Provincial Integrated Palliative Care Program position statement on medical assistance in dying (MAID)

The purpose of this document is to clarify the position of the Provincial Integrated Palliative Care Program on medical assistance in dying, and provide information to staff in the program on how to respond to patients on inquiries related to the above.

Palliative care aims at enhancing the quality of life of individuals and families affected by a life threatening illness. It aims at helping people live life as fully as possible until their natural death.

Medical assistance in dying is not part of the services we offer within our Provincial Integrated Palliative Care Program. However, if a patient indicates an interest, we are open to engage in a dialogue around options for care available to them, including medical assistance in dying. It is important that we clearly state that we do not offer this service within our program. We will however, direct the patient to where they can access this service.

Staff within our program recognise that this is an important issue for some Islanders and wish to reassure all that we respect individual perspectives on this matter and will continue to offer quality palliative care services to all regardless of their position.

As a Provincial Program, we support the Canadian Hospice Palliative Care Association’s (CHPCA) key messages:

Access to universal hospice palliative care is a priority for Canadians.
Hospice Palliative care does not include physician-assisted death.
Hospice Palliative care does not hasten nor prolong death.
Hospice Palliative care strives to end suffering not life.
Canadians needs universal access to hospice palliative care including good pain and symptom management.
All patients deserve access to information about end of life options, including physician-assisted death.
Additionally, at the CMA’s annual meeting in Halifax in 2015, two motions brought by the CSPCP (Canadian Society of Palliative Care Physicians) and were passes unanimously.

1. DM 5-63 “The Canadian Medical Association recognizes that the practice of assisted death as defined by the Supreme Court of Canada is distinct from the practice of palliative care.”

This motion is important as it challenges the assumption that providing physician hastened death should be the responsibility of palliative care.

2. DM 5-62 “The Canadian Medical Association will advocate that discussion of and access to a high-quality palliative approach to care be available to all Canadians, including those with life-limiting illnesses who are considering medical assistance in dying.”

Background

The WHO Definition of Palliative Care (1990) states that palliative care “affirms life and regards dying as part of the normal process of living” and it “neither hastens nor prolongs dying.” Current definitions also respect the process of dying naturally. Palliative care aims to help people live as fully as possible until their natural death occurs. Nowhere within palliative care definitions, values, and norms of practice or principles does palliative care claim to provide access to lethal medication so that individuals may control the timing and circumstances of their death.

According to the WHO’s 1990 definition, palliative care can “enhance quality of life and may positively influence the course of illness.” Recent medical evidence confirms that the introduction of palliative care early in the trajectory of metastatic lung cancer can control symptoms, reduce depression, improve quality of life, and help patients to live longer.¹ there is also evidence that patients with heart failure live longer when they are enrolled in the US hospice program of services.²

Studies of health care providers’ attitudes and willingness to be involved in physician-assisted dying show that palliative care providers are least likely to be in favor. This is not surprising, given that support for medical assistance in dying is highest among those with the least experience and the most anxiety around dealing with patients who are nearing death.³

The desire to end life is often driven by the patients’ and/or clinicians’ sense of hopelessness. There is ample evidence that palliative care interventions can mitigate the desire to die: People who at one time would have requested assisted suicide during the course of their terminal illness change their minds along the way.
Palliative care clinicians encounter multiple requests for hastening death and learn to work effectively with patients and families in order to understand and address the issues behind these requests. Recognizing suffering and working with patients and their loved ones to alleviate suffering is the essence of palliative care. Much of this work involves helping people adjust to and cope with their progressive illness. This includes supporting people in healing relationships, reconciling with estranged family, fostering a sense of meaning and, at its most fundamental, keeping people comfortable until they die.

Making a commitment to address suffering until the very end of life, and assuring patients and families that they will never be abandoned is, for most palliative care clinicians, incompatible to the role of eliminating the person or abandoning the sufferer to only one option—medical assistance in dying.


**Direction to staff**

**How do we handle a request for information?**

“Our responsibility as physicians is to understand each unique patient’s and family’s definition of dignity in dying so we can also assure them of a respectful death with or without medical assistance in dying.”

There are 3 ways to respond to request/statement/questions: **We expect staff to respond in an EMPATHETIC, PATIENT CENTRED WAY:**

**Legalistic response**

“I’m sorry, but even though I will support you in this difficult time, I can’t participate in MAID”

This response shuts down deeper conversation

“Just say No” – this response misses all we must say Yes to
Technical response

“So, to obtain the prescription, you must...” followed by detailed explanation of the law – this approach misses deeper issues

Empathic, patient-centered response
“I’m glad you asked me about this, but before I answer may I ask more about what led you to ask this question?”
-OR-
“I am honoured that you felt comfortable enough to talk to me about this, can you tell me what is leading you to ask about this?”
-OR-
“Thank you for trusting me enough to ask that question, It seems very important to you, can you tell me more?”
-OR-
“Thank you for trusting me enough to ask that question, It seems very important to you, can I finish ...... and come back so we have more time to talk about this?”

Exploring Requests for MAID
Accepting this role takes courage

To succeed, you enter into the patient/family story.
(Values/goals)
You become a part of the story.
You become vulnerable as another human sharing the mystery, pain, suffering, joy and wonder of mortality.

To do this, we need to engage into deep personal reflection, and learn to balance personal integrity and non-abandonment. Use your perspective teams as a sounding board to support you.

Caring Conversations: Transitioning from Cure to Care

Communication in palliative care: Ask-Tell-Ask (active listening: talk less than 50% of the time)

Ask
“What do you understand about you situation?”
“What do expect will happen next? How do you think things will go?”
“When you think about the future, what are you hoping for?”
“What is most important to you in the time you have?”
Tell
Provide relevant clinical information

Ask again
“What can we do to help you live the life you want to live?”
-And so on...-

Why do people request assistance to die?

It is important to understand the complexity of feelings behind a request for medical assistance in dying. It is also important to acknowledge that accepting one’s approaching death is a process. Patients often voice their feelings about dying—which can include expressing a desire for an early death or even suicide—as they work through their sense of loss and mounting grief. A qualitative study identified six stages, or “mind frames,” about death and dying:

- Neither ready, nor accepting of death;
- Not ready but accepting of death;
- Ready and accepting of death;
- Ready, accepting, and wish death would happen;
- Ready, accepting, are considering hastened death but have no plan;
- Ready, accepting, have a specific plan to hasten death.

People who are considering medical assistance in dying (mind frames 5 and 6) would likely enquire about the possibility of MAID if it were available. Individuals in mind frame 4 may also speak of death as part of their acceptance of its approach but do not necessarily wish it to be hastened.

As health care providers, it is crucial that we clarify exactly what patients are asking for and the reasons for their requests. It is also important for clinicians to understand that being open to these conversations, while respecting the boundaries of what is legally permissible, and is essential to developing a therapeutic dialogue meant to assuage suffering.

A number of studies about the desire for hastened death have been systematically reviewed and summarized. In general, poorly controlled physical symptoms such as pain or dyspnea are not drivers for the request for hastened death; although fear of these symptoms in the future can be. Depression and hopelessness have been found to positively correlate with a desire for hastened death, and clinical depression should be a consideration in all requests for hastened death. Perhaps the most useful way to summarize the evidence is to consider a 2012 systematic review and meta-ethnography of the underlying issues from the patient’s perspective. The study identified six themes that seemed to lie behind the request for hastened death:

- a response to total pain (physical/psychological and spiritual suffering);
- the loss of self—the loss of bodily function and the ability to manage one’s life leading to perceived loss of dignity and perceived loss of meaning in life;
• the fear of the dying process and imminent death;
• the perception of death as a way to end one’s suffering due to fear and loss of self;
• an expression of wanting to live—but just not in this way; and
• a way of maintaining control over one’s life.

Regardless of our individual viewpoints on these issues, we must become comfortable discussing the feelings behind individuals’ desire to die in order to understand and help those who are encountering end-of-life suffering.

Why do people follow through with medical assistance in dying?

The data gathered from places where physician-assisted dying is legal demonstrates that more people request hastened death or get a prescription for lethal drugs than those who actually complete the act. In Oregon from 1997 to 2012, 64% of the 1,050 individuals who received a prescription actually used it to cause their death. About 1 in 6 people discuss this issue with their families, and 1 in 50 discuss it with their doctors. Physician-assisted suicide accounts for about 1 in 1,000 deaths in Oregon. The main reasons given for the 77 people who chose to take a fatal prescription in 2012 were loss of autonomy (93.5%), decreasing ability to participate in activities that made life enjoyable (92.2%), and loss of dignity (77.9%). These three reasons have been consistent since the start of Oregon’s PAD program. Only two patients who completed suicide were referred for psychiatric or psychological assessment before receiving their lethal prescriptions. Those who oppose physician-assisted dying would view this with concern, citing the higher frequency of depression in those who request hastened death.4,5,6

In conclusion, the position of the Provincial Integrated Palliative Care Program is that medical assistance in dying is not offered within this program, palliative care units or designated palliative care beds. However, staff will provide information on all options available to patients including medical assistance in dying, and direct individuals to where they can receive this service.

Mireille Lecours, MD, CCFP (PC)
Provincial Palliative Care medical Consultant