



23 July 2018

Let's Talk Palliative Care
The End of Life Care Team
c/o Venetia Lawless
200 Eglantine Drive, A.L. 1904D
Ottawa, ON
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Dear Ms. Lawless,

On behalf of the Canadian Conference of Catholic Bishops (CCCB), please accept the following report as a contribution toward Health Canada's consultation on palliative care arising from the passage of Bill C-277, *An Act providing for the development of a framework on palliative care in Canada*.

For generations, Catholic dioceses and religious orders in Canada have been major contributors to the development and delivery of healthcare services across the country. The first hospital (Hôtel-Dieu) in Canada was established in 1639 by 3 Religious Sisters of the *Augustines de la Miséricorde de Jésus* to care for Indigenous populations living near the French colony in present-day Québec City. This hospital, which also happens to be the first hospital in North America, is still in operation. In addition, there are today 105 Catholic healthcare facilities across Canada, either self- or parent-governed by 43 Catholic organizations, which accounts for 13,738 healthcare beds in Canada. These facilities are supported by 19 dioceses and 14 Catholic sponsors. They span 6 provinces and 27 health regions/authorities. Catholic healthcare has been a leader in palliative care in Canada since 1974 when Saint Boniface General Hospital opened one of the first two palliative care units in the country. Today, across 30 Catholic healthcare facilities in Canada, there are a combined 353 palliative care beds. Moreover, in communities in which palliative care is offered by non-religiously affiliated healthcare facilities, a strong relationship often exists between the healthcare facility and the local Catholic parish. The parish often provides the neighbouring healthcare facility with pastoral services and volunteer support in the accompaniment of the patients receiving palliative care.

The existence of numerous Catholic healthcare institutions in our country and abroad bears witness to the deep religious commitment of their founders and of those who devote themselves to the mission of these institutions to this day. The investment of the Catholic community in healthcare is inspired by Christ. It is a response by Christians to be healing hands

for the sick; to provide compassionate care for those in need; to accompany the dying with self-sacrifice; and to bear witness to the inviolable dignity of the human person and our common responsibility to love our neighbour and to serve and protect human life at every stage. Despite its legalization in Canada and the support it has received among some segments of the population, the Catholic Church, drawing on the deepest sources of its tradition, remains strongly opposed to euthanasia and assisted suicide. While euthanasia and assisted suicide are also referred to as Medical Assistance in Dying (MAiD), these are not to be admitted within the definition and practice of palliative care. Likewise, the World Health Organization (WHO) and many secular providers of palliative care in Canada exclude euthanasia and assisted suicide from the definition of palliative care. Palliative care is a means of accompanying someone who is extremely vulnerable and significantly (if not entirely) dependent on others for care. It can be seen as an expression of human solidarity, for we all face moments of vulnerability and dependency in varying degrees from birth to natural death. Finally, while palliative care can be (and is) offered by trained practitioners in healthcare facilities, it can be (and often is) delivered by patient-identified caregivers in a number of settings, including the home.

There are many reasons to promote palliative care and many opportunities to improve its quality and delivery in Canada. At the same time, palliative care faces various hurdles and even barriers both in Canada and abroad. Some of the obstacles are concrete, such as a lack of funding, while others are attitudinal. When palliative care is reduced to a science, for example, it loses its potential to treat the human person in a holistic manner: the spiritual, psychological, and material needs of the ailing person, as well as those of the patient-identified caregivers (often close family and friends), go unacknowledged and unmet. Such was one of the many observations echoed in different quarters and diverse parts of the globe during a gathering of experts on palliative care organized in Rome earlier this year by the Pontifical Academy for Life.

The present submission draws on a number of insights and sources, both local and international. Two Catholic sources from Canada bear special mention:

- 1) A resource entitled *Palliative Care Matters: How Canada's Health System Needs To Change* by Covenant Health (a major network of Catholic healthcare providers in Alberta). This resource draws on the results of focus groups and an Ipsos survey of over 1,500 Canadians who shared their vision of a national palliative care strategy online.
- 2) A palliative care environmental scan produced in 2017 by the Covenant Health Palliative Institute at the request of the Catholic Health Alliance of Canada (a forum for sponsors of Catholic health and social services in Canada), which consists of a comprehensive inventory of palliative care facilities, services, and innovative practices within Catholic healthcare facilities.

Allow me to take this opportunity to extend gratitude to you and your team on behalf of the Catholic Bishops of Canada for your work on this important consultation and for accepting the CCCB's submission. Should there be another opportunity to be of service during this multiphase consultation, please do not hesitate to ask. The Canadian Conference of Catholic Bishops as well as its partners in this area – the Catholic Health Alliance of Canada (CHAC), Covenant Health, and Canadian Catholic Bioethics Institute (CCBI) – would be pleased to assist you in this critical matter.

Sincerely,

A handwritten signature in cursive script that reads "+Lionel Gendron, P.S.S." The signature is written in black ink and is positioned below the word "Sincerely,".

+Lionel Gendron, P.S.S.
Bishop of Saint-Jean-Longueuil and
President of the Canadian Conference
of Catholic Bishops



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**Submission by the Canadian Conference of Catholic Bishops
to Health Canada for its Consultation on Palliative Care in Canada**

Below are answers submitted by the Canadian Conference of Catholic Bishops (CCCBC) to questions asked by Health Canada in its consultation on palliative care stemming from the passage of Bill C-277, *An Act providing for the development of a framework on palliative care in Canada*. This submission draws on the list of key works cited above.

1. We appreciate that there are many operational definitions of palliative care in use in Canada. In the environment in which you work, what is the definition of palliative care?

Please find below two definitions of palliative care. One is from a multi-faith perspective, the other is drawn more specifically from the Catholic tradition.

Definition from an Interfaith Statement signed by the CCCBC

“As a comprehensive approach to end-of-life challenges, palliative care combines pain management with efforts to attend to a patient’s psychological, emotional, social, and spiritual needs, as well as caregiver support. We affirm the World Health Organization’s definition of palliative care, as well as the official positions of the Canadian Society of Palliative Care Physicians, the Canadian Hospice Palliative Care Association, and the Canadian Medical Association that the practice of palliative care does not include interventions which intentionally cause the death of the patient. This has been central to the philosophy of palliative care and is a fundamental distinction that must be maintained.”¹

Definition by Covenant Health

“[The Catholic tradition] has consistently upheld the dignity of human life, from conception to natural death. But while bodily existence is a good, it is not, in the Catholic tradition, an *ultimate* good. [...] We must take reasonable care of our lives, as stewards of creation, weighing any burdens associated with treatment with the proportionate benefits such treatments offer. So while life is a penultimate good, requiring us to take reasonable care of our lives, we are not morally obligated to seek or undergo burdensome therapies ‘at all costs’ that provide no benefit. Nor at the same time are clinicians morally obligated to ‘do everything possible’ if life has reached its natural conclusion and it is no longer medically appropriate. Such a stance is known as vitalism and is rejected by the Catholic moral tradition.”²

¹ “An Interfaith Call for a Palliative care Strategy for Canada.” In addition to the Canadian Conference of Catholic Bishops (CCCBC), the statement was also signed by Centre for Israel and Jewish Affairs (CIJA), the Canadian Council of Imams, The Evangelical Fellowship of Canada (EFC), the Armenian Prelacy of Canada, the Greek Orthodox Metropolis of Toronto & All Canada, the Canadian Conference of Orthodox Bishops, the Ottawa Muslim Association, and The Church of Jesus Christ of Latter-day Saints.

² Covenant Health, *Theological Reflection*, 3. Cf. Catholic Health Alliance of Canada, *Health Ethics Guide* (Ottawa, 2000), articles 92-101.



In June 2010, The Honourable Sharon Carstairs, Member of the Senate of Canada, released a report on palliative care entitled: *Raising the Bar: A Roadmap for the Future of Palliative care in Canada*. The Report remarked that an unfortunate blurring of terminology was developing between palliative care and other actions, such as euthanasia and assisted suicide, which mean to cause a patient's death. As the Report concluded: "in palliative care, physicians do not take specific measures to hasten death."³ In agreement with Senator Carstairs, the Catholic Bishops of Canada hold to the same conclusion: Palliative care must be understood clearly to be completely separate from euthanasia and assisted suicide/MAiD.

Elements which are unique to the Catholic understanding of palliative care

Those advocating or offering palliative care from a Catholic perspective will often adopt a person-centred approach which draws deeply from the scriptural understanding of healing, compassion and love. The aim of such an approach is to offer care which takes full account of body, mind, and spirit in an integrated program of care. Likewise, it manifests itself as a personal, communitarian and professional commitment which tries to bring relief to human suffering but also to answer the transcendent needs of the dying person and his/her loved ones, with special solicitude for the poor and the disadvantaged.

2. Has your organization considered or adopted an integrated approach to palliative care? If your organization has adopted an integrated approach to palliative care, how was this accomplished, and how is it working within your practice?

A number of healthcare providers have worked with Covenant Health to devise a Canadian (not exclusively Catholic) vision for an integrated palliative care model (IPCM). Their *Consensus Statement* affirms that an integrated palliative care approach improves the quality of life of all Canadians impacted by life-threatening illness, including family and community. The goal is to embody a model of care which fosters holistic approaches combining clinical, community, and volunteer support. It aims to enhance the quality of life of the dying patient and to create a support network for the patient in collaboration with their family and all caregivers.⁴ The *Consensus Statement* also notes "not everything we need to understand about palliative care will be the result of clinical research. The IPCM model will need to capture non-quantitative data to inform the IPCM experience beyond a bio-medical frame of reference."⁵ Some key examples of non-quantitative data might include feedback from the patient as well as from his/her family and friends regarding the care received. Anecdotal evidence from healthcare workers and patient-identified caregivers in a variety of settings (hospitals, hospices, homecare and nursing homes) could also be a valuable source of critical information about the value of palliative care.

Key to the success of an integrated palliative care model promoted in the *Consensus Statement* would be the Federal Government's involvement in the coordination of a national palliative care strategy. Coordination at the national level, as for example through a national

³ *Raising the Bar: A Roadmap for the Future of Palliative care in Canada*, Pg. 13

⁴ *Palliative care Matters – Consensus Statement*, 10.

⁵ *Ibid.*, 11.



secretariat, has its precedent in programs such as the Mental Health Commission of Canada's national framework for action.⁶ Through its coordinating role, a national secretariat would ensure that the long-term goals of an IPCM are met. Some of the activities of a national secretariat might include offering a national platform for experts to exchange research and experiences, organizing national public awareness campaigns, ensuring the sharing of resources and information between provinces and with the Federal Government, and promoting various kinds and levels of research.

3. What supports do you need to engage in advance care planning with people with life-threatening illnesses and their families?

Effective advance care planning presupposes that Canadians know a) that palliative care is an option, and b) are aware of what it can offer both to the dying person as well as to his/her family, friends and support network.⁷

i) *The need for more and better information*

The results of a 2016 Ipsos survey indicate that while those surveyed are concerned about the cost of information campaigns, 91% want to see more information about palliative care services and standards made available within the healthcare system.⁸

ii) *The need to tailor different awareness campaigns for palliative care*

Public awareness campaigns are effective to the extent that they are tailored to social and cultural needs. Raising awareness within healthcare systems across Canada requires culturally appropriate and piloted programs in each province. Such programs would need to take into account the concerns of marginalized and vulnerable groups; would need to include young people in the target audience; will require and depend on community involvement and engagement; and should foster coalitions and social inclusivity.

iii) *Using different media*

A variety of communication channels should be used to reach a range of Canadians of all ages, cultures and regions. These media should include the arts and humanities, particularly storytelling.

⁶ See, Mental Health Commission of Canada, *Advancing the Mental Health Strategy for Canada (2017-2022)*.

⁷ See *Palliative care Matters – Consensus Statement*, 10.

⁸ See Erin Roulston, *Canadians' Views of Palliative Care*. Ipsos Public Affairs. 1 September 2016.

<https://static1.squarespace.com/static/5755e91b044262d8f43cf6fa/t/57e2b1b3d2b8579de605c555/1474474421962/Palliative+Care+Matters+-+Ipsos+Report.pdf>



4. What could facilitate the integration of palliative care into the care you provide? What are the barriers?

The Federal Government and Facilitating the Integration of Palliative Care

The continuing provision and development of palliative care as a branch of medicine and the assurance that it is of the highest quality and equally accessible to all Canadians requires secure and consistent funding at both the provincial/territorial as well as national levels. It is important, therefore, that provinces and territories work more closely together to ensure consistency in the kinds and quality of palliative care across the country. The Federal Government, in particular, can support the provinces/territories both in terms of ensuring a sufficient and steady flow of cash as well as in the coordination and exchange of information between different stakeholders. The Federal Government can also assist by funding research and training, resulting in the quantitative data and expertise needed to identify and develop best practices essential for the delivery of quality palliative care across the country. As noted by former Senator Sharon Carstairs in her 2005 report *Still Not There*: “Without federal leadership there will continue to be a patchwork of services available to Canadians as no single province is equipped to provide the necessary leadership [for palliative care].”⁹ Former Senator Carstairs’ report identifies the following five elements essential to the future of palliative care in Canada: 1) a national strategy; 2) patient and caregiver support; 3) training and education for formal and informal healthcare providers; 4) government and citizens working together; and 5) planning for the future.¹⁰

Common Barriers Across the Country

The kinds of barriers which are frequently encountered are most frequently related to or have a direct impact upon national coordination and funding. The following observations and recommendations were brought forward by Covenant Health in its report to the Catholic Health Alliance of Canada.¹¹ This section also highlights some unique points raised this past spring at the Pontifical Academy for Life’s International Congress on Palliative care in Rome.

i) *Eliminating inconsistencies in the kinds and standards of palliative care across the country*

With the evolution of palliative care across Canada in recent times, significant gaps and inconsistencies have emerged with regard to its innovation, availability, and quality. One reason for this unevenness has been the absence of a common definition in respect of which the delivery of palliative care can be measured. But the organic and piecemeal manner in which palliative care has developed in Canada has also been a significant contributing factors. Both the absence of a national vision and strategy as well as overreliance on local resources and practices has resulted in unnecessary discrepancies

⁹ Sharon Carstairs, *Still Not There. Quality End-of-Life Care*, 1.

¹⁰ *Ibid.*, 3.

¹¹ See Covenant Health, *Environmental Scan* (27 November 2017), 7.



and varying degrees of effectiveness not only from one province to another, but sometimes between healthcare institutions in the same region.

Evidence from a number of countries similar to Canada suggests that a national strategy would provide better access to high quality palliative care in a fiscally responsible manner across all regions. To cite one example, the Australian National Palliative care Strategy (NPCS) implemented in 2010 has enhanced access, improved care services, and provided the evidence needed to develop and improve palliative care.¹² The Australian model considered all core components and brought together all relevant parties. The program benefitted from substantial, sustained funding along with regular audits to monitor and support the achievement of goals. An evaluation of the Strategy commenced in March 2016 and was finalized in October 2016 with outcomes published in a review of the Strategy in 2017.¹³

ii) *Overcoming prejudices based on misinformation*

As noted at the first PAL-LIFE meeting in Rome, one of the most significant cultural barriers is posed by misinformation surrounding the medical aspects of palliative care:

[Palliative care] also suffers from cultural misunderstanding, albeit for varying reasons. In some cultures there is resistance to the use of opioid analgesics because their use is misunderstood or because of their possible side-effects that are compared to euthanasia. In other cases, it is the misuse of certain Palliative care procedures that leads to opposition. Misinformation and economic reasons are the basis for the lack of governmental enthusiasm for Palliative care that is common everywhere and they are responsible for the scarcity of funding for Palliative care, even when governments are generally willing to fund other types of care. (D. Mosoiou).¹⁴

iii) *Changing perceptions among medical and governmental leadership*

The relatively recent developments in palliative care, both within the medical community and society at large, means practitioners and the general public will need help translating what it means into concrete practices. As noted at the PAL-LIFE meeting in Rome:

In Europe, for example, where palliative care is probably most fully developed, two factors have been crucial: the presence of charismatic figures able to promote the special character and value of palliative care in specific socio-cultural contexts, and the ability of persons in those various contexts to translate the ‘novel’ concept of palliative care into working programs of formation and research (C. Centeno).¹⁵

¹² See *Supporting Australians to Live Well at the End of Life* (2010).

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¹³ URBIS, *Evaluation of the National Palliative care Strategy 2010. Final Report* (September 2016).

[http://www.health.gov.au/internet/main/publishing.nsf/content/EF57056BDB047E2FCA257BF000206168/\\$File/Evaluation%20of%20the%20National%20Palliative%20Care%20Strategy%202010%20Final%20Report.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/EF57056BDB047E2FCA257BF000206168/$File/Evaluation%20of%20the%20National%20Palliative%20Care%20Strategy%202010%20Final%20Report.pdf)

¹⁴ Pontifical Academy for Life, *First PAL-LIFE meeting*.

<http://www.academyforlife.va/content/pav/en/projects/pallife/first-pallife-meeting.html>

¹⁵ Ibid.



Particular Barriers Facing Indigenous Peoples

- i) The absence of a clear mechanism for reporting on palliative, end-of-life and hospice care delivered to Indigenous populations.¹⁶
- ii) The absence of data has resulted in an incomplete picture of the kind and quality of palliative care which is offered to Indigenous Peoples. The 2011 Report of the Parliamentary Committee on Palliative and Compassionate Care, *Not to be Forgotten: Care of Vulnerable Canadians*, appropriately lamented: “Due to lack of services in their local communities [...] most First Nations people end up being transferred to regional and urban hospitals, dying isolated from family, friends and community; in an environment which conflicts with deeply held cultural, familial and spiritual values.”¹⁷
- iii) Slowness to implement Recommendation #5 of the Parliamentary Committee on Palliative Care in its 2011 Report, namely: “We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve.”¹⁸

5. Is person-centred care an appropriate goal? Why or why not? What barriers exist to prevent delivery of person-centred care?

The dignity of the person is at the centre of the approach by Catholic health facilities in providing palliative care and promoting the dignity of the human person. (Healthcare is delivered by people and for people). The person being treated should never be reduced simply to a number, statistic, or “another patient.”

While there are undeniable burdens and losses experienced in the dying process by both patient and caregiver, the person receiving care should be seen as a burden neither to themselves nor to others. Promoting and defending this vision of the human person at all stages of life is central to palliative care, to medicine, and to society.¹⁹ As noted by Covenant Health,

a major component of the person-centred approach is sharing compassion with the dying. The etymological root of “compassion” comes from the Latin *cum* (with or together), and *passiō* (suffering, submission) a derivative of *passus* (to suffer, submit). At its root, compassion means to be “together in suffering.” Compassion calls us to stay with one another, and to be present despite our helplessness in altering the disease trajectory. Palliative and end-of-life care is the epitome of this compassionate presence, in providing

¹⁶ *Ibid.*, 32.

¹⁷ *Not to be Forgotten*, 39.

¹⁸ *Ibid.*, 39.

¹⁹ See *Theological Reflection*, 3.



quality pain and symptom relief, attending to complex psychological and spiritual needs, and ultimately, being truly with a patient, resident and their family even when cure is not possible.²⁰

In terms of barriers to person-centred approaches in medical practice, the absence of adequately trained healthcare personnel and volunteers is critical. Likewise, patient-identified caregivers, who are central to the delivery of palliative care, are prevented from accompanying their dying loved ones because their employers impose stringent limits on the amount of time they can take off work. Could employment legislation not be adjusted to accommodate family members more generously during the process of accompanying a loved one who is dying?

In addition to the above, the following remarks were noted at the PAL-LIFE conference in Rome:

- i) *“The holistic approach to medicine is nice if you have it, but ultimately unessential”*
“Some representatives of contemporary medicine, limited by their ‘scientific’ orientation, consider a holistic approach to the patient, with the special importance that palliative care gives to psychological, social, and spiritual care of the sick and their families, as a kind of ‘do-gooding’ that is of course possible, and even praiseworthy, but not essential to clinical medicine. Palliative care is thus ‘trivialized’” (E. Bruera).²¹
- ii) *The question of the “bottom line”*
“Similar obstacles are set up by hospital administrators who devise structures based on a ‘health as a product’ model with measurable results. Of course, based simply ‘on the numbers,’ any care offered to incurable or terminally ill patients is inherently a ‘bad investment.’ In the view of those administrators, palliative care represents an expense that is hard to justify because it is delivered to patients whose prognosis is death, not healing.”²²
- iii) *Underestimating or dismissing the significance of spiritual accompaniment*
Even within the practice of palliative care there is a “danger of [...] its holistic attention to the person, to concentrate on symptoms and organic conditions, forgetting what in the patient is intangible. (C. Centeno). This danger can be glimpsed when spirituality is treated as only a complementary aspect of research rather than a primary one. (Ch. Puchalski). Spiritual accompaniment is an indispensable element of assistance to the seriously ill or terminal patient: for many of them, the priority at the end of life is to be at peace with God and to pray (E. Bruera), and leaving them in a situation of spiritual suffering easily results in their asking for assisted suicide.”²³

²⁰ Ibid., 4.

²¹ Pontifical Academy for Life, *First PAL-LIFE Meeting*.

<http://www.academyforlife.va/content/pav/en/projects/pallife/first-pallife-meeting.html>

²² Ibid.

²³ Ibid.



6. We are interested in new and original solutions to increase access to palliative care in underserved areas, and for special populations that may be particularly vulnerable. Please share examples of how you have/your organization has bridged gaps for people with life-threatening illnesses and their families.

i) *Meeting people where they are*

Places of worship, such as the Catholic parish, are the spiritual home to a wide spectrum of the population from diverse social, economic, regional, and cultural backgrounds. The demographic of the parish often includes a significant number of marginalized and vulnerable persons. For Catholics, the parish is a primary place where questions about life and suffering – both their meaning and purpose – are explored in silent prayer as well as in dialogue with others. For this reason, the **Canadian Conference of Catholic Bishops**, in partnership with **Pallium Canada**, **Dominican University College**, the **Catholic Health Alliance of Canada**, and the **Catholic Organization for Life and Family (COLF)**, has adopted the parish as a locus for canvassing and raising awareness about palliative care.

The CCCB, with the partners mentioned above, will be developing end-of-life educational resources for Catholic parishes in Canada. To ensure these resources address the real questions of people in our communities, a number of focus groups have been held to discuss end-of-life issues and palliative care with ordinary church-goers. These resources will attempt to close knowledge gaps as well as provide new information. They will promote a holistic approach, which draws from human experience, theology, medicine, and related fields, taking into account the cultural and psychological questions in play for patients and families dealing with an incurable illness which is killing the patient.

The **Canadian Catholic Bioethics Institute (CCBI)** has published several scholarly papers and studies on palliative care and end-of-life issues which are available on its website.²⁴ CCBI has also hosted several lectures and parish-based education sessions on palliative care.

The **Catholic Women's League of Canada (CWL)**,²⁵ a women's faith-based organization with 83,000 members across Canada, has undertaken several education campaigns to promote palliative care, including a major campaign in conjunction with the **National Hospice Palliative Care Week**.²⁶ The latter included "12 Hours of Prayer for Palliative Care," which took place in Catholic parishes across Canada. In addition to this and other important educational initiatives, the CWL has also undertaken advocacy to promote greater access to palliative care in Canada. At its 96th Annual National Convention, the CWL urged the Federal Government (a) to identify palliative care as an

²⁴ <http://www.ccbi-utoronto.ca/>

²⁵ CWL has over 80,000 members in Parish Councils in every province, the Yukon and Northwest Territories as well as military bases across the county, and has been heavily involved in advocating for palliative care

²⁶ The week is organized by the Canadian Hospice Palliative Care Association. <http://www.chpca.net/home.htm>



insured health service covered under the Canada Health Act; (b) to develop a national strategy for uniform standards and delivery of palliative care as defined by the World Health Organization; and (c) to amend the Canada Health Act to include homecare as an insured health service.

ii) *Pioneering innovations*

Catholic healthcare institutions have made a point of pioneering palliative care innovations. The term “innovations” in this context, as defined by Covenant Health, refers to practices aimed at addressing cracks in the system and the unmet needs of patients, administrators, and healthcare professionals. Such innovations can be of a social, scientific, or business nature.²⁷ Among the innovations listed by Covenant Health in its national survey of Catholic healthcare institutions are the following:

- Advanced Care Planning / Goals of Care Designation policy
- Patient Dignity Question
- Bereavement Training For PALLIATIVE CARE Volunteers
- Volunteer-Led Advance Care Planning Initiative
- Tele-Palliation
- Men’s Walking Group Program
- Horticultural Therapy Program
- 24/7 Access To Clinical Support
- Distributed Hospice Model
- Outpatient Clinic
- End of Life Pathway program

In its *Environmental Scan*, Covenant Health reported that there were 9 Canadian Catholic healthcare facilities with palliative care innovations, 6 of which were pioneered within the past 5 years. Since 2012, these 6 facilities generated a total of 21 palliative care innovations with plans for 14 more within the next 2 years. Of these 21 recent innovations, 48% have research-generated evidence. Data regarding 4 of these have already been published. A total of 43% of the recent innovations have replicated their results in at least one other setting or site.

7. As a healthcare provider, what do you consider appropriate training to provide a palliative approach to care? Do you feel you have the support you need to provide a palliative approach to care?

The following conclusions and recommendations were brought forward in the *Palliative care Matters Consensus Statement* with respect to appropriate training:²⁸

²⁷ Covenant Health, *Environmental Scan, Executive Summary*, 15.

²⁸ *Palliative care Matters – Consensus Statement*, 17, question 4b.



i) *Collecting Evidence*

While there are many educational materials dealing with palliative care and different ways of administering it, the collection of further evidence remains a priority in order that the effectiveness of palliative care may be empirically demonstrated to all stakeholders.

ii) *Boosting Training*

Nurses and healthcare assistants (HCAs) who are on the frontline need specialized training. Such training includes both classroom as well as on-the-job training in both initial and ongoing professional development. It is important to note that nurses and HCAs provide the bulk of care paid from public sources for patients receiving palliative care in their homes, hospices, long-term, and acute care facilities. Provincial and national organizations have created learning modules and curricula to advance learning about palliative care among new entrants to nursing/HCA programs. Consensus is needed, however, on the scope or breadth of training within such programs.

iii) *Providing Certification*

A national document outlining “professional competencies” related to palliative care could significantly contribute to the development of a training curriculum for healthcare professionals. A list of professional competencies could serve as a standard by which to evaluate students pursuing advanced degrees or professional certification in palliative care.

iv) *Ensuring evenly-distributed and reliable funding*

A reliable cash flow is needed not only to ensure ongoing research and development, as noted above, but to provide nurses and HCAs with appropriate training. At present, funding for continuing education in palliative care varies from province to province. Financial support from the employer is available in some jurisdictions; in others, the cost of additional training is the sole responsibility of the person pursuing it.

8. Are there barriers preventing you from accessing training to acquire palliative care skills and knowledge? If so, what are they?

With respect to barriers preventing access to acquiring palliative care skills and knowledge, the following conclusions and recommendations were brought forward in the previously cited *Consensus Statement*:

Regrettably, 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 continuing education levels.²⁹

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. Communication skills include, but are not limited to, difficult conversations about life-limiting illnesses, grieving, death, dying and interdisciplinary communication.³⁰

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.³¹

9. What practices are in place in your organization to support caregivers as important members of the healthcare team?

i) *FAMCARE-2*

“In response to Accreditation Canada’s recommendation, the Edmonton zone palliative care program and provincial Covenant Health palliative care has adopted the FAMCARE-2 tool as a measure of family caregiver satisfaction with palliative care services. A process evaluation study of the FAMCARE-2 was conducted in Edmonton hospices and the Grey Nuns Community Hospital Tertiary Palliative care Unit. It was also piloted at the St Michael’s palliative unit in Lethbridge to test the appropriateness of the tool in obtaining family satisfaction feedback. The tool is now utilized by all Edmonton and Covenant Health palliative units in Alberta, with regular reporting and posting of family caregiver comments for the staff.”³²

ii) *Expanding palliative care delivery teams beyond professional networks*

Patient-identified caregivers provide the most direct around-the-clock care to palliative patients at home. Their essential role in the care of the dying patient must be acknowledged. Medical staff are increasingly recognizing the importance of including patient-identified caregivers in the palliative care delivery team. The signatories of the *Consensus Statement* recommend that the Canada Health Act be amended to reflect the importance of patient-identified caregivers or integrated, palliative homecare.³³

iii) *Equipping patient-identified caregivers*

Including patient-identified caregivers in the delivery of palliative care entails equipping such caregivers for the task. The *Consensus Statement* recommends the following:

²⁹ Ibid., 18, question 4c.

³⁰ Ibid., 18, question 4c.

³¹ Ibid., 18, question 4c.

³² *Making a Difference: Highlights of the Covenant Health Palliative Institute 2012-2017*, 4.

³³ *Palliative care Matters – Consensus Statement*, 16, Question 4a.



- that caregivers be given ongoing education about disease progression so as to meet the changing needs of the situation;
- that the caregiver's needs for respite care and personal health assessments be supported by other members of the patient care team. This may include opportunities for the caregiver to discuss the concerns he or she is facing, including isolation, stress, anxiety, exhaustion, anticipatory grief, and confusion.

iv) Several Catholic dioceses/eparchies in Canada train and coordinate lay volunteers who provide pastoral services and spiritual accompaniment to the sick. These volunteers offer palliative care services available through the healthcare system, including the official chaplain. Sometimes, the setting for such care is the home (e.g., pastoral homecare). An extensive network of volunteers exists in both Calgary and Montreal, to cite two prominent examples.

10. How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented/reduced through early bereavement support?

i) *Bereavement teams*

Catholic healthcare facilities have identified the need to step up efforts in terms of bereavement support. Some Catholic parishes in Canada have implemented bereavement teams, which assist parishioners in the grieving process within a context of faith and community. Some of these initiatives are based on the model of compassionate care communities. All of them require training which equips volunteers to respond to differing situations which require personalized approaches, such as the circumstances of suffering and death, the nature of the relationship between the deceased and the caregiver, the particular needs of the family, and the resources available within the community.

ii) *Palliative care anticipates and helps the bereavement process*

The bereaved are often affected by the quality of care which they perceive their deceased loved ones received prior to death. High-quality, holistic, integrated palliative care, which also takes the caregiver's needs into account, often helps to reduce any natural "guilt feelings" that sometimes surround a loved one's death. Those in the palliative care delivery team often extend their contact with the patient's self-identified caregivers beyond the patient's death. In doing so, the members of the palliative care delivery team can offer the bereaved support and serve as a catalyst for the bereaved person's healing and forgiveness. Such final reconciliation can help a person achieve a sense of closure and peace.