

## **Submission of a brief on the study of Long-Term Care on Reserves**

**Jeffrey B. Moat, B.Comm**  
Chief Executive Officer, Pallium Canada

**Dr. José Pereira, MBChB, CCFP (PC), MSc**  
Scientific Officer, Pallium Canada  
Director of Research, College of Family Physicians of Canada  
Palliative Care Physician, William Osler Brampton Health Centre  
Professor, Division of Palliative Medicine, Department of Family Medicine, McMaster University  
Gilchrist Chair and Professor of Palliative Medicine, Queen's University

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

## The Need

Patients with progressive life-limiting illnesses experience multiple physical, psychological, spiritual, and social needs and complications across their illness trajectories, from diagnosis to end-of-life. These needs often negatively impact quality of life and are sometimes the source of significant suffering if unaddressed. This burden is also often borne by family members.

While the illness trajectory can be relatively short for some patients, for many it is prolonged, lasting many months and sometimes years. Notwithstanding the trajectory, ameliorating the sources of distress and improving quality of life is of paramount importance, as is ensuring the capacity of the health care system to respond to the needs, regardless of the settings of care that patients find themselves in.

There is a strong and an ever-growing body of evidence that shows palliative care, particularly when integrated earlier in the illness, improves patients' quality of life, yields greater satisfaction levels and fewer symptoms among patients, and reduces health care costs without reducing patients' life expectancy. The health care system reports more appropriate referrals, better use of hospice care, fewer emergency room visits and hospitalizations, and less use of ineffective interventions in the last days of life.

Patients who could benefit from a palliative care approach are found in many settings of care, from home and other community-based settings such as residential hospices and long-term care facilities, to acute care hospitals and hospital outpatient clinics, to name just a few.

According to recent large report on the status of palliative care in Canada by the Canadian Institute for Health Information (CIHI), among residents who died in long-term care in 2016–2017, 24% were identified as having less than 6 months to live; and 6% of all residents were recorded as having received palliative care in the last year of life.<sup>1</sup> Even though few long-term care residents had formal palliative care in the last year of life, it is likely that many got care that was palliative in nature, as most long-term care facilities consider care at the end of life to be a vital part of their practice. However, gaps in the quality of the palliative care provided have been noted in several reports and studies, particularly since most health care professionals and care providers working in LTC homes have minimal or no palliative care training. Moreover, many LTC facilities do not have access to specialist-level palliative care consultation and support teams to assist LTC staff care for residents with the more complex palliative and EOL care needs.

An earlier study by CIHI found that three-quarters of long-term care residents have a Do Not Resuscitate (DNR) directive, but fewer residents – 1 in 5 – have a Do Not Hospitalize (DNH) directive.<sup>2</sup> It is not possible to determine from the data what conversations were had with residents or their legal guardians at the time of a decision to hospitalize, and therefore whether the directive was appropriately followed. Close to half of hospitalizations among residents with a DNH directive were from potentially preventable causes. While safety incidents, such as injuries from falls and infections, were among the most common reasons for hospital transfers, others including end-of-life care needs. The report concluded that hospitalizations could be further reduced with the enhancement of palliative care services in long-term care settings.

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<sup>1</sup> Canadian Institute for Health Information. *Access to Palliative Care in Canada*. Ottawa, ON: CIHI; 2018.

<sup>2</sup> Canadian Institute for Health Information. *A Snapshot of Advance Directives in Long-Term Care: How Often Is "Do Not" Done?* Ottawa, ON: CIHI; 2016.

Among seniors in residential care, 11% reported worsened pain in the past three months. The prevalence of disruptive or intense daily pain was 34% among long-term home care clients; the prevalence of inadequate pain control among clients with pain was 22%<sup>3</sup>. Many of these residents experienced pain from progressive life limiting illnesses that could be improved with good palliative care.

The Canadian Hospice Palliative Care Association (CHPCA), in its report on palliative care in long term care homes which emanated from its “The Way Forward” reports, highlighted the need for interprofessional palliative care education in LTC homes so as to equip all staff in those facilities with basic palliative care skills to provide a palliative care approach. The CHPCA also highlighted the need for LTC facilities to have access to specialist-level palliative care teams with advanced palliative care training and skills to support LTC staff caring for patients with complex needs.

The CHPCA stresses that residents of long-term care facilities can benefit from palliative care, as many have life-limiting conditions, such as dementia, chronic obstructive pulmonary disease (COPD) and heart failure. Those admitted to long-term care stay for an average of 2 years, and most remain there until the end of life, so palliative care can be an important component of long-term care. In jurisdictions where data is available, almost 30,000 people died in long-term care facilities in 2016–2017, or 17% of all deaths in those jurisdictions.

The CHPCA goes on to state that providing care at end-of-life has become vital to LTC practice, however, palliative care has not been incorporated into the culture and self-perceived role of LTC. Further, homes are not equipped with some of the specialized knowledge and skills and dedicated resources to provide palliative care. Only once these gaps and barriers are addressed will we be able to create formal palliative care programs in LTC homes. Having these programs would enhance LTC homes’ capacity to provide resident centred care until the resident dies, allowing them to die at what they consider home with maximum comfort and dignity. In turn, improving capacity in LTC to provide palliative and end of life care will also help to alleviate unnecessary and unwanted transfers to hospitals and hospices. This capacity includes strengthening Interprofessional palliative care education and collaboration within LTC homes and with the community, and integrating the palliative care philosophy into residential care, which also requires education of LTC staff, residents and families.

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. More recently,

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<sup>3</sup> Health Care in Canada, 2011: A Focus on Seniors and Aging. Ottawa, ON: CIHI;2011

<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

palliative and end-of-life care needs of vulnerable populations such as Indigenous peoples<sup>5,6,7,8</sup> have been studied and published.

As the Committee undertakes a comprehensive study on long-term care on Reserves, it is important that it examines the level of workforce preparedness in this setting of care and ensures that moving forward, health care professionals acquire the necessary knowledge, skills and comfort level to properly care for patients and their family in all long-term care facilities, respecting the cultural sensitivities that exist in Indigenous communities.

## **Pallium Canada**

Pallium Canada is a pan-Canadian non-profit organization focused on building professional and community capacity to help improve the quality and accessibility of palliative care in Canada.

Pallium builds primary- or generalist-level capacity by providing palliative care education through its interprofessional Learning Essential Approaches to Palliative Care (LEAP) courseware and resources. To date, over 17,000 health care professionals working in different settings have been trained on LEAP.

LEAP courses are evidence-based, peer-reviewed and accredited by the College of Family Physicians of Canada, and the Royal College of Physicians and Surgeons. They have been developed by Canadian experts, for Canadians and for the Canadian context.

Pallium Canada has also trained and certified over 700 LEAP palliative care educators across Canada, a major force that is being galvanized and mobilized to scale up the work of educating and implementing quality improvement initiatives across the country.

Pallium's vision is to ensure that every Canadian who requires palliative care receives it early, effectively and compassionately. To realize this vision, we believe it requires a collective effort which is why Pallium can be described as a community – a community of clinicians, educators, researchers, carers, administrators, volunteers, Indigenous leaders and citizen advocates working together to accelerate the integration of palliative care in Canadian communities and health care systems.

## **Pallium's Experience with Indigenous Communities**

Pallium has been working with Indigenous leaders and health professionals since 2004 to integrate their learning and wisdom into its LEAP courseware. From 2004 to 2005, meetings and interviews were held

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<sup>5</sup> Kelly L, Linkewich B, Cromarty H, St Pierre-Hansen N, Antone I, Gilles C. Palliative care of First Nations people: A qualitative study of bereaved family members. *Can Fam Physician*. 2009 Apr; 55(4): 394–395.e7.

<sup>6</sup> Castleden H, Crooks VA, Hanlon N, Schuurman N. Providers' perceptions of Indigenous palliative care in British Columbia's rural interior. *Health Soc Care Community*. 2010 Sep;18(5):483-91. doi: 10.1111/j.1365-2524.2010.00922.x. Epub 2010 May 24.

<sup>7</sup> Kelley ML. Developing rural communities' capacity for palliative care: A conceptual model. *Journal of Palliative Care*, 2007;23(3), 143–153.

<sup>8</sup> Fruch V, Monture L, Prince H, Kelley ML. Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care. *International Journal of Indigenous Health*. 2016;11 (1):50-74

with the First Nations Elders in northern Alberta and NWT, the outcome from which led to the development of “Responsive Hospice Palliative Care with Indigenous clients and families” courseware.

This course was led by an Indigenous leader and educator and focused on the loss, grief and bereavement associated with the residential school system. Pallium also developed the “In our own voices: Indigenous perspectives in Hospice Palliative Care” video segments and “A Caregiver’s Guide: Handbook for the Inuktitut-speaking Family Members for communities in the far north.”<sup>9</sup> Video footage featured elders and other Indigenous representatives sharing their perspectives on Indigenous approaches to palliative care which was subsequently incorporated into several LEAP courses.

In 2014, Pallium collaborated with Cancer Care Ontario to engage Indigenous communities to develop education programs targeted at health care professionals who work with, or within, Indigenous communities. Early in the program, the First Nations community in southern Ontario recommended against developing a distinct LEAP course focused on the Indigenous community. Rather, they recommended that Indigenous perspectives be integrated into all existing LEAP courses.

Pallium introduced cultural sensitivity training modules as part of Pallium’s LEAP facilitator training program to ensure heightened sensitivity and awareness of LEAP facilitators to the unique needs of Indigenous Peoples and to highlight these in the courses, particularly when facilitating courses that includes health care professionals who care for Indigenous peoples.

To this end, Pallium held two LEAP Core courses that were specifically designated as being “for, by and with” First Nations groups. The first course was held at Kettle Stony Point First Nations in February 2017 and the second course at W’Sanec in October 2017.

These courses demonstrated that LEAP courseware is adaptable to reflect this unique setting, whether the course is delivered to non-Indigenous healthcare providers who work with Indigenous people or delivered to Indigenous healthcare workers who work in Indigenous communities.

Indigenous facilitators, leaders and participants in the courses stated that they want the best available education that is available elsewhere in Canada but want the courses to be delivered in an Indigenous congruent manner. This means, amongst others:

- Courses are held in an Indigenous community and “hosted” by that community;
- Courses are jointly planned by Indigenous representatives (community and healthcare workers) and local LEAP organizers;
- Each day is opened and closed with ceremony provided by a knowledge keeper or elder figure chosen by the community;
- An elder or healer is available during the course for those who might struggle with emotions related to course content or discussion;
- Food is made and served by the host community;
- Handout materials (pamphlets) are specific to First Nations communities (eg: ACP leaflet from Lakehead End-of-Life Care in First Nations Communities project);

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<sup>9</sup> Aherne M, Pereira J. Learning and development dimensions of a pan-Canadian primary health care capacity-building project. *Leadership in Health Sciences*. 2008;21(4):229-266

- A community information session linked to LEAP is offered parallel to each course – facilitated by the LEAP facilitator and co-hosted with community representatives;
- Courses are attended not only by healthcare providers but by community members who participate actively in the sessions and whose input, questions and answers are respected and valued by the healthcare course participants.

Facilitation of this kind of course requires a very high level of adaptability, a deep appreciation of the history of trauma undergone by Canadian Indigenous people and the intergenerational effects of colonialism, in addition to a clear sense of the local landscape from a culture, tradition, beliefs and resources point of view.

Every LEAP course module requires an intentional and continuous reflection on the part of the facilitator on these elements so that questions asked in the interactive discussion are appropriate and the emphasis put on certain materials came from an Indigenous perspective at every stage of the course.

The facilitator must not only demonstrate cultural respect and curiosity, but also foster these in course participants and help all to embrace the Indigenous narrative within and around the clinical learning.

### **Pallium and the Long-Term Care Setting**

In 2014, Pallium began working with a team of Canadian subject experts in the long-term care sector to design a course that met the growing needs of the sector to ensure the professionals engaged in this setting have the core competencies to deliver proper palliative care to residents and their families. Prior to that, Pallium had contributed to the work done by the Quality Palliative Care in Long Term Care Alliance's development of palliative care competencies of staff working on LTC homes, including personal support workers. These competencies were used to guide the development of the LEAP LTC courseware.

As a result of this work, LEAP Long-Term Care (LTC), a two-day course that provides participants with the essential skills and competencies of the palliative care approach, was developed, piloted and subsequently launched in 2015. This course takes an interprofessional approach and promotes teamwork and collaboration among different healthcare professionals who work in long-term care settings and nursing homes.

LEAP LTC is targeted at any healthcare professional (e.g. physicians, nurses, pharmacists, social workers, home care nurses, etc.) as well as personal support workers (PSWs) or care aides working in long-term care and nursing homes. The course was not designed to make palliative care specialists of the participants, but rather to provide them with the essential knowledge and skills to enable them to initiate and provide a palliative care approach as part of the care they provide.

A two-year study on the impact of Pallium's LEAP LTC course found that there is evidence of improvements health care workers' knowledge, attitude and comfort levels related to the palliative care approach as well as evidence of implementation of learnings into practice, across all professions. The course was also highly rated by all professions

A total of 39 LEAP LTC courses were held during the study period, the majority of them being held in Ontario, Nova Scotia and British Columbia. A total of 817 health care professionals participated in LEAP LTC courses during the study period; 429, 58, 33, 34, 9 and 541 nurses, physicians, social workers, personal support workers (PSWs), pharmacists and “other professions” respectively. The “other” group includes dietitians, physiotherapists, occupational therapists and administrators.

Participants in LEAP courses are asked to provide statements that describe the commitments they plan to make in their work practice and within their work environments upon completion of the course. These statements are referred to as ‘Commitments to Change’ (CTC) statements and are captured pre-course and post-course.

In analyzing 539 CTC statements that were shared 4-months post course, the following top six themes, which were similar across professions, were implemented into practice:

1. End-of-life care planning and discussions (including improved screening for symptoms)

Participants noted being comfortable in end-of-life and goals of care conversations with residents that in turn helped families reach agreement with residents. Many nurses reported success or progress on the implementation of screening tools while others remarked on their utility for resident care.

2. Pain control, opioids and other medications

Recognizing pain and discomfort was easier for participants as well as using techniques such as distraction when repositioning or understanding the source of pain. Participants were more aware that residents’ behaviours might indicate pain that wasn’t symptomatic or that the resident couldn’t articulate.

3. Introducing the palliative care approach

Many participants were using regular team meetings to facilitate discussions with colleagues around a palliative care approach (spreading the approach). Participants report being more accepting of death as part of palliative care and of the benefits that a palliative approach to care can bring to residents and their families.

4. Advocating for organizational changes

Participants were more comfortable talking with management, initiating discussions and putting forward recommendations on potential changes to policy.

5. Family engagement

Changes to support holistic care include discussions using precise palliative care terminology, sharing information with families, and listening with care to residents’ and families’ wishes with respect for their support needs.

6. Advance care planning

Initiating end-of-life and goals of care discussions at resident admission was a good and positive practice that many participants began implementing (depending on their role)

These successfully implemented commitments to change are early evidence that LEAP education is improving practice in palliative care. At the end of the LEAP LTC course, participants were eager to apply what they had learned to improve their residents' care.

All aspects of the course and the learning experience were highly rated across all profession groups. This included the course being relevant to their practices, learning needs being met, opportunities for discussions, cases being relevant to their practices, facilitators being knowledgeable and the overall learning experience.

Overall, 96.9% of participants indicated that they "Strongly Agree" or "Agree" with the statement "This course was relevant to my practice". In response to the statement "I would recommend this course to colleagues", overall, 96.9% of participants indicated that they "Strongly Agree" or "Agree".

These experiences and learnings, both in the LTC setting with respect to palliative care education of health care professionals and experiences in integrating Indigenous perspectives, places Pallium in a strong position to actively contribute to the development of a LTC strategy on Reserves. LEAP LTC can be adapted to include Indigenous perspectives to ensure it is relevant to the community in which it is being delivered.

## **Summary**

Canada is an aging country. For the first time in history, there are more seniors in Canada than children. By 2024, Canadians aged 65 years and older will account for more than 20 per cent of the population, while children under the age of 15 will represent just over 16 per cent of all Canadians.

This translates into higher costs for Canada's health care system, particularly as Canadian seniors advance to the later years of life. And the reality is, we are not equipped with sufficient palliative and end-of-life care. In Indigenous communities, the challenges are even greater.

As the Committee evaluates the long-term care setting on Reserves, a few critical success factors must be considered as part of a go-forward strategy:

- An appropriately trained workforce is critical to improve access, quality and consistency of palliative care in long-term care settings, which results in better staff, patient and family satisfaction and quality of life for patients.
- LEAP training can facilitate system connections, particularly when bringing together different professions working in a long-term care setting.
- LEAP courses help nurture increased linkages and relationship-building between health care professionals involved in the care of the same patients within and across sectors of care.
- Building competencies in palliative care among more health care professionals will result in more efficient use of resources
- An adequate number of palliative care physicians and nurses (specialty teams) and other professionals with advanced training and experience in palliative care is needed to provide specialist-level palliative care, consultation and shared care support to health care professionals in the long-term care setting



- In long-term care homes, participants who attend educational training programs to improve their palliative care skills will need to be backfilled to ensure consistent, uninterrupted care to patients