



Coming full circle

Planning for your care

Ensure your wishes are heard and respected.

Ensure your wishes are heard and respected.

Coming Full Circle: Planning for your care helps you to reflect on your values, beliefs and wishes for care and to share this information with your loved ones and healthcare providers before a medical crisis happens. It may not be easy to think about, but doing so now can help you, your family and your healthcare providers ensure you get the care you want.

This booklet will help you think through what is important to you, what concerns you have, and who you would want to make decisions for you if a time comes when you can't make decisions for yourself.





How to use this booklet

This will help you to organize your thoughts and feelings about what is important to you. You can go through this booklet by yourself or complete it with a trusted friend or family member(s). You can also use it as a guide when talking with your doctor, nurse and other healthcare providers about your wishes for care.

Take your time reading through the booklet. You can write your answers down if you like. You do not have to answer all of the questions at one time. Please go through the questions at your own pace.

This is not a legal document and cannot be used to provide consent for treatments. It is not a will and has nothing to do with the distribution of your property or finances. It is a guide to help you start having conversations about your care.

How can this booklet help you and your family?

Preparing for future health care

When people get difficult health news, they often say that they only heard a small part of what the doctor or nurse said. The rest is just noise. There is so much information, so many decisions, and so much to think about. Even simple decisions can be very hard. If you have already completed this booklet, it can make a difficult time for you and your family a bit easier. Making these decisions now can help you have other discussions about care and treatment.

If you can't speak for yourself

If you get sick or have an accident and cannot speak for yourself, making these decisions and talking with family ahead of time can:

- Let family and healthcare providers know what is important to you.
- Give you a say in who provides care to you and who does not provide care to you.
- Give you peace of mind that your wishes are known.
- Give you a say in where care is provided to you.
- Help your loved ones avoid conflict and stress when decisions about your care must be made.
- Help to develop trust with healthcare providers.

Taking back is really important, retrieving is very important, reclaiming is very important for us to take back what we lost... It allows us to be stronger for the future. It allows our young people to be stronger, to have more hope for the future and to have a better life, bolder dreams, and bigger aspirations for their own future.



Getting started: Thinking about what is important to you

First, think about the following: What is important to me? How do I want to live my life? These answers will help you to prepare to talk with your loved ones and healthcare providers.

Some things to think about:

Who are the important people in your life?

(This could include family, friends, spiritual or religious guides.)

What makes your life meaningful?

(For example, spending time with your family, being able to work, practising your spiritual beliefs, being outside, sewing and beading, hunting and fishing.)



Do you have spiritual, cultural or religious beliefs that are important to you?

What have you learned about life that you would want to share with others?

What are you most afraid of?

Thinking about your care

Next, think about your wishes for your care and what you value the most. How would you like your physical, emotional, social, and spiritual needs met?

Some things to think about:

If you were to get very sick, what would matter the most to you?

(For example, being able to spend time with your children or having your grandchildren near you; being in the comfort of your own home; having people around you who speak your language; being pain free; receiving excellent medical care; keeping your dignity.)



“I want to be looked after and be able to make my decisions and have everything prepared... I don’t want to burden my children. I want them to just be able to come and relax with me and spend time. I don’t want to go on machines or anything. When it is my time to go, I just want to go... I want to go peacefully.”



If you were to get very sick, what would you be the most concerned about?

(For example, making sure that your children are taken care of, needing to leave your community to receive care, not being able to work.)

I follow a traditional lifestyle and that would be part of my expectations in my care – that it would be woven into Western interventions. That might mean bringing plant medicines, teas or even ceremonies into that context. I would want my healthcare providers’ support to do that.



Answer the questions below by circling the answer closest to how you feel.

The statements at each end of the scales represent two opposite feelings. You can choose 1 or 4 as your answer. Or, if you do not completely agree with 1 or 4, you can circle either 2 or 3 depending on which answer is closer to how you feel.*

If I were to get very sick, I would...

1	2	3	4
<i>Want to know only the basics about my illness and treatment</i>		<i>Want to know all of the details about my illness and treatment</i>	

1	2	3	4
<i>Want my healthcare providers to make decisions about what they think is best for me</i>		<i>Want to have a say in every decision that needs to be made</i>	

1	2	3	4
<i>Not want to know how long I have left to live</i>		<i>Want to know my doctor's best estimate of how long I have to live</i>	

1	2	3	4
<i>Want to receive medical treatments for as long as possible, no matter how uncomfortable the treatments are</i>		<i>Choose to stop medical treatments if they impacted my ability to enjoy my life</i>	

1	2	3	4
<i>Not want traditional healing and medicine as part of my care</i>		<i>Want traditional healing and medicine as part of my care</i>	

1	2	3	4
<i>Want to spend my last days in the hospital</i>		<i>Want to spend my last days at home or in the community</i>	

1	2	3	4
<i>Want my loved ones to follow my wishes exactly, even if they do not agree with them</i>		<i>Want my loved ones to do what brings them peace, even if it goes against my wishes</i>	

1	2	3	4
<i>Want to live as long as possible even if it means leaving my community</i>		<i>Want to stay in my community even if it may shorten my life</i>	

1	2	3	4
<i>Want to be left alone</i>		<i>Want my loved ones to be around me</i>	

1	2	3	4
<i>Want to be kept alive with machines</i>		<i>Not want to be kept alive with machines if I won't recover</i>	

1	2	3	4
<i>Not want my loved ones to know anything about my health</i>		<i>Want my loved ones to know everything about my health</i>	

*These scales were adapted from The Conversation Project, developed by the Institute for Healthcare Improvement, www.theconversationproject.org

Sharing your wishes

Share your answers from this booklet with the people in your life (mom, dad, child/children, partner/spouse, sister/brother, friend, healthcare provider, Elder or spiritual guide, or others) to ensure that everyone is aware of your wishes. If there are things that you and your loved ones disagree on, it is helpful to know this and talk about it before a crisis happens.

Here are some ways to start the conversation:

“I’ve just filled out this booklet called ‘Coming Full Circle.’ It’s about planning 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 got sick.”

“I was talking with the Home Care Coordinator and they encouraged me to think about my future and make a plan in case I got sick. Can you help me?”

“One of my biggest fears is that if I got sick, my children/family would argue with each other about what is best for me. I want to share with you what I want so that everyone understands.”

“I was thinking about what happened to _____ when they got sick, and it made me realize that I would never want those things to happen to me.”

Making sure your wishes are honoured

Now that you have shared your wishes with the people in your life, you may want to choose one or two people you feel would honour your wishes and be able to make future health and life decisions on your behalf. This person(s) would speak for you and may be asked to give consent for treatments if you are not able to speak for yourself.

In some provinces/territories, the person(s) who speaks for you might be called a substitute decision-maker, healthcare proxy or health representative or agent.

When choosing who will speak for you, think about the following:

- Do you trust this person(s) to make decisions for you?
- Do you think this person would be willing to speak for you if you can not speak for yourself?
- Does this person meet the legal requirements to speak for you (varies across provinces/territories)?
- Can this person(s) talk clearly with your healthcare team?
- Can this person(s) make difficult decisions in stressful times?
- If you have more than one person speaking for you, have you included each person in the decision-making conversations?



“I have my travelling blanket for when I leave... I have friends who are going to give me my cedar bath and they are going to prepare me. That has already been arranged and looked after.”

Here are some additional questions that you may want to talk to them about:

What kind of medical treatments do you want or not want (for example, CPR or other resuscitation if your heart stops, breathing machine, feeding tubes) if you are unlikely to survive or to live independently after treatment? Why would you want or not want these treatments?

If you have to leave your community for care, who would you like to accompany you? What items would you like to take to remind you of home and family? What spiritual or religious items would you wish to have?

Who do you want or not want providing your care?

Do any of your loved ones disagree with your wishes?

Are there things that you still need to talk to your loved ones about?

(For example, getting your finances together, deciding who is going to take care of your children/grandchildren, preparing for ceremonies.)



I have discussed my wishes for future health and treatment with the person(s) named below. The person(s) who will speak for me if I am not able to speak for myself is:

Name: _____

Relationship to me: _____

Phone number or email: _____

Name: _____

Relationship to me: _____

Phone number or email: _____

I have also discussed my wishes with the following people:

Name: _____

Relationship to me: _____

Phone number or email: _____

Name: _____

Relationship to me: _____

Phone number or email: _____

Note: Some provinces and territories require you to complete certain legal forms to identify your “spokesperson.” Find out more about resources in your province or territory by visiting www.advancetcareplanning.ca and clicking on “Your Province/Territory.”

Remember: Once you have selected the person who will speak for you, let them know if your wishes, values, and beliefs change over time. Continue to talk with other loved ones and your healthcare providers to ensure everyone understands your wishes. They will then be better able to support the person speaking for you when decisions about your care need to be made.

You can always change your mind about your wishes for care as things change. You can also decide to choose a different spokesperson(s) at any time. It is important to talk about any changes with your loved ones.

One of the teachings of one of my Elders was ‘When I go, if you need me, I’m in the wind.’ When I thought about that, what I find really interesting is that everything that has ever lived on this Earth has left a breath in the wind. No wonder we can see spirits and hear them.



ADDITIONAL RESOURCES

For more information on advanced illness, advance care planning, palliative care, end-of-life care and grief, please visit:

Canadian Virtual Hospice www.virtualhospice.ca

Living My Culture www.livingmyculture.ca

Improving End-of-Life Care in First Nations Communities Project
www.eolfn.lakeheadu.ca

Speak Up! www.advancecareplanning.ca

ACKNOWLEDGEMENTS

This is an original document created by the Canadian Virtual Hospice. The project team would like to honour the members of the Elders' Circle for sharing their wisdom and knowledge with us throughout the development of this resource.

Elders and Knowledge Carriers

Helen Gartner

YT

Louise Halfe

SK

Peter Irniq

ON

Mary Jane Kavanaugh

ON

Rosella Kinoshameg

ON

Donna Loft

ON

Betty McKenna

SK

Albert McLeod

MB

Gerry Oleman

MB

Roberta Price

BC

Ruth Mercredi

NT

Stella Johnson

BC

Ella Paul

NS

Jeroline Smith

MB

In addition, we would like to acknowledge the following individuals, organizations, and projects whose knowledge and resources contributed to this document.

Holly Prince, Project Manager

Lakehead University

Indigenous Voices National Advisory Committee

(a list of names and organizations can be found at www.livingmyculture.ca)

Canadian Hospice Palliative Care Association

www.advancecareplanning.ca.

Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University. (2015). Developing Palliative Care Programs in First Nations Communities: A Workbook, Version 1, www.eolfn.lakeheadu.ca.

The Conversation Project for providing us with permission to extract, adapt, and use material located in the following document:

The Conversation Project: An initiative of the Institute for Healthcare Improvement, www.theconversationproject.org/.

Licensed under the Creative Commons Attribution-ShareAlike 4.0

International License, <http://creativecommons.org/licenses/by-sa/4.0/>



CANADIAN PARTNERSHIP
AGAINST CANCER



PARTENARIAT CANADIEN
CONTRE LE CANCER



Ontario Health **Santé Ontario**
Cancer Care Ontario Action Cancer Ontario



CancerCare Manitoba
Action Cancer Manitoba



Manitoba Region
First Nations
Home & Community
Care Program



This document was prepared by the Canadian Virtual Hospice. It is intended to provide general information only. Every effort has been made to ensure the accuracy of the information. The contents do not constitute medical or legal advice and should not be relied upon as such. If you have questions about your health or medical issues, speak with a healthcare provider. If you have questions about your legal rights or someone else's, speak with a lawyer or contact a community legal clinic.

Production of this brochure has been made possible through collaboration and financial support from the Canadian Partnership Against Cancer Corporation and Health Canada. The views expressed herein do not necessarily represent the views of Health Canada or the Canadian Partnership Against Cancer.

Aussi disponible en français :
www.PortailPalliatif.ca/BouclerLaBoucle