



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Speak Up

Start the conversation
about end-of-life care

Cancer and *Advance Care Planning* Tips for Oncology Professionals



Each year, more than 74,000 Canadians die with cancer

According to a 2012 Ipsos-Reid poll:

- 86% of Canadians have not heard of advance care planning
- Fewer than half have discussed health care treatments with a family member or friend to express what they would want if they were ill and unable to communicate
- Only 9% had ever spoken to a health care provider about their wishes for care
- Over 80% of Canadians do not have a written plan
- Only 46% have designated a substitute decision-maker – someone to speak on their behalf if they cannot communicate.

As well, in a U.S. multi-site study, only 37% of patients with advanced cancer reported discussing end-of-life care with their physician (Wright et.al., 2008).

Just Ask: You can be part of the solution to improving these statistics by broaching the topic of advance care planning with the patients and families you care for.

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When to Have the Discussion

Evidence shows that patients are interested in having these discussions with their physicians but may not know how to start.

These conversations can take place at different times throughout the cancer trajectory, including:

- at first assessment
- before initiation of systemic therapy, radiation therapy or surgery
- following Emergency Room visits or admissions to acute care
- at transition points in care, such as tumour progression
- at time of declining function and transition to the terminal phase of disease
- when treatments have not resulted in the “hoped for” effects

While advance care planning is important for all patients, it is critical for those:

- with a poor prognosis
- with clear intent to refuse certain types of care
- without a family member to speak for them
- with the desire to appoint a substitute decision-maker
- with a life expectancy of less than six months

Questions to Ask

Do you have an Advance Care Plan?

- What do you know about your cancer diagnosis and prognosis?
- How much do you want to know about your cancer diagnosis and prognosis?
- What is your understanding of the purpose of treatment? Do you understand whether your treatment is intended to relieve symptoms or to cure you of the cancer?
- What is most important to you regarding your quality of life?
- Have you discussed your wishes with your family?

Have you decided who would make decisions for you if you become unable to make decisions yourself?

- What gives your life meaning?
- What are you most worried about with regards to your cancer and treatment?

Steps in Initiating and Having a Conversation about Advance Care Planning

1. Create an appropriate and private environment for the conversation.
2. Ask the patient who he or she would like to include in the conversation.
3. Clarify medical information for the patient and family.
4. Talk about the goals of care and how they may change.
5. Explore values and beliefs about quality of life.
6. Explore possible life sustaining therapies.
7. Allow time for reflection and decision-making.
8. Arrange for appropriate support services if necessary.
9. Indicate other resources that are available, such as online resources and the patient information library.
10. Record the decisions in the patient's chart.
11. Review as necessary as the illness changes.

Adapted from EPEC™-O Canada, Module 9: Negotiating Goals of Care



Useful Phrases ¹

Sometimes it can be difficult to know what to say. The following phrases might help:

To start a difficult conversation:

- I need to speak to you about some difficult things.
- How much information would you like to hear today?

Regarding cancer treatment:

- The treatment is intended to maximize the possibility of eliminating the cancer cells in your body.
- Our goal is to shrink the cancer/tumour. We'll know in x weeks.
- Let's hope for the best but plan for the worst.
- We will concentrate on improving the quality of your life.
- We want to help you live meaningfully in the time that you have.

Regarding advance care planning:

- Advance care planning is similar to writing your will. It is good to be prepared and to let your wishes be known.
- I want to give you the best care possible. Knowing your wishes will help me do that.
- I'd like to talk to you about your wishes for care in case you get very sick. That might not happen, but if it does and you can't communicate, it would be important to know about your wishes for care.
- How important is it for you to maintain your independence?
- How do you usually make decisions?
- Let's discuss what we can do to fulfill your wish to x.
- This action plan may need to be adjusted should the situation change. It will be reviewed with you from time to time and adjusted with any changes in your health.

With family members:

- I want to ensure that your (family member) receives the kind of treatment that best aligns with his/her wishes.

Practical Suggestions

1. Introduce the topic of advance care planning when talking to your patient about the goals of treatments or prognosis.
2. You may need to make a second appointment to discuss any issues brought up by the patient or a family member – allow time for reflection and decision-making.
3. Involve other health care providers, such as oncology nurses, to provide further explanation as necessary.



Additional Background Information

Advance care planning is a process of reflection and communication about personal care preferences in the event that an individual becomes incapable of consenting to or refusing treatment or other care. Patients discuss their beliefs, wishes, values and/or instructions for future health care with their trusted substitute decision-maker, family and health care providers.

This planning may lead to an Advance Care Plan, which is a summary of the values and instructions designed to guide the substitute decision-maker in the event the patient is incapable of making decisions. An Advance Care Plan can be in written form, but can also be in the form of a video or voice recording.

Advance care planning results in greater adherence to a patient's wishes and improvements in quality of life and ratings of quality of care for patients and family members (Harle et.al., 2008). Investing in advance care planning is perhaps the single most important thing we can do as a society and a health care system to improve outcomes for care and to facilitate patient-centered communication and collaborative health care decision-making. In its essence, advance care planning assists you in discovering the answer to the question, "How best can I care for you?"



Advance Care Planning

Improves quality of life and quality of end-of-life care

A study published in the New England Journal of Medicine showed early palliative care consultation, including discussion of prognosis and goals of care, provided significant benefits for patients with metastatic non-small-cell lung cancer. Benefits included improved quality of life, mood, less aggressive end-of-life care and less chemotherapy at the end of life (Temel, 2010 and 2011).

A U.S. multi-site study of patients with advanced cancer found that end-of-life discussions were associated with less aggressive medical care near death and with earlier hospice referrals. Aggressive care was associated with worse quality of life for the patient. (Wright, 2008)

Improves communication between patients, caregivers and the health care team

Research with Canadian inpatients with cancer or end-stage medical disease indicates that those who recall a prognosis discussion with a physician were more satisfied with overall care (Heyland, 2009).

Reduces strain on the health care system

Advance care planning can provide patients, caregivers and the health care team with clear direction regarding preferences for treatment, reducing unwanted intervention, providing alternatives to hospital deaths and optimizing health care spending (Wright, 2008; Temel, 2010 and 2011).

Learn More

Advance Care Planning in Canada

Speak Up: About Advance Care Planning for Professionals

<http://advancecareplanning.ca/health-care-professionals.aspx>

Canadian Virtual Hospice

Tools for Practice: Advance Care Planning

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/Tools+for+Practice.aspx

Education in Palliative and End-of-Life Care for Oncology (EPEC™–O Canada)

A curriculum in palliative and end-of-life care for oncology professionals.

Materials can be ordered through the Canadian Partnership Against Cancer at cancerjourney@partnershipagainstcancer.ca.

Cancer Care Ontario

Advance Care Planning with Cancer Patients

[https://www.cancercare.on.ca/common/pages/UserFile.](https://www.cancercare.on.ca/common/pages/UserFile.aspx?serverId=6&path=/File%2oDatabase/CCO%2oFiles/PEBC/pebc19-1f.pdf)

[aspx?serverId=6&path=/File%2oDatabase/CCO%2oFiles/PEBC/pebc19-1f.pdf](https://www.cancercare.on.ca/common/pages/UserFile.aspx?serverId=6&path=/File%2oDatabase/CCO%2oFiles/PEBC/pebc19-1f.pdf)

Institute of Medicine

Advance Care Planning in People with Cancer

PowerPoint Presentation by Dr. Thomas Smith

http://iom.edu/~media/Files/Activity%2oFiles/Disease/NCPF/2011-Feb-28-Treatment-Planning/Smith_Thomas_Presentation.pdf

National Health Service

Advance Care Planning: A Guide for Health and Social Care Staff

http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Advance_Care_Planning_guide.pdf

Primary Literature

Harle I, et al. (2008). Advance Care Planning with Cancer Patients: Guideline Recommendations. Evidence-Based Series #19-1. Toronto: Cancer Care Ontario. <https://www.cancercare.on.ca/common/pages/UserFile.aspx?serverId=6&path=/File%20Database/CCO%20Files/PEBC/pebc19-1f.pdf>

Heyland DK, et al. (2009). Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life care. *Open Medicine*. 3(2):101–10.

Ipsos Reid. (2012). National Ipsos-Reid poll indicates majority of Canadians haven't talked about their wishes for care. <http://www.advancecareplanning.ca/news-room/national-ipsos-reid-poll-indicates-majority-of-canadians-haven%E2%80%99t-talked-about-their-wishes-for-care.aspx>

Temel JS, et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*. 363(8):733–42.

Temel JS, et al. (2011). Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care. *Journal of Clinical Oncology*. 29(17):2319–26.

Wright AA, et al. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association*. 300(14):1665–73.

Footnotes:

¹ Useful phrases have been adapted from *EPEC™-O Canada, Module 9: Negotiating the Goals of Care*.



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An agency of the Provincial Health Services Authority

The BC Cancer Agency, an agency of the Provincial Health Services Authority, provides a province-wide, population-based cancer control program for the residents of British Columbia and the Yukon. The Agency accepts patients who have been diagnosed with cancer and are referred by a physician.



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

This tool was developed in collaboration with the Advance Care Planning in Canada initiative found at www.advancecareplanning.ca and the BC Cancer Agency.

Advance Care Planning in Canada is funded by The GlaxoSmithKline Foundation and the Canadian Partnership Against Cancer.