

Submission to Joint Special Committee on Medical Assistance in Dying

Introduction

As a pan-Canadian organization, the Canadian Cancer Society (CCS) is committed to supporting people with cancer and their caregivers by ensuring they have the information and tools they need to make decisions about palliative care, advanced care planning and end-of-life care, including medical assistance in dying (MAiD). Everyone should have access to affordable, culturally safe, high-quality palliative care as well as the ability to make autonomous decisions about their care that will have an impact on the quality and outcome of their life. CCS's efforts remain focused on ensuring people with cancer have access to the information and support services they need and to spend their final days with dignity, with access to pain management and in a setting of their choice. CCS is also committed to supporting the needs of caregivers in decision-making, preparation, grief and loss.

Palliative care in Canada

Palliative care focuses on the quality of life of people who have a progressive, life-limiting illness. It includes pain and symptoms management, skilled psychosocial, emotional and spiritual support and comfortable living conditions with the appropriate level of care. As it relates to subsection 5(1) of An Act to amend the Criminal Code (medical assistance in dying), the state of palliative care in Canada is important to consider when making policies and decisions about end-of-life supports. Palliative care has been shown to be effective in improving quality of life and satisfaction with care, however, there exist many gaps drastically affecting the quality and availability of palliative care across Canada. These gaps include a lack of access, education and data.

In Canada, palliative care is a patchwork of uncoordinated services, delivered in multiple healthcare settings, with most healthcare systems in provinces and territories relying on small non-governmental organizations and charities to deliver it. In 2016, only 30% of Canadians have access to specialized palliative care, and with current funding and workforce shortages, specialist palliative care services in all jurisdictions are facing pressure from changing needs and expectations. According to the Canadian Institute for Health Information, while people with cancer in Canada generally had greater access to palliative care than those with other chronic or life-limiting illnesses, improvement is still needed - among people who died in hospital with a cancer diagnosis, less than half (41%) were hospitalized primarily for palliative care, and 3 in 4 had no indication of palliative needs before their final hospitalization².

Even when palliative care services are available, not all Canadians are aware of when or how to access them. Most healthcare providers and clinicians in Canada receive little to no training on the fundamental knowledge and skills of palliative care,³ and in a 2016 IPSOS

¹ Canadian Society of Palliative Care Physicians. (2016). How to improve palliative care in Canada. Retrieved from <u>Full-Report-How-to-Improve-Palliative-Care-in-Canada-FINAL-Nov-2016.pdf</u> (cspcp.ca)

² Canadian Institute for Health Information. (2018). Access to palliative care in Canada. Retrieved from https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf

³ A National Palliative Care Strategy for Canada. (2018). Retrieved from https://www.liebertpub.com/doi/pdfplus/10.1089/jpm.2017.0431



public poll, half of Canadians surveyed said they were unfamiliar with the terms "palliative care" and "advance care planning". These gaps in knowledge and awareness not only make it extremely difficult for people in Canada to properly plan for the end of life but can diminish their quality of life.

In addition, there is a serious lack of consistent data collection at a systematic level on palliative care, reducing the ability to both understand the quality of palliative care and to effectively hold governments accountable to make positive changes. Some jurisdictions and non-governmental organizations have been focused on this type of data collection; however, they are confined to certain provinces or regions. Without nationwide leadership, best practices in data collection will not become standard practice across the country.

Recommendations

CCS recommends the federal government:

- 1. Provide all healthcare providers, including allied providers, with appropriate education and training on the basic principles and practices of palliative care to ensure people with cancer receive the highest quality of care.
- 2. Improve palliative care research and systematic, standardized data collection by developing data systems to measure access to palliative care, both at home and in community settings such as long-term care facilities and residential hospices.
- 3. Develop and implement standards or practice guidelines to identify, assess and refer people with cancer to palliative care services earlier in their cancer experience to ensure optimal quality of life.

MAiD in Canada

At end-of-life, many decisions need to be made, taking into account an individual and their loved ones' values and preferences. CCS respects and supports all Canadians with cancer by helping them make informed choices and autonomous decisions about their care that will impact the quality and outcome of their life. These choices include MAiD. CCS's efforts remain focused on ensuring that people with cancer have access to the information and support services they need and to spend their final days with dignity, with access to pain management and in a setting of their choice. CCS is also committed to supporting the needs of caregivers in decision-making, preparation, grief and loss.

Recommendations

CCS recommends the federal government:

1. Provide adequate resources to ensure Canadians living with cancer have consistent access to timely, equitable and high-quality end-of-life care, including MAiD, across Canada, particularly in rural and remote communities. The resources must address

⁴ Retrieved from https://www.ualberta.ca/folio/2021/02/half-of-canadians-dont-even-know-what-palliative-care-is-so-why-is-it-so-important.html



- different cultural aspects of care, including those of First Nations, Inuit, and Métis communities.
- Expand data collection to better understand why Canadians seek MAiD, family
 experiences when provided with MAiD, and the implications for underserved
 populations and clinicians who provide the service. Findings should be shared with all
 stakeholders through formal channels.
- 3. Continuously evaluate and adapt the system including patient care practices in accordance with best practices and legislation.
- 4. Ensure an appropriate level of education and training for healthcare providers and students regarding all facets of end-of-life care, including their obligations and responsibilities relative to MAiD.

Contact information

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