



## PALLIATIVE CARE

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### Introduction

Palliative care is an approach that aims to relieve suffering and improve the quality of life of those facing life-limiting acute or chronic conditions by means of early identification, assessment, treatment of pain and other symptoms and support of all physical, emotional and spiritual needs. It may coexist with other goals of care, such as prevention, treatment and management of chronic conditions, or it may be the sole focus of care.

### General principles

#### Goals

1. All Canadian residents should have access to comprehensive, quality palliative care services regardless of age, care setting, diagnosis, ethnicity, language and financial status.<sup>1</sup>
2. The Canadian Medical Association (CMA) declares that its members should adhere to the principles of palliative care whereby relief of suffering and quality of living are valued equally to other goals of medicine.
3. The CMA believes that all health care professionals should have access to referral for palliative care services and expertise.<sup>2</sup>
4. The CMA supports the integration of the palliative care approach into the management of life-limiting acute and chronic disease.<sup>3</sup>
5. The CMA advocates for the integration of accessible, quality palliative care services into acute, community and chronic care service delivery models<sup>4</sup> that align with patient and family needs.
6. The CMA supports the implementation of a shared care model, emphasizing collaboration and open communication among physicians and other health care professionals.<sup>5</sup>
7. The CMA recognizes that the practice of assisted dying as defined by the Supreme Court of Canada is distinct from the practice of palliative care.

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## **Access to palliative care services**

8. The CMA believes that every person nearing the end of life who wishes to receive palliative care services at home should have access to them.
9. Comprehensive, quality palliative care services must be made available to all Canadians and efforts to broaden the availability of palliative care in Canada should be intensified.<sup>6</sup>
10. The CMA calls upon the federal government, in cooperation with provincial and territorial governments, to improve access to pediatric palliative care through enhanced funding, training and awareness campaigns.<sup>7</sup>
11. The CMA will engage in physician human resource planning to develop an appropriate strategy to ensure the delivery of quality palliative care throughout Canada.<sup>8</sup>

## **Education**

12. All physicians require basic competencies in palliative care and may require enhanced skills appropriate to their practice.
13. The CMA requests that all Canadian faculties of medicine create a training curriculum in palliative care suitable for physicians at all stages of their medical education and relevant to the settings in which they practise.<sup>9</sup>

## **Role of governments**

14. The CMA calls on governments to work toward a common strategy for palliative care to ensure equitable access to and adequate standards for quality palliative care.<sup>10</sup>
15. The CMA recommends that all relevant legislation be amended to recognize that any person whose medical condition warrants it is entitled to receive palliative care.<sup>11</sup>
16. The CMA supports emergency funding for end-of-life care for uninsured people residing in Canada.<sup>12</sup>

## BACKGROUND

In Canada, the impact of end-of-life care on both individuals and the health care system is “staggering,” and the demand for this care will continue to grow as the population ages.<sup>13</sup> It is estimated that the number of Canadians dying each year will increase by 40% to 330,000 by 2026. The well-being of an average of five others will be affected by each of those deaths, or more than 1.6 million people.<sup>14</sup> Against this backdrop, the availability of and access to palliative care is an urgent policy and practice imperative.

There has been mounting support for, and mounting criticism of the lack of, a national strategy for palliative care.<sup>15</sup> The delivery of palliative care varies greatly across Canada due to differences in regional demographics, societal needs, government involvement and funding structures. Similarly, funding and legislation supporting access to palliative care services vary significantly between jurisdictions.

A recent survey of Canadian physicians who provide palliative medicine found that: (1) Canada needs an adequate palliative medicine workforce; (2) primary care providers need more support for palliative care education and training; (3) palliative medicine as a distinct discipline must be further developed to better meet the complex needs of patients; and (4) Canada must ensure minimum palliative medicine standards are met.<sup>16</sup>

In an effort to address the current challenges in palliative care and improve both the quality of care and access to care, the CMA developed recommendations for a national call to action:

1. All patients should have a primary care provider that can support them with their palliative care needs or else refer these patients earlier to a palliative care team to establish goals of care.
2. Physicians should provide leadership at local, regional, provincial/territorial and federal levels to promote the establishment of integrated models of palliative care.
3. All physicians should obtain essential palliative care skills and knowledge to provide basic palliative care services to their patients.
4. Physicians should advocate for adequate and appropriate home palliative care resources so their patients can stay in their homes as long as possible.
5. Physicians should advocate for an adequate number of palliative and/or hospice care beds to meet their communities’ needs.
6. Continuing care facilities and long-term care homes should have in-house palliative care physician support on their palliative care teams.
7. Physicians should support the valuable work of hospice volunteers.
8. Medical students are encouraged to look at palliative care as a rewarding career.
9. Practising palliative care physicians are encouraged, if needed, to obtain additional certified training in palliative care from either the Royal College of Physicians and Surgeons of Canada or the College of Family Physicians of Canada.
10. Physicians acknowledge the value of and support the participation of family and friends in caring for their loved ones at the end of life.

## **Integrated palliative approach to care**

There are four main models of palliative care delivery in Canada: integrated palliative care programs, continuing care and long-term care facilities, residential hospices, and home-based palliative care.

Palliative care was originally developed in cancer care to provide patients dying of cancer with care at the very end of life by a specialized palliative care team.<sup>17</sup> This model has evolved significantly in response to the increasing occurrence of, and burden posed by, complex chronic disease<sup>18</sup>. Palliative care is now also provided to patients with multiple co-occurring morbidities who require multiple interventions. It is now recognized to benefit all those living with life-limiting acute or chronic conditions, including, or perhaps especially, when it is initiated earlier in the disease trajectory.

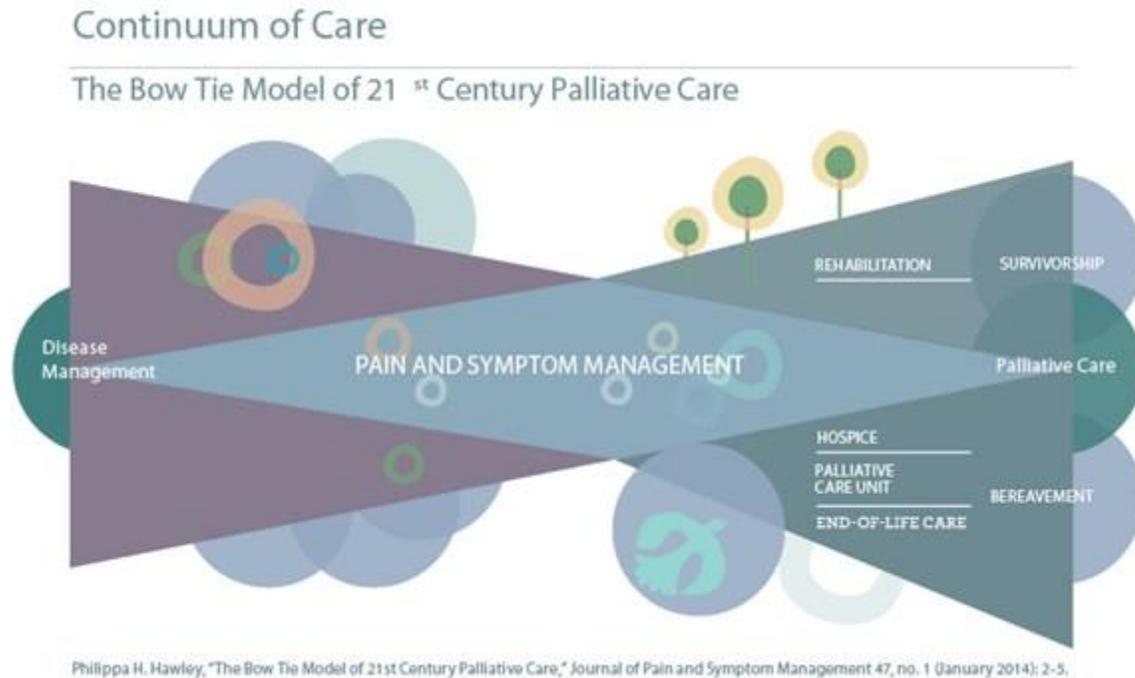
Evidence shows that integrated and early provision of palliative care leads to: (1) better outcomes than those obtained with treatment alone (e.g., improvements in symptoms, quality of life and patient satisfaction; positive effects on emotional wellness; decreased suffering; and at times increased longevity) and (2) better use of resources (e.g., less burden on caregivers, more appropriate referrals to hospice palliative care, more effective use of palliative care experts, less use of emergency and intensive interventions and decreased cost of care).<sup>19-20-21-22</sup> Taken together, these studies validate the benefits of integrating palliative care services with standard treatment and involving palliative care providers early, a collaborative approach that transcends the conventional view that palliative care is care delivered at the very end of life.

At present, there is strong support for the development and implementation of an integrated palliative approach to care. Integration effectively occurs:

- throughout the disease trajectory;
- across care settings (primary care, acute care, long-term and complex continuing care, residential hospices, shelters, home);
- across professions/disciplines and specialties;
- between the health care system and communities; and
- with changing needs from primary palliative care through to specialist palliative care teams.

The integrated palliative approach to care focuses on meeting a person's and family's full range of physical, psychosocial and spiritual needs at all stages of frailty or chronic illness, not just at the end of life.<sup>23</sup> It is provided in all health care settings. The palliative approach to care is not delayed until the end stages of an illness but is applied earlier to provide active comfort-focused care and a positive approach to reducing suffering. It also promotes understanding of loss and bereavement (Fig. 1).

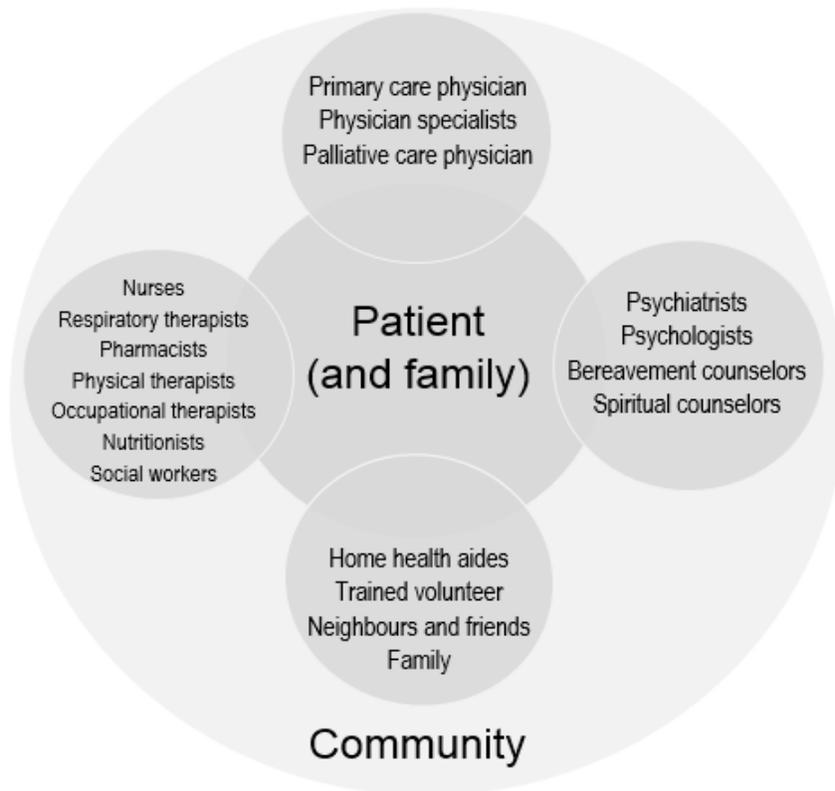
**Figure 1**



Specialized palliative units and hospices are essential for end-of-life care for some individuals but are not appropriate for all persons facing life-limiting chronic conditions. When a palliative approach is offered in multiple settings, people and their families can receive better care through the many transitions of chronic conditions like dementia, lung, kidney and heart diseases, and cancer. This requires that all physicians be competent in initiating a primary palliative approach: they must be able to engage in advance care planning discussions, ask about physical and emotional symptoms and make appropriate, timely referrals to other providers and resources. Primary care physicians may need to develop more expertise in palliative care. A cadre of expert palliative care physicians will be required to provide care in complex cases, engage in education and research, and provide support for health professional colleagues providing palliative care in multiple settings. All health professionals must be able to practise competently in an integrated palliative approach to care.

At the heart of an integrated palliative approach to care are a patient and family surrounded by a team of multidisciplinary professionals and community providers (Fig. 2). While team members vary depending on the needs of the patients and families, the principles of whole-person care and family care do not change. This allows patients and families to have their symptoms managed, receive care in the setting of their choice, engage in ongoing discussions about their preferences for care and experience a sense of autonomy in living their lives well.

**Figure 2**



Adapted from L. Alexander (2015)

A report on *The Way Forward*, a project of the Quality End-of-Life Coalition of Canada and the Canadian Hospice Palliative Care Association, summarizes the situation as follows: “Only a small proportion of Canadians will need the kind of complex, intensive or tertiary hospice palliative care provided by expert palliative care teams in institutional settings, such as residential hospices and acute care hospitals. However, everyone who is becoming frail or is faced with a chronic illness could benefit from certain key palliative care services. As our population ages, we must ensure that all Canadians have access to palliative services integrated with their other care that will help them manage symptoms, enhance their lives, give them a greater sense of control, and enable them to make informed decisions about the care they want. More equitable access to palliative care integrated with their other care will enable more Canadians to live well with their illness up to the end of life. It will also enable more people to receive care in the setting of their choice and reduce the demand on acute care resources.”<sup>24</sup>

### **Access to palliative care services**

There are currently no reliable data on the number of specialized or semi-specialized palliative care physicians in Canada. It is difficult to count these physicians because palliative care has not historically existed as a specialty. Physicians practising palliative

care have a wide variety of backgrounds and training, and many provide palliative care on a part-time basis. The Canadian Society of Palliative Care Physicians is currently working with partner organizations including the CMA, the Royal College of Physicians and Surgeons and the College of Family Physicians of Canada to better define the different types of palliative care physicians to conduct a meaningful count.

On the question of access, studies have found that palliative care services are not aligned with patient preferences. For example, while 70% of hospitalized elderly patients reported wanting comfort measures rather than life-prolonging treatment, more than two-thirds were admitted to intensive care units.<sup>25</sup> Most patients and caregivers report wanting to die at home<sup>26</sup> and in-home palliative team care is a cost-effective intervention,<sup>27</sup> but the value of this form of care is not reflected in many provincial policies. Instead, Canadian families frequently shoulder 25% of the total cost of palliative care because they must pay for home-based services,<sup>28</sup> such as nursing and personal care services, that are not provided by governments.

With the goal of improving the congruence between patient treatment preferences for end-of-life care and the services provided, Health Quality Ontario developed an evidentiary platform to inform public policy on strategies to optimize quality end-of-life care in in-patient and outpatient (community) settings. It identified four domains in which access to end-of-life care should be optimized to align with patient preferences: (1) location (determinants of place of death); (2) communication (patient care planning discussions and end-of-life educational interventions); (3) team-based models of care; and (4) services (cardiopulmonary resuscitation [CPR] and supportive interventions for informal caregivers).<sup>29</sup>

## **Education**

It is well recognized that education in palliative care is lacking in medical school and residency training. In response, the Association of Faculties of Medicine of Canada, in partnership with the Canadian Hospice Palliative Care Association and the Canadian Society of Palliative Care Physicians, conducted the *Educating Future Physicians in Palliative and End-of-Life Care Project*<sup>30</sup> to develop consensus-based competencies for undergraduate medical trainees and a core curriculum that was implemented in all 17 Canadian medical schools. Despite these efforts, a survey conducted by the Canadian Society of Palliative Care Physicians found that the competencies are not being consistently taught in medical schools, as evidenced by the fact that 10 medical schools offered less than 10 hours of teaching on palliative care and two offered none.<sup>31</sup>

Moreover, evidence suggests that Canadian physicians are not consistently or adequately trained in palliative care. There is a general lack of providers trained in palliative care for service provision, teaching, consultative support to other physicians and research. To fill the observed gap in education, the Royal College of Physicians and Surgeons of Canada is developing Palliative Medicine as a subspecialty, and the College of Family Physicians of Canada is developing a Certificate of Added Competence in Palliative Care.

What is more, different levels of palliative care competencies are required for different physicians:

- All physicians require basic skills in palliative care.
- Palliative consultants and physicians who frequently care for patients with chronic illnesses and/or frail seniors require enhanced skills.
- Palliative medicine specialists and palliative medicine educators require expert skills.

More broadly, the undergraduate curricula of all health care disciplines should include instruction in the principles and practices of palliative care, including how to access specialized palliative care consultation and services.

### **Role of governments**

Access to palliative care must be treated with the same consideration as access to all other medical care. Provincial/territorial and federal legislation, however, is vague in this regard and does not recognize access to palliative care as an entitlement.

Government funding of community-based hospice palliative care has not increased proportionately to the number of institutionally based palliative care beds that have been cut, leaving a significant gap in the health care system.<sup>32</sup> To address this issue, efforts to broaden the availability of and access to palliative care in Canada need to be intensified. It is imperative that governments develop a common palliative care strategy to ensure equitable access to and adequate standards for quality palliative care, including emergency funding for those who are uninsured.

### **Glossary**

**Integrated palliative approach to care:** An approach that focuses on quality of life and reduction of suffering as a goal of care. This approach may coexist with other goals of care — prevention, cure, management of chronic illness — or be the sole focus of care. The palliative approach integrates palliative care services throughout the treatment of a person with serious life-limiting illness, not just at the very end of life.

**Palliative care services:** Generally consists of palliative care provided by a multidisciplinary team. The team may include a primary care physician, a palliative care physician, nurses, allied health professionals (as needed), social workers, providers of pastoral care and counselling, bereavement specialists and volunteers. The team members work together in a shared care model.

**Shared care model:** An approach to care that uses the skills and knowledge of a range of health professionals who share joint responsibility for an individual's care. This model involves monitoring and exchanging patient data and sharing skills and knowledge among disciplines.<sup>33</sup>

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