

CBCN Advocacy Guide: Palliative Care in Canada

What is Palliative Care?

Palliative care is a philosophy of care and medical specialty provided by a team with the goal of improving quality of life for people living with advancing life-limiting illness and to their families, regardless of the underlying diagnosis. Anyone, at any age and stage of their illness can receive palliative care. Palliative care is active care that can be provided alongside disease modifying or life prolonging therapies. It can start as early as disease diagnosis and it continues for the whole trajectory of a disease, including through caregiver support and bereavement. It can happen in the home, hospital, or increasingly, in the outpatient setting, and it plays a critical role in healthcare^{1, 2}.

When faced with a serious illness, people want their pain and other symptoms managed, to be able to make decisions clearly, complete life tasks, get affirmation of themselves as a whole person, and to be able to contribute to others. Palliative care focuses on providing support to enable people to live as well as possible until they die, and palliative care specialists are expertly trained to help each person determine what matters most to them and to help their care team to develop a plan that supports them to achieve their hopes and goals. Palliative care has been shown to reduce stress and anxiety, improve quality of life and health outcomes, and it can foster hope¹. Receiving palliative care or talking about what the future will bring does not mean the team, family, or patient has given up hope. In fact, patients who receive palliative care are often extremely satisfied and would recommend such care to others, and it has also been shown that palliative care leads to fewer days in hospital when individuals using it get sick.

The Stigmatization of Palliative Care

One reason that palliative care is not known or well understood is due to stigmatization². It relates to the mismatch between the public perception of palliative care, the frameworks that govern it, and the lived experiences of those who receive such care. The public often has the false belief that palliative care is only for those at the end of life, but as illustrated above, it is so much more than that. At the same time, those receiving palliative care have varied experiences, largely dependent on whether they are able to access timely palliative care or not¹.

When palliative care is not well understood, those who need it are less likely to access it. When individuals experiencing a severe life-limiting illness are unaware of the benefits of palliative care, it can result in poorer quality of life and the potential for more extreme

medical interventions such as hospitalizations or emergency room visits. Put simply, when palliative care is well understood and used appropriately, patients experience better health outcomes¹.

Inequities in Palliative Care

National palliative care standards are still being developed and provincial quality indicators may not be mandatory in all regions. This means that palliative care services and its availability are not consistent across the country and vary greatly depending on which part of the country you live in. This impacts patient satisfaction with palliative care. Access to palliative care is further impacted by socio-economic factors¹. People between the age of 65-84 were the most likely to receive palliative care, and those in rural settings were more likely to receive care in hospital. Similarly, Indigenous People living in remote areas must often leave their communities to receive care in settings which may not be culturally safe due to language, food, and culturally inappropriate services. Finally, those who experience homelessness have significant barriers to accessing palliative care and tend to remain in the hospital longer, awaiting community supports¹.

Palliative Care and Breast Cancer

Life-limiting illnesses can take many forms, including cancer. In fact, the Canadian Institute for Health Information (CIHI) reported that people diagnosed with cancer were the most likely to be identified as palliative. Palliative care can be relatively well integrated into cancer care because the disease trajectory and treatments are well understood and generally predictable. Since people with cancer are living longer with many other conditions, palliative care plays a greater role in improving quality of life and managing cancer symptoms. Ultimately, the role of palliative care in cancer treatment will be unique to each person and decided in consultation between the patient, caregivers, and their healthcare team.

[1] Access to Palliative Care in Canada Canadian Institute for Health Information (pg 7, 15, 16, 21-23). Accessed October 17, 2023 [2] Dr. Naheed Dosani - Palliative Care in Canada. Canadian Health Information Podcast. Accessed October 17, 2023

Advocating for Palliative Care

Patients and their caregivers have the dual responsibility of managing a life limiting illness and advocating for access to palliative care, but resources about palliative care services can be difficult to find¹. By taking advocacy steps to reduce the stigma of palliative care, it generates social awareness and public support for this critically important, but grossly misunderstood care option. Shifting public perception of palliative care is an important first step towards ensuring everyone living in Canada gets the access to palliative care they need.

If you are living with a breast cancer diagnosis or caring for someone living with breast cancer, one important advocacy step you can take is simply talking about palliative care with healthcare providers, community, and family. The earlier the conversation happens, the more likely palliative care will be used at the appropriate time. When palliative care discussions happen early, it helps align treatment goals. Since treatment goals will be unique to each patient and family, knowing the role of palliative care as early as possible also prevents unnecessary delays should this care be needed. You can learn about palliative care options in your regions by clicking the link here and sharing these resources with your community or family.

A second step you can take is to advocate for the creation and implementation of national palliative care standards. In 2018, the federal government released The National Action Plan on Palliative Care to guide provinces and territories about palliative care (read here). You can advocate for national palliative care standards by contacting your provincial palliative care association to discuss what progress they are making towards the goals outlined in the Action Plan.

Finally, you can contact your MP or MPP. Ask them to speak publicly about ending palliative care stigma and to support palliative care education in their riding. By increasing public awareness about the important role of palliative care, MPs can be a partner in improving the health of their constituents. Use this guide on the benefits and importance of palliative care for individuals living with life-limiting diseases and illnesses to steer your conversation. You can find the contact information for your elected official here.

Provincial Palliative Care Associations

<u>Alberta Hospice Palliative Care Association</u>

British Columbia Hospice Palliative Care Association

Palliative Manitoba

New Brunswick Hospice Palliative Care Association

Newfoundland and Labrador Palliative Care Association

Nova Scotia Hospice Palliative Care

Hospice Palliative Care Ontario

Hospice Prince Edward Island

Quebec Palliative Care Association

Saskatchewan Hospice Palliative Care Association