



Canadian  
Cancer  
Society

**Submission to the Standing Committee on Health  
Study on Palliative Care in Canada**

**By the Canadian Cancer Society**

**July 2020**

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## Introduction

It is inherently human to comfort and provide care to those suffering from cancer, particularly those close to death. With growing evidence, there is no argument that palliative care is essential and a critical component of the cancer control continuum. Timely and comprehensive palliative care for people with cancer and their caregivers offers direct benefits; however, significant barriers limit access to care for many people with cancer.<sup>1</sup> According to the World Health Organization, palliative care is an approach which improves the quality of life of patients and their families facing problems associated with a life-threatening illness through the prevention and relief of suffering by any means of early identification and efficient assessment and treatment of pain, and other physical, psychosocial and spiritual problems.<sup>2</sup> End-of-life care is a component of palliative care that focuses on the specific needs of someone who is dying. There are significant gaps in palliative care across Canada.

The Canadian Cancer Society is pleased to make this submission to the Standing Committee on Health as part of their study on palliative and end-of-life care in Canada.

Summary of recommendations:

- CCS recommends healthcare administrators should adopt, develop and implement standards or practice guidelines to identify, assess and refer patients to palliative care services earlier in their cancer experience to ensure optimal quality of life.
- CCS recommends the need to improve data collection to better measure and report on palliative and end-of-life care in Canada.
- CCS recommends that the compassionate care benefit be extended to include a two-week period for bereavement.
- CCS fully supports Bill C-220 to extend Compassionate Care Leave for Canadians and we encourage all parties to support this Bill.
- CCS recommends that all people with cancer should have access to high-quality, person-centered palliative care and end-of-life care regardless of their age, where they live, or the disease they have.
- CCS recommends that the Government continue to focus on the Minister of Health's mandate letter commitment to make home care and palliative care more available across the country.
- CCS recommends that all healthcare personnel receive appropriate education and training to ensure people with cancer receive the highest quality of care.

## Palliative Care and Cancer

**CCS recommends healthcare administrators adopt, develop and implement standards or practice guidelines to identify, assess and refer patients to palliative care services earlier in their cancer experience to ensure optimal quality of life.**<sup>3</sup>

About 225,800 Canadians are expected to be diagnosed with cancer in 2020. Although advances in cancer treatment have been substantial, cancer is Canada's leading cause of death and about 83,300 Canadians will eventually die from the disease this year. More than

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<sup>1</sup> Kavalieratos D, Corbelli J, Zhang D, Dionne-Odom JN, Ernecoff NC, Hanmer J, Hoydich ZP, Ikejiani DZ, Klein-Fedyshin M, Zimmermann C, Morton SC, Arnold RM, Heller L, Schenker Y (2016) Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *JAMA* 316:2104–2114

<sup>2</sup> WHO. *WHO Definition of Palliative Care*. WHO; Available from: <http://www.who.int/cancer/palliative/definition/en/>. Accessed June 2, 2020

<sup>3</sup> Canadian Partnership Against Cancer. (2017). *Palliative and End-of-Life Care*. Retrieved from <https://s22457.pcdn.co/wp-content/uploads/2019/01/Palliative-and-end-of-life-care-report-2017-EN.pdf>

80% of cancer patients experience pain before their death, and patients may have symptoms related to the disease and the treatment.<sup>4</sup> It is increasingly recognized that the complete care of a person with cancer also includes palliative care early in the course of the illness, along with life-prolonging treatment.

Standards of end-of-life care and palliative care have evolved over the last few decades, partially due to the lack of understanding about the differences between end-of-life care and palliative care. Palliative care encompasses end-of-life care, however, focuses on the quality of life of patients and their families throughout the cancer journey – from diagnosis to end-of-life, including survivorship. This includes expert pain symptom management; skilled psychosocial, emotional and spiritual support; and comfortable living conditions with the appropriate level of care, whether at home, in a hospital or any other settings of a patients' choice. End-of-life care is a portion of palliative care that is directed towards the care of people in decline who are deemed to be terminal or dying in the foreseeable future.<sup>5</sup>

According to the Canadian Institute for Health Information, most patients are being identified as palliative only in their final admission to the hospital before death.<sup>6</sup> Earlier identification of patients with palliative care needs is essential to the initiation of palliative care. In Ontario, 80-85% of patients receiving palliative care are people with cancer, while in Nova Scotia, this proportion was reported to be 80-90%.<sup>7,8</sup> Close to 45% of cancer patients die in acute care hospitals even though about 75% of Canadians would prefer to die at home.<sup>9,10</sup> Data suggests that 13.5% of patients with cancer who died in acute-care hospitals had not been identified as needing inpatient palliative care. For patients who were identified, about 66% only received inpatient palliative care during their last hospitalization, which can be too late for patients to fully experience the full benefits of palliative care.

The Canadian Partnership Against Cancer published a report highlighting that patients who could benefit from palliative care are not being identified, assessed and referred to early enough in their cancer experience.<sup>11</sup> Starting palliative care earlier in routine care and treatment planning and providing this care in the community if the patient desires can: reduce unplanned emergency department visits – leaving needed resources to treat emergency patients; reduce the number of avoidable hospital admissions and shorten hospital stays – which will reduce use of health system resources; reduce avoidable physical and emotional distress for patients and their families; increase the opportunity, for patients with terminal cancer, of dying fully supported at home, when desired.

### **CCS recommends the need to improve data collection to better measure and report on palliative and end-of-life care in Canada.**

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<sup>4</sup> McCarthy EP, Phillips RS, Zhong Z et al (2000) Dying with cancer: patients' function, symptoms, and care preferences as death approaches. *J Am Geriatr Soc* 48(5 Suppl):S110-S121

<sup>5</sup> Canadian Institute for Health Information, Health care use at the End of Life in Atlantic Canada (Ottawa: CIHI,2011).

<sup>6</sup> Canadian Institute for Health Information (CIHI). End-of-Life Hospital Care for Cancer Patients. Toronto, ON: CIHI; 2013.

<sup>7</sup> Cancer Care Ontario. Improving the Quality of Palliative Care Services for Cancer Patients in Ontario. Toronto, Canada: Cancer Care Ontario; 2006.

<sup>8</sup> Cancer Care Nova Scotia, (2015). "Supportive Care." Available at:

[www.cancercare.ns.ca/en/home/nscancerservices/palliativeandsupportivecare.aspx](http://www.cancercare.ns.ca/en/home/nscancerservices/palliativeandsupportivecare.aspx)

<sup>9</sup> Canadian Institute for Health Information. (2013). "End-of-life hospital care for cancer patients."

<sup>10</sup> Dudevich A, Chen A, Gula C, Fagbemi J. End-of-life hospital care for cancer patients: an update. *Healthcare quarterly* (Toronto, Ont.). 2014;17(3):8-10.

<sup>11</sup> Canadian Partnership Against Cancer. (2017). Palliative and End-of-Life Care. Retrieved from <https://s22457.pcdn.co/wp-content/uploads/2019/01/Palliative-and-end-of-life-care-report-2017-EN.pdf>

Palliative care is currently delivered in several settings, including patients' homes, hospitals, outpatient clinics, hospices and long-term care facilities. This poses significant barriers to data collection to understand the full range and scope of the palliative care services provided. Our current data systems only provide information on end-of-life care measures, which is one component of palliative care, and only in a single sector (inpatient care in acute care institutions).

Canada's cancer control system needs to gather more national data on how we provide palliative care throughout the healthcare system. System-wide measurement will provide data on how palliative care is used across the country and help identify opportunities to provide better care. These should be measurable standards, such as number of palliative care and hospice beds, and number of palliative care healthcare professionals that are needed per 100,000 Canadians.

In order to measure performance against established standards, common practices in data collection and evaluation of palliative care services should be developed and implemented. This requires establishing a common set of indicators to allow for meaningful comparisons of palliative care across jurisdictions and over time. See a full list of proposed palliative care indicators in Appendix A.

### **Grief and bereavement**

**The Canadian Cancer Society recommends that the compassionate care benefit be extended to include a two-week period for bereavement.** Palliative care is not "giving up" or something to be feared. In addition, support for family caregivers must be improved to ensure that palliative care provided outside of a hospital setting does not result in significant financial impact to the family.

Under the current federal government Employment Insurance program, the Compassionate Care Benefit (CCB) provides compassionate care benefits to individuals who need time off work to care for a family member with a significant risk of death within 26 weeks. Individuals who qualify can access compassionate care benefits for up to six months. The recipient chooses which weeks in the six-month period to take leave, on the condition that they provide care to the family member while they are on leave from work.

Our recommendation will not cost any additional funds; just amend the benefit to be more flexible to the practical experiences of grief and bereavement. Palliative care does not necessarily end when someone has died. Family members, potential recipients of the compassionate care benefit, need support as they grieve the loss of a loved one and try to manage numerous strains and stresses. Bereavement programs are often part of the comprehensive care offered as part of palliative care.

According to Statistics Canada, one in ten caregivers were spending 30 or more hours a week providing some form of assistance to their ill family member or friend, most likely to an ill spouse (31%) or child (29%). When surveyed, out of eight kinds of support options caregivers said they would like to have received, 68% said they would like to receive or to have received

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greater financial supports.<sup>12</sup> **CCS fully supports Bill C-220 to extend Compassionate Care Leave for Canadians and we encourage all parties to support this Bill.**<sup>13</sup>

## **Access to palliative care and end-of-life care**

**CCS recommends that all people with cancer have equitable access to high-quality, person-centered palliative care and end-of-life care regardless of their age, where they live, or the disease they have.** Palliative care in Canada is a patchwork of uncoordinated services, delivered in multiple healthcare settings, with most healthcare systems in provinces and territories relying on small NGOs and charities to deliver palliative care. A recent survey of 1,540 Canadians showed that only 58% were aware that palliative care is available to people who need it.<sup>14</sup> Most people (90%) agreed that patients should have the right to receive care in their home at the end of life. However, not enough home palliative care resources or services are available to make this possible. Research also shows differences in palliative and end-of-life care highlighting inequities to required services based on where a person lives, their age and type of cancer.<sup>15,16</sup> Rural residents are more likely to be admitted to an acute-care hospital numerous times, make more emergency department visits and are admitted to ICUs more often at the end of life. Research shows that young patients with cancer are more likely to die in an acute-care hospital, to stay in hospital longer, to have more hospital and ICU admissions, and receive new chemotherapy near the end of life. The needs of underserved populations, including Indigenous populations and non-English/non-French speaking communities must be addressed to ensure they are receiving equitable access to palliative and end-of-life care.

Provincial and territorial governments should ensure that adequate community-based multi-disciplinary palliative care services are available at home, in hospices and in long-term care facilities to ensure that palliative and end-of-life needs are met and to reduce reliance on acute care. This includes access to underserved populations, including rural and remote communities, LGBTQ populations, Indigenous, Inuit and Metis, adolescents and young adults, and people who are unable to speak English or French.

In a three-province study, the average percentage of patients receiving palliative homecare from a nurse or personal support worker in the last 6 months before death was 42.2% in Ontario, 46.4% in Nova Scotia and 58.4% in British Columbia. Nationally, almost a quarter (23%) of patients are admitted to an acute-care hospital twice or more in the last month of life. While an acute care hospital may be the best place for a patient with complex medical needs, long and frequent gaps signal a gap in palliative care services. Closing these gaps will reduce poor outcomes at the end of life for people with cancer.

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<sup>12</sup> Caregivers in Canada <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm>

<sup>13</sup> The Compassionate Care Benefit is 1 of 5 special benefits of the Employment Insurance Program. Bill C-220 would amend part of the Canada Labour Code.

<sup>14</sup> Palliative Care Matters, 2016. Available from: <http://www.palliativecarematters.ca/home/>.

<sup>15</sup> Canadian Institute for Health Information. (2018). Access to Palliative Care in Canada. Ottawa, ON. Retrieved from <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>

<sup>16</sup> Canadian Partnership Against Cancer. (2017). Palliative and End-of-Life Care. Retrieved from <https://s22457.pcdn.co/wp-content/uploads/2019/01/Palliative-and-end-of-life-care-report-2017-EN.pdf>

## **Education and training**

**CCS recommends that all healthcare personnel receive appropriate education and training to ensure people with cancer receive the highest quality of care.**

Three in five doctors don't feel ready to provide palliative care, despite 80% of them seeing patients who need it. In order to ensure enough trained healthcare providers can meet the needs of the population, all healthcare professionals should have basic training in palliative care and should know when to refer a patient to a palliative care specialist.

At the same time, the number of palliative care specialists must be increased. The need for more healthcare providers and specialized palliative care physicians is supported by the results of the recent National Palliative Medicine Survey conducted by several healthcare professional and research organizations, as well as a recent call to action published by the Canadian Medical Association.<sup>17</sup> CCS is also looking forward to reviewing the Canadian Inter-Disciplinary Palliative Care Competency Framework, to guide curricula for educators and reference manual for health professionals and volunteers, being created by Canadian Partnership Against Cancer in partnership with Health Canada and provincial and territorial health authorities.<sup>18</sup>

## **Role of Canadian Cancer Society**

CCS offers a service called the Cancer Information Helpline, which is a national toll-free telephone service that provides current, reliable information to people with cancer, caregivers, families, friends, the general public and health care professionals. As well, the Cancer Information Helpline provides this support in over 200 languages through an interpreter, including Indigenous languages. Tracking usage data of the Cancer Information Helpline, over the past five years, "palliative care" was a logged topic in 2,834 inquiries, and "bereavement" was a logged topic in 1,020 inquiries for the same amount of time. The services provided by CCS are examples of how we are taking a leadership role in creating more accessible services for people with cancer who require palliative care.

Research and data are important components of a nationwide approach to improve access to palliative care for Canadians. For example, the Pan-Canadian Framework for Palliative and End-of-Life Care Research was published in spring 2017. Recommendations from the research framework outline how to consolidate and expand the existing research base and move research outcomes into practice for people with cancer. In order to better understand palliative and end-of-life care experiences of people with cancer, patterns of care need to be tracked across all health care settings.

## **Government response to palliative care**

**CCS recommends that the Government continue to focus on the Minister of Health's mandate letter commitment to make home care and palliative care more available across the country.** Steps have been taken by the federal government over the years to

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<sup>17</sup> Canadian Medical Association, "Palliative care: Canadian Medical Association's National Call to Action," Canadian Medical Association, Ottawa, 2014-2015

<sup>18</sup> Canadian Partnership Against Cancer. (2020). The Canadian Inter-Disciplinary Palliative Care Competency Framework: A curriculum guide for educators and reference manual for health professionals and volunteers.

develop recommendations to improve palliative care, however there are many gaps that remain to be filled. Since 1995, there have been nine major national consultations with Canadians dealing in whole or in part with hospice palliative and end-of-life care, some of which include the following:

- In June 2000, [Final report](#) of the subcommittee to update “of life and death” of the Standing Senate Committee on Social Affairs, Science and Technology. Senate of Canada. Chaired by the Honourable Sharon Carstairs.
- In November 2011, [“Not to Be Forgotten: Care of Vulnerable Canadians.”](#) Final report of the ad hoc Parliamentary committee on Palliative and Compassionate Care. Co-chaired by MPs Harold Albrecht, Joseph Comartin and Frank Valeriote.

In 2018, the Federal Minister of Health, Ginette Petitpas Taylor, tabled the Framework on Palliative Care in Canada. The new Framework set out the federal government’s plan for improving access to palliative care across Canada. The Framework builds the private member’s bill C-277, *An Act Providing for the Development of a Framework on Palliative Care in Canada*, sponsored by Marilyn Gladu, the shadow health minister at the time and Conservative MP. Bill C-277 passed into law in December 2017. The Minister of Health, as required by the *Framework on Palliative Care in Canada Act*, will report on the state of palliative care in Canada within 5 years time to Parliament. The Framework on Palliative Care in Canada<sup>19</sup> is a policy roadmap that sets out measures to ensure that all Canadians with life-limiting illnesses experience the highest attainable quality of life until the end of life. The Framework addresses the societal changes in Canada and their implications for palliative care. This includes; changing demographics (i.e. aging population), pressure on caregivers, changing expectations on person-centred care, gaps in professional training and increased public discussion about end-of-life care and decisions (like legalization of Medical Assistance in Dying).

In August 2019, Health Canada released the Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada.<sup>20</sup> The Action Plan is a five-year plan that will be coordinated by Health Canada. A list of indicators will be developed to measure the progress of the plan and identifies that the actions of the plan are specific to only the federal government. The implementation plan of the Action Plan is not yet available.

In the Common Statement of Principles on Shared Health Priorities, federal, provincial, and territorial (FPT) governments commit to work together to ensure health care systems continue to respond to the needs of Canadians.<sup>21</sup> These were developed and informed the development of bilateral agreements between the federal government and provinces and territories in 2017. The principles focus on two priority areas (home and community care, and mental health and addictions) where federal funding will be provided to PTs in response to increased demands. Palliative care is occasionally included in the home and community care priority area for individual provinces.

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<sup>19</sup> Health Canada. Framework on Palliative Care in Canada. 2018. Retrieved from <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>

<sup>20</sup> Health Canada. Action Plan on Palliative Care: Building on the framework on palliative care in Canada. 2019. Retrieved from <https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/action-plan-palliative-care/action-plan-palliative-care-eng.pdf>

<sup>21</sup> Government of Canada. (2017). A Common Statement of Principles on Shared Health Priorities. Retrieved from [https://www.canada.ca/content/dam/hc-sc/documents/corporate/transparency\\_229055456/health-agreements/principles-shared-health-priorities.pdf](https://www.canada.ca/content/dam/hc-sc/documents/corporate/transparency_229055456/health-agreements/principles-shared-health-priorities.pdf)

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## COVID-19 and palliative care

Devastating diagnoses of cancer do not stop during a pandemic. COVID-19 has led to a strain on palliative care resources, leading to accessibility barriers people with cancer. However, palliative care services will continue to be needed across many different care settings, including intensive care units, hospital wards, emergency departments and long-term care facilities. While shared decision-making between clinicians and patients is a key part of the process in palliative care conversations, the pandemic may impact patient autonomy in choosing life-prolonging measures and location of death due to public health restrictions and resources limitations.<sup>22</sup>

A 25-year old caregiver from Ontario shared her story with the Canadian Cancer Society to demonstrate the importance of palliative care for people with cancer and their families and how this has been impacted by COVID.

She said "I had gone months without seeing my mom before she passed. As a lung cancer patient, we were terrified of her getting the virus as it would surely mean the end for her. She was hospitalized for about a week due to her health taking a sudden decline. We were not allowed to go in with her, to sit by her side and hold her hand or visit at all. She was unable to answer any of the doctor's questions and he described her as very "agitated and restless". She was released on the Monday and went into hospice two days later. We were told to have her visit any family before going into hospice because once she was in, only one person would be allowed to see her. We said our goodbyes in the car before she walked in. As her delegated person, I was allowed to go in with her in full PPE to help her adjust and get her settled. I was given 24 hours with her, after that I would only be called back if she was passing. This was the hardest for me.

Before COVID, I went with my mom to almost every appointment, every treatment and spent as much time with her as I could. I brought her meals and visited with my daughter to cheer her up whenever I could. I was only ever a short drive away if she had questions, concerns or if she just needed to talk. Because of COVID, I felt as if we were a world apart. We were allowed window visits and phone calls, but my mom was not lucid enough to do these very often or for very long. My mom was confused, overwhelmed and ultimately alone. I imagine she was fearful of the caretakers who were in full PPE and would come to "bug her", as she would say. If I had been able to be by her side to reassure her, I feel this would all have been avoided. It was extremely hard to explain to her why we couldn't be there and I can't even begin to

*"Palliative care should not be seen as a luxury, but as a necessary part of the response to humanitarian crises"* – Dr. Amit Arya & Dr. Naheed Dosani, Palliative care physicians in Ontario

*"People in palliative care do not deserve to die alone, without a familiar face, soothing words and a hand to hold. They do not deserve to spend their final days looking at the faces of those they love through a window, unable to hear them clearly, unable to touch them and unable to feel their love."*  
- Caregiver, 25 years-old, Ontario

<sup>22</sup> Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: beyond ventilators and saving lives. CMAJ. 2020 Apr 14;192(15):E400-4.



describe the guilt I felt leaving her alone. Her caretakers were amazing and I thank God for the dedicated staff at the hospice. They tried to update us daily and let us visit in any way that we could. They tearfully told me one day that we could have been with my mom 24/7, could have laid beside her, hugged her and supported her. The hardest part for me was explaining to my 5-year-old why she couldn't hug her nana and had to see her through a window. It broke my heart to see her cry and run away from the window because she "just wanted to talk to her nana".

My mom was ultimately alone when she passed. It happened so suddenly they couldn't even call me to have me drive over... I was only 5 minutes away at the time. I have had a hard time coming to terms with the situation and everything this virus robbed us of. People in palliative care do not deserve to die alone, without a familiar face, soothing words and a hand to hold. They do not deserve to spend their final days looking at the faces of those they love through a window, unable to hear them clearly, unable to touch them and unable to feel their love. This was not the way we had pictured her final days."

Amit Arya and Naheed Dosani, palliative care physicians in Ontario said "Even at the best of times, Canada's palliative care system is under-resourced. One of the most distressing aspects of this disease is that it separates the dying from their loved ones...Palliative care should not be seen as a luxury, but as a necessary part of the response to humanitarian crises." The COVID-19 pandemic has demonstrated the need for people with cancer to form a plan and discuss it with their healthcare team and their family. Families who are generally at the bedside of palliative care patients are experiencing challenges as a result of restrictions on visitations in hospitals and hospice care facilities. On top of the pandemic highlighting problems in long-term care homes, where outbreaks have led to half of Canada's COVID-19 deaths, family caregivers are feeling increased levels of stress as a result of day-to-day care responsibilities for their loved ones.

While the pandemic has posed significant challenges across the healthcare system and particularly for the delivery of palliative care, physicians are working with families to remotely have these conversations with patients using Skype, FaceTime and other technologies to provide high-quality care. Telemedicine has provided hidden advantages, such as allowing practitioners to see patients' home environments that has traditionally not been available. The pandemic has had devastating impacts for people with cancer worldwide. Failing to provide and improve palliative care to people with cancer in Canada would compound this tragedy.

### **Blueprint for Action**

CCS is a member of the Quality End-of-Life Care Coalition of Canada. The Quality End-of-Life Care Coalition of Canada (QELCCC) is a group of 34 national organizations dedicated to improving palliative care for all Canadians. The Coalition believes that all Canadians have the right to quality hospice palliative care. To achieve this, there must be a well-funded, sustainable national strategy for hospice palliative care. It is the mission of the QELCCC to work together in partnership to achieve this goal.

In 2010, the Quality End of Life Coalition of Canada (QELCCC) released the Blueprint for Action 2010-2020 which identified priority areas and recommendations for the last 10 years and provided a summary of progress made to date, current knowledge, issues and gaps. Moving forward, the Coalition produced the Blueprint for Action 2020-2025 to continue to improve

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quality hospice palliative care and access for all Canadians. CCS supports the 2020-2025 Blueprint for Action. The following priorities are included as part of the updated Blueprint for Action:

- Increasing public awareness around hospice palliative care's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement.
  - Ensuring health care providers, volunteers, communities, caregivers and others have access to education and training to ensure they possess the required competencies to provide optimal care.
  - Contributing to research and systematic, standardized data collection on hospice palliative care with special interest including formal and informal caregivers, and grief and bereavement.
  - Advocating for universally accessible and culturally safe access to hospice palliative care for under-served populations and those who provide caregiving and experience grief and bereavement.
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## **Appendix A. List of indicators to measure palliative care**

### **1. Structure and Process of Care**

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment, in addition to ensuring adequate communication.

- 1.1. Percentage of health care professionals who have tools to identify people who would benefit from palliative care and assess their needs
- 1.2. Percentage of people identified to benefit from palliative care who have a documented assessment of their palliative care needs (physical, psychological, social, cultural, legal, ethical and spiritual)
- 1.3. Number of days between receiving first palliative care service and death\*
- 1.4. Number of days between referral to palliative care and receiving services
- 1.5. Percentage of people who receive palliative care (or their caregivers) who state that they have received care from two or more health care providers, such as a physician, nurse, social worker, psychologist, spiritual care provider, volunteer, and others (interdisciplinary care)

\*Palliative care services is defined to be consistent with the 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.”

### **2. Access to palliative care**

People with identified palliative care needs have access to palliative care support as needed.

- 2.1 Proportion of individuals who can access palliative care support in-person (within a one-hour drive) [or virtually 24/7]
- 2.2 Percentage of people identified to benefit from palliative care who state that they can receive community palliative care support, including afterhours care, when needed
- 2.3 Proportion of patients with 2 or more emergency room visits in the last 30 days of life (negative indicator)

### **3. Training and education for healthcare providers**

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

- 3.1 Percentage of people with identified palliative care needs (or their caregivers) who state that health care professionals helped them understand palliative care and provided information about available resources and supports
- 3.2 Availability of resources and tools for health care professionals to provide education about palliative care to patients, families, and caregivers
- 3.3 Percentage of health care providers and volunteers who provide palliative care who state that they have the knowledge and skills to provide palliative care

### **4. Management of pain and symptoms**

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

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- 4.1 Percentage of people who receive palliative care who have documented assessments of their pain and other symptoms in their medical record
- 4.2 Percentage of people who receive palliative care (or their caregivers) who rate the level of support to relieve their pain and other symptoms as excellent
- 4.3 Palliative care and hospice patients are screened for pain, shortness of breath, nausea and constipation during admission visit.

## 5. Psychosocial aspects of care

People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.

- 5.1 Percentage of people who receive palliative care who have assessments of their psychosocial needs documented in their medical record
- 5.2 Percentage of people who receive palliative care (or their caregivers) who state that they received timely psychosocial support to address their identified physical, psychological, social, cultural, legal, ethical and spiritual needs

## 6. Caregiver support

Families and caregivers of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

- 6.1 Percentage of people with identified palliative care needs who have a caregiver needs assessment documented in their medical record
- 6.2 Percentage of caregivers of people who receive palliative care who state that they and the caregivers' family members receive as much help and support as they need

## 7. Goals of care and decision-making

People with identified palliative care needs and their substitute decision-makers have discussions with their interdisciplinary health care team about their goals of care to help inform their health care decisions.

- 7.1 Percentage of people with identified palliative care needs who state that they have shared their wishes, values, and beliefs with their substitute decision-maker regarding the kind of health and personal care they would want to receive in the future
- 7.2 Percentage of people with identified palliative care needs who have documented discussions with a health care professional about their goals of care in their medical record

## 8. Setting of care and place of death

People with identified palliative care needs, their substitute decision-maker, their family and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

- 8.1 Percentage of people with identified palliative care needs who have documentation of their preferred setting of care and place of death in their medical record
  - 8.2 Percentage of caregivers of people who died of a progressive, life-limiting illness who think that the person they cared for died in the right place
-