EFC

The Evangelical
Fellowship of Canada

Submission to the Health Canada Consultation on Palliative Care

July 13, 2018

Introduction

The Evangelical Fellowship of Canada (EFC) supported the legislation to develop a framework on palliative care when it was moving through the House of Commons and the Senate. The EFC submitted a written brief on Bill C-277 to the House of Commons Standing Committee on Health in March 2017. We also joined with interfaith partners in a letter to all Senators asking them to support Bill C-277.

In June 2016 we participated in the *Interfaith Statement on Palliative Care*[1], calling on all levels of government to address the urgent need for high quality palliative care across Canada, including initiatives to:

- Develop a pan-Canadian palliative and end of life care strategy to address the need for high quality care for all Canadians;
- Increase the availability and accessibility of essential hospice and palliative care services in all settings;
- Improve the quality and consistency of palliative and end of life care;
- Provide more support for family caregivers in the form of flexible financial and tax benefits; and
- Ensure that the health care system respects the psycho-social and spiritual needs of patients and their families in the dying process.

The EFC is the national association of evangelical Christians in Canada. Our affiliates include 45 denominations, more than 65 ministry organizations and 35 post-secondary institutions. Established in 1964, the EFC provides a national forum for Canada's four million Evangelicals and a constructive voice for biblical principles in life and society.

Many of our affiliates provide end-of-life care in seniors residences and long-term care facilities, as well as hospice care. Within congregations, ministers provide pastoral care to those who are in crisis, who are elderly, who are ill or who are at the end of life. They also provide pastoral care to caregivers and those who are grieving. Many of our constituents are volunteers and offer assistance to their neighbours, within their communities, motivated by their faith.

As Christians, we are called to care for those who are vulnerable and to uphold the sanctity of life. We respond to suffering, and particularly to those who are living with illness or nearing the end of life, with care and compassion, journeying with those who are walking in the shadow of death.

Palliative care affirms the inherent dignity and value of each person's life, even in the face of life-limiting or terminal illness, and considers death a natural process that can be approached with thoughtful intentionality. It aims to improve quality of life without either hastening or postponing death. Palliative care also recognizes that we live, and come to life's end, in

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[1] https://www.evangelicalfellowship.ca/Communications/Official-statements/October-2016/Interfaith-Statement-on-Palliative-Care

community with others. At its best, palliative care provides comfort and care both to patients and to their families and loved ones.

Palliative care answers the question, how do you wish to *live*?

We welcome the opportunity to participate in this Health Canada consultation on palliative care. We will address five areas that relate to the development of a palliative care framework.

1. Definition of Palliative Care

Medicine is qualified to diagnose, respond to and treat physical pain and illness. But the experience of suffering is a broader human question, one that involves not just physical, but emotional, psychological, spiritual and social dimensions.

It is this kind of suffering that is commonly experienced by individuals who are living with terminal illness or nearing death, and responding adequately to this suffering is beyond the scope of medical treatment alone. It is best and properly addressed by good quality palliative care that considers not just illness and its symptoms, but the whole person and includes a range of supports for the patient and their loved ones.

Palliative care provides multidisciplinary care for a person who has been diagnosed with a progressive, life-limiting disease or who is near death. It is suitable for people of any age and at any stage of a serious illness. This approach manages pain and symptoms while also addressing the psychological, spiritual and social needs of patients and their families.

The EFC affirms palliative care as an appropriate and compassionate response that supports and cares for people who have a life-limiting disability or illness, or who are at the end of their lives.

We agree with the many voices in the palliative care community who contend that physician-hastened death has no part in palliative care. We urge you to respect those voices and maintain that distinction in the definition of palliative care.

We recommend that Health Canada follow the model of the World Health Organization Definition of Palliative Care.[2]

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;

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[2] www.who.int/cancer/palliative/definition/en

- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."

In the online discussion, Health Canada's consultation asks, "What could be done to reduce the stigma around 'palliative care'?"

As the online discussion demonstrates, there are people with terminal illness who have encountered a negative perception of lesser care for those who 'are dying anyway' as they seek out medical care. This points to the lack of access to good quality palliative care for all Canadians, as well as the need for more palliative care training for health workers. It is estimated that only 15 to 30% of Canadians who need palliative care are able to access it. Lack of availability means that far too few Canadians receive this kind of life-affirming care.

Further, the legalization of euthanasia and assisted suicide has likely heightened this perception, along with the fear that they may be pressured to have a hastened death. If people fear palliative care as a place where they will receive lesser care, how much more would fear of being euthanized prevent them from accessing proper care?

The EFC was one of the many groups who raised the need for quality palliative care with the Special Joint Committee on Physician-Assisted Dying. As our brief stated:

> Underlying arguments for assisted dying is the exercise of autonomy, the exercise of choice. But without access to high quality palliative care there is no real choice at the end of life. Without access to quality palliative care, people will be vulnerable to feelings of isolation, despair, to feeling like a burden to family or caregivers, and to the medical system. Assisted death must not be the only choice…We urge the government to establish a national strategy to address the availability of high quality palliative care.[3]

It is important to maintain palliative care's focus on life-affirming care that improves quality of life, and not include actions to bring about the end of life such as medical assistance in dying.

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[3] http://files.evangelicalfellowship.ca/si/Euthanasia/PhysicianAssistedDying-EFCSubmissionFeb2016.pdf

Inclusion of medical assistance in dying as part of palliative care would increase the fear and reluctance of patients to seek out palliative care.

2. Community Engagement

Palliative care is an area in which volunteers make a critical contribution. Many Evangelicals are volunteers and offer assistance to their neighbours, within their communities, out of the calling and deep convictions of their faith. Churches and pastors provide social, emotional and spiritual support to many.

We believe faith-based communities could play an even greater role in offering or supporting palliative care. It is a natural extension of our belief that God calls us to care for those who are vulnerable.

The EFC has developed a faith-based *Palliative Care Toolkit*[4] with practical tips and information about palliative care. We are making this toolkit widely available, free of charge, as a way to raise awareness of what palliative care is and how individuals and church communities can help offer practical assistance to those in need, at the end of life or who have been bereaved. We would be pleased to offer it as a resource to be made available in any Health Canada clearinghouse of palliative care resources.

3. Health Care Provider Training and Supports

There are health care providers within many fields, such as doctors, nurses, PSWs, pharmacists and administrators, who have deeply-held beliefs that prevent them from participating in ending the lives of others through medical assistance in dying (MAID).

Many health care professionals have entered the field of palliative care out of a desire to help patients live fully to the end of their natural life and are opposed to the practice of MAID. A patient who refuses medical interventions or a doctor who provides pain relief that has the secondary effect of shortening life are not the same as intentionally bringing about the death of a patient through MAID.

The federal and provincial governments must take steps to support health care providers who have conscientious objections to MAID. It is essential to ensure that health care providers are not compelled to participate in the MAID process, including a requirement to provide effective referrals for MAID. It is also important to ensure that health care training programs and medical schools do not screen out applicants who conscientiously object to performing MAID.

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[4] http://www.evangelicalfellowship.ca/palliativetoolkit

4. Person and Family-Centred Care – Meeting Individual Needs

Isolation and stigma often come with incurable illness. People are vulnerable to feelings of despair and to feeling like a burden to family or caregivers, and to the medical system. In Oregon, people who end their lives under the *Death with Dignity Act* consistently identify a concern about being a burden to family, friends or caregivers.[5]

One of the hallmarks of palliative care is its holistic approach that cares for the patient's physical, spiritual and psychological wellbeing, as well as the needs of the caregivers and community. Spiritual care helps to meet the needs of patients who are isolated or afraid and who may be grappling with issues of meaning, purpose and connection.

In a Canadian Medical Association report on palliative care, Dr. Balfour Mount spoke of the challenge of maintaining skills and knowledge, saying, "The challenge is particularly rich in our field since the foundational arenas of concern are broad in scope, including the physical, psychosocial and existential/spiritual components of conscious and unconscious experience that are always operative in 'total pain' and suffering."[6]

In the same report Dr. Konrad Fassbender discussed some of the ways that palliative care differs fundamentally from care in other contexts. He pointed out that the aim of palliative care is to relieve suffering in order to improve quality of life, and went on to say, "Finally, suffering is not confined to physical dimensions. Psychological, social, spiritual and existential sufferings are all prevalent at end-of-life."[7]

One of the unique aspects of palliative care is how it prioritizes the patient's spiritual needs and makes room for those needs to be met.

5. Research and Data Collection

In order to develop better access, support and training with respect to palliative care, it is advisable to collect data on the care that is currently available – what kind of care, who offers it, who receives it, where it is offered and received, how people learn what services are available and how they access them. As well, it is important to collect information on where there are gaps in the availability of care.

The Canadian Institute for Health Information pointed to the need for increased data coordination in its 2013 report *End-of-Life Hospital Care for Cancer Patients:* "A great deal of

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[5] Oregon Public Health Division, *Oregon Death with Dignity Act – 2017 Data Summary*. https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

[6] https://www.cma.ca/Assets/assets-library/document/en/advocacy/palliative-care-report-online-e.pdf

[7] https://www.cma.ca/Assets/assets-library/document/en/advocacy/palliative-care-report-online-e.pdf

this work has focused on delivering safe, accessible, responsive and integrated end-of-life care. Good data is a key aspect of monitoring and measuring progress in these areas. And while some improvements have been made, there continue to be challenges in collecting and reporting data across all care sectors: home, primary and community care; hospital, continuing and residential care; and hospice care."[8]

Conclusion

The need for increased access to and support for high quality palliative care in Canada is urgent for many reasons. Most importantly, it relieves suffering and provides compassionate care for those living with terminal illness or who are at the end of life. This approach makes a significant difference in the experiences of Canadians facing the end of life, and of their families and loved ones. Ensuring that all Canadians have access to this kind of care is critically important.

We concur with the *Final Report of the External Panel on Options for a Legislative Response to* Carter v. Canada (December 2015) that there is an urgent need for improved access to excellent palliative care. As the foreword to the report states:

> With the advent of physician-assisted death, it has become critically, even urgently, apparent that Canadian society must address its deficiencies in providing quality palliative care…. Our country must rise to this challenge, as no Canadian approaching end of life should face the cruel choice between physician-assisted death and living with intolerable, enduring suffering in the absence of compassionate, comprehensive quality care.[9]

We are pleased to see the groundwork being laid for a palliative care framework in Canada. We believe it is essential to provide life-affirming, compassionate and holistic care for patients, caregivers and families that is distinct from the provision of MAID.

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[8] https://secure.cihi.ca/free_products/Cancer_Report_EN_web_April2013.pdf

[9] External Panel on Options for a Legislative Response to *Carter v. Canada*, Final Report, 2. http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf