



# ACTION PLAN ON PALLIATIVE CARE

BUILDING ON THE FRAMEWORK ON PALLIATIVE CARE IN CANADA



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Health Canada is the federal department responsible for helping the people of Canada maintain and improve their health. Health Canada is committed to improving the lives of all of Canada's people and to making this country's population among the healthiest in the world as measured by longevity, lifestyle and effective use of the public health care system.

Également disponible en français sous le titre :

PLAN D'ACTION SUR LES SOINS PALLIATIFS - CONSTRUIRE SUR LE CADRE SUR LES SOINS PALLIATIFS AU CANADA

To obtain additional information, please contact:

Health Canada

Address Locator 0900C2

Ottawa, ON K1A 0K9

Tel.: 613-957-2991

Toll free: 1-866-225-0709

Fax: 613-941-5366

TTY: 1-800-465-7735

E-mail: [hc.publications-publications.sc@canada.ca](mailto:hc.publications-publications.sc@canada.ca)

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Publication date: August 2019

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PDF Cat.: H22-4/19-2019E-PDF

Pub.: 190197

ISBN: 978-0-660-31796-0

# Living Well Until the End of Life

## MAKING PALLIATIVE CARE A PRIORITY

Most Canadians living with life-limiting illness wish to remain independent and receive the care they need at home or in their community. Improved access to palliative care in a variety of health care settings is critical to making that happen. That is why the Government of Canada has made palliative care a priority.

## SHARED HEALTH PRIORITIES SUPPORTED BY FEDERAL INVESTMENT

In August 2017, federal, provincial and territorial governments<sup>1</sup> agreed to the Common Statement of Principles on Shared Health Priorities, including a commitment to work together to improve access to home and community care, including palliative care. To support this work, the federal government is providing the provincial and territorial governments with \$6 billion over 10 years. Many provinces and territories are using some of this funding to improve access to palliative care.<sup>2</sup> In addition, the federal government has allocated \$184.6 million over five years for home and palliative care for Indigenous communities.

## THE FRAMEWORK ON PALLIATIVE CARE IN CANADA

In late 2017, the *Framework on Palliative Care in Canada Act* was passed by Parliament with all-party support. In the spring and summer of 2018, Health Canada consulted with provincial and territorial governments, federal departments, and national stakeholders, as well as people living with life-limiting illness, caregivers and other Canadians.

“We had great doctors for my father, but none of them understood the importance of the palliative approach. We have so far to go in helping not only the public, but also the health care system understand this wonderful field and why early intervention is so crucial.

Everyone deserves to have access to good palliative care.”

These consultations informed the development of the *Framework on Palliative Care in Canada (Framework)*,<sup>3</sup> which was tabled in Parliament in December 2018. It serves as a reference point to help governments, stakeholders, caregivers, and communities identify common directions and opportunities, share best practices and close gaps. The Framework indicated that it would be followed by an action plan laying out initiatives aligned with the Framework that fall under federal responsibility.

## Guiding Principles of the Framework

- » Palliative care is person - and family-centred care
- » Death, dying, grief and bereavement are a part of life
- » Caregivers are both providers and recipients of care
- » Palliative care is integrated and holistic
- » Access to palliative care is equitable
- » Palliative care recognizes and values the diversity of Canada and its peoples
- » Palliative care services are valued, understood, and adequately resourced
- » Palliative care is high quality and evidence-based
- » Palliative care improves quality of life
- » Palliative care is a shared responsibility

# Taking Action

This Action Plan lays out Health Canada's five-year plan to tackle issues uncovered through the development of the Framework. It aims to improve quality of life for people living with life-limiting illness, families and caregivers, and enhance access, quality of care and health care system performance. It complements current financial support to provinces and territories under the Common Statement of Principles on Shared Health Priorities.

The goals and areas for action outlined below are quite broad. Health Canada will work within them, making strategic and targeted choices on specific activities, mindful of the federal government's mandate and levers for action in the health sector. Some activities outlined are already underway, while others are in the development stage.

Health Canada will oversee and coordinate the implementation of the Action Plan, connecting governments and stakeholders and serving as a knowledge centre to share best practices. To ensure the ensuing Action Plan stays on track, a set of indicators will be developed to measure the progress of the outlined initiatives.

## GOALS AND ACTIONS

### 1. RAISE AWARENESS AND UNDERSTANDING OF HOW ADVANCE CARE PLANNING AND PALLIATIVE CARE CAN IMPROVE QUALITY OF LIFE UNTIL THE END OF LIFE

1. Support increased awareness of the importance of advance care planning and end-of-life care discussions through public education, activities, community workshops and new resources for a range of audiences.
2. Host a palliative care webinar series for health care providers to raise awareness and understanding of key palliative care topics, including the non-medical aspects of palliative care.
3. Launch an awareness campaign targeting the public and health care providers who are not palliative care specialists to increase awareness, understanding, and acceptance of the benefits of introducing palliative care early—and in conjunction with—the treatment process, as well as the non-medical aspects of palliative care.
4. Hold a palliative care event aimed at highlighting innovations in palliative care delivery, supports for caregivers, and partner successes in implementing their own plans related to the Framework.
5. Prepare a report on the state of palliative care in Canada to be tabled in Parliament.

"As a person with a life-limiting illness, I have talked to my family and doctor about what care I want. But I am concerned the care team will not be told that I have an advance care plan, will not know where to find it, or will not follow my wishes, and the resources I need will not be available when I need them."

## 2.

## SUPPORT HEALTH SYSTEM QUALITY BY IMPROVING PALLIATIVE CARE SKILLS AND SUPPORTS FOR HEALTH CARE PROVIDERS, FAMILIES, CAREGIVERS, AND COMMUNITIES

1. Support the increased scope and availability of post-graduate palliative care training for health care providers.
2. Promote the expansion of existing initiatives to train paramedics to provide palliative care at home.
3. Promote consistent and quality care delivery by teams that integrate the knowledge and methods of a range of health care providers, volunteers and caregivers through the development of a national interdisciplinary palliative care competency framework. This framework will document the skills and abilities essential for each team member and how they can work effectively together.
4. Support the development of tools and resources for health care providers to enable people living with life-limiting illness to stay at home or in home-like settings (including long-term care homes), and prevent unwanted and unnecessary transfers to emergency departments.
5. Promote improvements in home-based palliative care by disseminating knowledge and expanding leading practices and skill acquisition, while emphasizing communication with people living with life-limiting illness, families and caregivers.
6. Support the development and adoption of existing technologies and platforms to link community-based care providers and caregivers with palliative care expertise. This includes facilitating referrals and consultations with palliative care specialists using web-based technology rather than waiting for face-to-face meetings; and enhancing online platforms that caregivers and people living with life-limiting illness can turn to for evidence-based information, and communities of support.
7. Explore innovative approaches to palliative care navigation—for example, by using trained volunteers to help people living with life-limiting illness and their caregivers find supportive services.
8. Support the growth of emerging “compassionate community” projects through seed funding, starting with official language minority communities. Explore ongoing work with the compassionate community movement to increase the spread of successful initiatives across Canada.

“The doctor said my wife did not meet the criteria for ‘palliative care’ because she had received treatment to improve her organ function. We couldn’t imagine it was one or the other: treating her illness, OR palliative care. How could it be?”

“Because she wasn’t referred to palliative care, we were only given a bit of support from community health services, and our requests for palliative-type supports were never granted—because a physician couldn’t acknowledge she was dying.”

“My spouse wanted to stay at home during his final illness, and I did my best to respect that wish. But it put a lot of stress on me. Because the person with the illness is the focus, caregivers can feel isolated and burnt out. I felt like I was the only one going through it.”



### 3. SUPPORT HEALTH SYSTEM QUALITY IMPROVEMENT THROUGH ENHANCED DATA COLLECTION AND RESEARCH

#### DATA COLLECTION

1. Foster improvements in palliative care data 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.
2. Evaluate the effectiveness of care in improving outcomes and experiences and reducing hospital visits for people living with life-limiting illness. Evaluate standardized measures for the early integration of palliative care and symptom assessment.

“We need research to build the evidence base for quality care. But palliative care research is still under-funded and lacking in basic infrastructure supports.

For instance, small grants could make a big difference in enabling networks to meet, to launch and maintain multi-site studies.

These networks provide mentorship and support, resulting in more applications for operational funding and a sustainable foundation for the future.”

#### RESEARCH

Working with partners such as the Canadian Institutes of Health Research (CIHR) and others:

3. Explore the development of a common research agenda to focus on key palliative care questions related to innovations in palliative care delivery.
4. Explore making targeted investments in innovative approaches and early-stage research aimed at improving health system performance and quality of care for people living with life-limiting illness and caregivers.

### 4. FOSTER IMPROVED ACCESS TO PALLIATIVE CARE FOR UNDERSERVED POPULATIONS

1. Support the online dissemination of resources and supports for caregivers and community members in both official languages.
2. Convene multilateral discussions with stakeholders and other interested parties to explore innovative ways to improve access to and share knowledge about culturally appropriate advance care planning and palliative care for underserved populations.
3. Support the development of culturally and linguistically appropriate tools to help increase discussions about advance care planning.
4. Support other federal departments in their efforts to improve palliative care delivery to their mandated populations (e.g., Veterans Affairs, Correctional Services Canada).

“People who are homeless or vulnerably housed need flexibility and an understanding of their lives. Implementing any new approach involves community engagement and community capacity development.

It takes time and skilled facilitators who already have a good rapport established to help navigate between their community and the health system.”

# 5.

## IMPROVE ACCESS TO CULTURALLY SENSITIVE PALLIATIVE CARE FOR INDIGENOUS COMMUNITIES

1. Work with national Indigenous organizations as well as organizations representing the interests of Indigenous peoples, traditional knowledge holders, and Indigenous Services Canada to develop an Indigenous-led engagement process for creating a culturally sensitive distinctions-based Indigenous palliative care framework.
2. Support initiatives that improve awareness and understanding of the socio-cultural and socio-linguistic dimensions of discussing palliative care and end-of-life care with Indigenous peoples.
3. Scale up and spread capacity- and community-building models that improve palliative care planning and delivery in Indigenous communities.
4. Work with Indigenous knowledge holders and health care provider professional associations to develop a common understanding of the importance and feasibility of integrating traditional Indigenous practices into mainstream palliative care, where appropriate.

“First Nations people and other cultural communities in Canada have long-standing traditions for supporting one another and caring for people who are seriously ill and dying. These cultural traditions do not normally include hospital care or formalized palliative care programs, although [recipients] would benefit from excellent pain and symptom management.”

# Looking Forward

## A COLLABORATIVE APPROACH

The actions described in this Plan represent the contributions of one player – Health Canada – to a complex system. Many will require ongoing collaboration with partners in order to implement them successfully.

Alongside this Action Plan, provinces and territories, stakeholders, and communities will develop and implement their own plans aligned with the Framework. Many provincial and territorial governments already have strategies or policies that address palliative care. They have also identified activities to advance palliative care delivery using funding from the bilateral agreements under the Common Statement of Principles on Shared Health Priorities. Health Canada will continue to work with them, as well as with people living with life-limiting illness, caregivers, and other stakeholders, to complement their important and ongoing work.

Health Canada will implement some of the activities in the Action Plan directly. The majority, however, are being or will be carried out through federal funding to national stakeholder organizations (such as the Canadian Hospice Palliative Care Association, the Canadian Virtual Hospice, Pallium Canada and the Canadian Home Care Association) and the federally funded pan-Canadian health organizations.

These pan-Canadian organizations work closely with Health Canada and each other on common initiatives. Those that will be engaged most directly in the area of palliative care are the Canadian Foundation for Healthcare Improvement (CFHI), the Canadian Institute for Health Information (CIHI), and the Canadian Partnership Against Cancer (CPAC). Their roles and activities in this area are set out below. In addition, the Canadian Institutes of Health Research (CIHR), Canada's federal funding agency for health research, has a role in developing and supporting the evidence base for palliative care.

**Canadian Foundation for Healthcare Improvement**  
CFHI supports partners to accelerate the identification, spread and scale of proven health care innovations, such as expanding successful programs where paramedics provide palliative care in the home and staff in long-term care homes embed a palliative approach to care.

### Canadian Institute for Health Information

CIHI produces comparable data and information to accelerate improvements in health care, health system performance and population health across the continuum of care. CIHI collects pan-Canadian data on palliative and end-of-life care, and is working with jurisdictions to improve data collection from home and community settings.

### Canadian Partnership Against Cancer

CPAC is the steward of the Canadian Strategy for Cancer Control. The newly refreshed Strategy includes a focus on the issue of limited and unequal access to palliative and end-of-life care across Canada. CPAC has supported a number of palliative care initiatives, including the development of online resources and training, as well as the systematic scale and spread of the use of patient-reported outcome measures and the early integration of palliative care and best practices in advance care planning. CPAC also works to build capacity among care providers, including paramedics in partnership with CFHI. CPAC has also supported the Palliative and End-of-Life Care National Network, which serves as a forum for members to work together on ways to advance palliative care and share best practices for the delivery of palliative and end of life care.

### Canadian Institutes of Health Research

CIHR supports the creation of research evidence and its translation into improved health outcomes for Canadians, as well as more effective health services and products, and a strengthened Canadian health care system. CIHR's annual research investments include support for research on palliative care and late-life issues.



## NEXT STEPS

Canadians deserve to live out their lives with dignity and in comfort, with access to care that respects their wishes and is appropriate to their needs.

The compassionate community approach recognizes that it is everyone's responsibility to care for each other. Similarly, achieving the vision of the Framework—that all Canadians with life-limiting illness live well until the end of life—will be possible only through the combined efforts of governments, stakeholders, health care providers, caregivers, and communities.

The Government of Canada understands the vital role that palliative and end-of-life care plays in our health care system and is committed to taking action to help make the Framework's vision a reality.

As required by the *Framework on Palliative Care in Canada Act*, the Minister of Health will report on the state of palliative care in Canada within five years of its release. That report will provide an opportunity to take stock of the landscape of palliative care in Canada and propose next steps.

## END NOTES

<sup>[1]</sup> The Government of Canada and the Government of Quebec agreed to an asymmetrical arrangement distinct from the Common Statement of Principles on Shared Health Priorities and based on the asymmetrical agreements of September 2004.

<sup>[2]</sup> The bilateral agreements can be found at <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities.html>

<sup>[3]</sup> The Framework on Palliative Care in Canada may be found at: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>