Early Integration of Palliative Care
The Algorithm

STEP 3: PLAN/MANAGE

Presentation #6

PEI Provincial Integrated Palliative Care Program

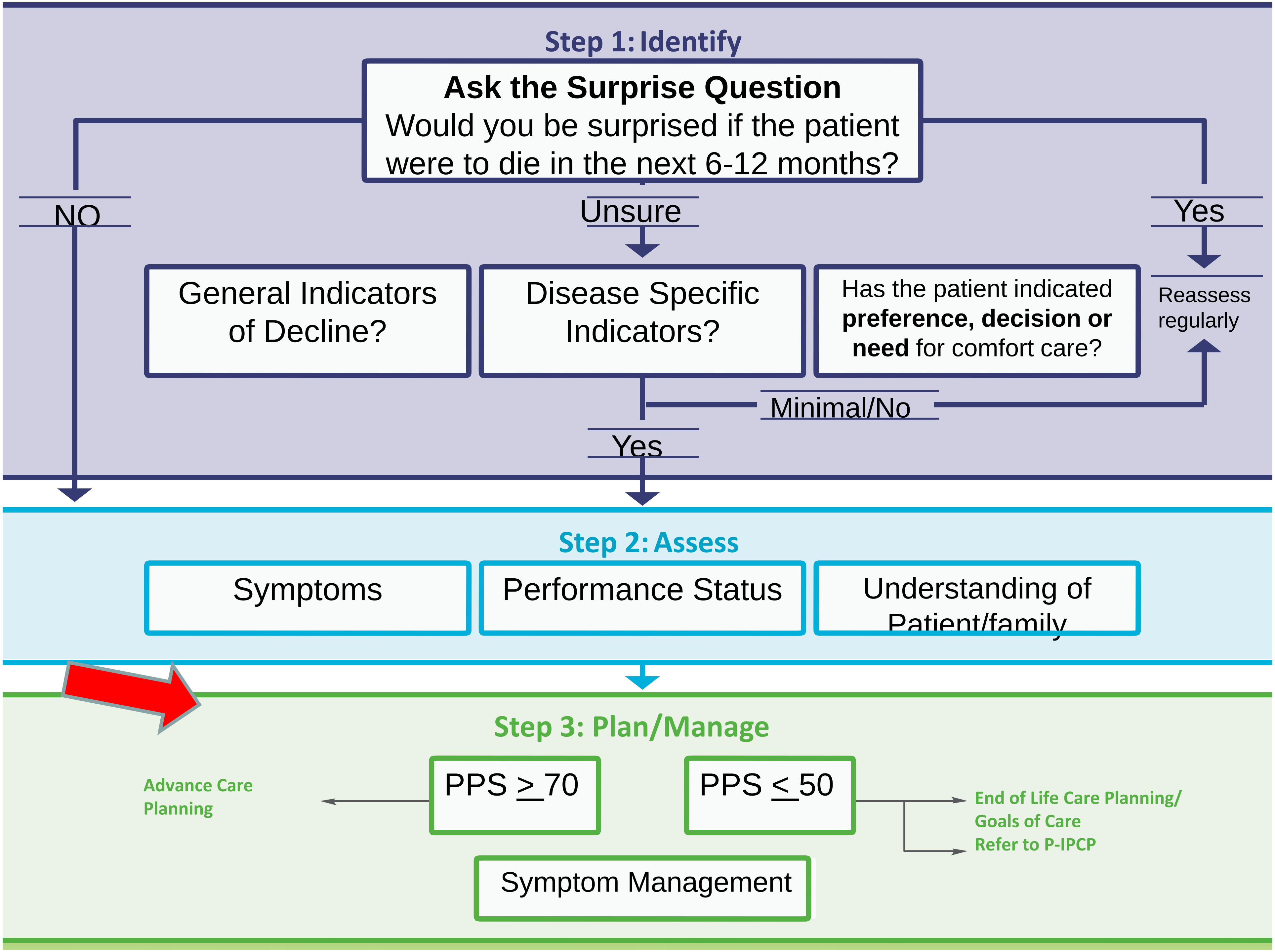
Health PEI

One Island Health System

What will you learn?

At the end of this presentation, you'll have an understanding of:

1. Identifying symptoms and needs using symptom guides
2. Using PPSv2 to prompt care planning
3. Introducing Advance Care Planning (ACP) to patients
4. Introducing Goals of Care (GOC) to patients
5. When to hold ACP conversations
6. Resources provided by the Provincial Integrated Palliative Care Program



Step 1: Identify

Ask the Surprise Question
Would you be surprised if the patient were to die in the next 6-12 months?

NO

Unsure

Yes

General Indicators of Decline?

Disease Specific Indicators?

Has the patient indicated **preference, decision or need** for comfort care?

Reassess regularly

Minimal/No

Yes

Step 2: Assess

Symptoms

Performance Status

Understanding of Patient/family

Step 3: Plan/Manage

Advance Care Planning

PPS ≥ 70

PPS ≤ 50

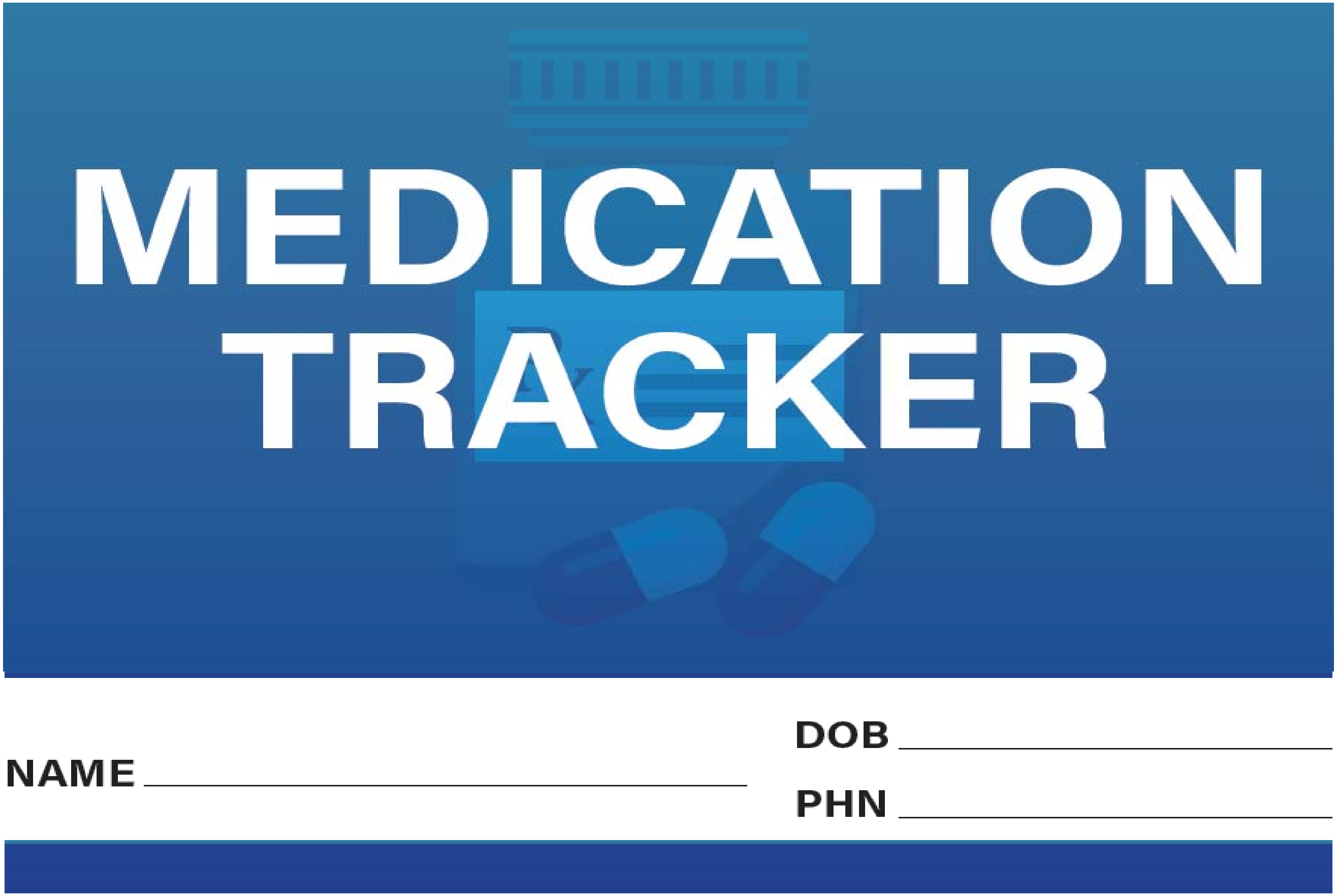
End of Life Care Planning/
Goals of Care
Refer to P-IPCP

Symptom Management

STEP 3: PLAN/MANAGE – SYMPTOMS

- ☐ Promptly manage identified symptoms and needs through use of symptom guides:
  - BC Guidelines http://www.bc-cpc.ca/cpc/symptom-management-guidelines/
  - Pallium Pocketbook e-Book available www.pallium.ca/resource-app

STEP 3: PLAN/MANAGE – SYMPTOMS



MEDICATION TRACKER

NAME ______________________

DOB ______________________

PHN ______________________

PAIN MANAGEMENT

My Long Acting Medication is: ______________________________

My Breakthrough Pain Medication is: ______________________________

Date: ______________________________

There are three simple goals for pain management;

- *A good nights sleep*
- *Pain control during the day while at rest and*
- *Pain control when they are active and ambulatory*

A breakthrough medication is one you take when your regular medication isn't quite enough. It can also be taken when planning an activity that you know may induce pain (this type of pain is called "incident pain").

Continuous pain requires continuous pain medication: your doctor may consider prescribing regular doses rather than just "as needed" doses.

CHART BREAKTHROUGH USE HERE

	0:00	1:00	2:00	3:00	4:00	5:00	6:00	7:00	8:00	9:00	10:00	11:00	12:00	13:00	14:00	15:00	16:00	17:00	18:00	19:00	20:00	21:00	22:00	23:00
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SAT																								
SUN																								

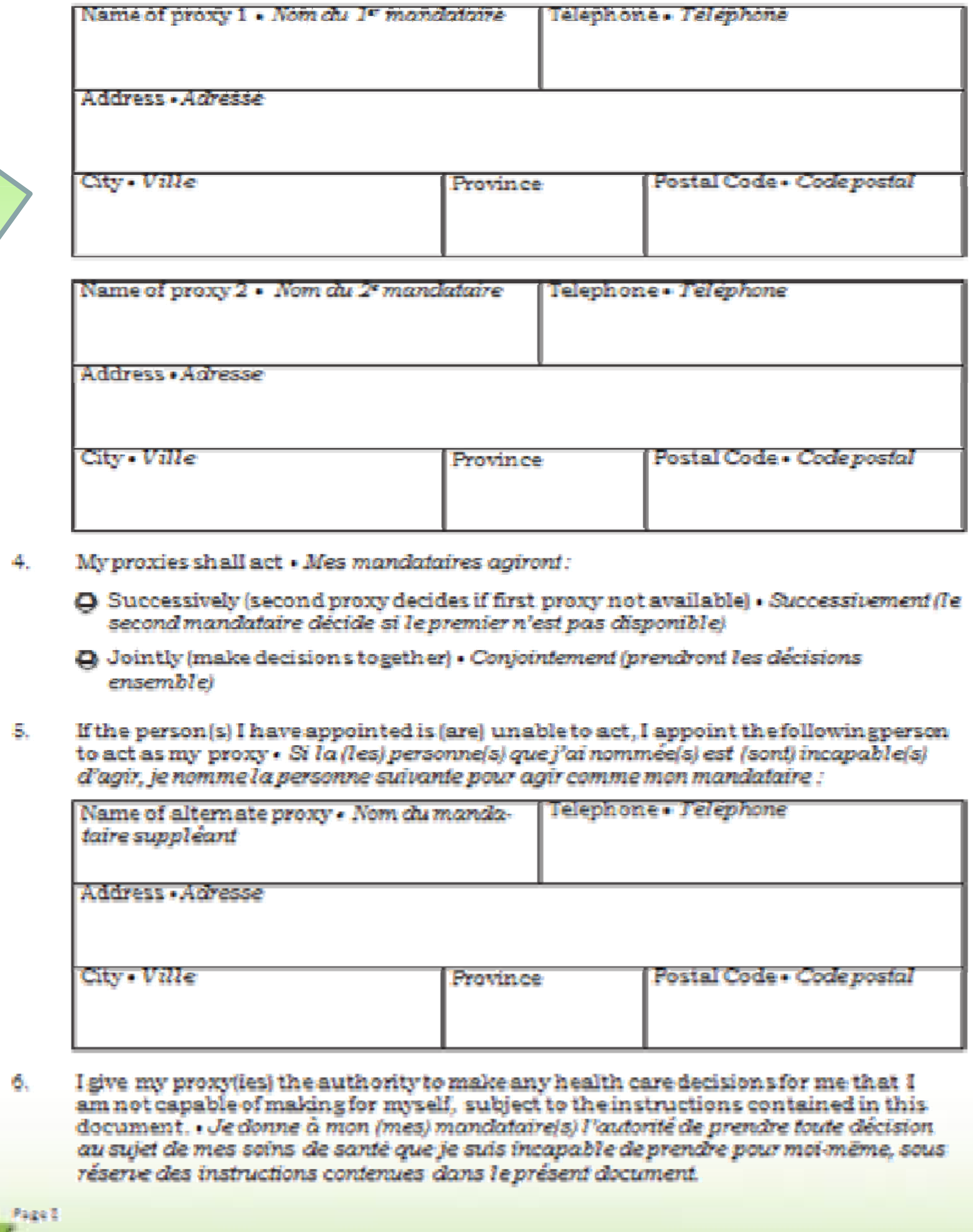
STEP 3: PLAN/MANAGE - CARE PLANNING

- ☐ Use functional status to prompt care planning and assess needs in home/community
  - If PPSv2 is **≥70 (ECOG≤2)**, then engage in ACP with patient and their substitute decision-maker *(Identify Proxy…)*
  - If PPSv2 is **≤50 (ECOG≥3)**, EOL care planning with patient and their SDM and think about referral to Home Care Provincial Integrated Palliative Care Program *(particularly if there is a wish to remain home or die at home)*

STEP 3: PLAN/MANAGE - ACP

- Introduce the topic of ACP
- First, focus on: **“who will make decisions for you if you are incapable of making those decisions yourself?”** This will help identify a Proxy(ies). Record the Proxy(ies) in the Health Care Directive (HCD).
- Refer patients to the Speak Up: Advance Care Planning Workbook - PEI Edition to help them explore their values and wishes. See www.advancecareplanningpei.ca
- Think about making a separate appointment to discuss ACP **(after they reviewed website or material).** Ask your patient to bring their SDM/Proxy(ies) to that appointment. Allow time for reflection and decision-making (GOC/HCD).
- Record values and wishes within a HCD. **Make sure you, the patient and their SDM/Proxy(ies) have copies.**
- Ensure there is a copy in your chart (Green Sleeve)
- Fax copy to Home Care IPCP if they are involved or when you make a referral.

Record Proxy(ies) on Page 2 Health Care Directive



Name of proxy 1 • *Nom du 1er mandataire*		Telephone • *Téléphone*
Address • *Adresse*		
City • *Ville*	Province	Postal Code • *Code postal*

Name of proxy 2 • *Nom du 2e mandataire*		Telephone • *Téléphone*
Address • *Adresse*		
City • *Ville*	Province	Postal Code • *Code postal*

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*
Address • *Adresse*		
City • *Ville*	Province	Postal Code • *Code postal*

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.*

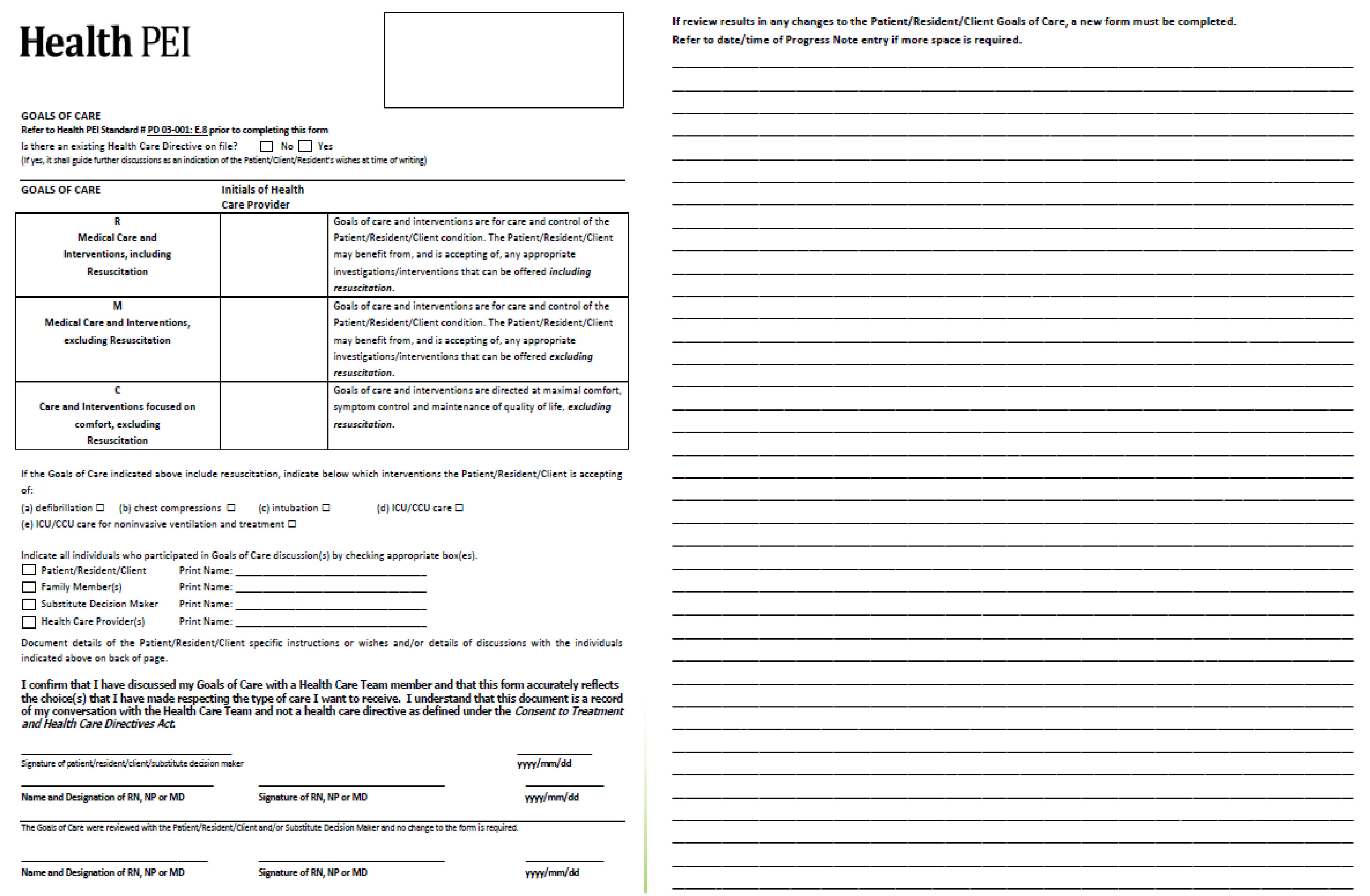
Page 2

STEP 3: PLAN/MANAGE - GOC

- GOC discussions should complement ACP and should be directed at preferences around specific clinical interventions

- Consider the following checklist:
  - Always verify consent for treatment as events develop
  - Consider consult or referral to palliative care for complex management issues (i.e. expected need for palliative sedation for severe SOB)
  - Facilitate communication when there is a transfer to a new setting (i.e. fax GOC and HCD forms to facilities)

Goals of Care Form



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GOALS OF CARE

Refer to Health PEI Standard # PD 03-001: E.8 prior to completing this form

Is there an existing Health Care Directive on file? ☐ No ☐ Yes

(If yes, it shall guide further discussions as an indication of the Patient/Client/Resident's wishes at time of writing)

GOALS OF CARE	**Initials of Health Care Provider**	
R **Medical Care and Interventions, including Resuscitation**		Goals of care and interventions are for care and control of the Patient/Resident/Client condition. The Patient/Resident/Client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered ***including resuscitation.***
M **Medical Care and Interventions, excluding Resuscitation**		Goals of care and interventions are for care and control of the Patient/Resident/Client condition. The Patient/Resident/Client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered ***excluding resuscitation.***
C Care and Interventions focused on comfort, excluding Resuscitation		Goals of care and interventions are directed at maximal comfort, symptom control and maintenance of quality of life, ***excluding resuscitation.***

If the Goals of Care indicated above include resuscitation, indicate below which interventions the Patient/Resident/Client is accepting of:

(a) defibrillation ☐ (b) chest compressions ☐ (c) intubation ☐ (d) ICU/CCU care ☐

(e) ICU/CCU care for noninvasive ventilation and treatment ☐

Indicate all individuals who participated in Goals of Care discussion(s) by checking appropriate box(es).

☐ Patient/Resident/Client Print Name: ______________________________

☐ Family Member(s) Print Name: ______________________________

☐ Substitute Decision Maker Print Name: ______________________________

☐ Health Care Provider(s) Print Name: ______________________________

Document details of the Patient/Resident/Client specific instructions or wishes and/or details of discussions with the individuals indicated above on back of page.

I confirm that I have discussed my Goals of Care with a Health Care Team member and that this form accurately reflects the choice(s) that I have made respecting the type of care I want to receive. I understand that this document is a record of my conversation with the Health Care Team and not a health care directive as defined under the *Consent to Treatment and Health Care Directives Act.*

______________________________ ____________

Signature of patient/resident/client/substitute decision maker yyyy/mm/dd

______________________________ ______________________________ ____________

Name and Designation of RN, NP or MD Signature of RN, NP or MD yyyy/mm/dd

The Goals of Care were reviewed with the Patient/Resident/Client and/or Substitute Decision Maker and no change to the form is required.

______________________________ ______________________________ ____________

Name and Designation of RN, NP or MD Signature of RN, NP or MD yyyy/mm/dd

If review results in any changes to the Patient/Resident/Client Goals of Care, a new form must be completed.

Refer to date/time of Progress Note entry if more space is required.

STEP 3: PLAN/MANAGE - EOL Planning

- Discuss and document GOC with patient and family, if not done already
- **Revisit ACP** and discuss treatment withdrawal or withholding as frequently as needed **when condition changes (frequently, patients don't agree to a "DNR" before they feel the end is very near!)**
- Screen for specific EOL psychosocial/cultural issues for patient and family **(wishes, coping skills, is there enough family members to provide care in the home?)**
- Identify if patient could benefit from specialized palliative care services or require home care services in the home **(IPCP)**
- Home Care IPCP nurses will proactively help you develop a plan for Expected Death in the Home **(EDITH)** and ensure timely access to ***"PEI terminal drug kit"*** if needed for a home death
- **Plan for Home Care P-IPCP early**, ensuring proper resources are in place; particularly if you are planning a home death

STEP 3: PLAN/MANAGE - Consult/Referrals

- ☐ Resources to support patients and families. Connect with the P-IPCP to access support if needed:
  - P-IPCP (PPSv2 ≤ 50/ECOG≥2)
  - Nutrition/Dietitian
  - Physical/Occupational Therapy
    - Walker/commode/hospital beds
  - Spiritual Services/Clergy
    - Dignity therapy
  - Social Work
    - Help with GOC/counselling/caregiver support
  - Home Support Services
    - Respite
  - Other Community Support Services
    - Meals-on-Wheels
  - Hospice PEI
    - Volunteers

Critical Importance of Communication

Six key components

1. Talking with patients in an honest and straightforward way.
2. Willing to talk about dying: Not abandoning/avoiding the dying patient.
3. Giving bad news in a sensitive way: Balancing being realistic with maintaining hope.
4. Listening to patients.
5. Encouraging questions.
6. Sensitive to patients readiness to talk about death.

Weinrich et al. Communicating with dying patients within the spectrum of medical care from terminal diagnosis. AIM 2001; 161: 868-874; Curtis, J Gen Intern Med 2000; 16:41

When to Hold ACP Conversations

- Patients often give you an opening…
- Patient history form/intake assessment
- Annually for all adults: “I talk with all my patients about this and we talked a little about this last year…”
- Part of chronic disease management: “Hope for the best but plan for the worst…” "This illness can have a fairly predictable (or fairly unpredictable) course…here are some things you need to think about ahead of time…"
- Following emergency department/hospital admissions: “I understand you have been in the hospital. What did the doctors say?”
- An Advance Care Plan ensures that the patient's wishes would be listened to no matter who is present

https://www.princeedwardisland.ca/en/information/health-pei/advance-care-planning

You will be a better communicator if you…

- Assess understanding: “What you understand about your illness and what is going on right now?
  - What are some of your worries as your disease progresses?
  - What are your biggest fears?
- Assess informational needs: “Are you the kind of person who wants to know all the details about your illness or just an outline?”
- Assess decision-making style: “Do you like to make decisions on your own or as a family?”

Use the serious illness conversation guide!

Serious Illness Conversation Guide

Clinician Steps

Set Up

- Thinking in advance
- Is this Okay
- Hope for the best, prepare for the worst
- Benefit for patient/family
- No decision necessary today

Guide (right column)

Act

- Affirm commitment
- Make recommendations about next step
- Acknowledge medical realities
- Summarize key goals/priorities
- Describe treatment options that reflect both
- Document Conversation
- Provide patient with Family Communication Guide

Conversation Guide

Understanding	What is your understanding now of where you are with your illness?
Information Preferences	How much information about what is likely to be ahead with your illness would you like from me? For Example: Some patients like to know about time, others like to know what to expect, others like to know both.
Prognosis	Share prognosis as a range, tailored to information preferences.
Goals	If your health situation worsens, what are your most important goals?
Fears/Worries:	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes?
	(suggest bringing family and/or health care agent to next visit to discuss together)

Adapted with permission by Ariadane Lab July 2015

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ACP: Process and Intervention

- ☐ Discuss, document, and review goals of care at various transitions
- ☐ Break “bad news” across all transition points
- ☐ Include the family in the process (It will make your life easier: Families are frequently involved in decision-making when a patient deteriorates)
- ☐ Provide information for the patient/family to make informed decisions throughout their illness
- ☐ Plan for acute episodic and crisis events (use the Medication Tracker as a guide!), declining function, and terminal phase management
- ☐ Planning ahead gives patients and family some control

Communication Pearls

All healthcare providers can:

- Initiate or encourage ACP conversations
- Share information
- Contribute to clarifying needs/preferences and establishing goals of care
- Support families to keep talking
- **Clinicians** can be healers through listening, supportive conversations and genuine presence

"The secret of caring for the patient

is caring about the patient." Peabody 1929

ACP Website

https://www.princeedwardisland.ca/en/information/health-pei/advance-care-planning

Advance Care Planning

Advance Care Planning is about having a conversation with your family, friends and your health care provider, so they will know your health care wishes, if you become unable to communicate your own decisions.

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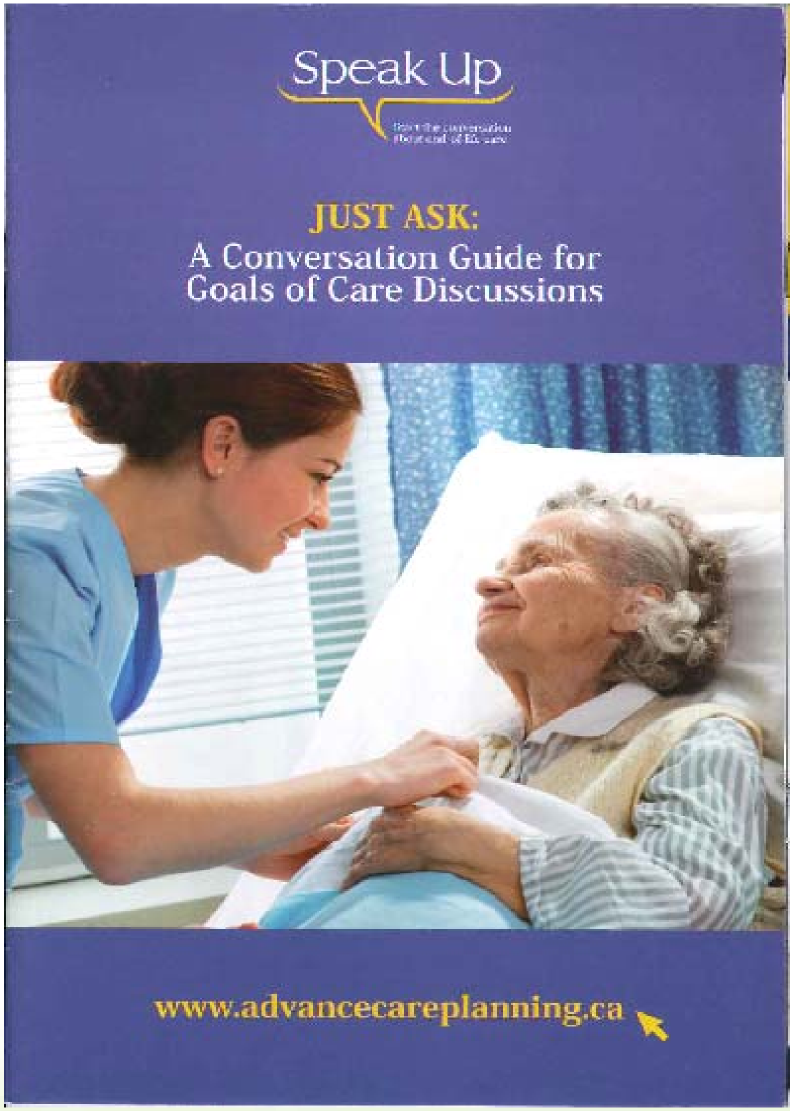
Resources

- Advance Care Planning Online Interactive Workbook
- Advance Care Planning Word List
- Speak-up: Advance Care Planning
- Compassionate Care Benefits

What is Advance Care Planning?

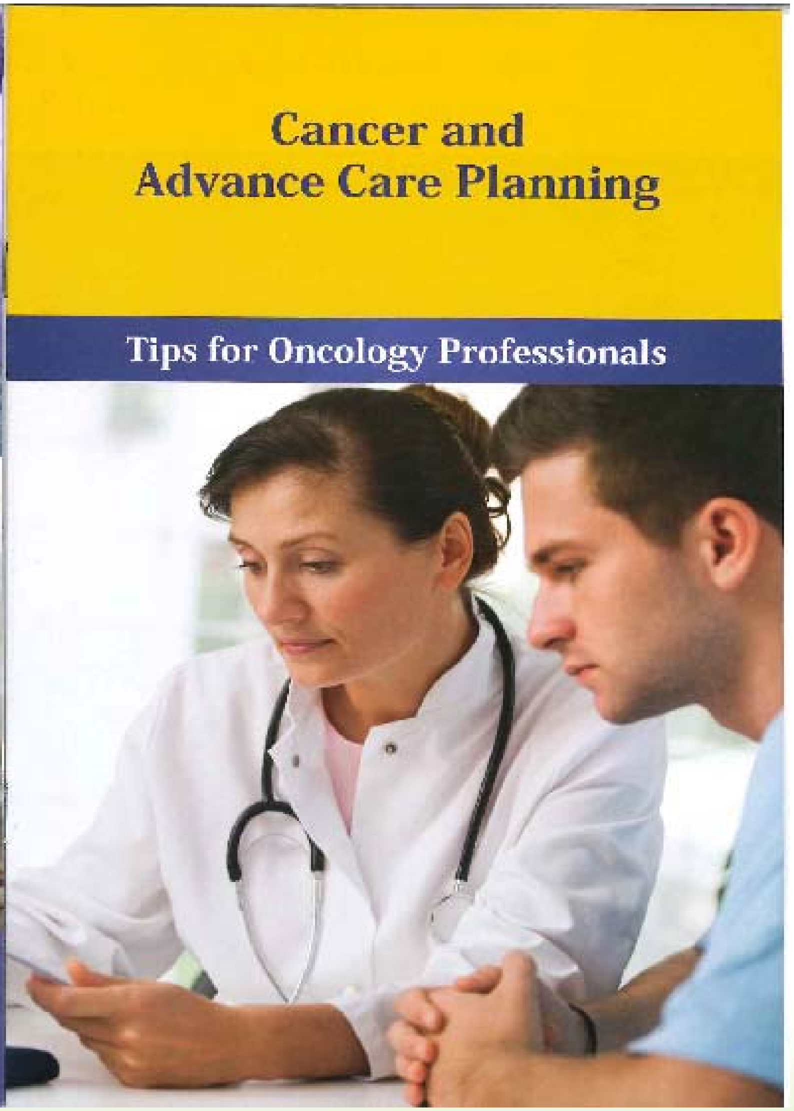
Health Care Provider Resources



Speak Up

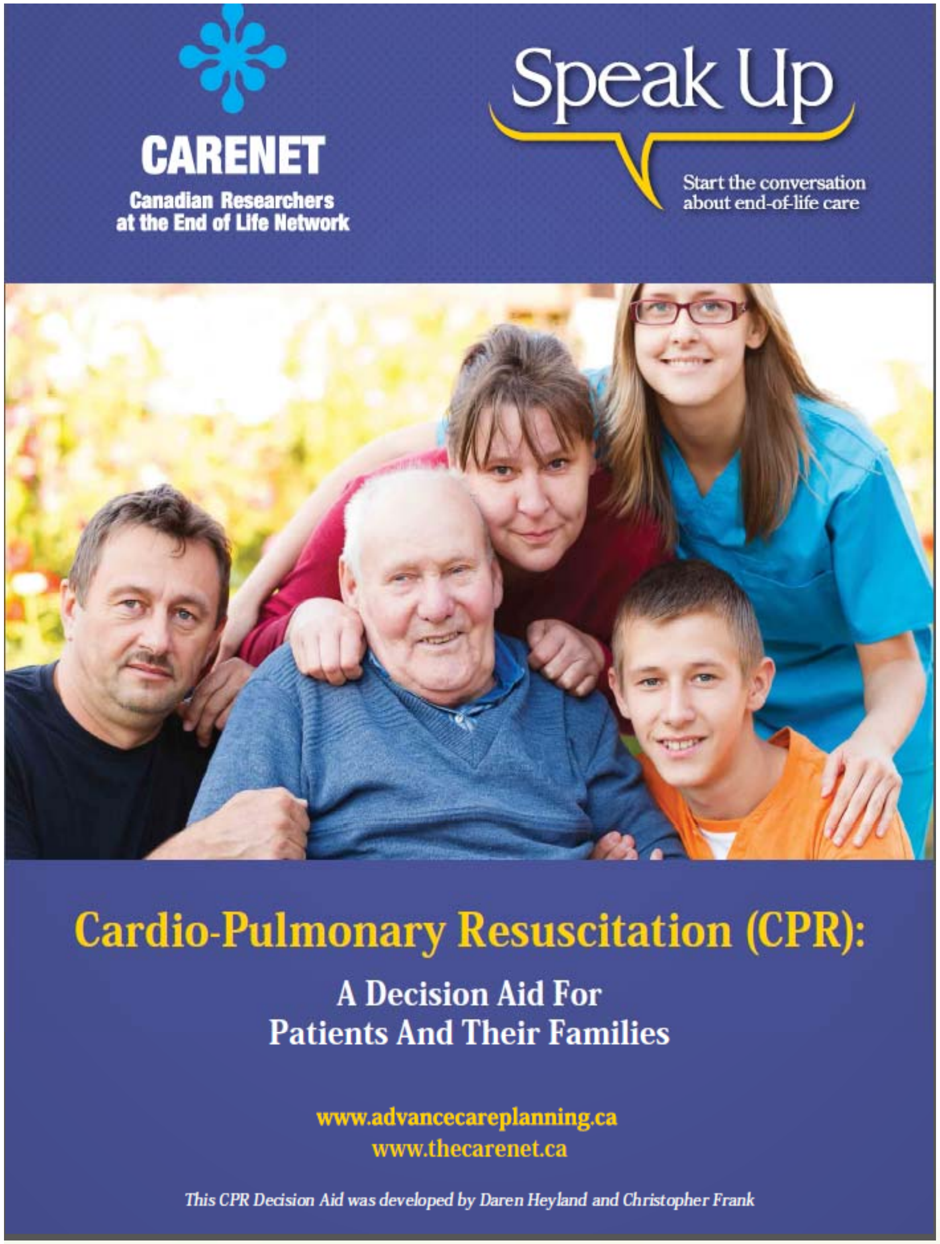
JUST ASK:
A Conversation Guide for
Goals of Care Discussions

www.advancecareplanning.ca



Cancer and
Advance Care Planning

Tips for Oncology Professionals


CARENET

Canadian Researchers
at the End of Life Network

Speak Up

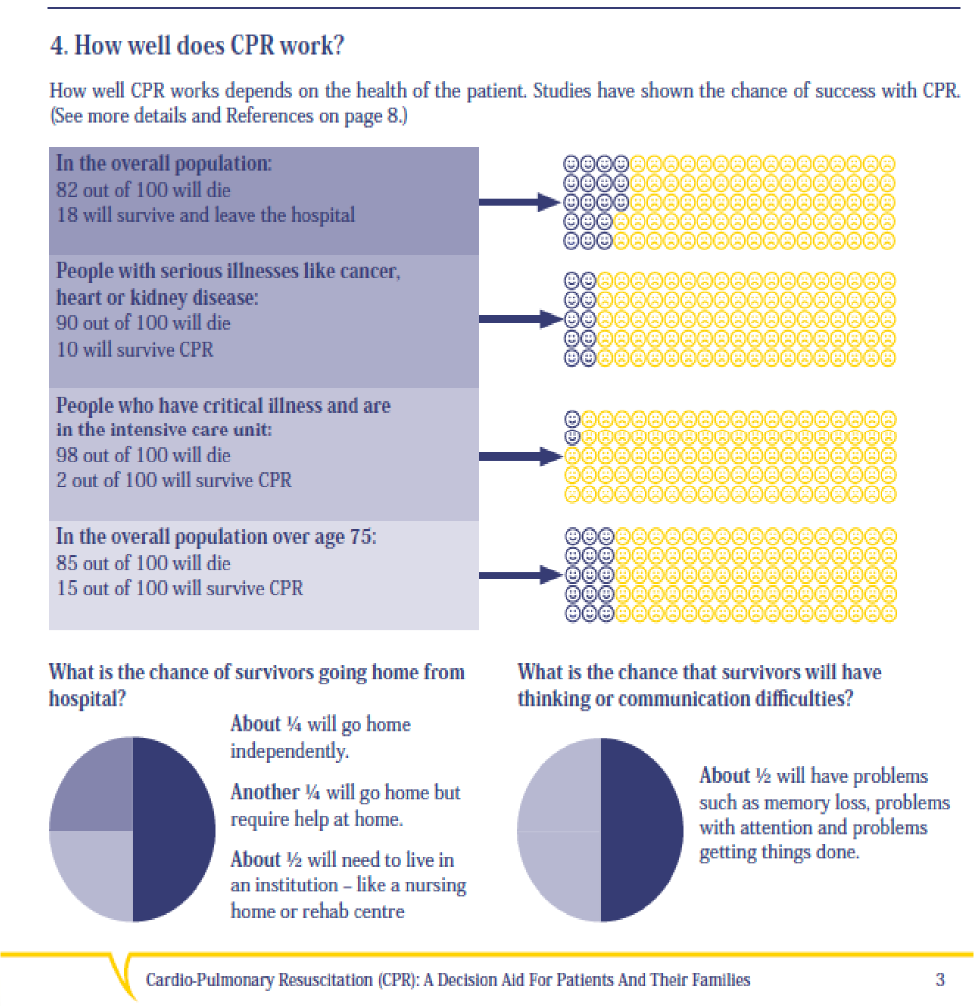
Start the conversation
about end-of-life care

Cardio-Pulmonary Resuscitation (CPR):

A Decision Aid For Patients And Their Families

www.advancecareplanning.ca
www.thecarenet.ca

This CPR Decision Aid was developed by Daren Heyland and Christopher Frank


4. How well does CPR work?

How well CPR works depends on the health of the patient. Studies have shown the chance of success with CPR. (See more details and References on page 8.)

In the overall population:
82 out of 100 will die
18 will survive and leave the hospital

People with serious illnesses like cancer, heart or kidney disease:
90 out of 100 will die
10 will survive CPR

People who have critical illness and are in the intensive care unit:
98 out of 100 will die
2 out of 100 will survive CPR

In the overall population over age 75:
85 out of 100 will die
15 out of 100 will survive CPR

What is the chance of survivors going home from hospital?

About ¼ will go home independently.

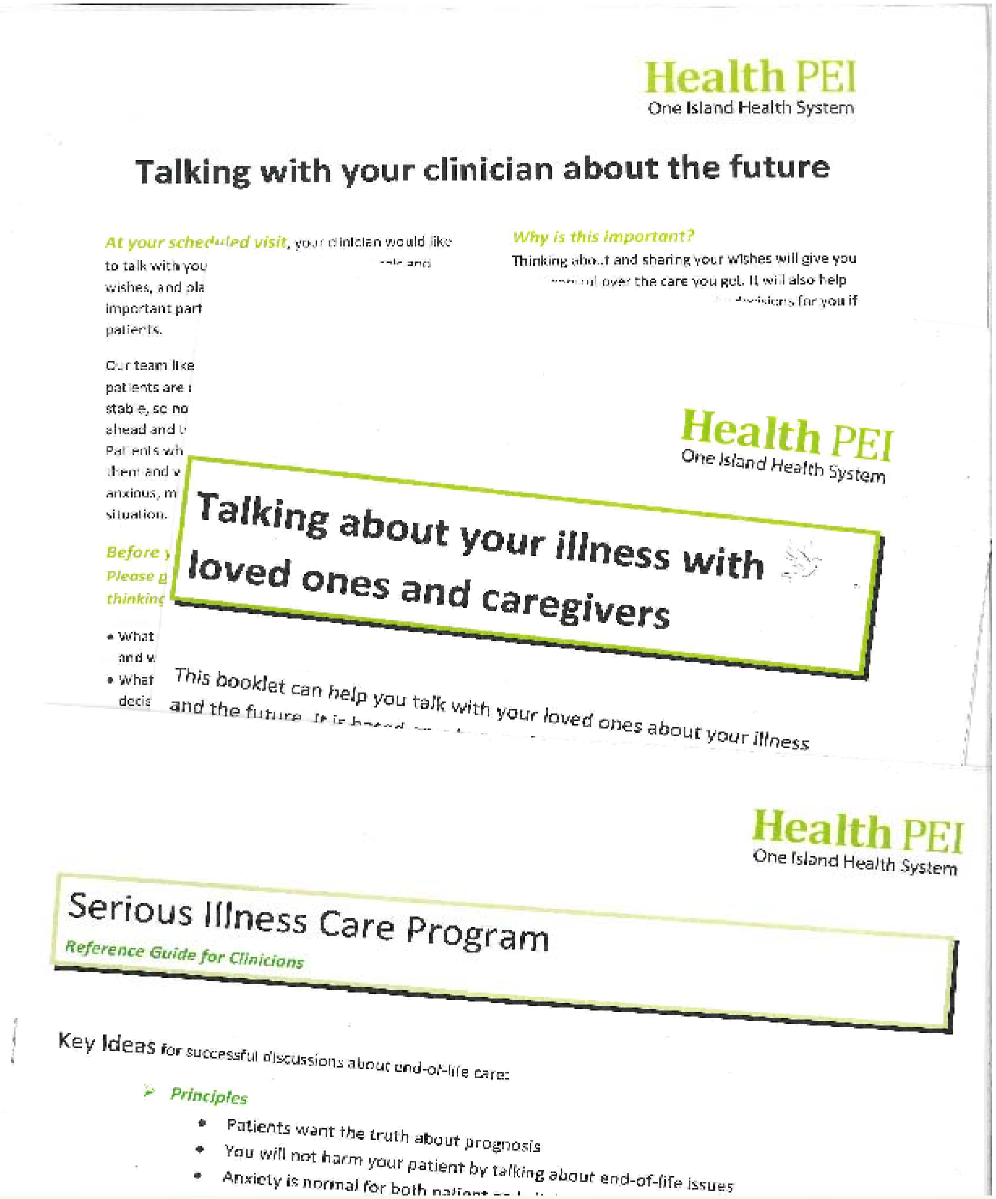
Another ¼ will go home but require help at home.

About ½ will need to live in an institution – like a nursing home or rehab centre

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

About ½ will have problems such as memory loss, problems with attention and problems getting things done.

Cardio-Pulmonary Resuscitation (CPR): A Decision Aid For Patients And Their Families 3



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Talking with your clinician about the future

At your scheduled visit, your clinician would like
to talk with you
wishes, and pla
important part
patients.

Our team like
patients are
stable, so no
ahead and t
Patients wh
them and v
anxious, m
situation.

Before y
Please g
thinking

- What
  and w
- What
  decis

Why is this important?
Thinking about and sharing your wishes will give you
over the care you get. It will also help
decisions for you if

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Talking about your illness with loved ones and caregivers

This booklet can help you talk with your loved ones about your illness and the future.

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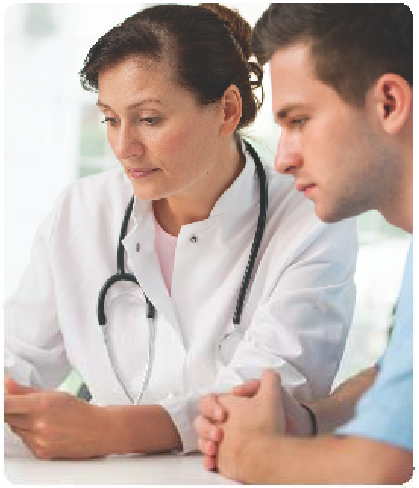
Serious Illness Care Program

Reference Guide for Clinicians

Key Ideas for successful discussions about end-of-life care:

- *Principles*
  - Patients want the truth about prognosis
  - You will not harm your patient by talking about end-of-life issues
  - Anxiety is normal for both patient

Why should you encourage Advance Care planning conversations?



You have a relationship with your patients and they trust you. This allows you to initiate the discussion and provide education about the importance of advance care planning.

- You have knowledge and expertise about their illness.
- Research shows us that advance care planning:
  - Improves quality of life and quality of end-of-life care;
  - Reduces stress and anxiety for patients, families and caregivers;
  - Improves communication between patients, families and the health care team; and
  - Reduces strain on the health care system.

Advance Care Planning is a process of reflection and communication. It is a time for patients to reflect on their values and wishes, and to let others know what kind of health and personal care they would want in the future if they became incapable of consenting to or refusing treatment or other care. It involves having discussions with family and friends – especially their Proxy/Substitute Decision Maker(s) – who is the person (or people) who will provide consent or refusal of consent for care and treatment if the patient is mentally incapable.

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

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www.healthpei.ca/advancecareplanning

(continued...)

Patient Resources

Speak Up

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Advance Care Planning provides guidance, confidence and strength to those close to you in the event that you become too ill to make health care choices on your own. The time to prepare your Advance Care Plan is now.

Please visit
www.healthpei.ca/advancecareplanning
or see our new interactive
online workbook at
www.advancecareplanningpei.ca

Ce dépliant est également offert en français.

Cut off and keep in wallet

I have a Health Care Directive and a Proxy/Proxies who can speak for me if I am unable to communicate my wishes regarding health care and treatment:

Name of Proxy/Proxies: ______________________

Relationship to me: ______________________

Phone # of Proxy/Proxies: ______________________

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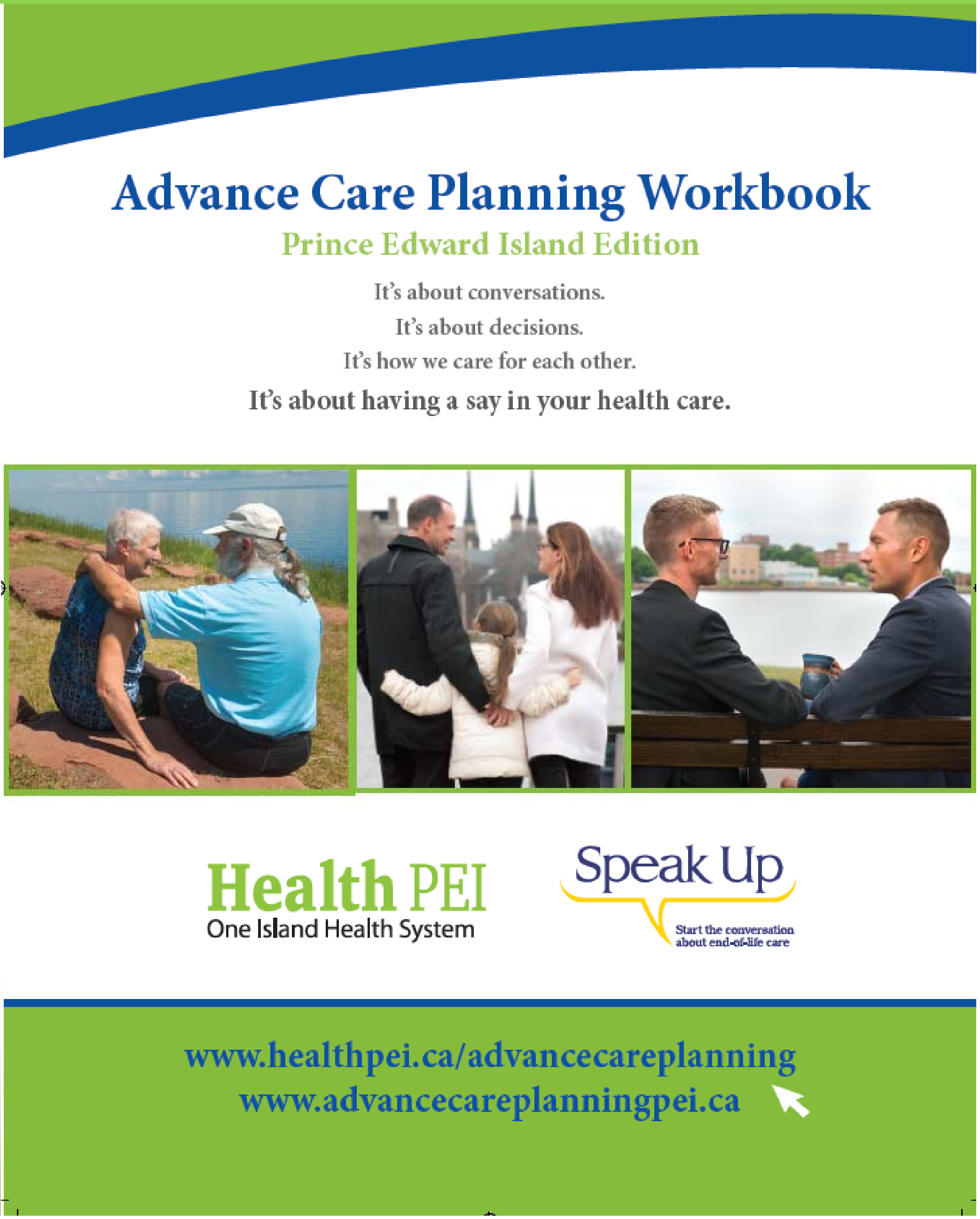
Wallet Card



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.

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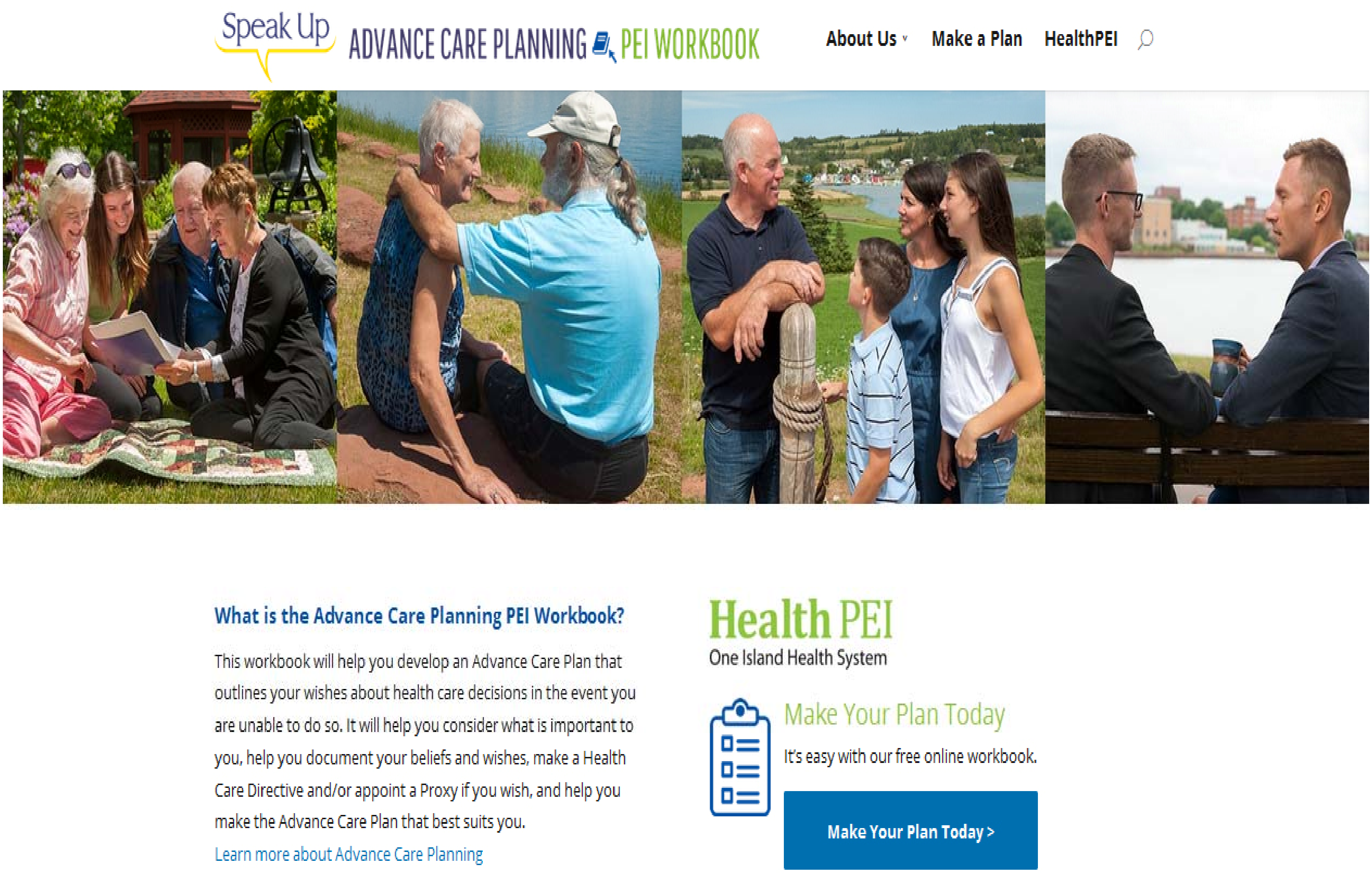
Speak Up
Start the conversation about end-of-life care

www.healthpei.ca/advancecareplanning
www.advancecareplanningpei.ca

On-Line ACP Interactive Workbook
www.advancecareplanningpei.ca/



What is the Advance Care Planning PEI Workbook?

This workbook will 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 consider what is important to you, help you document your beliefs and wishes, make a Health Care Directive and/or appoint a Proxy if you wish, and help you make the Advance Care Plan that best suits you.

Learn more about Advance Care Planning

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Make Your Plan Today

It's easy with our free online workbook.