planning is a process, not just a document. It's conversations that you have with close family and friends about your values and beliefs as well as the medical procedures that you want and don't want. It is also about the experiences and people that you want around you when you are ill or at the end-of-life. Thinking about and discussing your values and beliefs can make it easier to make health care and personal care decisions if and when necessary.

## There are 5 Steps to Advance Care Planning:



### STEP 1. THINK

What are your values and wishes about your care and treatment?



### STEP 2. LEARN

Learn about specific medical procedures and what they can and can't do.



### STEP 3. DECIDE

Prepare a Health Care Directive:

- (a) include your care and treatment wishes in the event you are unable to make or communicate care and treatment decisions on your own behalf;
- (b) appoint someone you trust who is willing and able to speak for you if you can't speak for yourself (as discussed, in PEI, there are special rules that need to be followed to officially appoint a Proxy(ies) – someone who can speak on your behalf).



### STEP 4. TALK

Talk about your wishes with your Proxy(ies), loved ones and your doctor.



### STEP 5. RECORD

It is a good idea to write down your care and treatment wishes if you have not already done so in a Health Care Directive or if the wishes you expressed in your Health Care Directive have changed.



# Step 1



## THINK

### What makes my life meaningful?

Begin by reflecting on your values, beliefs and understanding about end-of-life care or specific medical procedures, such as drug therapies, cardiopulmonary resuscitation (CPR) or dialysis. Think about any situations that you may have experienced with others and how it made you feel. You should also speak with your health care providers to ensure you have accurate information about your own health condition in order to express wishes about medical procedures that you may or may not want.

The following questions can help you think about your values and beliefs, and what you would like others to know. You can answer as many of the questions as you like, and your answers will become part of your plan summary when you complete your Workbook.

### Ask Yourself. What's important to me?

Here are some questions that can help you think a bit more about what interventions you would or would not want:

#### What makes my life meaningful?

(For example, is it important that I be able to: spend time with family and friends; be able to practice my faith; remain active; be able to still do my hobbies?)

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#### How important is it that I be comfortable and suffer as little as possible?

- Not at all important
- Not too important
- Somewhat important
- Very important

#### How important is it that I live as long as possible?

- Not at all important
- Not too important
- Somewhat important
- Very important

#### How important is it that I avoid being attached to machines and tubes?

- Not at all important
- Not too important
- Somewhat important
- Very important

## Step 1 - continued

**How important is it that I be allowed a natural death?**

- Not at all important
- Not too important
- Somewhat important
- Very important

**How important is it that I respect values of my family when making decisions about my care?**

- Not at all important
- Not too important
- Somewhat important
- Very important

**How important is it that others respect my wishes for care?**

- Not at all important
- Not too important
- Somewhat important
- Very important

**How important is it that I am involved in making decisions about my care?**

- Not at all important
- Not too important
- Somewhat important
- Very important

**What do I value most about my mental and physical health?**

*Choose any of these that are important to you – and add other comments if you wish.*

- Being able to live independently
- Being able to recognize others
- Being able to communicate with others
- Having my privacy
- Being able to still do my hobbies
- Keeping my dignity
- Having family and friends nearby
- Other \_\_\_\_\_

## Step 1 - continued

**What would make prolonging my life UNACCEPTABLE for me?**

*Choose any of these that are important to you – and add other comments if you wish.*

- Losing all or most of my mobility (ability to move with ease and without restriction)
- Having to rely on others for all or most of my care
- Being unable to communicate with others
- Being a burden to family members
- Losing my privacy
- Losing control of my bodily functions
- Being in pain
- Being in a coma most of the time
- Being kept alive with machines with no chance of survival
- Other \_\_\_\_\_

**Would I want all available measures used to prolong my life?**

- Yes
- No

**Are there certain measures I would NOT want taken to prolong my life?**

*See word list for specific terms and their definitions on page 22.*

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**If I were ill, what would be important for others to know?**

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**When I think about dying, are there things that I worry about happening?**

*Choose any of these and add other comments if you wish.*

- Being in pain
- Struggling to breathe
- Being alone
- Losing my privacy
- Losing my dignity
- Other \_\_\_\_\_

## Step 1 - continued

**Who can I talk to about these worries?**

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**If I were nearing death, what would I want to make things more peaceful for me?**

*Choose any of these that are important to you – and add other comments if you wish.*

- Family and friends nearby
- Be able to die at home
- Have spiritual or religious support
- Having specific music played
- Having specific photos
- Other \_\_\_\_\_

**Where would I prefer to die?**

- At home
- In the hospital
- In a palliative care setting
- Other \_\_\_\_\_

**What might change my mind about my choice of where I would prefer to die?**

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**Do I have any spiritual or religious beliefs that would affect my care at the end of life? If so, what are they?**

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**Other wishes and thoughts**

*Write down anything that would help others understand and support you at the end of life*

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## Step 2



### LEARN

#### Familiarize Yourself with Relevant Terms

Some individuals want to prolong life as long as possible using medical interventions, while others would not want to be hooked up to machines at the end of life if there is no chance of recovery. By learning more about medical terms and treatments, and legal requirements, you can make better decisions about your plan.

We've included a word list of advance care planning, medical and legal terms starting on page 22 to help you decide what is right for you.



# Step 3



## DECIDE

### Who will speak on your behalf?

Think carefully about whom you feel would understand, honour and follow your wishes, and would be most capable of making medical decisions on your behalf. This may be a spouse, an adult child, a trusted family member or a good friend. You should choose someone who knows you very well and who you can trust. They must be willing to respect your views and values and act on your wishes, not their own. And they should be able to make difficult decisions in stressful situations.

Before you choose someone, you need to understand what the law says about what you must do to appoint someone as your Proxy(ies). You also need to know what happens if you do not appoint someone to act for you through that legal process.

Legal requirements regarding the appointment of a Proxy(ies) vary across the country and from province to province. You need to follow the law that is applicable in the province or territory in which you live when you appoint someone to be your Proxy(ies).

What do you need to know about the law in Prince Edward Island regarding Advance Care Planning and Substitute Decision-Maker?

In Prince Edward Island, the *Consent to Treatment and Health Care Directives Act* provides a framework for choosing a person or person(s) to make decisions on your behalf, known as your Proxy(ies), and for completing a written document outlining your health and treatment wishes. This document is called a Health Care Directive (HCD). Your Health Care Directive may:

- Name your Proxy(ies).
- Provide written instructions about your wishes for your care and treatment.
- Do both of these things.

The Act also allows you to set out instructions or general principles about how your health and treatment care decisions will be made. It also explains how a Substitute Decision-Maker is identified and chosen, as well as his/her roles and responsibilities.

The following pages will explain how advance care planning is done in Prince Edward Island, according to the law. It will give you some points to consider when thinking about your wishes and identifying who might speak on your behalf if you cannot speak for yourself. You can find more information at [www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning).

In Prince Edward Island, your Proxy(ies) can be anyone you wish, a neighbour, friend, relative, etc. However, they must be over the age of 16. This person should know you well and needs to be willing and able to make complex decisions on your behalf and be able to be contacted. If you do not prepare a Health Care Directive that names your Proxy (ies), the law determines who will make decisions on your behalf in the event you are unable to make or communicate them on your own behalf. Here is how it works:

#### Proxy

If you appoint someone responsible for making health care and treatment decisions for you in your Health Care Directive, this person is known as your **Proxy**. The term Proxy is used in the *Consent to Treatment and Health Care Directives Act*. This person will make health care and treatment decisions on your behalf if you become incapable of doing so or are unable to communicate your decisions.

## Step 3 - continued

Your Proxy must take into consideration any instructions or wishes you may have written in your Health Care Directive, unless you notify him/her that your previously expressed wishes have changed since you wrote your directive. In this case, your Proxy must follow your latest wishes. Similarly, if medical or technological advances or new circumstances would have caused you to change your wishes, your Proxy must take this into consideration.

If you do not have any written instructions, your Proxy must make the decision he/she believes you would have wanted, based on what he/she knows about your values, beliefs and any other wishes. If your Proxy does not know what you would have wanted, he/she must act in your best interest.

You can name more than one Proxy in your Health Care Directive. Where more than one Proxy is named and the directive does not indicate whether the Proxies are to act jointly or successively, they shall act successively, in the order in which they appear in your Health Care Directive

### **Substitute Decision-Maker**

If you become incapable of making decisions for yourself, have not formally appointed a Proxy(ies) to make them for you, and do not have a written Health Care Directive in place, someone will be appointed to make decisions for you, in accordance with the Prince Edward Island *Consent to Treatment and Health Care Directives Act*. This person will be known as a Substitute Decision-Maker. The Act sets out a hierarchy of relatives that will be asked to make decisions for you. They must make decisions based on knowledge of your wishes, values and any verbal instructions expressed. If they do not know your wishes, they must base the decisions on your best interests.

The Prince Edward Island *Consent to Treatment and Health Care Directives Act* includes a hierarchical list of Substitute Decision-Maker(s). The person or people in your life who are the highest ranked in this hierarchy and who meet the related requirements will be your Substitute Decision-Maker(s) for health care decisions. The list is as follows, in descending order of priority:

- a) Your Proxy(ies) if you have a Health Care Directive
- b) Your Guardian: This is someone who is appointed by the court to be your Substitute Decision-Maker and who has the authority to give or refuse consent to treatment.
- c) Your Spouse. Two people are considered “spouses” if they are:
  - a) Married to each other; or
  - b) Living in a marriage-like relationship and,
    - i) have lived together for at least three (3) years, or
    - ii) are the natural or adoptive parents of a child together.
- d) Your Son or Daughter, or Parent, or a person who has assumed parental authority and who is lawfully entitled to give or refuse consent to treatment on your behalf.
- e) Your Brother or Sister (if you have more than one brother and one sister, they must make decisions together or jointly decide who will act as your Substitute Decision-Maker).
- f) A person whom the health care provider considers to be a trusted friend of yours, with a very good knowledge of your wishes.
- g) Any other Relative (someone you are related to by blood, marriage or adoption).

## Step 3 - continued

If there is more than one person in your life at any level of the hierarchy, and they are the highest ranking in the hierarchy, they must make decisions together or jointly decide who will act as your Substitute Decision-Maker.

If there is a conflict among people who are equally entitled to act as your Substitute Decision-Maker, and they all want to act but cannot agree on the decisions about treatment for you, the Public Trustee and Guardian may become involved.

### Requirements of a Substitute Decision-Maker

The person (or persons) in your life who is (are) highest ranking on that hierarchy would be entitled to act as a Substitute Decision-Maker for you only if they meet certain requirements. The requirements that person or persons must meet are that he or she must be:

1. 16 years of age unless he or she is the parent of the incapable person;
2. Mentally capable; and
3. Has knowledge of the incapable patient's circumstances and has been in recent contact with the patient.

*There is a sample Health Care Directive form provided at the end of this Workbook along with more detailed instructions regarding developing a Health Care Directive and appointing your Proxy(ies).*

**It is important to note that the Advance Care Plan is NOT a legally binding document. It is a tool to help you identify your values, wishes and preferences for future health care, which can be used to create a Health Care Directive.**

Completing this Workbook may lead you to want to make a legally binding Health Care Directive to ensure your wishes are known and are able to be respected should a health care provider determine that you are unable to make health care decisions for yourself.

### What if I change my mind?

Your personal circumstances change over time. As long as you are capable, you can change or cancel (revoke) your Advance Care Plan and/or Health Care Directive at any time.

Make sure you regularly review your Advance Care Plan, and your Health Care Directive, and make sure that your Proxy (if you still want him/her to be your Proxy) is still willing and able to make decisions for you if you are in a situation where you cannot speak for yourself. If you make any changes to your Health Care Directive, it is your responsibility to destroy your old copies, inform anyone you've given copies to that you have made changes, and provide them with copies of the updated Advance Care Plan and/or Health Care Directive, requesting that they also destroy any old copies in their possession.

Before changing or cancelling your Advance Care Plan be sure you have up-to-date knowledge about your current health condition and any new health care treatments available to you.

Remember that you can change your Health Care Directive at any time.

## Step 3 - continued

You should consider who will make medical decisions and speak for you if you become too sick and cannot speak for yourself. Think carefully about who would be willing and able to make these decisions for you. This person will be your Proxy. They may be your spouse, or an adult child, or even a good friend.

### **My Proxy is:**

I have discussed my wishes for future health care with the person named below:

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Telephone \_\_\_\_\_ Cell phone: \_\_\_\_\_

E-mail: \_\_\_\_\_

### **Do you have more than one Proxy/Substitute Decision-Maker?**

*Add their information here*

\_\_\_\_\_

\_\_\_\_\_

### **Health Care Directive**

If you want to specify one person to make health decisions for you, you must complete a Health Care Directive, in which you can appoint a person, called a Proxy, to make health care decisions for you when you can't communicate them yourself. Specifying a Proxy above is not a legally binding appointment.



# Step 4



## TALK

### Start the Conversation

It's time to talk to your Proxy, your family and your health care team. These conversations may not be easy – but they will help you and your loved ones know what's important to you.

There are many ways to get the conversation started! Remember, it may take a few attempts to get things started. Don't feel like you have to have the entire conversation at once.

#### Be straightforward.

"I have just filled out a workbook about my wishes for future health care and I want to share it with you."

"My health is good right now, but I want to talk to you about what I'd want if I was sick and needed you to make decisions for me."

#### Find an example from your everyday life.

"Pastor Jones was talking about our choices for health care if something happened, and I realized that I haven't told you about my wishes – we should talk about that."

"My doctor wants me to think about my future health care and to make an Advance Care Plan. Will you help me?"

#### Find an example from the news.

"Remember the man who was in a coma for years? I would never want that to happen to me."

"That story about the family fighting about their mom's care made me realize that we should talk about these things so the same thing doesn't happen to our family."

Do not forget to talk to others too, such as your doctor, other health care professionals involved in your care, your lawyer and other family members or friends. Share with those concerned, particularly your Proxy(ies), where you have stored important documents. Share the name and contact information of your Proxy(ies) with your doctor(s) or nurse practitioner.

You may also wish to share your wishes with your doctor or request that the information be noted in your medical record. This step is important because, if you become mentally incapable, your doctor will be better able to discuss your wishes about your care and treatment with your Proxy(ies).

Keep in mind that, even if your health care professionals document your wishes in your medical record, they cannot use this information to direct your care. Before providing any treatments, they are required to get an informed consent from you if you are mentally capable, or from your Proxy(ies) or Substitute Decision-Maker if you are not competent. They will only use your written information about your wishes if you are unable to communicate with them to ensure all health care decisions are consistent with your previously expressed wishes.

## Step 4 - continued

### Who do I want to talk to?

- Partner/Spouse
- Child/Children
- Mom/Dad
- Siblings or other relatives
- Caregiver
- Doctor
- Lawyer
- Friend
- Spiritual leader
- Other \_\_\_\_\_

### When is a good time to talk to them?

*Think about when you might approach your loved ones – for example, at a family gathering, over a meal, before my next big trip, etc.*

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### Where is a good place to talk?

*Think about where you might have the conversation – for example, at the kitchen table, at a restaurant, during a walk or drive, at the cottage, etc.*

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### What do I want to be sure to say?

*List the most important things you want to make sure you'll talk about during your conversations:*

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# Step 5



## RECORD

### Write Down Your Plan

This workbook has provided the opportunity for you to write down or record your wishes and your plan. This can make it easier for others to understand what's important to you, and to make decisions for you if you couldn't speak for yourself.

Once you've completed the workbook, don't forget to share it with others, especially your Proxy.

### My Other Planning Documents:

In addition to this Workbook, I have also completed the following documents: (check all that apply and note the location of each document):

- Health Care Directive.....Location: \_\_\_\_\_
- Power of Attorney (financial).....Location: \_\_\_\_\_
- Will.....Location: \_\_\_\_\_
- Financial Information.....Location: \_\_\_\_\_
- Insurance.....Location: \_\_\_\_\_
- Organ Donation registration/card...Location: \_\_\_\_\_

### Any other documents?

*Please document any other documents you might have and their location here.*

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### Other wishes and thoughts?

*Write down anything that would help others understand and support your future health care treatment plan or end-of-life care wishes.*

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### Questions you may have

#### What is Advance Care Planning?

Advance Care Planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health care preferences in the event that a health care provider determines you are not capable to make and/or communicate your own health care choices. Advance Care Planning means having discussions with family and friends, especially your Proxy (if you have named one in a legally binding Health Care Directive), or with family and friends who may be called upon to be your Substitute Decision-Maker (the person who will speak for you) if a Proxy has not been named in a Health Care Directive. It may also include preparing a written Advance Care Plan, creating a Health Care Directive, and may even involve talking with health care providers and financial and legal professionals.

## Step 5 - continued

### **Why do I have to write it down – my family will know what to do?**

Writing it down helps make sure your wishes are clear for everyone. You may believe that they know you well enough that they will know what to do; but perhaps they don't. Maybe your values and beliefs have changed over time and are no longer consistent with the wishes I expressed in the past. Completing the Advance Care Plan Workbook helps identify your wishes and beliefs, as well as what you would consider acceptable with regard to your overall condition and treatment options.

You can use what you have written in this workbook as a guide for the conversations you will have with your family, Proxy(ies) and health care providers. For example, you may have said something like: "Pull the plug if a machine is all that's keeping me alive"; but you need to be clear about what that really means to you. Your family may also have questions about the choices that you've made.

### **What is the difference between an advance care plan and a health care directive?**

An Advance Care Plan is a record of your health care preferences that is made while you are capable of providing consent to health care treatment. An Advance Care Plan does not provide authority for any treatment, nor does it authorize anyone to act as your Proxy. A Health Care Directive is a legal instrument that is made while you are capable of providing consent to health care treatment. In your Health Care Directive, you can appoint a Proxy and specify medical procedures for which you provide consent or refuse consent. A Health Care Directive comes into effect when you lose capacity to provide consent to health care treatment.

### **Will my wishes be followed?**

The wishes expressed in a legally binding Health Care Directive must be followed, provided they are legal, realistically possible, and are consistent with the ethical standards of the health care provider responsible for your care and treatment. You can't direct anyone to do anything illegal or unethical.

The wishes expressed in an Advance Care Plan are not legally binding. The information contained in your Advance Care Plan may be useful to you in creating your Health Care Directive, or serve to guide individuals called upon to make decisions about your care and treatment (your Proxy—if you have named one in your Health Care Directive) or Substitute Decision-Maker—if a Proxy has not been appointed, or is not able or willing to act on your behalf).

### **What is a Health Care Directive?**

A Health Care Directive is a legally binding document in which you explain, in writing, your wishes about health care and treatment in case a health care provider has determined you are not capable to either make and/or communicate their own health care choices. In your directive, you can appoint another person, called a Proxy, to make health care decisions for you when you are not capable to either make and/or communicate them yourself. Everyone is presumed to be capable of making a health care directive, although a Proxy must be at least 16 years of age to accept a Proxy appointment.

A Health Care Directive needs to be in writing, and be dated and signed in order to be valid. A Health Care Directive never takes priority over a capable person's consent.

Your Health Care Directive may be very detailed about what treatments you want or don't want, or may be a general outline of your values, beliefs and wishes, without details. Your directive will guide your Proxy or Subsequent Decision-Makers in the decisions to be made about your treatment when a health care provider has determined that you're not capable of doing this yourself.

## Step 5 - continued

### What does Health Care Directive include?

A Health Care Directive is a record of your current wishes. In any directive, you may include some or all of the following:

- your appointment of another person or persons as Proxy to make health care decisions for you when you cannot make or communicate them yourself;
- what treatments, procedures, or medications you want, don't want, or would like to have stopped; when you would like to die a natural death and receive only the care necessary to reduce pain and suffering;
- your statement that specifies an event or circumstances when your Health Care Directive takes effect;
- any other instructions you have concerning your health care or treatment.

You do not have to include all of these areas. You can use the directive to name a Proxy only. You don't have to outline details of your wishes about treatment.

Your directive may be very detailed about what treatments you want or don't want. Your directive may be a general outline of your beliefs and wishes, without details. Your directive will guide your Proxy and others in the decisions to be made about your treatment when you're not capable of doing this yourself.

Remember that you can change your Health Care Directive at any time. If you make any changes to your Health Care Directive, it is your responsibility to destroy your old copies, inform anyone you've given copies to that you have made changes, and provide them with copies of the updated document, requesting that they also destroy any old copies.

### I already have a Health Care Directive – isn't that good enough?

Having an Advance Care Plan in addition to a Health Care Directive, can aid in having conversations about your values, beliefs and wishes with key individuals and loved ones. It will help those called upon to make the best decisions for you when you can't make decisions or speak for yourself.

### What if I don't have a Proxy(ies) or my Proxy(ies) is/are not able or willing to make decisions for me?

If you don't have a Proxy(ies) or your Proxy(ies) is/are not able or willing to make decisions for you, a Substitute Decision-Maker will be appointed in accordance with the provisions of the *Consent to Treatment and Health Care Directives Act*. The following is a list, in order of priority, of individuals who would qualify to be your Substitute Decision-Maker as specified in the *Consent to Treatment and Health Care Directives Act*:

- Your Proxy(s) if you have a Health Care Directive
- Your Guardian: This is someone who is appointed by the court to be your Substitute Decision-Maker and who has the authority to give or refuse consent to treatment.
- Your Spouse. Two people are considered "spouses" if they are:
  - a) Married to each other; or
  - b) Living in a marriage-like relationship and,
    - i) have lived together for at least three (3) years, or
    - ii) are the natural or adoptive parents of a child together.
- Your Son or Daughter, or Parent, or a person who has assumed parental authority and who is lawfully entitled to give or refuse consent to treatment on your behalf.
- Your Brother or Sister (if you have more than one brother and one sister, they must make decisions together or jointly decide who will act as your Substitute Decision-Maker).
- A person whom the health care provider considers to be a trusted friend of yours, with a very good knowledge of your wishes.
- Any other Relative (someone you are related to by blood, marriage or adoption).

## Step 5 - continued

### **Do I need a Health Care Directive as part of my advance care plan?**

No. However, it is recommended you make a Health Care Directive so that your health care providers, Proxy or other individual called upon to be your Substitute Decision-Maker will know your preferences for consenting to, or refusing treatment or care.

However, you may wish to have a Health Care Directive to appoint someone to act as your Proxy to make health care decisions on your behalf in the event that a health care provider determines that you are not capable of providing or refusing your consent for health care treatment. You can also use a Health Care Directive to direct your Proxy with respect to the types of treatment that you would consent or refuse to consent to, and in what circumstances.

### **What does capable mean?**

A person is capable (has capacity) with respect to treatment if a person is, in the health care provider's opinion, able:

- to understand the information that is relevant to making a decision concerning the treatment;
- to understand the information that applies to his or her particular situation;
- to understand that the person has a right to make a decision; and
- to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

Capable means that you are able to understand the information relevant to making a decision about treatment and to appreciate the consequences of that decision. Capacity can fluctuate—you may be not capable at one time and capable at another; or not capable of making some treatment decisions yet capable of other treatment decisions.

It might be helpful for you to speak with someone you trust, such as family, friends or primary health care provider, etc. Completing the Advance Care Plan Workbook may assist you in determining your values, beliefs and wishes that you may want to include in your formal Health Care Directive. You may want to enlist the assistance of the person you will list as your Proxy in your Health Care Directive so that they will have a better understanding of your values and beliefs.

### **What if I change my mind?**

Life changes, and so may your wishes for your future health care and treatment. Make sure you regularly review your Advance Care Plan and your Health Care Directive, and make sure that your Proxy (if you still want him/her to be your Proxy) is still willing and able to make decisions for you if you cannot speak for yourself. If you make any changes to your Health Care Directive, it is your responsibility to destroy your old copies, inform anyone you've given copies to that you have made changes, and provide them with copies of the updated Advance Care Plan and/or Health Care Directive, requesting that they also destroy any old copies in their possession.

### **These type of documents are only for old people or people who are sick, right?**

No. You can't predict how and when you may become incapable of making health care decisions for yourself, either due to illness or as the result of an accident. You should discuss and take part in Advance Care Planning. Having an Advance Care Plan and Health Care Directive, and having conversations about your values, beliefs and wishes with key individuals will help those called upon to make the best decisions for you when you can't make decisions or speak for yourself. You can change your plan as often as you like, and as your life changes.

## Step 5 - continued

Maybe I would say, "I have a Power of Attorney, is that not good enough?"

Power of Attorney allows you to appoint someone to look after your money, property and financial affairs when you are not mentally capable of making financial and property decisions, or if you wish them to assist you with your financial affairs when you are still capable. It is only in effect when you are alive and a Power of Attorney does not appoint anyone on your behalf to make health care and treatment related decisions. That is what a Health Care Directive is for.

Health PEI has provided a Health Care Directive form for you to use if you want. This form can be used to write your Health Care Directive and name your Proxy (See a sample of this form at the end of this Workbook) You do not have to use this form, as long as your Health Care Directive meets a number of criteria. Your Health Care Directive is valid under the *Consent to Treatment and Health Care Directives Act* if:

- You are capable of understanding the nature and effect of your Health Care Directive when you complete it. It is in writing and dated.
- You sign it in the presence of a witness and your witness signs it.
- If you are physically unable to sign, but are mentally capable, another person can sign for you in the presence of both you and the witness.
- The witness is neither your Proxy nor the spouse of your Proxy.

You do not need a lawyer to prepare a Health Care Directive but you may wish to speak with a lawyer when you are discussing end-of-life planning.

### What to do with a Health Care Directive once it is signed:

- Give an original to your Proxy(ies) so it is readily accessible if and when they are called upon to use it to make health care decisions on your behalf. Or, alternatively, keep the original at home in a special location and tell people where it is so people can find it easily in an emergency.
- Give copies to other trusted family members and friends if you want everyone to know and be aware of whom you have appointed and/or what your wishes regarding health care and treatment are.
- Give a copy to your physician, primary care provider and other people who will be providing care to you.
- If you are traveling, take a copy with you. Many provinces and U.S. states will honour your wishes. Some will follow the rules in place in their province or U.S. state. If you plan to travel, you should check the procedure in that location. In any event, ensure you have the most up-to-date contact information for your Proxy on the form in case it is needed.
- If you are admitted to a hospital or a long-term care facility, take a copy with you.
- List the people who have copies of your Advance Care Plan and Health Care Directive and keep this list with your Health Care Directive. If you change or cancel your Plan, let these people know.

### Changing your Health Care Directive?

Care Directive will help you make sure that everyone has copies of your most current wishes. It is a good idea to review your Health Care Directive every year, whenever you or your Proxy have a significant change in health, or when you experience a significant event in your life such as the death of a loved one, a marriage or a divorce.

If you write some new wishes, date and sign the paper. The most current wishes made while you are still capable will be followed. The most current wishes override anything you previously put in your Health Care Directive.

If you would like more information on the advance care planning process in general and useful links on this topic go to <http://www.healthpei.ca/advancecareplanning>.

## Word List

These are some definitions of terms that are commonly used in health care. These can help you develop an Advance Care Plan that truly reflects your wishes.

**Advance care plan** is a verbal or written summary of wishes or instructions about the kind of health care and treatment you want or do not want in the event that you cannot speak for yourself. An Advance Care Plan can be written down or simply told to someone who will likely be asked to speak on your behalf (i.e. Proxy or Substitute Decision-Maker). It can guide your Proxy or Substitute Decision-Maker if that person is asked by a health care provider to make treatment decisions on your behalf.

**Advance care planning** is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health care and treatment preferences in the event that a health care provider determines you are not capable to either make and/or communicate your own health care choices. Advance care planning means having discussions with family and friends, especially your Proxy (if you have named one in a legally binding Health Care Directive), or with family and friends who may be called upon to be your Substitute Decision-Maker (the person who will speak for you) if a Proxy has not been named in a Health Care Directive. It may also include preparing a written Advance Care Plan, creating a Health Care Directive, and may even involve talking with health care providers and financial and legal professionals.

**Allow natural death** refers to a decision NOT to have any treatment or procedure that will delay the moment of death. It applies only when death is about to happen from natural causes and means that a person does not want this process to be obstructed by medical procedures. However, you would continue to receive any treatments to keep comfortable. The continuation of nutrition and hydration (food or drink) in the vast majority of cases is not part of comfort measures.

**Blood transfusion/transfusion of blood products** is the transfer of blood or blood components from one person (the donor) into the bloodstream of another person (the recipient) through an intravenous line (a needle in your vein). Blood transfusion may be done as a lifesaving measure to replace blood cells or blood products lost through bleeding or due to depression of the bone marrow.

**Capable (capacity)** to be capable or have capacity to make health care and treatment decisions, a person must, in the health care provider's opinion, be able:

- to understand the information that is relevant to making a decision concerning the treatment;

- to understand the information that applies to his or her particular situation;
- to understand that the person has a right to make a decision; and
- to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

**Cardio pulmonary resuscitation (CPR)** refers to medical procedures used to restart your heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest to electric shocks that attempt to restart the heart and machines that breathe for the individual. CPR can be useful in some situations, but not in all situations.

**Comfort measures or comfort care** are treatments to keep you comfortable (for example, medication for managing symptoms including pain, psychological support, physical care or oxygen for shortness of breath,) but not to keep you artificially alive or cure any illness. The continuation of nutrition and hydration (food and drink) in the vast majority of cases is not part of comfort measures.

**Dementia** is a term used to describe the symptoms of many illnesses that cause a loss of memory, judgment, ability to think clearly, recognize people and communicate, as well as changes in behaviour and mood. These symptoms may be temporary and related to another condition, or they may gradually get worse over time. Symptoms can range from mild to severe. The most common form of dementia is Alzheimer's disease.

**Dialysis** is a medical procedure that cleans your blood of toxins by machine (hemodialysis) or by fluid passed through the abdomen (peritoneal dialysis) when your kidneys can no longer do so.

**End-of-life (EOL) care** refers to health care provided at the end of a person's life. This type of care focuses on you living the way you choose during your last days or weeks and providing comfort measures until the time of death. Care provided during this time may be called supportive care, palliative care or symptom management. End-of-life care addresses physical, psychological, and spiritual concerns and focuses on comfort, respect for decisions, and support for the family. Palliative care is not restricted to care during those last weeks of life and, in fact, can start years before your death in conjunction with other curative or life prolonging measures. Palliative care early in the course of a disease is associated with an increase in quality of life.

## Word List - continued

**Feeding tube** is a surgical intervention to feed someone who can no longer swallow food. A person who cannot eat or drink needs a feeding tube to get nourishment. The tube is inserted into the stomach either through the nose or a small hole cut into the abdomen.

**Goals of Care (GOC)** is a communication and decision-making process that occurs between a clinician (physician, nurse practitioner or registered nurse) a patient, and/or a Proxy(ies)/Substitute Decision-Maker(s) to establish a plan of care. It is intended to clarify and document goals of the treatment plan that assures patients' wishes are met.

**Guardian** is a person legally authorized or appointed to exercise powers for a person who is mentally incompetent or is incapable of managing his or her personal affairs.

**Health Care Directive (HCD)** is a legally binding document in which you explain, in writing, your wishes for health care and treatment in the event a health care provider has determined you are not capable to either make and/or communicate your own health care choices. In your directive, you can appoint another person(s), called a Proxy(ies), to make health care decisions for you when you are not capable to either make and/or communicate them yourself. Everyone is presumed to be capable of making a Health Care Directive, although a Proxy(ies) must be at least 16 years of age to accept a Proxy appointment.

A Health Care Directive needs to be in writing, and be dated and signed in order to be valid. A Health Care Directive never takes priority over a capable person's consent.

Your Health Care Directive may be very detailed about what treatments you want or don't want, or may be a general outline of your values, beliefs and wishes, without details. Your directive will guide your Proxy or Substitute Decision-Makers in the decisions to be made about your treatment when a health care provider has determined that you're not capable of doing this yourself.

**Informed consent** refers to the permission you give to health care providers that allows medical investigations and/or treatments. Health care providers are required to offer you, and you are entitled to receive, explanations of the investigations/treatments and their risks, benefits and side effects; alternatives to these options; and what would likely happen if you refuse the options. Health care providers must also answer any questions you have about the treatments before you give verbal consent or sign a consent form.

**Intravenous (IV)** is a medical term that means giving you fluids or medications through a vein in your hand or other part of your body using a syringe or intravenous catheter (tube) and bag.

**Intubation** is where a tube is inserted down your airway (throat) so that you can breathe. If you are unable to breathe on your own, intubation may result in the use of a ventilator or breathing machine (this means the breathing tube will be attached to a breathing machine that will breathe for you). Some people may want to be resuscitated, but may not want to be intubated. A definition of "cardiopulmonary resuscitation" is included above.

**Life support with medical interventions** is a medical term meaning health care treatments like tube feedings, ventilators (breathing machines), kidney dialysis, medications, and cardiopulmonary resuscitation. They are considered medically appropriate care when the goal of care is to continue or prolong life. All of these use artificial means to restore and/or continue life. Without them, you would die.

**Life-limiting illness** refers to an incurable medical condition caused by injury or disease.

**Major surgery** is a medical term meaning any invasive operative procedure in which an extensive surgical procedure is performed, e.g. a body cavity is entered, organs are removed, or normal anatomy is altered.

**Organ/tissue donation** is a medical term that refers to allowing organs (lungs/heart/kidney) and/or tissues to be donated in certain circumstances, either during your life or upon your death, under the *Human Tissue Donation Act*. A person can register their wishes about donating their organs and/or tissue or state their wishes in a Health Care Directive.

**Palliative care** is the way we care for people who have a life-limiting illness. Palliative care can be provided anywhere, at any stage of any illness along with care and treatment aimed at curing or prolonging life. It focuses on maintaining a good quality of life. It incorporates a holistic approach, which means considering social, spiritual, relational needs along with physical treatments. Palliative care always involves best possible pain control and control of other symptoms such as shortness of breath, nausea, anxiety or depression. Palliative care involves medicines, treatments, physical care, psychological/social services and spiritual support, both for you and for those who are helping to care for you. Early palliative care interventions are associated with better quality of life and decreased stress for both patients and caregivers.

## Word List - continued

**Permanent coma** is a state of unconsciousness where there is no reasonable expectation of regaining consciousness. You would need to be in bed and receive nourishment through a feeding tube. You would need 24 hour care.

**Power of Attorney** is a legal instrument that allows you to appoint someone to make financial and legal decisions on your behalf should a health care provider determine that you are not capable of making decisions on your own behalf. In PEI, a Power of Attorney has authority in relation to finances only and has no decision-making authority over health care or treatment-related decisions. The only way to appoint someone to make health care or treatment-related decision on your behalf in PEI is by a Health Care Directive.

**Proxy** is a term taken from the *Consent to Treatment and Health Care Directives Act* (PEI). It means the person or person(s) appointed by the maker of a Health Care Directive to make decisions on his or her behalf and may include alternate(s) in the event that the person or persons appointed is unable to act. The role of a Proxy is fully defined in the *Act*. In essence, it is someone who is appointed to make decisions on your behalf in the event you are unable and to consider your expressed wishes and best interests when making care and treatment decisions. It is a good idea to appoint a second Proxy who would act if the your first Proxy predeceases you or is unable to act. When the decision of a Proxy is required and the directive does not give specific instructions, the Proxy shall make a decision based on your best interests. If you name more than one Proxy, you can indicate how you wish them to act: **SUCCESSIVELY** (second Proxy decides if the first Proxy is not available) or **JOINTLY** (make decisions together). If how you wish them to act is not indicated, Proxies shall act successively.

You can also appoint an **ALTERNATE PROXY** in the event none of your proxy(ies) are available (for example if your proxy is away on travel).

To be valid, a health care directive must be written, dated, and signed by you. Any Proxy you name must also sign the section of the form where they agree to be your Proxy. If your named Proxy/Proxies have not signed the form, their appointment is not valid. A Proxy must also be capable and at least 16 years of age to accept this appointment.

If you cannot sign the directive yourself, someone else can sign the directive for you at your direction. If someone else is signing for you, you will also need a witness. In either case, whether you are able to sign or someone must sign on your behalf, the witness cannot be your Proxy or your Proxy's spouse. You, your signer, and the witness must all be present when your directive is signed.

**Spouse** in PEI, spouses are defined as two people who are legally married or two people who have lived together in conjugal (sexual) relationship for at least 3 years or are the natural or adoptive parents of a child or children.

**Stroke** is a potentially life threatening event in which parts of the brain are deprived of blood carrying oxygen. Strokes are commonly caused by either blockage of a blood vessel (usually in the form of a clot) or by breaking of a blood vessel that results in bleeding in or around the brain. The impact of a stroke on you physically and mentally can range from mild to severe. Stroke may affect your ability to walk resulting in the need for a cane, or a wheelchair or confinement to bed or a chair. Depending on the part of the brain affected, stroke may affect your ability to communicate (e.g., speaking and/or understanding). You may have the supports at home to meet your needs or you may need to live in a continuing care home. How well you recover from a stroke will depend on many factors.

**Substitute Decision-Maker (SDM)** is someone who makes health care and treatment decisions on your behalf when you are not able to do so yourself. It may be someone you formally appoint to make health care decisions for you (known as a Proxy) or may be someone else who is chosen based on the hierarchy set out in the *Consent to Treatment and Health Care Directives Act* (PEI).

If you have formally appointed a Proxy or Proxies, that is the person or people who will be your substitute decision-maker(s) for health care decisions.

If you have not formally appointed a Proxy or Proxies, if your Proxy(ies) are unable or unwilling to act, or if the appointment was not done properly, then the *Consent to Treatment and Health Care Directives Act* (PEI) provides a list identifying individuals who are authorized to act as a Substitute Decision-Maker on your behalf, and in what priority.

A Substitute Decision-Maker must be at least 16 years old and be capable of making health care decisions themselves. In addition (except for a Proxy), a Substitute Decision-Maker must have knowledge of your circumstances and have been in recent contact with you at the time they are being asked to make the health care decision for you.

**Surgery** could include minor surgery (such as having wisdom teeth removed or feeding tube inserted) or major surgery (such as having a gall bladder removed).

**Symptoms** are signs that you are unwell – for example, pain, vomiting, loss of appetite, or high fever, shortness of breath, confusion, weakness.

**Terminal illness** means an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.

**Ventilator** is a machine that helps a person breathe when they cannot breathe on their own.

## Congratulations on taking the first step!

Now that you've made your plan, it's time to tell others about it.

### Start the conversation about end-of-life care.

Talk to your Proxy(ies)/Substitute Decision-Maker(s) about your plan and your wishes. They may have questions about your decisions or want more details about what you've written in your plan. That conversation can give them the confidence to make decisions during a difficult time.

Talk to your family members, friends and health care team too. They need to know your wishes if you cannot communicate for yourself. Talking now will help to reduce any anxiety and will help them better understand and honour your wishes at the end of life.

The choices you make at the end of life—for yourself and others—are important. Make sure that your voice is heard.

**For more information about advance care planning, please visit: [www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning)**



## Health PEI

Health PEI is the provincial agency responsible for health services on PEI. In 2012, the Advance Care Planning (ACP) Steering Committee was formed by Health PEI to lead the ACP process for the province. Prior to the formation of the committee, there was no consistent or standardized process for ACP in the facilities and programs operated by Health PEI.

The ACP Steering Committee includes representation from a number of health groups and community organizations. The primary role of the committee is to raise awareness of the importance of ACP to all Islanders and health care providers through education, public engagement and partnerships. The work of this committee also focuses on ensuring processes are in place for health care providers to engage and support patients/clients/residents in the ACP process. This is particularly important given PEI's aging population and the implications on the health care system.

**Health PEI supports Patient and Family-Centred Care** and strives to provide care to you that is clinically indicated and appropriate and seeks to understand your values and wishes regarding care provisions. Having a voice in decisions about your health care plan and treatment is important. There may come a time in your life when, due to illness or injury, you are incapable of expressing your treatment wishes to health care providers. By planning in advance, you can be sure that your family, friends and/or health care providers know your wishes, values and beliefs, and can ensure your wishes are followed.

In PEI, we have legislation to guide the ACP process known as the *Consent to Treatment and Health Care Directives Act*. The legislation allows capable adults to put plans into place that outline the health care treatment they consent to or refuse based on their beliefs, values and wishes. It also addresses the making of a Health Care Directive, a document made in accordance with the Act in which you set out decisions or wishes or instructions respecting your treatment, appoint a Proxy or a person or persons to make decisions on your behalf, or both. If you have no decision/plan in place, PEI's consent to treatment legislation gives health care providers specific direction regarding whom they must choose to make decisions on your behalf.

The ACP Steering Committee, in partnership with Canadian Hospice Palliative Care Association (CHPCA), has developed this ACP interactive workbook as a tool to help you develop an advance care plan that outlines your wishes about health care decisions in the event you are unable to do so. It will help you to consider what is important to you, help you document your beliefs and wishes, make a Health Care Directive and/or appoint a Proxy(ies) if you wish, and help you make the Advance Care Plan that best suits you.

**It is important to note that this workbook is NOT your Health Care Directive, a document made in accordance with the Act—it is a tool to help you create a Health Care Directive.** We hope that by filling out this workbook it will lead you to make an official Health Care Directive by completing the Health Care Directive form to appoint a Proxy(ies) and/or to ensure your wishes regarding your health care and treatment are known and respected. Your official Health Care Directive can be completed without the assistance of a lawyer or notary public, although as part of your end-of-life planning, you may wish to consult legal or financial resources.

*It is the goal of the ACP Steering Committee that our ACP interactive workbook engages you and more Islanders to start the conversation about your end of life care. Speak Up and start your conversation today!*

— Health PEI ACP Steering Committee

**Visit Health PEI for more information:  
[www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning)**

## Health Care Directive / Directive relative aux soins de santé

For assistance in providing a Health Care Directive, please see the notes section.

*Si vous avez besoin d'aide pour donner une directive relative aux soins de santé, consultez la section des Notes.*

1. This is the health care directive of: • *Le présent document est la directive relative aux soins de santé de :*

Name • Nom	Date of Birth • Date de naissance	
Address • Adresse		
City • Ville	Province	Postal Code • Code postal
Telephone • Téléphone	Personal Health Number • Numéro de la carte-santé	

2. I understand that this Health Care Directive and the authority of a proxy become effective if I am not capable of making or communicating a decision about treatment.

*Je comprends que la présente directive relative aux soins de santé et l'autorité du mandataire entrent en vigueur si je suis incapable de prendre une décision ou de la communiquer à propos de mon traitement.*

3. Proxy – See Notes – You may name **one or more persons** who will have the authority to make decisions concerning your health care when you do not have the ability to make those decisions yourself. **Appointing proxies is optional.**

*Procuration – Voir les Notes – Vous pouvez nommer **une ou plusieurs personnes** qui auront l'autorité de prendre des décisions à propos de vos soins de santé si vous êtes incapable de décider vous-même. **La nomination d'un ou de plusieurs mandataires est facultative.***

I revoke any previous health care directive made by me and appoint the following person(s) to be my proxy(ies):

*Je révoque toute directive antérieure relative aux soins de santé et je nomme la (ou les) personne(s) suivante(s) pour être mon (mes) mandataire(s) :*

Name of proxy 1 • Nom du 1 <sup>er</sup> mandataire	Telephone • Téléphone
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Address • Adresse	
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City • Ville	Province	Postal Code • Code postal
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Name of proxy 2 • Nom du 2 <sup>e</sup> mandataire	Telephone • Téléphone
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Address • Adresse	
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City • Ville	Province	Postal Code • Code postal
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4. My proxies shall act • Mes mandataires agiront :

- Successively (second proxy decides if first proxy not available) • Successivement (le second mandataire décide si le premier n'est pas disponible)
- Jointly (make decisions together) • Conjointement (prendront les décisions ensemble)

5. If the person(s) I have appointed is (are) unable to act, I appoint the following person to act as my proxy • Si la (les) personne(s) que j'ai nommée(s) est (sont) incapable(s) d'agir, je nomme la personne suivante pour agir comme mon mandataire :

Name of alternate proxy • Nom du mandataire suppléant	Telephone • Téléphone
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Address • Adresse	
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City • Ville	Province	Postal Code • Code postal
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6. I give my proxy(ies) the authority to make any health care decisions for me that I am not capable of making for myself, subject to the instructions contained in this document. • Je donne à mon (mes) mandataire(s) l'autorité de prendre toute décision au sujet de mes soins de santé que je suis incapable de prendre pour moi-même, sous réserve des instructions contenues dans le présent document.

#### 7-A. My Directions for Health Care

(See notes for examples of health conditions and treatment options.)

This section is where you consider potential health conditions and treatment options. You may indicate wishes either to request or to refuse a treatment; you may want to state that you are unsure about a treatment preference and that you would like a certain treatment for a period of time but discontinued if no improvement results.

##### ***Mes instructions relatives aux soins de santé***

(*Voir dans les Notes les exemples d'états de santé et d'options de traitement.*)

*Dans la présente section, vous étudiez les états de santé possibles et les options de traitement. Vous pouvez indiquer que vous souhaitez soit demander un traitement, soit le refuser. Ou encore, vous pouvez vouloir dire que vous n'êtes pas certain à propos d'une préférence de traitement, et que vous aimeriez qu'on essaie un certain traitement pour une période de temps, mais qu'on l'arrête s'il n'y a pas d'amélioration.*

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#### 7-B. My Personal Value Statement

(See Notes for examples of value statements)

Because all potential situations cannot be covered by this form, you may choose to make a general statement(s) about your values regarding health care treatment. This will assist your proxy(ies) or other substitute decision-maker in making decisions on your behalf.

##### ***La déclaration de mes valeurs personnelles***

(*Voir dans les Notes les exemples de déclarations de valeurs.*)

*Parce qu'il est impossible de traiter de toutes les situations possibles dans ce formulaire, nous vous offrons le choix de faire une ou plusieurs déclarations au sujet des valeurs auxquelles vous croyez dans les soins à vous donner. Cela aidera votre/ vos mandataire(s), ou les autres personnes ayant à décider au nom d'autrui, à prendre des décisions en votre nom.*

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8. **Organ and Tissue Donation** – Donation is optional.

I wish to donate

- My body    any needed organs or tissues
- The following organs or tissues: \_\_\_\_\_  
for the following purpose(s):  therapeutic    transplantation    medical education    scientific research OR  any purpose authorized by law

**Don d'organe et de tissu ( facultatif )**

Je souhaite donner

- mon corps    tout organe ou tissu dont on a besoin
- les organes ou les tissus suivants : \_\_\_\_\_  
pour les fins suivantes :  thérapeutiques    transplantation    formation médicale  
 recherche scientifique OU  toute autre fin autorisée par la loi

9. I want the wishes and directions expressed in this health care directive and the spirit of this document carried out to the fullest extent possible. No person who carries out this health care directive, whether a health practitioner, proxy, hospital administrator, friend, family member or any other person, shall be held responsible in any way – legally, morally, professionally – for any consequences arising from the implementation of my wishes.

*Je veux que mes souhaits et instructions exprimés dans la présente directive relative aux soins de santé et que l'esprit du présent document soient respectés en entier.  
Aucune personne qui exécute cette directive relative aux soins de santé, qu'il s'agisse d'un(e) professionnel(le) de la santé, d'un mandataire, d'un administrateur d'hôpital, d'un(e) ami(e), d'un membre de la famille ou de toute autre personne, ne peut être tenu(e) responsable d'aucune façon – légalement, moralement ou professionnellement – d'une conséquence émanant de l'application de mes souhaits.*

10. I sign this document while capable. • *Je signe le présent document alors que je suis capable de le faire.*

Date \_\_\_\_\_ My signature • *Ma signature* \_\_\_\_\_

**OR** if you are capable but for some reason unable to sign, this document must be signed by another person and witnessed. The person signing and the witness **CANNOT** be the proxy or spouse of the proxy. • **OU** si vous êtes incapable de signer pour quelque raison que ce soit, ce document doit être signé par une autre personne en présence d'un témoin. La personne qui signe et celle qui est témoin **ne peuvent pas** être votre mandataire ni son conjoint(e).

Date \_\_\_\_\_ Signature \_\_\_\_\_

Date \_\_\_\_\_ Witness • *Témoin* \_\_\_\_\_

11. I agree to be proxy for the maker of this health care directive. Proxy appointment is not valid unless signed by the proxy(ies) or another person at the direction of the proxy. • *Je consens à être mandataire pour la personne qui donne la présente directive relative aux soins de santé. La nomination d'un(e) mandataire n'est pas valide à moins qu'il/elle signe ou qu'une autre personne signe à la demande du mandataire.*

Date \_\_\_\_\_ Proxy 1 • *1<sup>er</sup> mandataire* \_\_\_\_\_

Date \_\_\_\_\_ Proxy 2 • *2<sup>e</sup> mandataire* \_\_\_\_\_

Date \_\_\_\_\_ Alternate Proxy •  
*Mandataire suppléant* \_\_\_\_\_

## Notes for Completing a Health Care Directive

### Proxy

The role of a proxy is to consider your expressed wishes and best interests when treatment decisions need to be made on your behalf. It is a good idea to appoint a substitute proxy who would act if the first proxy predeceases you or is unable to act. The *Consent to Treatment and Health Care Directives Act* says a proxy must have knowledge of your circumstances, and have been in recent contact with you. When the decision of a proxy is required and the directive does not give specific instructions, the proxy shall make a decision based on your best interests. If you name more than one proxy, you can indicate how you wish them to act: SUCCESSIVELY (second proxy decides if the first proxy is not available) or JOINTLY (make decisions together). **If how you wish them to act is not indicated, proxies shall act successively.**

### Examples of Health Conditions

- Terminal illness—there is no known cure, such as some types of cancer.
- Irreversible condition – there is no possibility of a complete recovery. Examples of conditions include AIDS, certain cancers, stroke, Parkinson’s disease, or Alzheimer’s disease.
- Reversible condition – a condition that may be cured without any remaining disability, such as pneumonia, bleeding ulcers.
- Permanent coma – a permanent state of unconscious.
- Stroke – damage to the brain causing weakness, partial paralysis, difficulty with speech, etc. Symptoms may or may not improve.
- Dementia – a progressive and irreversible deterioration in brain function causing trouble with thinking clearly, recognizing people and communicating. Dementia gradually worsens.

### Examples of Treatment Options

- Cardiopulmonary resuscitation – chest compressions, drugs, electric shock and artificial breathing to restore heartbeat.
- Mechanical breathing – respiration by machine, through a tube in the throat.
- Artificial nutrition and hydration – giving nutrition and fluid through a tube in the veins, nose or stomach.
- Major surgery – such as gall bladder removal.
- Kidney dialysis – cleaning the blood by machine or by fluid passed through the abdomen.
- Chemotherapy – using drugs to fight cancer.
- Minor surgery – such as wisdom teeth removal.
- Invasive diagnostic tests – such as using flexible tube to look into the stomach.
- Simple diagnostic tests – such as blood tests or x-rays.
- Blood or blood products – such as giving transfusions.
- Antibiotics – drugs to fight infection.
- Pain medications – drugs to ease pain and suffering but which may dull consciousness and indirectly shorten life. Consider that you may have more than one serious health condition. For example, you had a severe stroke and later developed pneumonia requiring treatment with antibiotics to live. If you had not experienced a stroke, would your wishes for antibiotic treatment be different?

### Examples of Value Statements

- Do everything possible to maintain life.
- I would prefer to receive treatment at home if this does not cause undue stress on my caregivers.
- I only want measures that enhance comfort and minimize pain.
- I do not want invasive procedures (surgery).
- My religious beliefs will not allow me to consent to the following treatments or procedures....

### Organ/Tissue Donation

The *Human Tissue Donation Act* provides for a person to consent to the donation of their body or body parts for purposes indicated on the form.

### **Agreement of Proxy**

The appointment of a proxy is valid **only** if the proxy or another person at the direction of the proxy agrees to the appointment in writing prior to your incapacity. A proxy shall be at least 16 years of age and capable of making health care decisions.

### **Health Care Directive Background Information**

#### **What is a health care directive?**

A health care directive is a legal document describing the amount and type of health care you want, should you become incapable of making decisions on your own. Anyone who is 16 years of age or older and capable of making health care decisions can make a directive. A health care directive needs to be in writing, dated and signed in order to be valid. This form is a sample, since a special form or format is not required. A health care directive never takes priority over a capable person's consent.

#### **What does a health care directive include?**

In your health care directive you can appoint a proxy – a person whom you trust – to make health care decisions on your behalf. Your directive can be specific, outlining treatment, procedures or medication that you may or may not wish to have. Or your directive can be general, simply stating your beliefs and directions should decisions need to be made for you by others. For example, you may state that if you are in a coma you do not wish to have life support beyond a certain period of time.

#### **Will my wishes be followed?**

A health care practitioner must decide if you are capable of making health care decisions. If you are not capable, the wishes expressed in your directive must be followed, provided they are realistically possible and are consistent with the ethical standards of the health care practitioner.

It helps to let others know that you have prepared a health care directive – your family, friends, clergy, lawyer or doctor. You may want to discuss your decisions with them, provide them with copies of your health care directive, and have a copy placed in your medical records file at your local hospital.

#### **What does capable mean?**

Capable means that you are able to understand the information relevant to making a decision about treatment and to appreciate the consequences of that decision. Capacity can fluctuate – you may be incapable at one time and capable at another; or incapable of some treatment decisions yet capable of other treatment decisions.

#### **Can I change my mind about my health care directive?**

A health care directive is a record of your current wishes. You may change your health care directive or your proxy at any time. It is important to destroy all copies of your previous health care directive(s) to ensure that your most recent wishes are followed.

#### **For more information:**

Visit the Health PEI website at: [www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning)

#### **For copies of the Consent to Treatment and Health Care Directives Act, you may contact:**

Island Information Service  
(902) 368-4000

11 Kent Street, PO Box 2000, Charlottetown, PE C1A 7N8  
Or visit our website at: [www.gov.pe.ca/law/statutes](http://www.gov.pe.ca/law/statutes)

## Notes supplémentaires à la directive relative aux soins de santé

### Mandataire

Le rôle du mandataire consiste à réfléchir à vos préférences et au mieux de vos intérêts quand il faut prendre des décisions de traitement en votre nom. Ce n'est pas une mauvaise idée de nommer un mandataire suppléant qui agira si le premier mandataire décède avant vous ou s'il est incapable d'agir. La Consent to Treatment and Health Care Directives Act (loi sur le consentement au traitement et les directives relatives aux soins de santé) affirme qu'un mandataire doit connaître votre situation et avoir été en contact récemment avec vous. Lorsque la décision d'un mandataire est requise et que la directive ne fournit pas d'instructions précises, le mandataire doit prendre une décision au mieux de vos intérêts. Si vous désignez plus d'un mandataire, vous pouvez indiquer comment vous désirez qu'ils agissent: SUCCESSIVEMENT (le second mandataire décide si le premier n'est pas disponible) ou CONJOINTEMENT (qu'ils prennent des décisions ensemble). **Si vous n'indiquez pas comment vous désirez qu'ils agissent, ils agiront successivement.**

### Exemples d'états de santé

- Maladie terminale – pour laquelle on ne connaît pas de cure, telle que certains types de cancer.
- Maladie irréversible – sans possibilité de rétablissement complet. Au nombre des maladies irréversibles, mentionnons le SIDA, certains cancers, l'accident vasculaire cérébral (AVC), la maladie de Parkinson et la maladie d'Alzheimer.
- Maladie réversible – maladie qui peut être guérie sans laisser de trace, telle que la pneumonie, les saignements gastriques.
- Coma permanent – état d'inconscience permanent.
- Accident vasculaire cérébral – dommage au cerveau causant une faiblesse, une paralysie partielle, des difficultés à parler, etc. Les symptômes peuvent s'améliorer ou non.
- Démence – détérioration progressive et irréversible de la fonction cérébrale, laquelle empêche de parler clairement, de reconnaître les gens et de communiquer. La démence s'aggrave progressivement.

### Exemples d'options de traitement

- Réanimation cardio-respiratoire – compressions thoraciques, médicaments, chocs électriques et respiration artificielle pour rétablir le rythme cardiaque.
- Ventilation mécanique – machine qui permet de respirer au moyen d'un tube dans la gorge.
- Alimentation et hydratation artificielles – donner de la nourriture solide et liquide au moyen d'un tube dans les veines, le nez ou l'estomac.
- Chirurgie importante – telle que l'ablation de la vésicule biliaire.
- Dialyse rénale – nettoyage du sang au moyen d'une machine ou en faisant passer des fluides par l'abdomen.
- Chimiothérapie – utilisation de médicaments pour combattre le cancer.
- Chirurgie mineure – telle que l'ablation d'une dent de sagesse.
- Techniques diagnostiques envahissantes – telles que l'utilisation d'un tube flexible pour voir dans l'estomac.
- Tests de diagnostic simples – tels que les analyses sanguines ou les rayons X.
- Sang ou produits sanguins – tels que donner des transfusions.
- Antibiotiques – médicaments pour combattre l'infection.
- Médicaments contre la douleur – médicaments pour soulager la douleur et les souffrances mais qui peuvent endormir la conscience et indirectement raccourcir la vie. Pensez que vous pourriez avoir plus d'une maladie sérieuse. Par exemple, avoir souffert d'un accident vasculaire cérébral et développer une pneumonie par la suite exigeant un traitement avec des antibiotiques pour survivre. Si vous n'aviez pas eu d'accident vasculaire cérébral, souhaiteriez-vous que le traitement aux antibiotiques soit différent?

### Exemples de déclarations de valeurs

- Faites tout votre possible pour me garder en vie.
- Je préférerais être soigné(e) à la maison si cela n'est pas trop difficile pour les personnes qui me soignent.
- Je ne veux rien d'autre qu'un traitement qui me donne plus de confort ou minimise mes douleurs.
- Je ne veux pas de procédure envahissante (chirurgie).
- Mes croyances religieuses ne me permettent pas de consentir aux traitements ou aux procédures suivantes....

### Don d'organes ou de tissus

La Human Tissue Donation Act (loi sur le don de tissus humains) prévoit qu'une personne peut consentir à donner son corps ou des parties de son corps aux fins mentionnées sur le formulaire.

## **Accord du mandataire**

La nomination d'un mandataire **n'est valide que si le mandataire, ou une autre personne à sa demande, consent à la nomination par écrit avant votre incapacité.** Le/la mandataire doit être âgé(e) d'au moins 16 ans et être capable de prendre des décisions relatives aux soins de santé.

## **Renseignements généraux sur la directive relative aux soins de santé**

### **Qu'est-ce qu'une directive relative aux soins de santé?**

Une directive relative aux soins de santé est un document juridique décrivant la quantité et le type de soins que vous voulez si vous devenez incapable de prendre vos propres décisions. Toute personne âgée de 16 ans ou plus, et capable de prendre des décisions relatives aux soins de santé, peut donner une directive. Une directive relative aux soins de santé doit être faite par écrit, datée et signée. Le présent formulaire n'en est qu'un exemple, car on n'exige pas de formulaire ou de forme particulière. Le consentement d'une personne capable a toujours préséance sur la directive relative aux soins de santé.

### **Que comprend une directive relative aux soins de santé?**

Dans votre directive relative aux soins de santé, vous devez nommer un mandataire – une personne en qui vous avez confiance – pour prendre des décisions relatives aux soins de santé en votre nom. Votre directive peut être particulière et décrire le traitement, les procédures ou les médicaments que vous désirez avoir ou non. Ou bien, votre directive peut être générale et énoncer simplement vos croyances et vos instructions si d'autres personnes devaient prendre des décisions pour vous. Par exemple, vous pouvez déclarer que, si jamais vous tombez dans le coma, vous ne souhaitez pas que l'on maintienne vos fonctions vitales au-delà d'une certaine période.

### **Mes souhaits seront-ils suivis?**

Un(e) professionnel(le) de la santé doit décider si vous êtes capable de prendre des décisions relatives aux soins de santé. Si vous en êtes incapable, les souhaits exprimés dans votre directive doivent être suivis, à condition qu'ils soient réalistes et conformes aux normes éthiques du/ de la professionnel(le) de la santé.

Il est utile de laisser savoir aux autres – votre famille, vos amis, le clergé, un avocat ou un médecin – que vous avez préparé une directive relative aux soins de santé. Vous pouvez discuter de vos décisions avec ces personnes, leur donner une copie de votre directive relative aux soins de santé et en faire placer une copie dans le dossier de votre hôpital local.

Être capable, qu'est-ce que cela signifie?

Être capable, cela signifie que vous êtes capable de comprendre les renseignements appropriés pour prendre une décision au sujet d'un traitement et de saisir les conséquences d'une telle décision. La capacité peut changer – vous pouvez être incapable à un certain moment et capable à un autre; ou encore incapable de prendre certaines décisions en matière de traitement, tout en étant encore capable d'en prendre d'autres dans le même domaine.

### **Puis-je changer d'idée à propos de ma directive relative aux soins de santé?**

Une directive relative aux soins de santé est un dossier de vos souhaits actuels. En tout temps, vous pouvez la modifier ou changer votre mandataire. Il est important de détruire toutes les copies de vos directives antérieures relatives aux soins de santé pour garantir que vos souhaits les plus récents soient suivis.

### **Pour obtenir plus de renseignements :**

Rendez-vous sur le site de Santé Î.-P.-É. : [www.healthpei.ca/planificationprealabledessoins](http://www.healthpei.ca/planificationprealabledessoins)

### **Pour obtenir un exemplaire de la Consent to Treatment and Health Care Directives Act, vous pouvez communiquer avec :**

Service de renseignements de l'Île  
902-368-4000

11, rue Kent, C.P. 2000, Charlottetown (Î.-P.-É.) C1A 7N8

Ou visitez notre site Web, à l'adresse : [www.gov.pe.ca/law/statutes](http://www.gov.pe.ca/law/statutes)



Visit Health PEI for more information: [www.healthpei.ca/advancecareplanning](http://www.healthpei.ca/advancecareplanning)