



## **CSPCP submission to Special Joint Committee on Medical Assistance in Dying April 2022**

Palliative care provides medical assistance in living every day to patients and their families, to help them live as fully as possible until their natural death.

This document was created to help clarify and define the role of palliative care within the Canadian context of legalized euthanasia and assisted suicide (referred to in Canada as “MAiD”), to describe the impact of MAiD on palliative care practice, and to provide recommendations on how palliative care must be improved in Canada.

### **Background:**

The Canadian Society of Palliative Care Physicians (CSPCP) is concerned that continuing to expand MAiD services without investing in the necessary resources to support universal access to palliative care negatively impacts patient outcomes. Tragically, we all know of patients who have opted for MAiD due to lack of adequate palliative homecare resources to remain in their homes or home communities (1).

Many of our concerns and recommendations are not new; we have consistently outlined these in past documents since the Supreme Court of Canada’s Carter ruling (2-5).

Even though palliative care is a vital service with clear economic, health and social benefits (6) and the development of the 2018 National Framework on Palliative care was unanimously supported by parliamentarians in recognition of its importance for Canadians with life-threatening illnesses (7), palliative care continues to receive inadequate attention and patients continue to have limited access to their best support via this essential service.

Health Canada data on MAiD and access to palliative care is limited by reliance on self-reporting by MAiD providers. There is no way to know the quality or quantity of palliative

care or who provided it, including no requirement for clinicians to have specific training or expertise in palliative care. Sadly, we know that many healthcare professionals have little knowledge of current evidenced based standards for palliative care, and the information a patient receives about palliative care as part of informed consent for MAiD may be limited. This is not captured in the Health Canada reporting. Even with these limitations, the Health Canada data shows that approximately one third of Canadians who received MAiD either did not receive any palliative care or received it far too late to potentially make a difference in addressing their suffering. In most other medical disciplines, this would be considered an egregious level of medical error (8, 9).

To complicate matters, in Belgium, where Euthanasia has been legal for longer than in Canada, physician's raising palliative care are seen as obstructing euthanasia (10).

Access to MAiD has been guaranteed a right through the C-14 and subsequent C-7 legislative processes, but access to palliative care and other supports for living, including home and disability services has not.

Canadians need universal access to high quality, comprehensive palliative care to address the suffering experienced by patients with life-threatening illness and their families. No one should feel compelled to choose an early death because of inadequate care at home (11).

### **Safeguards**

When MAiD was legalized, palliative care was listed as a safeguard. In order for palliative care to act as that safeguard, it needs to be entirely separate, should not need to compete for the same resources and funding as MAiD services. We cannot rely on MAiD providers and MAiD data to tell us about the state of palliative care. There is an inherent conflict of interest when MAiD providers are left to assess if the palliative care safeguard has been satisfied.

Many palliative care services have had to integrate MAiD into their programs in order to continue to receive provincial or federal funding. Resources, including palliative care unit and hospice beds, skilled nurses and doctors, and operating budgets have been diverted from already stretched palliative care programs to support MAiD services.

Conflating palliative care with MAiD ensures palliative care remains associated with 'end of life' and this has created unnecessary and unintended barriers to the integrated and timely access to palliative care services that are needed early on in the disease trajectory. Patients not contemplating death but who may significantly benefit from palliative care, may be denied palliative care services by their families or clinicians, due to its association with MAiD. Patients may also refuse palliative care services out of fear of it hastening their death (12, 13). Hospices and palliative care units that choose not to provide MAiD,

should be free to do so, especially as there are many other facilities that can provide MAiD.

Requests for MAiD need to remain patient-driven. Clinician-initiated discussions or recommendations to a patient that they should consider MAiD as an option may put pressure on a patient to choose early death rather than seek alternative services such as palliative care, and for this reason other jurisdictions have required discussions about MAiD to be explicitly patient-initiated (14). Ultimately, when physicians bring up MAiD first, it is likely to be seen as a recommendation by a trusted expert, and coercion becomes a possibility that cannot be ruled out. These safeguards serve to ensure people, particularly those who are vulnerable, have additional protection from the risk of coercion.

### **Informed consent**

It's important that patients are provided with information on palliative care and its benefits for addressing symptoms that may arise in life-threatening illness, for improving quality of life and adjusting to the life changes that accompany illness. Unfortunately, many clinicians do not understand palliative care and its current evidence base with advances in management for complex symptoms and interventions to address suffering. When patients are faced with making decisions about their death, they need to be fully informed about all that palliative care has to offer.

Patients can easily find many publications on the virtues of MAiD in media but little on similar ones featuring palliative care or a natural death. CTV recently aired a series in which MAiD was presented as the only option for a dignified and peaceful death. Palliative care and/or a natural death were not included (15). This is consistent with other articles and videos featured on dying in the Canadian media. A similar publication bias also exists in medical literature. A simple search on the internet brings up many examples of MAiD from major Media platforms that patients are likely to be familiar with, along with clinical scenarios that they can relate to. People fear that they will have a painful death and see MAiD as the only way to ensure they are pain free, perpetuated by the portrayal of MAiD in the media. Put another way, based on information in the media and medical literature, both patients and clinicians perceive that patients have to choose between suffering or death.

Patients don't have access to information on palliative care to the same extent as MAiD. They are not aware that palliative care could help relieve their pain. Not only is there a lack of information on palliative care, what does exist is often incorrect. Patients are often misled by well-meaning public figures and clinicians who have a strong bias towards MAiD. Abby Hoffman, Senior Executive Advisor to the Deputy Minister recently incorrectly suggested that "...MAiD and Palliative care are not distinct" and that patients with

“...advanced cancer approaching end of life will have intense pain”. Sadly, this type of misunderstanding and misrepresentation of palliative care is far too common and is associated with the ongoing stigmatization of palliative care (16).

### **Inadequacy of data on palliative care for those receiving MAiD**

Although Health Canada asserts that over 80% of individuals receiving MAiD in 2019 and 2020 reportedly received palliative care services, the adequacy of the services offered was not determined, nor was it articulated how palliative care services were defined, what criteria were used to determine the involvement of palliative care, and if these involvements were adequate (17, 18). Clear data regarding availability, access, quality and types of palliative care (e.g. specialist palliative care, primary palliative care or palliative approach) are essential, not only for those requesting or receiving MAiD, but in general, in order to better inform areas for improvement. Currently we do not have an adequate or effective system to collect data in Canada about palliative care quality or accessibility to draw any meaningful conclusions about palliative care for those receiving MAiD.

In order to improve palliative care for Canadians in the context of legalized MAiD, the CSPCP recommends the following:

#### **1. Recommendation to prioritize palliative care as a distinct service from MAiD with separate funding and resources**

Without access to high quality palliative care, some patients who are suffering may feel that MAiD is their only option because their needs have been inadequately addressed.

Palliative care should remain distinct from MAiD to ensure clarity and to avoid the risk of confusion and the potential for people to refuse palliative care services (3). **This does not preclude people who contemplate, request, or opt for MAiD from receiving palliative care.**

Asking for permission to refer to specialist palliative care teams after a person has chosen MAiD, risks refusal by the patient due to fears that the palliative care team will try to dissuade the patient from undergoing MAiD or that they will not be eligible if their symptoms are relieved. This is already the case in Belgium, where a referral to palliative care after a patient has chosen euthanasia is seen as obstructing euthanasia (10). Specialist palliative care services should be integrated **early** so that when there are complex medical issues, patients receive timely and appropriate quality care.

#### **2. Recommendation that MAiD must be a patient-initiated discussion**

To safeguard against any possibility of subtle or overt pressure on patients, physicians should not initiate a discussion about MAiD or suggest the option of MAiD unless brought up by a patient.

The expectation that physicians introduce MAiD in the absence of a request from a patient, may be all that is needed to drive that patient to choose MAiD. If a patient raises questions or requests MAiD, health professionals should have the ability to fully explore these issues, including their underlying suffering, and provide information or direct them to someone who can provide information (3).

In other jurisdictions where physician assisted death is legalized, this risk of coercion due to the power imbalance and differential of expertise present in the physician-patient relationship is addressed directly in the law or policy regulating assisted death. For example, in Victoria, Australia, legislation states that a healthcare practitioner must not initiate a discussion or suggest assisted death (MAiD) to a patient, precisely because of the risk of coercion (19).

### **3. Recommendation for funding so that every Canadian has a right to high quality comprehensive palliative care**

CSPCP strongly advocates for the prioritization of, adequate investment in, and enhancement of palliative care services as outlined below.

The Government may mistakenly feel that combining palliative care and MAiD is economical and efficient, yet palliative care and MAiD are distinct services. Ensuring separate funding for palliative care and other high-quality resources that enable Canadians to be cared for in their homes, throughout their disease trajectory would require a capital investment. The Government needs to remember that in the long term, palliative care is overall economical, and is a vital service to improve the quality of life of Canadians while reducing overall healthcare costs (6).

Programs and policies for MAiD implementation and oversight, should ensure that MAiD and palliative care programs are funded and administered separately so that scarce and specialized palliative care resources are not being utilized to deliver MAiD and that palliative care is not being confused with MAiD or promoted as being on a spectrum.

A recent study exploring how the Canadian Medical Assistance in Dying legislation affects end-of-life care discussions between patients and multidisciplinary specialist palliative

care providers determined that “It remains essential to address psychosocial and existential suffering, but also to provide timely palliative care to ensure suffering is addressed before it is deemed irremediable. Palliative care provided late in the disease trajectory, is like a person having pneumonia for days, who is coughing, has fever and has been feeling unwell for some time, before coming to the hospital and unable to breathe. Even though they are put on life support systems, they often die because the infection has spread to so many other key organs. Hence, clarification is required regarding assisted dying as an intervention of last resort. Furthermore, professional and institutional guidelines need to better support palliative care providers in maintaining their holistic standard of care, as they navigate the legislative and cultural shifts.” (20).

Such support for palliative care and palliative care providers has not been afforded in Canada since legalization of MAiD as health authorities and institutional policies have consistently placed MAiD within palliative care programs, palliative care units and hospices.

Decisions about investment in and the provision of palliative care, should not be defined and led by people who lack expertise in the field.

The Government needs to recognise that the philosophy, intention and approach of palliative care, as a safeguard, is in conflict with MAiD. It needs to be funded and administered separately.

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