

# BILL C-277, AN ACT PROVIDING FOR THE DEVELOPMENT OF A FRAMEWORK ON PALLIATIVE CARE IN CANADA

Brief for the Senate Standing Committee on Social Affairs, Science and Technology

October 2017

CNA is the national professional voice of over 139,000 registered nurses and nurse practitioners across Canada. CNA advances the practice and profession of nursing to improve health outcomes and strengthen Canada's publicly funded, not-for-profit health system.

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### **Background**

This brief was prepared by the Canadian Nurses Association (CNA) for consideration by the Senate standing committee on social affairs, science and technology regarding its study of Bill C-277, An Act Providing for the Development of a Framework on Palliative Care in Canada.

CNA was pleased to see most of our recommendations on Bill C-277 considered by the House of Commons standing committee on health.¹ While CNA supports the most recent version of Bill C-277 — and has provided its sponsor, MP Marilyn Gladu, with a letter of support — we believe our recommended revisions will lead to a stronger and more comprehensive framework for palliative care in Canada.

CNA is a strong advocate for establishing high-quality palliative care, accessible to all Canadians, in settings that best suit each individual's care needs. Given that registered nurses (RNs) and nurse practitioners (NPs) play a fundamental role in the care of palliative patients,<sup>2</sup> we are highly attuned to the issue and eager to see the most favourable result.

Palliative care, as an essential part of improving quality of life for patients, families and caregivers, is generally understood to mean care at the end of life. Yet, CNA and other stakeholders think of it more broadly, something represented by the words "palliative approach to care." A palliative approach is different than specialized palliative care. It includes advance care planning and care for people with life-limiting illness. Across all health-care settings it seeks to improve quality of life and manage pain and symptoms holistically through physical, psychological, social and spiritual care.<sup>3</sup>

The benefits of such care include increased satisfaction among patients and caregivers, fewer hospital admissions and shorter hospital stays. Early palliative care has been shown to not only improve quality of life but also to reduce unnecessary hospitalizations and the use of health-care services.<sup>4</sup>

World Health Organization (WHO) recommendations on palliative care are particularly relevant in Canada, where a palliative approach to care aligns with the principles of our universal health coverage. WHO also emphasizes the importance of integrating palliative care into primary care, as well as into home- and community-based settings,

<sup>&</sup>lt;sup>4</sup> (World Health Organization, 2015)



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<sup>&</sup>lt;sup>1</sup> (Canadian Nurses Association [CNA], 2017)

<sup>&</sup>lt;sup>2</sup> (CNA, Canadian Hospice Palliative Care Association [CHPCA], & Canadian Hospice Palliative Care Association Nurses Group [CHPCA-NG], 2015)

<sup>&</sup>lt;sup>3</sup> (Sawatzky et al., 2016)

and supporting health-care providers and caregivers in adopting the palliative approach to care.<sup>5</sup>

CNA's joint position statement with the Canadian Hospice Palliative Care Association and the Canadian Hospice Palliative Care Nurses Group endorses the palliative approach across the continuum of care, along with its central aim of helping people live well and with dignity until death.<sup>6</sup>

CNA also wishes to highlight the Canadian Indigenous Nurses Association's call for the federal government to enhance the \$25 million investment (over four years) for better health-care outcomes for First Nations, Inuit and Métis communities. Not only are many of these communities facing HIV/AIDS and hepatitis C rates that are higher than the general population, the affected individuals do not always have equitable access to services such as home care and end-of-life care.<sup>7</sup>

## Ways to improve Bill C-277

With these issues in mind, CNA would like to offer four suggestions before presenting specific recommendations on Bill C-277.

# Suggestion 1. The need for a greater emphasis on the palliative approach to care in a framework on palliative care in Canada.

Instead of representing palliative care as a discrete type of care provided for a fixed period at the end of life, Bill C-277 would be improved by referring to a palliative approach to care, which is guided by the core tenets of palliative care (dignity, hope, comfort, quality of life and the relief of suffering) and applied early in the course of an illness and through to the process of advance care planning.<sup>8</sup>

The palliative approach to care is person-centred, and it honours an individual's values, wishes and dignity by promoting autonomy. It also fosters shared decision-making, which enables patients and families to exercise greater control over the provision of their care. In addition, such care is holistic, taking spiritual, mental, physical, social, psychological and practical aspects into account, and continues after a patient has died with the provision of ongoing support to the bereaved family and friends. Canada's nurses have a fundamental role in this approach, since it puts patients and their families

<sup>6</sup> (CNA, CHPCA, & CHPCA-NG, 2015)

<sup>&</sup>lt;sup>9</sup> (CHPCA, 2013)



<sup>&</sup>lt;sup>5</sup> Ibid.

<sup>&</sup>lt;sup>7</sup> (Canadian Indigenous Nurses Association [CINA], 2017)

<sup>&</sup>lt;sup>8</sup> (CNA, CHPCA, & CHPCA-NG, 2015)

at the centre of all decisions and considerations of care. There is strong evidence demonstrating how this approach would benefit people with life-limiting illness.<sup>10</sup>

# Suggestion 2. Develop and implement national evidence-based standards for integrated palliative care.

Currently, no nationwide policies or evidence-based standards exist to ensure integration of the palliative approach to care across the continuum. Some provincial and territorial governments have carried out small-scale planning for palliative care, but these plans are the exception and are not widespread. In addition, there are no standardized methods or tools to guide health-care providers on how and when to implement a palliative approach.

The shortage of high-quality, comprehensive health information also confounds the design and delivery of palliative care. Gaps in the information available on home and community care and outpatient services remain an issue. 11 Across jurisdictions we still lack consistent data definitions and interoperable data collection systems. Sharing and linking data to other health and social datasets is challenging, if not impossible. Additionally, underserved populations such as First Nations, Inuit and Métis are not well-represented in the data, which impedes our ability to understand, assess and improve care for these populations. To improve quality of care, we must also balance the safeguarding of personal information with broader access to data. 12 Better data collection and reporting would help our capacity to assess and deliver end-of-life care.

Without being able to follow and compare performance, provinces and territories have a limited capacity to understand whether, where and how to improve palliative care. National evidence-based standards for integrated palliative care and comprehensive, high-quality data would greatly enhance our understanding of system gaps and the impact of quality improvement initiatives.

## Suggestion 3. Provide support to increase public awareness about current palliative care programs and services.

Alongside the numerous reports and studies identifying priorities and actions to improve palliative care access and quality<sup>13</sup> is an ongoing disparity between current end-of-life care options and patient or family preferences.<sup>14</sup> Consequently, CNA supports the recommendations in *The Way Forward National Framework* from the

<sup>14 (</sup>CPAC, 2017)



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<sup>&</sup>lt;sup>10</sup> (Sawatzky et al., 2016)

<sup>&</sup>lt;sup>11</sup> (Canadian Partnership Against Cancer [CPAC], 2017)

<sup>12</sup> Ibid.

<sup>&</sup>lt;sup>13</sup> (Covenant Health, 2016; CPAC, 2017))

Quality End-of-Life Care Coalition of Canada (QELCCC). <sup>15</sup> CNA is a member of the QELCCC, along with 38 other national organizations (nurse educators, hospice palliative care nurses, chronic disease organizations and other health-care provider groups), whose vision is that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by loved ones, in the setting of their choice.

To achieve the QELCCC vision, substantial and sustained funding must be allocated to develop, implement and maintain a national palliative care framework that includes recommendations outlined in *The Way Forward*.

## Suggestion 4: Provide more equitable health service delivery to Canada's Indigenous populations.

CNA supports the Canadian Indigenous Nurses Association recommendations to the standing committee on finance: that all levels of government support more equitable services to Canada's Indigenous populations, "including improved access to health services [on reserve], increased awareness of health needs in communities and a standard availability of culturally safe care. . . . These services need to incorporate the following:

- Ensure Indigenous health care professionals provide care
- ► Provide culturally sensitive services
- Coordinate care to address the multiple/complex health needs of indigenous peoples
- ► Facilitate self-management
- Provide cultural training to staff
- ▶ Ensure that patients have timely access to appropriate referral and specialist care
- ▶ Ensure patients have access to timely and efficient testing
- ▶ Ensure there is no unnecessary delay between testing and treatment" 16

### Recommendations

#### Recommendation 1.

CNA suggests that clause (a) under section 2 (1), which currently reads "defines what palliative care is," be revised to include "a palliative approach to care."

<sup>&</sup>lt;sup>16</sup> (CINA, 2017, pp. 1-3)



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<sup>&</sup>lt;sup>15</sup> (Quality End-of-Life Care Coalition of Canada, Canadian Hospice Palliative Care Association, & Government of Canada, 2015)

The revised clause would read: "defines what palliative care and a palliative approach to care are"

When the palliative approach to care is integrated into primary care and provided earlier in the course of a disease, it offers significant advantages to patients and families. Ensuring that patients with chronic, life-threatening illnesses have early access to palliative care is important, as they can experience complex pain and symptoms requiring multiple forms of care and support well in advance of death.<sup>17</sup>

### Recommendation 2.

To include the development of evidence-based standards for integrated palliative care, CNA recommends that clause (d) under section 2 (1), which currently reads "promotes research and the collection of data on palliative care," be revised to include "national evidence-based standards."

The revised clause would read: "promotes research and reporting on indicators related to national evidence-based standards on palliative care"

#### Recommendation 3.

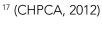
That the federal government support the development and implementation of a national campaign strategy on palliative care that would include information on federal government caregiver and palliative care programs.

#### Recommendation 4.

That the federal government improve home care services, including culturally safe endof-life care, to address the needs of Indigenous communities in northern and remote areas.

### Conclusion

CNA's suggestions and recommendations on BILL C-277 will lead to a stronger and more comprehensive framework for palliative care in Canada. The implementation of a national framework is needed to give all Canadians equitable access to a palliative approach to care. This option will assist in addressing inequities in end-of-life care while enhancing patient autonomy and choice.





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