Palliative Care in modern times

Cancer patients are living longer with cancer and being cured more often because of new drugs and other effective anti-cancer treatments. It is hard to keep up with them all. It is especially hard to give patients clear advice on how long they might live with cancers that, until recently, ran a fairly predictable course.

When the term “palliative care” was first brought to Canada, it mainly focused on end of life care. It was invented as an alternative to “hospice” which some people think is a negative word. We now know that parts of hospice care, (e.g. good pain and symptom management, clear communication and access to expert care coordination) that are helpful at end of life are equally helpful right from the time of diagnosis.

Research shows that cancer patients who get early access to specialists in Palliative Care have a better quality of life. They are also more likely to spend their last days in the setting of their choice, often at home. Interestingly, research shows that the cost of care is also less when palliative care needs are met earlier.

The term “hospice” still has a place in modern palliative care. However, it now refers to the part of palliative care that caters to needs of patients approaching end of life. End of life is usually considered to be the last few weeks to months of someone’s life.

Language may seem confusing but the bottom line is that no one should be afraid to talk to specialists in palliative care.

Overcoming barriers

Patients need better access to palliative care services like good symptom management, clear and sensitive communication, and expert co-ordination. BC Cancer is working hard to make changes in order to overcome barriers so patients can have better access to palliative care services.

BC Cancer is:

• partnering with the University of British Columbia to ensure that all new doctors have adequate palliative care knowledge and skills by the time they enter practice. This project is funded by the Canadian Partnership against Cancer.
• teaching health care professionals more modern palliative care approaches.
• committed to having conversations with patients earlier on about their needs and wishes should illness progress. When we do this, patient wishes can be included in care planning.

Having serious illness conversations

Being diagnosed with cancer can be very frightening. Patients often experience a range of feelings from fear and worry to hope and determination. If the diagnosis is early there is often a determination to “beat it”. If the diagnosis is of advanced disease there may be a fear of suffering and death. It is a good idea to have conversations with your doctor, your family and other providers about what you would like if your illness progresses.

These conversations are not supposed to be about doom and gloom – they are about sharing and clarifying information, answering questions and expressing your personal wishes about your care when your cancer advances.

BC Palliative Care Benefits are provided through your BC Pharmacare plan and cover certain drugs, medical supplies, and equipment that are used in palliative care. These benefits are available to individuals who have reached the end stage of a life threatening disease or illness and who wish to receive palliative care at home. Your doctor must apply for this program for you.

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Your doctor can explain the medical terms and discuss the outcome and likely course of your disease. They may talk about hoping for the best with your treatments but also being prepared in case things do not go as well as you would like.

Your doctor or other members of your health care team may ask about your goals. An example of a goal is living long enough to see a grandchild born. You would need to think about how much you would go through in terms of side effects and the kinds of treatment you are willing to undergo to achieve that goal.

They may ask you about your wishes for your care towards end of life or they may ask you about who you would like to speak for you if you are not able to speak for yourself. This person is your “substitute decision maker.” Your doctor may also ask you about your wishes regarding bringing you back to life known as or Cardio-Pulmonary Resuscitation (CPR).

It is important to keep your loved ones informed about your condition, to share the concerns you may have and to let them know your needs and wishes so that they can support you. Together you can identify a person who will be your substitute decision maker (someone to speak on your behalf if you are unable).

These are not single conversations. Speak with your loved ones and health care team often and repeatedly over the course of your illness.

Advance Care Planning is your decision

Advance Care Planning (ACP) is important for everyone but it is especially important for people who have a cancer diagnosis. ACP is about health care decision-making in case you are incapacitated and unable to speak for yourself. A plan can include legal documents but it is not always necessary. BC Cancer website has a section on Advance Care Planning where you can learn more.

You will want to think about the following when you start planning:
- Who is important to you?
- What is your doctor saying about your cancer diagnosis, prognosis and treatments?
- What are the things in life that give you meaning?

You will also want to have ongoing conversations with important people and write down your decisions and wishes.


Editions of this newsletter are also available as a pdf download on our website at: www.bccancer.bc.ca/our-services/services/patient-family-counselling

**Caregiver resources**

**Compassionate Care Benefits** are Employment Insurance benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death. If you think you might qualify, visit: www.canada.ca/en/services/benefits/ei/caregiving.html

**Family Caregiving Society of BC** is a registered non-profit dedicated to help caregivers who are supporting aging, ailing or disabled family members. Find information and support groups in your area by visiting: www.familycaregiversbc.ca

**BC Bereavement Helpline** is a non-profit, free, and confidential service that connects the public to grief support services within the province of BC. Call 604-738-9950. Monday – Friday 9-5.

**Cancer Chat Canada** provides professionally led online support groups. To learn more and register visit: https://cancerchat.desouzainstitute.com or call 1-844-725-2476.

**Steps to creating your Advance Care Plan**

**THINK**
- What and who is most important to you? What are your personal values, beliefs, hopes and wishes?

**LEARN**
- What are the types of medical procedures and treatments? How will they affect you, such as prolong your life and manage your symptoms?

**DECIDE**
- Who do you want to speak for you if you can’t speak for yourself?
- Get their contact information.

**TALK**
- Have conversations about your thoughts, decisions and wishes with your loved ones and your medical team.

**RECORD**
- Record the information and put it in a safe, accessible place. Make sure the people who need it can find it, quickly.