

# Cancer and *Advance Care Planning*



**You've been diagnosed with cancer.  
Now what?**

You have a lot to think about and it can be difficult to know where to start. One important thing you should think about is your *wishes* for your care in case you can't speak for yourself. This is called **advance care planning**.

**Benefits of Advance Care Planning:**

- Peace of mind for your loved ones
- Knowing your voice is heard
- A gift to your family

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## ***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;
- A way to give your loved ones peace of mind in making decisions about your care and treatment during a difficult time.

You may never need an ***advance care plan*** but if you do, your family and other caregivers will appreciate knowing what you would want done next.

# Diagnosis and Treatment Plans



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*Advance care planning is like retirement planning – it is important to start early, even if you don't need it for many years to come.*

*– Health Care Provider*

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You might have a number of questions during the course of your cancer treatment. It's important to discuss them with your doctor and other members of your cancer care team so that you can make informed decisions about your **Advance Care Plan**:

What impact will cancer have on your life?  
What is the likely course?

What are your options if your health quickly gets worse?

- How will the treatment plan start? Is the treatment meant to **cure** the cancer or just make you more comfortable or both?
- What **side effects** or complications could be caused by your treatment?

## What is the best you can hope for with this treatment?

- Are you eligible for a **clinical trial** or experimental treatment?
- How will you know if the cancer has progressed? Will there be any signs or **symptoms**?
- How do we make decisions about whether you should be in hospital or at home?
- Does having advanced cancer change the effectiveness of any other **treatments** you might have in an intensive care unit?

## What options are available to you if you don't want to start or continue treatment?

- What are your options if your health quickly gets worse?
- When would someone consider palliative care? What palliative care services are available in your community?
- What about **life prolonging** or **life sustaining treatments**? How do you decide whether or not to have these **treatments**?

Make sure that you ask these questions throughout your cancer treatment, not just at the beginning. It's important to tell your health care team how much information you would like and what is important to you.

# Advance Care Planning

When you are capable of speaking for yourself, **health care providers** will always speak directly with you. But, should the time come when you cannot speak for yourself, your substitute decision maker and/or your advance care plan will make sure that your voice is heard.

## How Do You Plan?

- Learn about cancer treatments: Some may improve your quality of life; others may only keep you alive longer.
- Think about what's right for you: What are your values, wishes, beliefs and understanding about your care and specific cancer **treatments**?
- Talk about your wishes: It is important to discuss your wishes with your loved ones, your family physician and your cancer care team.
- Choose a substitute decision-maker: Choose someone who would honour and follow your wishes if you can't speak for yourself.
- Record your wishes: It's a good idea to write down or make a recording of your wishes.

***Talking with my family wasn't easy for me. I feel more at peace now that they all know what I want if the day comes when I can't tell them.***

***– Patient***



The following questions can help you identify personal goals, wishes and values to guide your discussions and decisions:

**What is most important to you about your health and the care you receive right now?**

- What makes each day worthwhile?
- What makes you happy?
- How do your decisions about your cancer, your care and your treatment affect your loved ones? Does this change the way you feel about treatment?
- Do you have fears or worries regarding your treatment?
- Do you have a preference regarding location of care (for example, at home, in a health care institution) if your cancer gets worse?
- Is there anything that feels “undone” about your life?
- Who can you rely on to help you through any challenges?
- Do your religious, cultural or personal beliefs affect your decisions?



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*I wish we had made a plan earlier. Things happened really fast, and by the time he was on a ventilator, it was difficult to know what he would have wanted.*

*- Family member*

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# Where can you go for more information about cancer and *Advance Care Planning*?

## Advance Care Planning

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

This website has lots of information and tools to help you make a plan.

The *Speak Up Workbook* can help you explore your values and write down your wishes for care so that you can share them with others. You can also download a wallet card so that others will know who your substitute decision-maker is.

## Newfoundland and Labrador

<http://www.swsd.gov.nl.ca/publications/index.html#seniors>

This is a web link to a booklet that explains how to make an Advance Health Care Directive and appoint a Substitute Decision Maker in Newfoundland and Labrador.

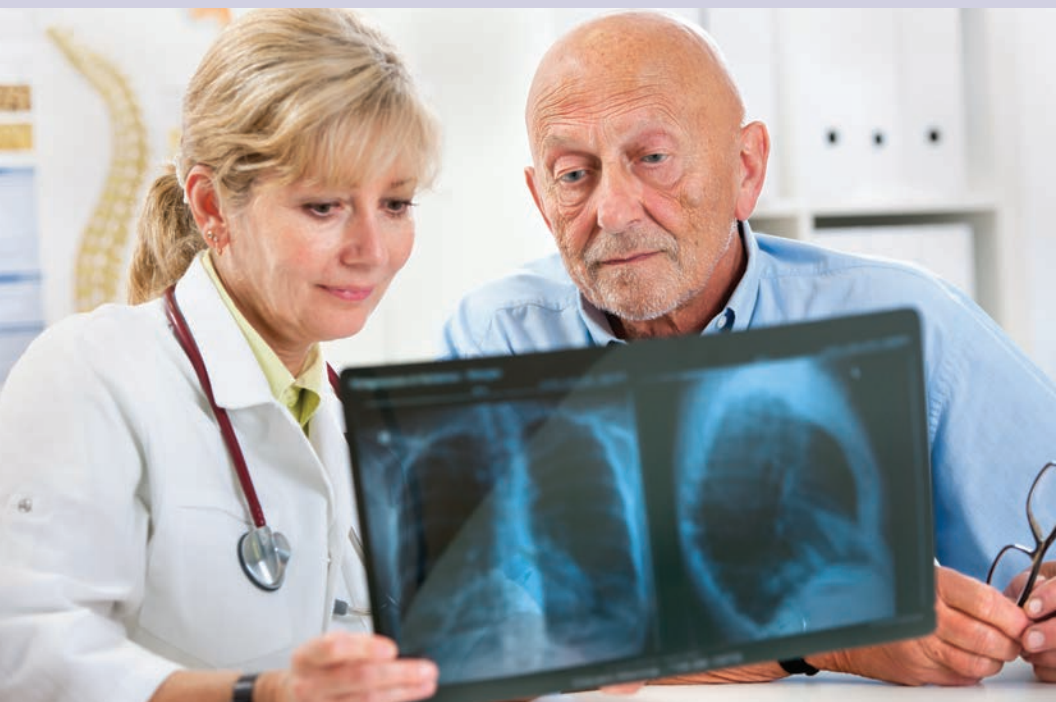
(Note: you must click on “For seniors” and then “How to make an Advance Health Care Directive.”)

Members of your cancer care team, including counsellors, social workers, nurses and doctors, can also tell you about resources in your community, province or territory.

### What could happen if you don't make an *advance care plan*?

- Your loved ones may not be sure what you would want.
- Your loved ones might disagree on what care you would want.

# Definition of Terms<sup>1</sup>



**Advance Care Plan (ACP):** A verbal or written plan to let others know what kind of health and personal care you want if you become incapable of consenting to or refusing treatment or other care. An ACP is based on a process of reflection and considers your values, wishes and beliefs.

**Clinical trial:** The study of new cancer treatments.

**Cure:** The treatment causes the cancer to be eliminated from the body.

**Health care provider/health care professional:** A person licensed, certified or registered in their province or territory to provide health care, such as doctors, nurses and social workers.

**Life sustaining/life prolonging treatment:** A medical treatment that is not meant to cure the cancer but to support how the body is working, such as CPR, fluids, breathing machines or antibiotics.

**Oncologist/Hematologist:**

A doctor who specializes in treating cancer. Some doctors specialize in a particular type of cancer treatment where as others specialize in certain types of cancer. For example, a radiation oncologist specializes in treating cancer with radiation. A hematologist specializes in treating blood cancers.

**Palliative Care:** Palliative care focuses on providing good quality of life – in other words, keeping you as comfortable and free of pain and other distress as possible. Palliative care may involve medicines, *treatments*, physical care, psychological/social services and spiritual support for you, your family and others who are helping to care for you.

**Progression (of cancer):** Cancer spreads or grows larger in the body.

**Recurrence:** Cancer that has returned, usually after a period of time during which the cancer could not be detected. The cancer may come back to the same body part as the original (primary) *tumour*, or it can affect another part of the body. *Recurrence* can also be called “recurrent cancer”.

**Remission:** A decrease in or disappearance of signs and *symptoms* of cancer. In partial *remission*, some, but not all, signs and *symptoms* of cancer have disappeared. In complete *remission*, all signs and *symptoms* of cancer have disappeared, although cancer may still be in the body.

**Side effects:** Physical or psychological effects of the treatment or the cancer itself. For example, *side effects* can include pain, tiredness, nausea, depression or anxiety.

**Symptoms:** Signs that you are unwell. For example, pain, vomiting, loss of appetite or high fever can be signs that something is wrong.

**Tumour:** An abnormal mass of tissue in the body that happens when cells divide more than they should or do not die when they should. *Tumours* may be benign (not cancer) or malignant (cancer), and they can also be called a neoplasm.

<sup>1</sup> Definitions adapted from Speak Up ([www.advancedcareplanning.ca](http://www.advancedcareplanning.ca)) and National Cancer Institute ([www.cancer.gov/dictionary](http://www.cancer.gov/dictionary))

This tool was developed for **Newfoundland and Labrador** in collaboration with the **Advance Care Planning Canada initiative** found at [www.advancecareplanning.ca](http://www.advancecareplanning.ca) and the **Cancer Care Program of Eastern Health**.

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**The Cancer Care Program of Eastern Health** is a provincial program that operates four cancer centres within the province including the Dr. H. Bliss Murphy Cancer Centre in St. John's and regional cancer centres across the province located in Gander, Grand Falls-Windsor and Corner Brook. The Cancer Care Program also supports the delivery of oncology services in a number of hospitals throughout the province.

**Advance Care Planning in Canada and the Speak Up campaign are managed by the Canadian Hospice Palliative Care Association (CHPCA)**, a national, bilingual charitable non-profit association with membership comprised of individuals and hospice palliative care programs and services from every province and territory.

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