

Advance Care Planning and Goals of Care

A Guide for Cancer Patients and their Families

Nova Scotia Edition



NOVA SCOTIA
Hospice Palliative Care
ASSOCIATION



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

www.nshpca.ca



A diagnosis of cancer is life altering.

Cancer treatment plans and outcomes vary significantly based on your particular diagnosis and health. At some point in your cancer journey, your care team will ask you about the types of decisions you may wish to make in terms of your treatment and how these decisions would be made if you couldn't speak for yourself.

This is lot to think about and it can be difficult to know where to start. This booklet will help you get started. It will help you and those closest to you work with your care team and provide additional resources that you may want to consult.





Advance Care Planning and Goals of Care

What is advance care planning?

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 what kind of health and personal care you would want in the future if you could not speak for yourself. It involves deciding who would speak for you—that is who would provide consent, or refuse consent, for treatment or other care. It also helps you to think about the type of health and personal care you would want should your illness become more serious and/or you are approaching the end of your life.

Advance care planning can be done at any time. You and your family may have talked about some of your values and wishes for future health care, but more in the context of “what if something happens to me?”

Advance care planning is:

- An opportunity for you to reflect on your values, beliefs and wishes for care;
- Conversations with family and friends to let them know your future health and personal care wishes in case you become unable to speak for yourself;
- Deciding on a substitute decision maker (you may also hear this person referred to as your delegate or proxy) – someone who will make decisions if you become unable speak for yourself;
- A way to give your loved ones peace of mind in making decisions about your care and treatment during a difficult time.

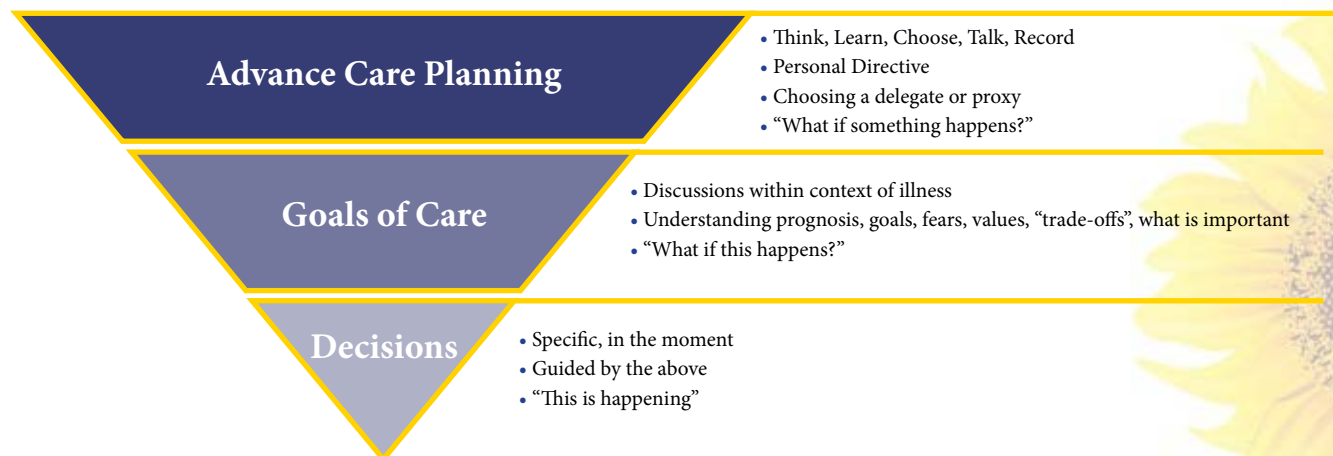
What are Goals of Care?

Goals of care conversations occur with your healthcare team. These conversations provide an opportunity to incorporate any advance care planning you may have done into specific plans for your cancer care and treatment. It can include medical orders for specific treatments, or for the use or non use of life-sustaining measures.

Goals of care conversations can occur at anytime during your treatment and may occur more than once if your condition changes. To help prepare you for a goals of care conversation your doctor or healthcare team may have provided you with the following documents:

- **“Talk with your clinician about the future.”** This is to help prepare you to have a goals of care conversation with your healthcare team. It will help you to start thinking about what is important to you in relation to the care that you will receive.
- **“Talking about your illness with loved ones and caregivers”** is designed to help you talk to your loved ones about your illness and the future.

What do we mean by...



This document will guide you through the advance care planning process so that you may be better prepared for goals of care discussions with your health care team, and those close to you.



Advance Care Planning: Let's Get Started

1. THINK about what's right for you.

Begin by reflecting on your values, beliefs and understanding about your health, certain medical procedures and what you might want, should your cancer diagnosis change, get worse or should you be approaching the end of your life.

Some questions you may want to ask yourself:

- What personal beliefs influence my healthcare wishes?
- Have I had past experiences with family or friends where healthcare decisions had to be made?
- What types of things make me happy and provide me with quality of life: being able to be independent, being able to communicate with my family, enjoying a good meal, going outside?
- What would a "good death" mean to me: Would I prefer to die at home, in a hospital? What types of services would I and those caring for me need to support my choice? Are there family members, spiritual providers or other companions that I would like with me?
- Are there conditions under which I do or do not want certain treatments or procedures?
- Do I have any fears about my illness or death that I may want to discuss with my healthcare team?

5 STEPS to Advance Care Planning:

THINK • LEARN • CHOOSE
TALK • RECORD



1. THINK
about what's
right for you.



2. LEARN
about medical
procedures.



3. CHOOSE
who will make
decisions for
you.



4. TALK
about your
wishes.



5. RECORD
your wishes.





2. LEARN about your condition and related medical procedures.

Even if you're feeling well, it's still important to make sure your health care team knows your wishes. In order to be able to plan for the future you will need to understand your prognosis and what to expect from your illness in the future. It will be of benefit to know what is possible in terms of medical treatment, what to expect, and what you may need to do to assist in your treatment. (take time off work, exercise, etc.)

Some questions you may want to ask your healthcare team:

- “Can you tell me what I can expect from this illness? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?”
- “What can I expect about my ability to function independently?”
- “What are some possible big changes in my health that my family and I should be prepared for?”
- “What can I expect to improve (or not improve) if I choose this course of treatment, or another course of treatment?”
- “Are there conditions under which I do or do not want certain treatments or procedures?”
- “What can I expect if I decide to do nothing?”

Discussing some of these issues with your healthcare team will help prepare you to work with your providers to develop formal treatment plans and goals of care.

Remember, you can discuss these types of questions at any time during your illness and treatment, you do not have to wait until your healthcare team requests a formal appointment with you to discuss goals of care.



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3. CHOOSE who will make decisions for you.

One of the most important choices you will make in terms of your health care is choosing who will make decisions for you if you are unable to speak for yourself. He or she will give or refuse consent to treatments proposed by a health practitioner if you are incapable of doing so yourself. This person can also make decisions regarding your personal care. Personal care decisions include decisions about nutrition, hydration, shelter, clothing, hygiene, comfort, recreation, support services, health care and placement.

You may hear this person referred to as a substitute decision maker, a statutory decision maker or proxy. In Nova Scotia the legal term for this person is “delegate.” Although the terms may be different, they all refer to the individual that you have appointed to make health and personal care decisions for you when you are unable to do so.

How do you choose?

There are a few questions you may want to consider in selecting your delegate:

- Do I trust this person to make healthcare decisions with my healthcare team based on my values and wishes?
- Are they able to communicate clearly?
- Would they be able to make difficult decisions in stressful situations?
- Is this person willing and available to speak for me if I were unable to make healthcare decisions for myself?

Before you choose someone, you need to understand what the law says about what you must do to appoint someone as your delegate. You also need to know what happens if you do not appoint someone.

In Nova Scotia, the Personal Directives Act provides a framework for choosing a substitute decision maker, known as a delegate, and for completing a written document outlining your health and personal care wishes. This document is called a Personal Directive. You can find more information at www.novascotia.ca/just/pda.

However, some key points about the Personal Directives Act and selecting a delegate are:

- Your substitute decision maker/delegate must follow any instructions you may have written in your personal directive. However, she or he can also consider any conversations you may have had since writing the personal directive. If the delegate believes that certain medical advances or technologies would have impacted your instructions if you had known them, s/he

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3. CHOOSE who will make decisions for you. (cont'd)

should consider this when working with your healthcare team to decide on your care and treatment.

- If you do not have any written instructions, your delegate must make a decision they believe you would have wanted based on what they know about your values and beliefs and any other wishes. If your delegate does not know what you have wanted, they must act in your best interest.
- You can only name one person to be your delegate. However, you can delegate different kinds of decisions to different people. For example you can designate your spouse to make healthcare decisions for you, but you can designate your sister to make the decision regarding nursing home placement or personal care decisions. You can also instruct your delegate to consult family members or friends before making a decision. If you wish, you can also designate someone to act as an alternate for your delegate, in case your delegate cannot be reached or is no longer capable of making decisions for you.
- Your delegate can be anyone you wish, a neighbour, friend, relative, spouse etc. However, they must be over the age of 19. This person should know you well, be willing and able to make complex decisions on your behalf and be able to be contacted.
- If you become incapable of making decisions for yourself and you have not named a delegate to make decisions for you, and you do not have a written personal directive in place, the Personal Directives Act provides a substitute decision maker for you. The Act requires health care providers to begin asking your relatives, beginning with those most closely related to you (spouse or parent). His or her decision making is more limited than the person you would have appointed. If a relative cannot be found, health care providers will turn to the public trustee. More information on this process can be found at www.novascotia.ca/just/pda.
- If you do not wish to name anyone to make decisions for you, but want to set out certain instructions for healthcare providers to use, you can write down the instructions and/or talk to your healthcare providers. However, it is very difficult to write instructions that are specific to every situation. If your instructions are unclear or not applicable to a specific situation then your healthcare providers would turn to your statutory decision maker.

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4. TALK about your wishes.

It is important to discuss your wishes with your loved ones, your family physician and your cancer care team.

Your future delegates or statutory decision makers may find the conversation difficult, or they may be relieved to know exactly what kind of care you would like to receive. Every attempt at the conversation is valuable. This is the first of many conversations—you don't have to cover everyone or get everything right the first time.

If you do decide to put written instructions in a Personal Directive, make sure that your future delegates have a copy of your document.

Do not forget to tell others too, such as your doctor, other healthcare professionals involved in your care, your lawyer, and other family members or friends. Let your doctor know who you have appointed to be your future delegate and that you have shared your wishes, goals and values with them.

Conversation starters:

"I need your help with something."

Remember how someone in the family died—was it a "good" death or a "hard" death? How will yours be different?

"I was thinking about what happened to _____, and it made me realize..."

"Even though I'm okay right now, I'm worried that _____, and I want to be prepared."

"I need to think about the future. Will you help me?"

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In Nova Scotia, written documentation of your health and personal care wishes is known as a Personal Directive.

Personal Directives can consist of simply naming a delegate who will make decisions for you, or you may wish to provide instructions about relevant health and personal care scenarios that are important to you. These written instructions can be very detailed or they can speak more broadly to your wishes and values regarding your health, personal care and quality of life.

More information can also be found at the Nova Scotia Department of Justice Website at www.novascotia.ca/just/pda. The information also includes sample Personal Directive Templates.

You do not have to use the templates from the website to write your personal directive, they were developed as guides. You can write your instructions on any piece of paper, as long as it is signed, dated and witnessed appropriately. You also do not need a lawyer to write a personal directive, although you may wish to consult one depending on your personal circumstances.



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Congratulations!

You have taken the first step in ensuring that you receive health and personal care that meets your needs, values and wishes. Occasionally, you will need to revisit and revise the advance care planning process and any written documents. Some times to consider this review are:

- When there is a change in your health status
- When there is a change in your treatment location
- When life changes (marriage, divorce, deaths)
- Annually

Where to go for more information:

More information on advance care planning and other end-of-life issues relevant to Nova Scotia can also be found at the Nova Scotia Hospice Palliative Care Association website at www.nshpca.ca.

The NSHPCA also has a more detailed workbook on advance care planning which is available through the website above.

More information on the Nova Scotia Personal Directives Act can be found at: the Nova Scotia Department of Justice Website at www.novascotia.ca/just/pda.

More information on living with cancer can be found through Cancer Care Nova Scotia Website at: www.cancercare.ns.ca/en/home/patientsfamilies/default.aspx





The Nova Scotia Hospice Palliative Care Association is the provincial voice for hospice palliative care in Nova Scotia. The association works to bring awareness to end-of-life issues facing Nova Scotians through education, public engagement and partnerships.

The Association is secretariat, chair and founding member of the Quality End of Life Care Coalition of Nova Scotia, a group of 22 health and community organizations that believe all Nova Scotians have a right to quality end of life care, which allows them to die with dignity, free from pain, surrounded by loved ones in a setting of their choice.

The information provided within this guide 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 might receive or the need for such advice.

If you have questions about your health or about medical issues, 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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For more information about advance care planning, please visit our website at:

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www.nshpca.ca

e-mail: info@advancecareplanning.ca

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Speak Up in Nova Scotia is coordinated by the Nova Scotia Hospice Palliative Care Association.





FOR MORE INFORMATION about advance care planning, please visit our website at: www.nshpca.ca