

**Palliative Care**  
**Matters** | Building  
National Consensus

**L'importance des**  
**soins palliatifs** | Forger  
un consensus national



# Palliative Care Matters: How Canada's Health System Needs to Change

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## CONSENSUS STATEMENT

of the *Palliative Care Matters* Lay Panel

Ottawa Canada | November 9, 2016



**Palliative Care  
Matters** | Building  
National Consensus

ORGANIZED BY:



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*Palliative Care Matters:*  
How Canada's Health System Needs to Change

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Ottawa Ontario

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## Acknowledgments

The Consensus Development Conference is part of a larger initiative, *Palliative Care Matters*, spearheaded by Covenant Health through its Palliative Institute. *Palliative Care Matters* is a direct expression of Covenant Health's belief in a future where every Canadian has access to quality palliative care and all caregivers are supported with the knowledge, expertise and resources they need.

We want to thank all Canadians. *Palliative Care Matters* is giving voice to the many people in our country who need palliative care. The Initiative began with listening to Canadians through focus groups and the Ipsos survey, where over 1500 Canadians shared their views on a palliative care system for Canada. It continued with the Lay Panel members, chosen to represent the views of broad groups of Canadians.

*Palliative Care Matters* is co-chaired by Karen Macmillan, Senior Operating Officer at Covenant Health and Fred Horne, former Alberta health minister and health policy advisor. Joining them are national stakeholder organizations including Accreditation Canada International, Canadian Hospice and Palliative Care Association, Canadian Medical Association, Canadian Society of Palliative Care Physicians, Canadian Partnership Against Cancer, ALS Society of Canada, Catholic Health Sponsors of Ontario, Canadian Foundation for Healthcare Improvement, Health Canada, Saint Elizabeth Health Care, Canadian Nurses Association, Alberta Health Services and Canadian Frailty Network.

Don Newman, C.M., led a panel of Canadians from all walks of life and regions of Canada. The [Lay Panel](#) worked many hours to review and question the evidence, deliberated the issues together and brought forth recommendations on how quality palliative care should be provided across the country. Your work was invaluable. If we are going to improve the system, we must listen closely to patients and families.

Conference evidence was gathered under the guidance of Dr. Konrad Fassbender, Assistant Professor, University of Alberta Faculty of Medicine and Dentistry and Scientific Director, Covenant Health Palliative Institute, and Carleen Brenneis, Director, Covenant Health Palliative Institute. They were supported in this work by the [Canadian Reference Working Group](#), who determined the questions to be deliberated by the Lay Panel, and the [Expert Panel](#) who did the all-important work of examining the scientific evidence for each question.

BUKSA is [Project Manager](#) for the three phase initiative and has assembled a team of professional communicators, writers, project managers and experts in logistics to organize and deliver on Covenant Health's vision for *Palliative Care Matters*.

Covenant Health is grateful for the early contributions of the Canadian Foundation for Healthcare Improvement for supporting the overall initiative, the Canadian Partnership Against Cancer for funding the Ipsos research survey and Health Canada, for supporting the preparation of The Conference Board of Canada Final Report. Other financial sponsors include the Canadian Medical Association, Accreditation Canada International, Canadian Nurses Association, Catholic Health Alliance of Canada, Catholic Health Corporation of Manitoba, St. Joseph's Health System, St. Joseph's Health Care Society, St. Joseph's General Hospital, Canadian Virtual Hospice, Providence Healthcare, St. Joseph's Health Centre, and Saint Elizabeth.

Covenant Health is Canada's largest Catholic health care organization, providing compassionate, quality care to people of all faiths and traditions as a key partner in Alberta's integrated health system. As a major provider of palliative care, Covenant Health established the Palliative Institute which is committed to relieving suffering for patients and their families.

For further information, visit the *Palliative Care Matters* [website](#).

## Inspiration

Jim Mulcahy opened the Palliative Care Matters Consensus Development Conference. His profound words on the meaning of care in the face of illness and death illuminated the deliberations and inspired the recommendations. Here is the essence of what he said:

“When the efficacy of curative medicine has run its course, quality medical care becomes not so much a matter of what you do to the patient as a matter of who you are willing to be with that person. Such profoundly vulnerable and personal relationships are not only acts of transformative healing compassion, but act of courage as well. The courage to abandon the security and protection of familiar roles and routines, the clinical postures and personas we adopt to effect an insulating distance. The courage to ultimately surrender the struggle to intervene to make life conform to our own wishes and let the current of the illness carry us where it will. And the courage to abide attentively in the kinship of silence when words are too weak or intrusive or disruptive to be spoken.

The hardest thing is to remain in that kinship of silence. We want to do something or say something, rather than to remain in the intensity of those moments. But that is the very time we cannot abandon the suffering. This state of vulnerable kinship is the still point in the turning world of palliative care. It is the lived acknowledgement and therapeutic significance of an authentic, personal, compassionate relationship between the caregiver and the patient. A relationship of trust, commitment and tenderness (another word we have lost in our medical lexicon) between the caregiver and the patient.

It is a gift, a blessing given and not without cost by the caregiver to the patient—the gift of community, the gift of consolation, meaning and companionship. A gift which ennobles the caregiver and the patient in equal measure.

I’m going to repeat that because it is so important. I get so sick and tired of tired people talking about the professions in terms that deny the possibility that it just might be an act of nobility to dedicate your life to caring for people.

My wife is not a health care consumer. She is a person and she has a name. She is not just a pathology. And people who care for her genuinely in my estimation are noble. It is a gift that ennobles the caregiver, as well as the patient, in equal measure. A gift given until we are no more. It is the ancient, archetypal expression of human solidarity that one should care for another. And it is the measure of what is best in us as people and as a country.”

*Born and raised in Halifax, Jim Mulcahy taught English and drama in in Antigonish, Nova Scotia public schools for over thirty years. Forced to retire after his second cancer diagnosis, Mr. Mulcahy became actively engaged as a patient advocate serving on local, provincial, and national healthcare committees. He has an honorary doctorate from St. Francis Xavier University for his contributions as educator and patient advocate. For the past twelve years Mr. Mulcahy has been his wife Sarah's primary caregiver. Sarah is in the latter stages of Huntington's and three of their four adult children have the same disease. Last year, their three year old grandchild was diagnosed with an incurable, life threatening blood disorder.*

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## Background

### About this Consensus Statement

This Consensus Statement was prepared by an independent 12 member Lay Panel of Canadians from diverse walks of life and regions of the country. This statement reflects their analysis of the views of Canadians and scientific evidence. It is supported by their expertise and lived experience to bring forward the collective wisdom of all Canadians regarding palliative care. *Palliative Care Matters* will work to ensure that their insights and recommendations are heard across Canada and lead to better palliative care for all.

The Statement was informed by:

- Research papers prepared by a panel of experts in palliative care,
- Relevant studies and reports assembled by the Initiative's leadership,
- The focus group research and public opinion survey conducted by Ipsos,
- The lived experiences of patients and caregivers who spoke at the conference and through multimedia presentations made possible through the work of the Virtual Hospice,
- The lived experiences of Lay Panel members
- Questions and comments from conference and webcast attendees during open discussion periods, and
- The private deliberations of the Lay Panel.

The Consensus Development Conference was held in Ottawa, Ontario and webcast live across Canada to encourage participation by all Canadians. Lay Panel members, audience members and those watching the free webcast could ask questions of the experts, provide comments and answer polls related to the topics. The success of the webcast is notable. By the second day of the Conference, 394 sites had registered to view the webcast. The sites were from across the entire country and the United States. The webcast was recorded and archived as a resource.

The resulting recommendations were read aloud by Don Newman, the Lay Panel chair, in an open session on the closing day of the conference, November 9, 2016. Mr. Newman's introductory comments at the session are included with this Consensus Statement.

### The Consensus Development Conference Model

Consensus development conferences bring together citizens, decision-makers and experts to address issues of public importance. The conferences involve a series of experts who deliver scientific evidence on a subject to a Lay Panel of 10 - 12 people before an audience of several hundred.

The Lay Panel hears the evidence and takes it into consideration when they develop a consensus statement in the form of a series of recommendations. These are then read to the experts and audience and are used to develop policy going forward (Institute of Health Economics, n.d.).

There are five basic steps in the consensus development conference model, which were adopted and adapted to the specifics of the *Palliative Care Matters* Consensus Development Conference.

1. A series of six to ten of the most pressing questions related to the topic are set. These questions for *Palliative Care Matters* were determined after a review of recommendations made in the last twenty years by other reports on palliative care.
2. [Scientific experts](#) are assigned the questions. For this Initiative, the experts reviewed the evidence and prepared a short report which was provided to the Lay Panel prior to the conference. The questions also formed the basis of the national public survey conducted by Ipsos Research on behalf of the Initiative. The Ipsos [findings](#) were part of the evidence weighed by the Lay Panel.
3. At the conference, presentations are made to the Lay Panel and audience. For *Palliative Care Matters*, Ipsos and the scientific experts made presentations to address the questions posed. The Lay Panel and audience, which in this instance included Canadians who participated through the free live webcast, questioned and sought clarification from the experts.
4. The Lay Panel reviews the evidence prior to the conference, listens to the evidence at the conference, questions the experts and prepares written answers to the questions.
5. On the last day of the conference, the Lay Panel chair reads the consensus statement and takes questions from the audience. The consensus statement consists of specific answers to the questions posed and usually includes recommendations.

### Choosing the Questions

*Palliative Care Matters* is building on work done by others in Canada. The Consensus Development Conference was organized around six questions gleaned from a review of recommendations made in Canada on palliative care over many years. The questions focus on issues that represent the greatest barriers to a national system of quality palliative care and align with one or more recommendations from national reports on palliative care. The final questions were determined using a nominal group technique undertaken to synthesize the recommendations and reach consensus on areas of focus. This work was undertaken by *Palliative Care Matters* with members of a committee called the [Canadian Reference Working Group](#). Members of the Working Group were nominated by Steering Committee organizations.

### Patients as Experts

*Palliative Care Matters* is built upon the recognition that people are experts in their own experiences, feelings and fears, hopes and desires (BMJ, 2003). Canadians come to the experience of life limiting illness and end of life with much of their experience behind them. The time remaining to them is extraordinarily valuable and there is little that is more important than honouring how they wish to live it. That is why the work of *Palliative Care Matters* began by asking Canadians what they wanted to see happen with regard to palliative care. Who they want caring for them. What that care should encompass. Where they want that care provided. This is also why the Lay Panel members come from different walks of life; palliative care is intensely personal and the patient and family perspective should always be in the fore.

### Disclosure Statement

All of the Lay Panel members who participated in this conference and contributed to the writing of this statement were identified as having no financial or scientific conflict of interest.



## Lay Panel Chair's Introduction

Palliative care matters to all Canadians. As a society, we need to place as much emphasis on this critical part of the life journey as we do on bringing life into the world. That means addressing the gaps in care and support which currently exist in our country.

This Consensus Development Conference on palliative care occurred because people and organizations across Canada are passionate, compassionate and recognize that we can and must do better. We would not be here without the leadership of Covenant Health and its Palliative Institute. As well, this would not be the pan-Canadian initiative it is without the fourteen national organizations who joined in planning and supporting this Initiative, as well as the many other organizations who gave money and time to the effort.

I also want to acknowledge and thank my fellow Lay Panel members for their hard work and wisdom. It has been an honour working with you. It has also been an honour to hear from the experts in palliative care and public polling. You spend your lives researching these issues that mean so much and all of Canada owes a debt of gratitude to you for your insights and knowledge.

This conference is the second stage of *Palliative Care Matters*. The first stage involved listening to Canadians and hearing their views on what they believed needed to be in place and how they wanted to be supported in providing care to their friends and family. It also involved commissioning the scientific research that, together with views of Canadians gathered by Ipsos, formed the basis for the deliberations of the Lay Panel.

The second stage has been about reaching a consensus on what steps need to be taken to ensure that all Canadians have access to quality palliative care. It is our hope that the findings and recommendations in this Consensus Statement will take hold and, together with all the other good work being done in Canada, make a difference in the lives and deaths of Canadians.

This Consensus Statement, however, is not the end of the Initiative's work. If we stopped here, our work would be for nought unless *Palliative Care Matters* can help create real, substantive change.

This is why in phase three The Conference Board of Canada has been tasked with studying the Statement. In early 2017, they will release a report outlining policy options and ways that our recommendations can be implemented in order to make better palliative care a reality.

The Lay Panel has listened to national and international experts over two days. We spent many hours in the evenings poring over what we heard and discussing amongst ourselves what it means and its implications for Canada.

Our task was more than an analysis and weighing of the scientific evidence, as important as that is. We are also here to acknowledge the human dimensions of living our lives to their end. We are here to speak about what we must do as a caring and compassionate society must act upon if we are to improve the care and support that people needing palliative care deserve.

We also acknowledge the support needed for the people providing care. No matter how deeply we love those we support, being a caregiver is one of the most singularly challenging and important tasks we undertake.

We also recognize that the health care providers who choose this important work need to be supported. We are all human. We all need to help each other with the emotional, physical and spiritual elements of caring for people at the end of their lives.

As a Lay Panel, we were limited only by our ability to absorb and reflect on what we have heard. Members of the audience came up to us individually and delivered a strong message: Please, be bold. Our work must help make the difference. Too many people are suffering as they die. Too many of the ones who are left behind are devastated by the process.

Mindful that the Government of Canada has committed \$3 billion to home care, including palliative care, as part of the current Health Accord negotiations, our ultimate recommendation is an overarching one. It is a necessary precursor to all the other issues that we address in our recommendations and it is this:

First and foremost, palliative care must be guaranteed under the Canada Health Act. Criteria need to be set by governments and the continuum of palliative care services should be publicly funded. There are many care providers in the system, including community organizations, private deliverers and primary care teams, to name only some. Their services should be funded so that all Canadians requiring it can access the palliative care they need.

While this is necessary, it isn't sufficient. We also have to examine the social support fabric within our provinces and federally and ensure that it is robust enough to support people as they make difficult decisions around supporting the people they love and care for.

Ensuring that the suffering of our fellow citizens is alleviated is at the heart of a civil society. We heard that clearly at the Consensus Development Conference and deeply know it to be true. It isn't enough to care; Canada must turn its caring into commitment that ensures that palliative care is a part of the Canadian health system and receives the attention and resources it needs.

These are our findings:

## Question One: What are the essential elements of an integrated and coordinated palliative care program that will help to improve access to quality palliative care in Canada?

Integrated palliative care has positive health and societal benefits. However, despite two decades of work by many organizations and numerous reports and recommendations, the majority of Canadians don't have access to regional, comprehensive, coordinated and integrated palliative care.

Work needs to be done to involve communities in planning palliative care and palliative care should be integrated throughout every stage of the health care system. Palliative care is currently delivered in the context of silos. These must be bridged.

Canada needs to define what integrated palliative care should look like for the country. The Lay Panel has developed a definition for an Integrated Palliative Care Model (IPCM) using the World Health Organization (Ewert et al., 2008) and inSUP-C (van der Eerden et al., 2014) definitions as a starting point:

An integrated palliative care approach improves the quality of life of all Canadians, inclusive of their families and community, impacted by life-threatening illness. The goal is to embody a social model of care to support holistic frameworks consisting of clinical, community and volunteer support. It aims to achieve quality of life and a well-supported dying process for the person in collaboration with their family and all caregivers.

Key characteristics of the Canadian Integrated Palliative Care Model (IPCM) should be clearly understood. IPCM is more than a bio-medical model of care. It is a collaborative model that takes into account the continuum of care and range of people who need to provide it: friends, families, healthcare professionals including specialists, home care providers and primary care, social workers, and spiritual care. Social inclusion is an important part of an IPCM.

*"My wife is NOT a pathology and she is not a health care consumer. She is a person."*

Jim Mulcahy

The IPCM needs to be anchored by and embedded in the cultural norms of society. It should address society's perception of death, including the fear of death. It should also encompass the emotional and non-medical side of care.

Communication is key to the successful implementation of the IPCM and supports smooth transitions for patients and families. It should be a model sustained and driven through public awareness communications. Canada needs to undergo a process where we discuss palliative care openly and share our stories. We envision a national palliative care narrative initiative. Another key aspect of communication is information sharing; people providing care need to be able to communicate amongst each other knowing that their information is secure, accessible, and consistently delivered.

*"Death, like the Sun, cannot be looked at steadily."*  
Francois de la Rochefoucauld, in 1670.

Not everything we need to understand about palliative care will be the result of clinical research. The IPCM is a model that needs to capture the non-quantitative data that informs the IPCM experience beyond a bio-medical frame of reference.

## Recommendations

1. We recommend to the Government of Canada and the provincial governments that Canada become a leader in a nationally supported Integrated Palliative Care Model (IPCM) and develop a national palliative care strategy.
2. We recommend that an Integrated Palliative Care Model (IPCM) be enshrined in the *Canada Health Act*. IPCM must be accessible, equitable, portable and adequately resourced.
3. We recommend the creation of an IPCM National Secretariat to support the long term sustainability of an IPCM. The secretariat will:
  - Create a national committee forum
  - Create a source for national messaging in IPCM
  - Create a national place for cultural interactions
  - Become the consistent link between provinces and the Federal Government

- Be responsible to create a national conversation that captures our stories and humanizes palliative care
- Become a national centre for research on qualitative, quantitative and non-parametric research

## Question Two: Do public health awareness campaigns effectively improve the awareness and quality of palliative care?

Awareness campaigns are organised communication activities designed to raise awareness, induce behaviour change and improve quality outcomes for individuals and populations (Masiulienė, 2015). The implementation of an Integrated Palliative Care Model under the Canada Health Act will require an awareness campaign. Canadians are not fully aware of palliative care and the majority have not taken steps to manage their own future care through the use of advance care plans and personal directives.

Public health awareness campaigns require significant funding and not all are effective. If Canadians are going to become more aware of palliative care and advance care planning, the techniques used to raise awareness and promote engagement need to be thoughtfully chosen. In the Ipsos survey commissioned by *Palliative Care Matters*, people indicated that they are concerned about the cost of campaigns, but want to see more information disseminated throughout the health system (91% approval) and information about palliative care services and standards.

*Palliative care was not giving up, but rather allowing our child to live while she was alive.*

Video testimonial, Canadian Virtual

Despite continuing low awareness levels, the Lay Panel acknowledges that much good work has been done by national and regional organizations to raise awareness. Care needs to be taken to involve these organizations so that their learnings can be incorporated into the planning of a national campaign.

Research suggests that effective public awareness campaigns about palliative care and advance care planning should be culturally appropriate and piloted, target marginalized groups, include young people in the targeted demographics, involve communities, build coalitions and be socially inclusive.

*"Caring is the relationship between caregivers and patients that regulates the heartbeat of palliative care."*

Lay Panel Member.

Tools to deliver effective public awareness campaigns would include the use of a variety of communication channels in order to reach a range of Canadians of all ages and regions. They should also capitalize on the arts and humanities, particularly storytelling.

Features of successful public awareness campaigns include:

- The use of clear and concise, easy to understand language;
- Networking with stakeholders to draw in their expertise; and
- Employing systematic monitoring and evaluation to ensure efficacy. This latter point was specifically identified by Canadians in the Ipsos survey.

## Recommendation

4. Develop a public awareness campaign about palliative care. The campaign should support the implementation of a national palliative care strategy, including the Integrated Palliative Care Model recommended in question one. It should be implemented along with the national strategy and start by outlining the nature of palliative care, including an emphasis that palliative care be woven throughout the health care system. The campaign should also encourage people to discuss palliative care with their health care provider or other members of their support networks, including the importance of advance care planning. The campaign should highlight the importance of involving all members of Integrated Palliative Care teams, particularly patients and caregivers as experts in their own right.

## Question Three: What are the essential components of quality palliative home care services for all Canadians?

Palliative home care should become a standardized service across the country. The amount and type of home care provinces pay for varies, yet most people want to be cared for and die at home. Palliative home care is the most specialized type of home care. It deals with more complex symptom management and has a clear end-of life intent.

Successful palliative home care programs involve linkages between home care providers, primary care, community services and hospitals. These linkages, multidisciplinary care teams, a mix of providers with various skills and levels of expertise, along with training for caregivers and a continuum of care which is there when people require assistance, are some of the elements of a successful palliative home care program.

Public funding for home-based palliative care across Canada is inadequate. The health care system is about to be overwhelmed by demands for palliative care. Palliative home care and support for home-based caregivers relieves the pressure on other sectors of health care system and provides Canadians with the care they want. Support and provision of home care expands the options of where people can choose to receive palliative care.

We know that palliative home care is important to Canadians. The Ipsos survey confirms the desire of Canadians to die at home; 90% said that patients should have the right to receive care in their own home at the end of life. They also said that the public health system should cover the costs of palliative health care so everyone could access it as needed (86%).

Support for the delivery of comprehensive range of palliative home care services is also strong amongst Canadians. In the Ipsos survey, people were provided with a list of 15 potential components of home-based palliative care. Among the most essential were 24/7 access to a nurse specialized in palliative care, daily help with caregiving, and access to equipment, at 91% support for each. The survey respondents also identified the need for more knowledge, including education and information for caregivers, someone in the system to coordinate care (all at 91% support)

*The heart of a civil society is that we care for each other - this needs to be translated into legislation with adequate funding.*

Dr. Brazil.

and a single point to call or access when they needed help (90%).

## Recommendations

5. We recommend that the Canada Health Act be amended to include integrated, palliative home care. It must have universal access, provide support for patients and caregivers, and be customized to suit their medical and psycho-social needs. Home care must be transportable from province to province with no restrictions or waiting period.
6. Given that death is part of life, we recommend that a holistic approach to palliative care be adopted in order to deliver a better quality of life to individuals. Care in the home must be one of those choices. Palliative home care must be culturally responsive and have an integrated approach. The scope of home-based care must be widened to overcome historical forms of alienation and difference. All Canadians should be treated equally in the design, support and delivery of palliative care in the home. Home-based palliative care must also accord with the Canadian Charter of Rights and Freedoms and the UN Declaration on the Rights of Indigenous Peoples, in order to address current inequities as they affect indigenous peoples.
7. To develop excellent palliative home care, better qualitative data is required. Standardized quantitatively-oriented methodological practices do not fully capture the experience of illness and death from the perspective of a patient or caregiver. Other methodological practices are required to represent those experiences and have them included in the development of appropriate home-based care.
8. Home-based caregivers should be considered providers and be included as members of palliative care delivery teams. Patients should have the ability, if desired, to play a key role in the design and implementation of their palliative care treatment.

## Question Four A: What resources are required to ensure adequate education, training & mentorship for caregivers of Canadians experiencing a life-limiting illness?

Family members and friends provide personal care and companionship to people during a life limiting illness and end of life. They provide physical and emotional support that is beyond measure from a human perspective. Their care saves the health care system millions of dollars each year, but is a considerable emotional, physical and financial burden to those providing the care.

The caregiving role is critical and Canadian society needs to ensure that caregivers receive the support they require through adequate caregiving education, training, mentorship and support services. These supports need to be tailored to the caregiver's circumstances to ensure they can provide care throughout the period required and can do so feeling confident and effective. Patient-identified caregivers provide the most direct around the clock care to palliative patients at home and must be recognized as an essential part of the patient care team.

*"The courage to abide attentively in the kinship of silence when words are too disruptive to be spoken."*

Jim Mulcahy



## Recommendations

9. Include caregivers as part of the patient care team.
10. Develop knowledge and training for caregivers based on the IPSOS identified Elements of Palliative Home Care.
11. The information needs of caregivers will change over the progression of the disease or condition of the person they are caring for. Therefore, caregivers will require ongoing education about disease progression. Information that is shared needs to be sensitive to the caregiver's comprehension and acceptance of the diagnosis.
12. The patient care team will also need to be supportive of the caregiver's needs for respite care and personal health assessments. They also need to provide opportunities to discuss the challenges being faced. These can include isolation, stress, anxiety, exhaustion, anticipatory grief and confusion.

## Questions Four B: What resources are required to ensure adequate education, training and mentorship for nurses and health care assistants who provide palliative care?

There are many educational materials and ways of delivering education in palliative care. However, there isn't a lot of evidence showing how effective they are. A palliative care strategy needs to address the education, training and mentorship needs for nurses and health care assistants (HCAs). This includes both formal training and on the job or other professional development opportunities.

Nurses and healthcare assistants provide the majority of paid care for patients receiving palliative care in homes, hospices, long term care facilities and acute care facilities.

The curricula used to educate these care providers has not benefitted from a document of competencies that is universal. The Registered Nurses are able to expand their knowledge and practice abilities by passing professional certification exams and/or earning an advanced degree as a clinical nurse specialist in the field of palliative care.

Funding support for continuing education in palliative care varies from province to province. Employer support is available in some jurisdictions, but is the responsibility of the individual nurse in others. Healthcare assistants are underserved in their educational programs and may be doubly handicapped by not having access to user-friendly continuing education.

Provincial and national organizations have made learning modules and curricula that would benefit new entrants to nursing/healthcare assistant programs. However, there is no current consensus on the scope of information required for each group of learners.

## Recommendations

Because of the importance of providing competence building for these two groups of care providers, the following recommendations have been developed:

13. Accreditation standards for nursing programs need to include palliative care content that meets the recommendations of the CNA, CHPCA and CHPC-NG. The content should reflect the importance of communication skills; psychosocial competency; and cultural awareness, sensitivity, competence and cultural safety. Palliative care education standards for healthcare assistants need to be developed at the provincial level.
14. Access to ongoing palliative care education within the workplace needs to be developed and delivered in ways that are affordable and portable.
15. Curricula development for both groups needs to be informed by patients and families, palliative care interest groups and interdisciplinary colleagues. Nurses need to be educated to initiate early entry to palliative care and to teach members of the palliative care support team how this knowledge should be utilized.

### Question Four C: What resources are required to improve education, training and mentorship for physicians who provide palliative care?

Canadian physicians are not being adequately trained in palliative care. Ten out of 17 medical schools provide fewer than 10 hours of palliative care curriculum in their undergraduate programs and many residents are not able to complete an elective in palliative care because there are few available. Once licensed, physicians have to complete a set number of continuing medical education hours. Even there, few learning opportunities focus on palliative care. It is difficult to visualize a medical practice where death doesn't occur and virtually every physician in Canada should be able to provide basic palliative care. There are barriers to ensuring physicians are skilled in palliative care that need to be addressed through improvements at the undergraduate, graduate and education levels.

*Improving palliative care is as much about changing medical culture as it is about teaching skills and knowledge.*

Resources for teaching palliative care in Canada must be better deployed. To ensure that all physicians have basic palliative care skills, the two core competencies, symptom management and communication skills, need to be taught throughout medical training and into continuing education. Academic institutions and clinical teaching sites need support to develop capacity for these competencies to be taught.

Strengthening communication between all palliative care team members, including patients and families, must be a strong component to the integrated collaborative model that has been recommended.

'Culture has a way of eating training for lunch.' Practicing physicians less familiar with the palliative care approach will require peer to peer mentorship within an inter-disciplinary setting. Patient and family outcomes will be improved as a result of this shift in education and culture.

### Recommendations

16. Teaching palliative care will be incented by partnering with accrediting bodies and colleges/licensing bodies to ensure these competencies are taught and tested.

17. All physicians should be required to have basic skills in palliative care.

## Question Five: What have strategic frameworks and plans accomplished for palliative care when adopted by countries?

In 2014, the World Health Organization (WHO) called on members to develop and implement policies to ensure evidenced-based, effective and equitable palliative care is integrated into national health services as an element of the continuum of care.

Evidence from a number of countries similar to Canada suggests that national strategies can ensure better access to high quality palliative care in a fiscally responsible manner. They appear more successful when:

*Nothing about us without us.*

- Clinicians, educators, researchers, service providers, advocates and policy makers are all involved in the strategy development,
- Governments are responsible for implementation and funding, and
- Milestones are established and regularly audited.

Palliative care development in Canada has been organic rather than strategic, largely influenced by local resources and practices.

There is a recognition that health care costs will be shifted to home care and other palliative modalities and are unlikely to increase but new funding will be required for training to build capacity and research on the evidence base.

There are areas of excellence in Canada which need to be incorporated as Canada moves toward an integrated palliative care model.

The Australian National Palliative Care Strategy (NPCS) can inform the work ahead:

- Australia is comparable in terms of wealth, population size, geographic size and population make-up, with a Federal/state governance structure.
- The Australian NPCS resulted in programs focused on enhancing access, improving care services and increasing the evidence base.
- Their strategy gave thought to all core components and brought together all relevant parties.
- There was substantial, sustained funding.
- There are regular audits to support achievement of the goals.

Among the stakeholders which need to be engaged in the development of an Integrated Palliative Care Model for Canada are:

- Charitable organizations
- Advocacy groups
- Policy makers
- Funders
- Private philanthropists
- Health care providers
- Patients and family

It is critical that stakeholders get involved early so that the strategy is collaborative.

## Recommendation

18. The Federal government must provide substantial and sustained funding for the development and implementation of a national strategy, including capacity building, standards development and monitoring, and research.

## Question Six: Does measuring indicators that address desired outcomes, including patient/family reported outcomes and experience, improve the quality of and access to palliative care?

Measurement is necessary for improvement, but measuring performance in palliative care is complex: Care gets delivered in a variety of sites and measurements have to capture aspects important to patients and families.

The most important measures look at outcomes - what has been achieved for the patient and within the healthcare system. There is evidence that using patient surveys can improve quality of life. While other countries have established frameworks for measuring palliative care, Canada is at the beginning stages of developing a series of common benchmarks and common ways to collect and report on patient surveys. Canada needs to be more than a country of pilot projects and needs to establish a coherent national framework for measuring palliative care.

Accreditation Canada standards recommend that organizations track performance measures for palliative care patients and this information should be collected and analyzed nationally.

An integrated system can only be built upon reliable data and evidence that captures the information needs of each of the players in the system. To improve the efficacy of palliative care a wide range of data is needed.

*An integrated system must be built on the collection of information that identifies the very needs that the system is designed to address.*

There is insufficient qualitative data that describes desired palliative care patient outcomes. Kamal et al (2014) identified some 284 indicators, of which less than 5% reflect psycho-social, spiritual or cultural quality measures. Quality outcome measures, indicators and necessary common data elements are available and have demonstrated value in improving outcomes and the quality of care. However, these data are largely based on quantitative measures and may only partially capture the patient's experience of palliative care.

Currently, there is no national coordinating body that would direct research, collect and manage data. This is further complicated by inconsistencies in methodology and the types of data collected; the lack of commensurability makes it challenging to compare the efficacy of palliative care measurements. Quality improvement in palliative care is difficult without evidence to demonstrate how improvement might be achieved.

Also, it is important to recognize that different metrics may be needed within different communities and cultural backgrounds. Similarly, measuring Patient Reported Outcomes (PROM) is difficult and there are questions of reliability when administered to an ailing patient or a patient in rapid decline.

The Australian Palliative Care Outcomes Collaborative (PCOC) can provide a model for Canadian data collection. These standards and data should be identified and collected using pluralist or mixed methodologies (quantitative and qualitative research methods.) All participants in an IPCM would have input into the purpose, design and use of the research. Data collection across all locations must be obtained consistently where palliative care is delivered including hospitals, hospice, long term care facilities and in the home and community.

### **Recommendations**

19. Quantitative, and especially, qualitative data collection and analysis needs to be appropriately funded and appropriate to the needs of all participants in the IPCM.
20. As part of the IPCM Secretariat established in question one, a well-funded National Centre of Research should be established to coordinate and disseminate national research to fulfil the following functions:
  - National service level performance data that is derived from the common outcome measures;
  - National benchmark standards against which individual services compare themselves;
  - Nationally employed staff that support palliative care services to identify priorities for clinical and systems change and help implement quality improvement initiatives;
  - Collection of aggregated data that is analysed and reported back to each service; and
  - Regular audits that will ensure the delivery of palliative care services meets the culturally defined expectations of communities.

## **Conclusion**

Canadians have clearly said that living with illness and end of life need not be synonymous with pain, suffering and isolation. They know that doing better in this area means more support for the people who need palliative care. It also requires supporting the family members and friends who are there for their loved ones in the last part of the life journey. Doing better also has to translate into better training and support for the health professionals and workers who form the living infrastructure of our palliative care system.

Palliative care matters. That is why palliative care needs to be embedded in the Canada Health Act.

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