



National Association  
of Federal Retirees

Association nationale  
des retraités fédéraux

# A Framework for Palliative Care

## Health Canada Consultation

## A National Framework for Palliative Care

The National Association of Federal Retirees is the largest national advocacy organization representing active and retired members of the federal public service, Canadian Armed Forces, Royal Canadian Mounted Police (RCMP) and retired federally appointed judges, as well as their partners and survivors.

We believe that every Canadian, today and in the future, should enjoy dignity in retirement, with better retirement security and a strong, sustainable health care system – including palliative and end-of-life care, which are integral to the health care continuum.

Palliative care affects Canadians of all ages, and while it is not only needed for the elderly, we know there are now more seniors than children in Canada and seniors represent the fast-growing age-group. With this increased senior population, the rate of chronic disease diagnosis and death from chronic disease are expected to rise. This demographic is changing the face of Canadian society and adding new policy needs at all levels of government.

Palliative care services are short and have been unable to keep up with patient and family needs. Only a third of Canadians currently have access to palliative care, and often for just a short time before death.<sup>1</sup>

It doesn't have to be this way. The gaps in palliative care can and must be addressed urgently with national leadership and action. And, palliative care not only benefits patients and their families but is an efficient use of healthcare dollars that can help support a more sustainable healthcare system.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem 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.”

The level of palliative care varies based on patients needs and is guided by a patient's wishes, values and goals of care as determined and communicated through advance care planning<sup>2</sup>. The care can be delivered by multi-disciplinary teams in a variety of settings, and can include specialists and non-specialists: physicians, nurses, social workers in hospital, or at home, hospice or long-term care facility. Most importantly, it should be delivered in the patient's setting of choice.

Federal Retirees polled our members for their feedback and experiences with palliative care based on the *Let's Talk Health* online consultation questions. Over 2,100 people responded in French and English from across the country, the results of which are included in this submission. We are happy to have the opportunity to share it here and support the government in creating a palliative care framework.

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<sup>1</sup>Vogel, L. (2017, January 9) *Canada needs twice as many palliative specialists*. Retrieved from <http://www.cmaj.ca/content/189/1/E34>

<sup>2</sup> Canadian Cancer Society (2016). *Right to Care: Palliative Care for All Canadians*. Retrieved from <https://www.cancer.ca/~/media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en>

## Public Awareness and Education

Canada needs to broaden its approach and understanding of palliative care.

Many Canadians are unfamiliar with the concept of palliative care, or unaware of the programs and services that may be available to them. Misconceptions and stigma persist and create barriers to planning for and receiving palliative care. Many still attribute it with the last days of life and are reluctant to discuss it. Too often people think that palliative care means that the system has given up on them.

Only 30 per cent of Federal Retirees members said they have an advance care plan, and 22 per cent of those with an advance care plan were not confident that their wishes will be followed.

Many of the respondents of our poll said they are unsure if they know what services and resources are available in their community, especially those to help cope with stress and pressures.

From our survey we learned that most people will turn to a health care professional for information about palliative care (34%), followed by their local health authority or network (29%), and their primary care provider (26%).

Only 22 per cent answered that they go online for information and resources.

Many studies have confirmed the positive impacts of advance care planning, such as improved quality of end-of-life care, person-centred care that is better aligned with a patient's goals and preferences as well as increased use of community care, including hospice and home care.

We don't have to recreate the wheel to get started in helping Canadians understand palliative care, or to look for examples on which to build access and innovation. For example, Pallium Canada is a national, non-profit organization focused on expanding and improving palliative care in Canada. Its Compassionate Community model can be support as one way to spread education and understanding about palliative care. "Compassionate communities acknowledge that caregiving, dying, death and grieving is everyone's business and is best when inclusive of health and social service along with community members and neighbours".<sup>3</sup> Pallium Canada provides a toolkit to help people develop and launch compassionate communities in their own neighbourhoods and networks.

Finally, the role of the caregiver and their distinct needs as they support a loved on through palliative care, cannot be ignored. Public education must also focus on caregivers, including financial support, self-care, health system navigation and services to address and support their own health needs – including mental health.

A national framework will mitigate stigma and misconceptions surrounding palliative and end-of-life care, and support access to this care by:

- Working with provincial governments and non-government organizations to build awareness and understanding of palliative care services, so that people have the education, tools and support they need to engage in discussions about and access palliative care.

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<sup>3</sup> Pallium Canada (2018). *Launching a Compassionate Community*. Retrieved from <https://pallium.ca/work-with-us/launch-a-compassionate-community/>

- Working with care providers to ensure the public and health care providers to discuss advance care planning early and often, and to encourage Canadians to have advance care plans in place.
- Applying a multi-faceted, culturally competent approach to communications, education and promotion to reaches diverse audiences of Canadians from coast-to-coast-to-coast.
- Ensuring caregivers’ distinct needs and interests are addressed.

### **Improving Access to Palliative Care**

There are significant disparities across Canada with respect to access to palliative and end-of-life care, the quality of care provided and out-of-pocket costs for patients. The federal government, along with the provinces and territories must work to ensure access to adequate and appropriate palliative care resources does not depend on one’s postal code.

Among those who answered our poll, almost half said the lack of palliative care services and resources was the greatest obstacle preventing them from accessing palliative care.

Palliative care should be available to patients in a variety of settings, including the home, hospital, hospice, long-term care or other settings depending on what is most appropriate for a patient’s care needs and preferences.

Expanding palliative care services would benefit patients and families as well as the health care system. There is a growing body of evidence that shows that palliative care, particularly when integrated earlier in the illness, improves patients’ quality of life and reduces health care costs without reducing life expectancy.<sup>4</sup>

Yet in Canada, there is a severe shortage of palliative care specialists. Thirty per cent of people who responded to our polls indicated the lack of specialists would prevent them from access palliative care. Additionally, many primary care providers are uncomfortable or lack the training to provide this care.

Health service provider training is key and needed urgently.

Only 15-30 per cent of Canadians have access to specialized palliative care.<sup>5</sup> The Canadian Society of Palliative Care Physicians (CSPCP) warns Canada needs twice as many palliative care specialists to meet the palliative care needs of Canadians.<sup>6</sup>

Canada is also facing a shortage of gerontologists. In Canada, there is one geriatrician for every 15,000 adults. This is unacceptable if our senior population is going to age with dignity and care.

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<sup>4</sup> The Way Forward Initiative (2012). *Cost-Effectiveness of Palliative Care: A Review of the Literature*. Retrieved from <http://www.hpcintegration.ca/media/36290/TWF-Economics-report-Eng-final-webmar7.pdf>

<sup>5</sup> Pallium Canada (2018). *A New Approach*. Retrieved from <https://pallium.ca/a-new-approach/>

<sup>6</sup> Vogel, L. (2017).

The Canadian Medical Association recommends that all patients should have a primary care provider that can support them with their palliative care needs or else refer patient earlier to a palliative care team.<sup>7</sup>

However, most medical schools provide less than 10 hours of training and doctors are often referring patients for palliative care when it is too late.<sup>8</sup> Along with action to address the shortage of specialists in Canada, support to expand palliative care training to all doctors and health professionals is needed.

Greater training opportunities and building capacity for non-specialists in health care in a palliative care approach will also help to expand access to palliative care. For example, Pallium Canada's Learning Essential Approaches to Palliative and End-of-Life Care (LEAP) has provided training to over 15,000 health care professionals across different settings with the skills and tools to provide a palliative care approach.

The [Paramedics Providing Palliative Care at Home Program](#) available in Nova Scotia and P.E.I. is an innovative model of care helping to address the palliative care needs of the community. Through this program, trained paramedics provide palliative care patients with pain and symptom management at home, after-hours. In 2016, the program in P.E.I. had 315 palliative care calls and of that amount, 35 per cent of patients were able to remain at home<sup>9</sup>.

We know most people would prefer to die at home, yet about 75% of deaths in Canada still occur in hospital or long-term facilities.<sup>10</sup> A home death is not easily achieved, but with support most people should be able to die at home or elsewhere in their community. Receiving palliative home care has been associated with a 50% reduction in the likelihood of dying in hospital.<sup>11</sup>

For patients to be able to stay at home however, greater support for patients and families is needed. Community-based palliative care services, like home visits, must be more available, accessible and less costly.

Over a quarter of respondents to our poll said that financial barriers would prevent them from accessing palliative care. Studies show Canadian families frequently bear 25 per cent of the total cost for palliative care, due to costs associated with home-based services, such as nursing and personal support services and equipment.<sup>12</sup>

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<sup>7</sup> Canadian Medical Association (2015). *Palliative Care: Canadian Medical Association's National Call to Action*. Retrieved from <https://www.cma.ca/Assets/assets-library/document/en/advocacy/palliative-care-report-online-e.pdf>

<sup>8</sup> Vogel, L. (2017).

<sup>9</sup> <https://www.cbc.ca/news/canada/prince-edward-island/pei-demand-increase-paramedics-palliative-home-care-1.4193223>

<sup>10</sup> Canadian Hospice Palliative Care Association (2007). *Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging*. Retrieved from [http://www.chpca.net/media/7487/Brief\\_to\\_Spec\\_Sen\\_Comm\\_on\\_Aging-HPC\\_in\\_Canada.pdf](http://www.chpca.net/media/7487/Brief_to_Spec_Sen_Comm_on_Aging-HPC_in_Canada.pdf)

<sup>11</sup> Health Quality Ontario (2016). *Palliative Care at the End of Life*. Retrieved from <http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf>

<sup>12</sup> Canadian Hospice Palliative Care Association (2017). *Fact Sheet: Hospice Palliative Care in Canada*. Retrieved from [http://www.chpca.net/media/557647/new\\_fact\\_sheet\\_hpc\\_in\\_canada-summer2017-final-en.pdf](http://www.chpca.net/media/557647/new_fact_sheet_hpc_in_canada-summer2017-final-en.pdf)

Residential and community-based hospice care also provide a tremendous amount of support and care for patients and families at their end of life. Yet, as of 2017, there were only 85 residential hospices in Canada, with an average of nine beds.<sup>13</sup>

Residential hospice palliative care programs rely on donations, fundraising and volunteers to ensure these services are available for the community. Innovative programs such as the hospice volunteer online training course that was developed by Saint Elizabeth Health Care, in partnership with Hospice Palliative Care Ontario should be explored and shared to help build hospice volunteer capacity across the country.<sup>14</sup>

Community-based palliative care is less costly to the health care system. According to a 2014 Ontario Auditor General's report, the cost of palliative care during the last month of life are \$1,100 per day in an acute-care hospital versus \$770 per day in a palliative care unit in hospital, \$460 per day in a hospice bed and under \$100 per day in the home.<sup>15</sup>

Not all provinces have designated hospice palliative care as a core service under their provincial health plans.<sup>16</sup> Hospice palliative care may be included in provincial home care budgets or other health service budgets, leaving the funding vulnerable to budget reductions.

The investment of \$6 billion over 10 years through the bilateral health agreements is a positive step towards improving access to home, community and palliative care in Canada.

A national framework will boost Canadians' access to palliative and end-of-life care by:

- Working with provincial governments and other actors, such as the Canadian Medical Association and other health organizations, to support human resources and training/development strategies. This will ensure professional palliative care capacity is enhanced and continuously developed, as recommended by organizations noted above. Goals should be measurable and continuously monitored/assessed.
- Supporting development and expansion of innovative, community- and volunteer-based programs like home visits that leverage paramedic and other professional and para-professional resources, so that home-based options are more available, accessible and less-costly.
- Investing federal health funds, with strings attached, to ensure provinces invest in hospice and palliative care infrastructure, and to ensure hospice palliative care is a covered service under provincial health plans.

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<sup>13</sup> Ubelacker, S. (2016, August 23). *Changes needed to boost end-of-life care in Canada: doctors*. Retrieved from <https://www.cbc.ca/news/health/canada-end-of-life-care-improvements-1.3731900>

<sup>14</sup> Engel, Shirlee (2016, June 7). *Innovations in palliative care could improve access for Canadians*. Retrieved from <https://globalnews.ca/news/2747577/innovations-in-palliative-care-could-improve-access-for-canadians/>

<sup>15</sup> Office of the Auditor General of Ontario (2014) *Palliative Care in Annual Report 2014*. Retrieved from <http://www.auditor.on.ca/en/content/annualreports/arreports/en14/308en14.pdf>

<sup>16</sup> Canadian Hospice Palliative Care Association (2017). *Fact Sheet: Hospice Palliative Care in Canada*. Retrieved - from [http://www.chpca.net/media/557647/new\\_fact\\_sheet\\_hpc\\_in\\_canada-summer2017-final-en.pdf](http://www.chpca.net/media/557647/new_fact_sheet_hpc_in_canada-summer2017-final-en.pdf)

## Caregiver Support

A national palliative care framework must include support for caregivers. More than 35% of Canada's workforce provides unpaid, informal elder care for up to 30 hours or more per week, while balancing job responsibilities.

Eighty per cent of members who completed our poll said that family is the first person they talk to about their end of life wishes. Family and caregivers can take on much of responsibility and care. Based on an Ontario study, palliative care clients were cared for primarily by the spouses or partners (57%) or their children or children-in-law (29%).<sup>17</sup>

Analyses of the number of hours spent and type of work done by family caregivers estimate that the economic contributions of family caregivers in Canada was in the range of \$25-billion in 2009.<sup>18</sup> The financial costs incurred by caregivers, in addition to the mental and emotional stress of caring for a loved one, are significant.

Federal Retirees have long advocated that family caregivers' contributions and their importance should be recognized. This government should improve awareness of the Canada Caregiver Credit and amend it to make it a refundable tax credit

According to our survey, knowing what to expect and how to prepare was the greatest challenge caregivers faced (58%). The second greatest challenge caregivers face was home and community care support (48%) followed by respite services (45%).

Palliative care must also include care and support for the caregiver. Caregiver often experience their own physical and mental health distress in the caregiving role. Information, resources, and support including respite, grief and bereavement must be easily accessible and available.

A national framework will address the unique needs of and support caregivers, and encourage their participation in this important aspect of care, by:

- Working with provincial governments to build awareness and understanding of palliative care services and resources from the distinct perspective of caregivers.
- Ensuring caregiver resources for respite, grief and bereavement are included in provincial palliative care programs and services.
- Working with professional and volunteer organizations to encourage advance care planning conversations with health professionals to include supportive conversations with family and caregivers.
- Making the Canada Caregiver Tax Credit refundable.

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<sup>17</sup> The Change Foundation (2011) *Facing the Facts*. Retrieved from <http://www.homecareontario.ca/docs/default-source/Family-Caregiving/facing-the-facts-what-do-we-know-about-families.pdf?sfvrsn=6>

<sup>18</sup> Canadian Cancer Society (2016).

## **National Seniors Strategy and Minister for Seniors**

Palliative care significantly impacts seniors and our aging population. Federal Retirees have long called upon this government to appoint a minister responsible for seniors. We should have a dedicated voice advocating for their unique needs within government, and to ensure we always view public policy decisions, like a national framework for palliative care, through a seniors lens.

In addition, a National Seniors Strategy is directly related to this conversation about a palliative care framework and many similar factors would be addressed via a Seniors Strategy. [A National Seniors Strategy encompasses social determinants of health](#), from health care, housing, social interaction to predictable retirement income. The focal point for this palliative care conversation is on health – and as noted above, palliative care is an essential component of a strong, sustainable continuum of health care.

In 2017, under Liberal MP Marc Serré's private members' motion M-106, development of a National Seniors Strategy attained support of all political parties in the House of Commons. [Study by the Commons Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities](#) revealed broad support for a National Seniors Strategy that includes palliative and end-of-life care supports.

Seniors, their families and advocates have been consistent and clear.

With approximately one year left in this government's mandate, it's time to speak to seniors, to ensure they are represented, and to set the stage for healthy aging for Canadians. It is time for a minister for seniors and a National Seniors Strategy to holistically address concerns, including palliative and end-of-life care.