

**PALLIATIVE CARE FOR ALL CANADIANS – FROM ANALYSIS TO ACTION**

Jeffrey B. Moat, BComm  
CEO, Pallium

Dr. José Pereira, MBChB, CCFP (PC), MSc  
Scientific Officer, Pallium

Gerald Savoie BSC, MHA, CHE  
Board Chair, Pallium

On behalf of

**Pallium Foundation of Canada**



[www.pallium.ca](http://www.pallium.ca)

**Recommendation**

Pallium recommends that the Government of Canada invest in addressing gaps related to accessing palliative care education and palliative care services in underserved populations and communities in the face of unprecedented demographic, economic and policy changes.

## The Need

Despite the great need, many jurisdictions across Canada continue to report sub-optimal access to palliative care.<sup>1</sup> The Canadian Hospice Palliative Care Association, for example, has estimated that only 15% to 30% of Canadians have access to palliative care services.<sup>2</sup> Despite a large body of evidence from many studies across Canada and internationally that support the benefits imparted by palliative care, many Canadians never get to benefit from it, or receive it too late. This gap adds to the tremendous social and economic burden of caregivers in Canada. Over 2 Million Canadians with parents over 65 incur direct costs associated with caregiving at an estimated cost of \$6 Billion annually and more than double that number will take time off work to provide care at an estimated cost to Canada's economy of \$27 Billion.<sup>3</sup>

While recent developments, including emphasis on home and palliative care within the federal-provincial bilateral agreements and the passing of Bill 277, have provided some impetus, they remain short of the investments required to achieve meaningful, long-term, nationwide impact. Many gaps require ongoing federal leadership and investments.

Canadians living in rural and remote communities and Indigenous peoples continue to experience challenges achieving equitable access to healthcare services<sup>4</sup>, including palliative care. Canada's official language minorities' needs are often not considered in health care planning. Many vulnerable or underserved populations, such as refugees and immigrants, do not benefit from palliative care, or it is initiated too late in the illness journey. Language barriers prevent some from sharing their needs, fears and hopes, while the cultural needs of others are not honoured.

Moreover, investment is needed to study innovative strategies and to assess their impact on Canadian patients and the health care system. This includes identifying excellence in palliative care delivery in different sectors and scaling them to address gaps. It has been estimated that the provision of high-quality palliative care can save the health care system \$7,000-8,000 per patient and millions annually.<sup>5</sup> Pallium is well positioned to contribute significantly to this work.

## Pallium

Pallium is a pan-Canadian non-profit organization that builds professional and community capacity to provide palliative care. Pallium builds primary- or generalist-level capacity through its interprofessional Learning Essential Approaches to Palliative Care (LEAP) courseware and clinical decision-making aids, which are accredited by leading Canadian professional organizations. Since 2014, over 15,000 healthcare professionals working in different settings have been trained on LEAP.

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<sup>1</sup> The Way Forward National Framework: Roadmap for an Integrated Palliative Approach to Care. A national consensus document. Canadian Hospice Palliative Care Association 2015.

<sup>2</sup> The Way Forward National Framework: A Roadmap for an integrated palliative care approach to care. Canadian Hospice Palliative Care Association. March 2015. Last accessed 29 December 2017

<sup>3</sup> CIBC In Focus 2017. Who Cares: The Economics of Caring For Aging Parents by Benjamin Tal and Royce Mendes

<sup>4</sup> College of Family Physicians of Canada, Society of Rural Physicians of Canada. *The Rural Road Map for Action: Directions. Advancing Rural Family Medicine: The Canadian Collaborative Taskforce.* Mississauga Ontario 2017

<sup>5</sup> The Way Forward National Framework: Cost-Effectiveness of Palliative Care A Review of the Literature. Canadian Hospice Palliative Care Association 2015.

Pallium has leveraged federal seed grants to develop courseware and aids, including resources and knowledge that can be harnessed for large-scale deployment. It has, for example, developed self-sustaining, cost-recovery models to reach professionals in practice. It has also trained and certified over 680 LEAP educators across Canada, a major resource that can be mobilized in different ways, including deploying quality improvement initiatives.

Research undertaken by Pallium and its partners demonstrates the impact of its work. A recent study of over 7,000 health care professionals who participated in LEAP courses over 2 years shows significant improvements in their knowledge, attitudes and comforts related to the provision of palliative care. Thousands of examples were provided of how learners have implemented the knowledge they acquired, directly benefiting patients, families and the healthcare system.

In Nova Scotia and PEI, training of paramedics resulted in significantly fewer patient transfers from home to emergency departments. This training resulted in increased patient satisfaction, greater comfort for first responders, more efficient use of EMS resources, and an estimated net cost savings of \$2.5 Million.

Pallium has undertaken pilots aimed at addressing the specific needs of rural and remote communities and special populations, including Indigenous populations. These pilots have been limited by funding constraints but can, with further investment and partnerships, be scaled up to help close gaps.

Beyond course development, Pallium is a systems improvement and change agent and has begun working with provinces to diffuse the palliative care approach to increase workforce readiness, act as a catalyst for quality improvement, and help mobilize the community as a key partner in palliative care, bridging the divide between the health care sector and the community.

## **Proposed solutions**

### **1. Capacity building in rural and remote communities**

Pallium has its roots in building capacity in rural and remote settings and has a long history of collaborating with these communities.<sup>6</sup> Pallium has taken education into smaller communities across the prairie provinces and in the north. For example, Pallium tested a monthly “Conversation on Caring” program, directed at diffusing the palliative care approach to rural and remote communities.<sup>7</sup> This consisted of monthly audio-conferencing continuing professional development events for rural and remote care providers. At its height, over 110 health care stations across the north signed-in to these monthly events. These sessions were recorded and released as “Conversations on Caring” in 2007 as one of Apple Canada’s earliest iTunes professional development podcasts.

Drawing on key partnerships, Pallium proposes these learnings and early experiences be reactivated and updated to leverage new media, technologies and opportunities.

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<sup>6</sup> Michael Aherne, José Pereira. A generative response to palliative service capacity in Canada. *Leadership in Health Services*. 2005; Vol. 18 Iss: 1, pp.3 - 21

<sup>7</sup> Aherne M, Pereira J. Learning and Development Dimensions of a Canadian Primary Health Care Capacity Building Project. *Leadership in Health Services*. 2008; 21(4):1751-1879.

## **2. Integrating Indigenous perspectives and building capacity**

Pallium has undertaken foundational work in this area. From 2004 to 2005, it interviewed and video-taped elders speaking about perspectives on end-of-life care. Working with First Nations leaders, Pallium developed and delivered pilot courses to train professionals on addressing loss and grieving related to residential schools and Indigenous hospital experiences.

One of the most profound learnings for Pallium in building palliative care capacity for Indigenous Peoples occurred as part of the INTEGRATE project in collaboration with Cancer Care Ontario. While engaging the Six Nations communities in southern Ontario, the direction received was to focus on integrating Indigenous perspectives, wisdom and sensitization into existing LEAP courseware instead of developing a LEAP specifically for health care professionals working in First Nations communities. This led Pallium to require cultural sensitization training by all LEAP Facilitators.

It was also evident that we need to recognize and respect the many different perspectives and approaches to serious disease, dying, death, and grieving, held by Indigenous peoples across Canada.

The next phase of Pallium's work in this area needs to involve working with communities to determine how to integrate flexibility within LEAP courseware and materials to support this variation and to disseminate the community-building model by Kelley et al<sup>8</sup> that offers a proven framework to develop palliative care in Indigenous communities.

## **3. Addressing official minority languages needs**

Pallium LEAP facilitators, who are health care providers and educators, often report that in many communities, official minority language needs of patients are not being met. A 2016 study undertaken in the Greater Toronto Area, for example, revealed that tens of thousands French-speaking Canadians do not have access to palliative care in their own language.

The capacity inherent in Pallium's compassionate communities program can be leveraged to address these needs across Canada. In partnership with an organization such as la Société Santé en français, Pallium is ready to co-design and deliver regional community engagement events in select minority francophone and anglophone communities across Canada. This will bring together community members and leaders, health care professionals, and palliative care experts with the goal of increasing awareness and access to palliative and end-of-life health care services in support of local communities. This community engagement approach will catalyze the creation of local compassionate communities in minority francophone and anglophone communities.

Pallium's compassionate community program and its hundreds of facilitators, many of whom represent and work in these communities, are well positioned to accelerate this work. Early discussions with these community leaders have begun, but further investment is required to build the necessary partnerships and provide common tools, supports, and networking for communities across the country that can be leveraged and adapted at the local level to meet community needs.

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<sup>8</sup> Koski J, Kelley ML, Nadin S, Crow M, Prince H, Wiersma EC, Mushquash CJ. An Analysis of Journey Mapping to Create a Palliative Care Pathway in a Canadian First Nations Community: Implications for Service Integration and Policy Development. *Palliative Care: Research and Treatment* 2017; 10: 1–16

#### **4. Identifying and spreading best practices and models.**

Pallium is committed to maximizing resources and investments by identifying, through evaluations and research, strategies that are most effective, efficient and provide high returns on investment. Pallium uses Kirkpatrick's Evaluation Model, and the Phillips addition to that model, to evaluate its LEAP courseware. Learnings from recent research on learners' knowledge, attitudes and learning experience is being leveraged to enhance LEAP courseware and their delivery models to increase access, learner engagement, and impact. This research is also driving the development of quality improvement (QI) toolkits that can help learners put their knowledge into practice and can be integrated into existing provincial QI initiatives.

However, assessments of higher level impact, such as impact on patients directly and health care system efficiencies, access and economics, requires dedicated funding that is has not been included in past or current seed funding contributions. Additional funding would support a network of expert researchers in Canada, facilitate data integration with provincial and federal datasets, and increase researcher and system capacity to evaluate health system change, innovations and impacts related to large-scale workforce and community preparedness in the provision of palliative care.

In addition, we know that in many countries, large-scale, national evaluations of service availability, in the form of service atlases, have proven to be very effective change agents. These atlases have explored best practices related to palliative care education, and services such as: palliative care teams in the community and in acute care settings, palliative care units and hospices, and palliative care home care services, and help spread them to regions where there are gaps.

For example, a major barrier in Canada is inadequate integration of palliative care in the curricula of medical and nursing schools, residency programs, and in other allied health professions. Canada would benefit from a large-scale pan-Canadian mapping of palliative care content, models and resources across different schools, colleges and programs, to identify excellence and best practices and spreading these to where gaps exist.

No such Atlas exists in Canada. Pallium and its academic partners would like to change that. A Canadian Atlas, developed by a multi-partner research team, would map out each region in each province. It would then use the Atlas to spread and scale up excellence.

#### **Conclusion**

The government's investment in Pallium has paid tremendous dividends. It is well positioned to leverage its past successes and current infrastructure to provide national leadership through its collaborative pan-Canadian network and partnerships to mobilize positive systemic change and focus attention in underserved communities and populations, while ensuring the proper evaluation and reporting mechanisms are in place to report progress and impact.