

POSITION STATEMENT



PALLIATIVE CARE

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The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹ Palliative care cuts across sectors, being delivered in hospitals, outpatient centres, hospice, residential care facilities and at home.

BC NURSES' UNION BELIEVES THAT:

1. World Health Organization (2021). WHO definition of palliative care. <http://www.who.int/cancer/palliative/definition/en/>
2. BC Ministry of Health (2013). Provincial End-of-Life Care Action Plan. <http://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf>
3. Canadian Institute for Health Information (2018). Access to palliative care in Canada. Ottawa: ON. Available at <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-3n-web.pdf>.
4. Carstairs, S. (2010). Raising the bar: A roadmap for the future of palliative care in Canada. Ottawa: The Senate of Canada.
5. Canadian Institute for Health Information (2018). Access to palliative care in Canada. Ottawa: ON. Available at <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-3n-web.pdf>.
6. Widger, K, Davies, D, Rapoport, A, Vadeboncoeur, C, Liben S, Sarpal, A, Stenekes, S, Cyr, C, Daoust, L, Gregoire, MC, Robertson, M, Hodgson-Viden, H, Laflamme, J & Siden H (2016). Pediatric palliative care in Canada in 2012: A cross-sectional descriptive study. *CMAJ Open*, 4(4), E562 – E568.
7. Freeman, S. (2013). Breaking down barriers: Hospice palliative care as a human right in Canada. *Educational Gerontology*, 39(4), 241 – 249.
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British Columbians need and deserve excellent care at all stages of life, up to and including death and bereavement, and that nurses are central to quality palliative and end-of-life care. BCNU believes that British Columbians should have the right to choose from a full range of quality, publicly funded palliative and end-of-life services in the care setting of their choice.

WHAT IS PALLIATIVE CARE?

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual!” Palliative care cuts across sectors, being delivered in hospitals, outpatient centres, hospice, residential care facilities and at home.

BACKGROUND

Fewer people die suddenly, and more people are living with chronic diseases than ever before². The Canadian health care system is adapting to increasing numbers of Canadians living with life-limiting illness, who wish to receive care at home or in their communities as much as possible. Canadians also have a relatively new option to consider in the context of death and dying; in 2016, new legislation on Medical Assistance in Dying (MAiD) came into effect across the country, presenting new choices and new challenges for patients, families and health care professionals. This legislation continues to evolve, with significant changes made in 2021 to broaden the scope of individuals able to access MAiD in Canada. Further study continues at the national level to inform decisions on eligibility for other populations as well. In making decisions on expanding eligibility criteria for MAiD, particular attention must be paid to ensuring that Canadians have timely, equitable access to all forms of treatment and support, such that decisions about MAiD are made without the overwhelming stress of financial hardship.

All British Columbians should have the opportunity to benefit from equitable access to appropriate services as they cope with serious illness and eventual end of life. However, a recent CIHI review showed that just 25% of Canadians who died in acute care and 15% of those receiving home care services received palliative care services, and most of those who did receive such care were only able to access it in their last month or last days of life³.

WHAT'S GETTING IN THE WAY?

Diagnosis

Palliative care was developed mainly with advanced cancer in mind. Referral to many palliative services requires a prognosis of less than six months to live. Physicians have often been reluctant to make that determination in patients with non-cancer diagnoses, as their disease trajectory tends to be less predictable⁴. What this means in practice is that cancer patients make up over 90% of palliative care referrals, despite accounting for just 30% of deaths in Canada⁵.

Age

Traditional palliative services are designed for older adults and their families. The needs of youth, children and infants facing life-limiting illnesses are different, and require specialized services. Although pediatric palliative care programs are on the rise in Canada⁶, they are only available in urban centres, most often connected to children's hospitals.

Place of Residence

There are only around two hundred palliative care specialists in Canada, and the vast majority work in urban centres⁷. This means that Canadians living in rural and remote communities are least likely to access palliative care services, and end up spending more time in hospital at the end of their lives, far from their homes and their families⁸. Nurses living and working in rural areas struggle to provide quality palliative care, as they are more likely to work alone, having to make do with very few supports⁹.

British Columbians who live in residential care facilities also have greater difficulty

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14. BC PharmaCare (2016). BC Palliative Care Benefits. <http://www2.gov.bc.ca/assets/gov/health/health-drug-coverage/pharmacare/palliative-patientinfo.pdf>
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17. Carstairs, S. (2010). Raising the bar: A roadmap for the future of palliative care in Canada. Ottawa: The Senate of Canada.
18. iPANEL (2016). Initiative for a Palliative Approach in Nursing: Evidence & Leadership. <http://www.ipanel.ca/>
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21. Canadian Hospice Palliative Care Association (2015). The way forward national framework: A roadmap for an integrated palliative approach to care. <http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf>
22. Carstairs, S. (2010). Raising the bar: A roadmap for the future of palliative care in Canada. Ottawa: The Senate of Canada.

accessing appropriate palliative care, despite the medicalized nature of where they live. Inadequate staffing, education, access to appropriate palliative medications and protocols for assessing and monitoring pain and other symptoms near the end of life are just some of the barriers that contribute to unnecessary suffering at the end of life in residential care¹⁰.

Social Diversity

Care that respects and honours the spiritual and cultural practices of families is particularly important at the end of life, but access to all kinds of health services, including palliative care, can be particularly challenging for people who experience discrimination based on race¹¹, sexual orientation¹², ability¹³ and other social determinants of health.

Cost

Palliative care is not specifically covered under the Canada Health Act; it is considered an extended health service. The result is that palliative services provided in different settings differ in terms of the direct cost to patients.

Many of the costs associated with home palliative care, including medical equipment, supplies and medications, are covered by the BC Palliative Benefits Program¹⁴. However, to qualify for coverage, patients must often meet a high threshold of symptom experience, leaving families to manage on their own until their loved one is 'sick enough' to receive benefits.

While home palliative care can be well-suited to the wishes of many patients and families, we must ensure that patients are not making this choice simply because they are unable to afford the fee for residential hospice care, which amounts to \$39.61 per day for publicly subsidized hospice care¹⁵.

When providing end-of-life care options in the community, we must ensure that sufficient supports are in place to safeguard against the downloading of costs from the public to patients and their families. Canada is already poorly rated among economically comparable countries in measures of end-of-life care because of the high cost of palliative care outside of the acute system¹⁶. Unpaid caregiver time for patients receiving palliative care at home has been identified as the most expensive component of palliative care; it is estimated that family caregivers provide \$25-26 billion of unpaid care per year¹⁷.

ADDRESSING THE BARRIERS: AN INTEGRATED PALLIATIVE APPROACH TO CARE

Continuing to rely on a specialty model that treats palliative care as a separate health service will only increase existing inequities.

In order to meet the needs of the 90% who will live with a serious illness, we need to make a shift towards embedding palliative care into everyday practice. A group of BC-based nurse researchers, practitioners and administrators called iPANEL (Initiative for a Palliative Approach in Nursing: Evidence and Leadership), have generated a great deal of research on what a shift towards this model might look like¹⁸.

REDEFINING PALLIATIVE CARE

We often think of palliative care as beginning when all else fails – comfort care immediately preceding death. iPANEL researchers and other experts, however, are seeking to expand this definition by including palliative care alongside other interventions for serious conditions such as heart disease, kidney disease, lung disease, dementia and frailty, among others¹⁹.

A palliative approach includes some basic palliative principles: team-based care; maximizing quality of life; relief from pain and other symptoms; addressing psychological and spiritual needs; support for families and other caregivers; and supporting dying as a normal process. Patients who receive palliative care alongside other services report better quality of life, symptom management and satisfaction of care than those who receive treatment as usual²⁰. Providing an integrated palliative approach to care has also been shown to decrease hospitalization and emergency room visits, while facilitating more appropriate referrals and better use of community-based services²¹.

SUPPORTING THE ROLE OF NURSES

The increasing demand for palliative care services will require further reliance on nurses and nurse practitioners²². The need to educate nurses to meet these needs is strong; research shows that many health care professionals, including nurses, are not comfortable with palliative care²³. According to research conducted by the iPANEL team, nurses in BC report needing education in particular around spiritual and social needs and ethical and legal issues²⁴.

Nurses who work with patients at the end of life also need support for their own mental, emotional and spiritual health to protect against their increased risk for compassion fatigue, burnout and vicarious traumatization²⁵. This support should include adequate time and encouragement for debriefing and grieving after the loss of a patient, inclusion of palliative care nurses and spiritual health practitioners where appropriate, education on death and dying for care team members, patients and families; decreasing job stress as much as possible, and working to ensure that nurses

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27. Government of Canada (2016). Medical assistance in dying. <http://healthycanadians.gc.ca/health-system-systeme-sante/services/palliative-palliatifs/medical-assistance-dying-aide-medicale-mourir-eng.php>

28. Health Canada (2019). First annual report on Medical Assistance in Dying. Available at <https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf>.

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30. Canadian Nurses Association (2015). Physician-assisted death: Brief for the Government of Canada's External Panel on Options for a Legislative Response to Carter v. Canada. Ottawa: CNA.

31. College of Registered Nurses of British Columbia (2016). Medical Assistance in Dying (MAiD): Scope of practice standards for registered nurses. <https://www.crnbc.ca/Standards/Lists/StandardResources/802MAiD.pdf>

32. College of Licensed Practical Nurses of BC (2016). Medical Assistance in Dying. <https://www.clpnb.org/Practice-Support-Learning/Practice-Resources/Medical-Assistance-in-Dying>

enjoy a high degree of satisfaction in their roles²⁶.

Supporting the role of nurses also means ensuring that they have the time they need to provide a palliative approach to care. Adequate staffing is a necessary element of providing the quality care that patients need when facing serious illness.

MEDICAL ASSISTANCE IN DYING

In Canada, we have special legislation allowing physicians and nurse practitioners to prescribe a self-administered drug or to directly administer a drug that causes death to patients who qualify for MAiD without facing criminal repercussions. In order to qualify, a patient must:

- > be eligible for health services funded by the provincial, territorial or federal government;
- > be at least 18 years old and capable of making health care decisions;
- > suffer unbearably as a result of a "grievous and irremediable medical condition" (a serious illness, disease or disability in an advanced, irreversible state of decline);
- > not be pressured or influenced by others into making their decision; and
- > give informed consent after receiving information about their diagnosis, available treatment and palliative care²⁷.

The uptake in Canada since the legislation was implemented has been steady; MAiD accounted for 2% of all deaths in Canada in 2019, and 2.5% in 2020. Of those who have accessed MAiD in Canada, the majority had cancer as their primary diagnosis, and over 80% were over the age of 65. Though some feared that Canadians would choose MAiD because of a lack of access to palliative care, evidence to date does not support this view. Over 80% of those who chose medical assistance in dying since 2019 had accessed palliative care prior to choosing MAiD^{28, 29}.

33. College of Registered Nurses of British Columbia (2016). Medical Assistance in Dying (MAiD): Scope of practice standard for registered nurses. <https://www.crnbc.ca/Standards/Lists/StandardResources/802MAiD.pdf>

34. Lehto, RH, Olsen, DP, & Chan, RR (2016). When a patient discusses assisted dying: Nursing practice implications. *Journal of Hospice & Palliative Nursing*, 18(3), 184 - 191.

THE ROLE OF NURSES IN MAiD

Research shows that patients often approach nurses first with questions about MAiD³⁰. Though the assessment to determine if a person is eligible for MAiD must be completed by the physician or nurse practitioner who will carry it out, nurses can assist outside of the formal assessment process by supporting patients and their loved ones with information and emotional support.

LPNs, RNs and RPNs are permitted to aid in the provision of MAiD, but there is no requirement for a nurse to participate if they object^{31, 32}. Nurses in BC are allowed to insert an IV, but are not allowed to administer the medication that will end the patient's life. The BC College of Nurses & Midwives recommends that nurses refrain from handling MAiD medications in any way. Nurses are also not allowed to encourage, recommend, counsel or advise a person to consider MAiD, pronounce death related to MAiD, document any aspect of the procedure, or aid in the provision of MAiD for a member of their family.

The BCCNM requires registered nurses aiding in the provision of MAiD to have additional education³³. Resources created through the provincial MAiD working group include a series of three learning modules and a decision support tool, available through the Health Authorities Research shows that nurses who receive this education are more open to discussing these difficult topics with patients and their families³⁴.

As advocates for patients and families, nurses can work to ensure that the necessary resources are in place to provide the full range of options to British Columbians at the end of life.

These resources must include:

- > timely, equitable access to palliative care services for patients and their families at no cost;
- > appropriate staffing levels to ensure that nurses have the time they need to provide palliative care;
- > comprehensive palliative care education for nurses;
- > appropriate tracking of patient MAiD requests, approvals, denials and referrals to ensure that safeguards are being maintained without preventing access to MAiD;
- > evidence-based resources and supports for nurses engaged in MAiD; and
- > research on the effects of MAiD on patients, families, caregivers and health care professionals in Canada.