Medical Assistance in Dying for PSWs

Medical assistance in dying was legalized in Canada in June, 2016. This document is based on the section discussing medical assistance in dying (MAiD) and physician assisted dying (PAD) in the text "Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse" and adapted, to help PSWs prepare for working with people who may request assistance in dying.

Understanding Medical Assistance in Dying

Requesting and receiving medical assistance in dying (MAiD) raises complex issues for the dying person, the family, health care professionals (HCPs), and hospice palliative care communities. This section is not intended to discuss whether MAiD should be legalized. Laws in Canada have clearly established that MAiD is a health care service that is or will be available to certain people at the end of life—people who meet specific criteria and who want to choose their time of death. The goals of this section are to:

- Clarify terminology and identify hospice palliative care principles that pertain to MAiD
- Help you to consider your beliefs and identify challenges that you may face when engaging with the dying person, the family, and your colleagues when MAiD is being contemplated or pursued as an end of life care practice

It is timely and appropriate for personal support workers (PSWs) (this document refers to all individuals that work in similar roles with different titles as PSWs) to address MAiD, because integrating a palliative approach includes relieving suffering and supporting people as they consider their care options. As a community and as individuals, PSWs need to learn to engage in reflection, dialogue, and exploration to support the dying person and their family in their process of considering MAiD.

Terms Relating to MAiD

Laws are evolving in Canada in response to the call for patient-centred care and as part of a global social movement that is "concerned with the ultimate control of one's body at life's end" (McInerney, 2000). This movement seeks to empower people to choose the timing and manner of their own death. Terms relating to MAiD vary by location and legislation, causing confusion for the dying person and the family, as well as for PSWs and other members of the health care team.

Legislation regarding MAiD

In Canada, law was passed in 2016 permitting "Medical Assistance in Dying (MAiD)" that is defined as,

> *The administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or*
> *The prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.*

(Government of Canada, 2016)

This definition of MAiD means that

- The person might receive a lethal dose of medication administered orally or intravenously by a physician/nurse practitioner *or*
- The person might receive a prescription for a lethal dose of medication for later self-administration

Canadian federal law is explicit in conferring on *both* physicians *and* nurse practitioners the authority to prescribe, provide, and administer MAiD. The federal law also explicitly exempts any person from criminal prosecution for aiding a physician/nurse practitioner in providing MAiD.

Before the federal legislation was enacted, a law was passed in Quebec that enabled physicians to legally end the life of a dying person by injecting or providing intravenous medications, but it did not permit them to provide medications that the person would later self-administer orally with the explicit purpose of causing their own death. Thus, although the Canadian federal legislation now also applies in Quebec, existing policies in that province currently define MAiD in a narrower sense than does the federal legislation. This is one example of regional and provincial differences in how the federal legislation is interpreted and applied, according to policies written by the provincial government, medical, nursing, and pharmacy regulatory authorities, and individual health care organizations, to name just a few. (See the "Know and Be Clear about the Terms Used in Your Jurisdiction" section in this document.)

Eligibility Requirements for MAiD in Canada

In Canada, the person requesting MAiD must meet specific eligibility requirements that are set out by law, and then follow the process outlined before receiving the life-ending medication.

The person may receive MAiD only if they meet all these criteria:

- They are eligible to receive health services funded by a government in Canada.
- They are at least 18 years of age and capable of making decisions with respect to their health.
- They have a grievous and irremediable medical condition.
- They have voluntarily requested MAiD and did not do so as a result of pressure from other people.
- They give informed consent to receive MAiD after having been informed of the means available to relieve their suffering, including palliative care.

For further information on MAiD and related safeguards, and for clarification of terms, check the policy in your jurisdiction and facility.

The Process for Requesting MAiD

The Joint Centre for Bioethics at the University of Toronto created a document that provides a detailed process for health care institutions for addressing and responding to requests for MAiD. The process, detailed below, can be adapted to meet the laws and guidelines of your jurisdiction within Canada.

First, the dying person inquires about or clearly requests MAiD. A thoughtful and exploratory discussion will follow between the person and their physician/nurse practitioner or care team that probes the underlying factors motivating the person's interest in MAiD. Questions that should be addressed at this stage include these:

- Have all care options that might be acceptable to the person been considered?
- Are the perspectives of all appropriate people (e.g., family members) known?
- Has there been meaningful involvement of palliative care and other specialist services (e.g., psychosocial services, including spiritual counselling) that might contribute toward alleviation of suffering?

A person who has discussed the issues described above with their HCP or care team, and who decides to choose MAiD, must make a formal written request in front of two independent witnesses. A physician/nurse practitioner assesses the person's eligibility (see the "Eligibility Requirements for MAiD in Canada" section in this document), after which a mandatory 10-day period of reflection ensues. During this period, a second physician/nurse practitioner must confirm the person is eligible to receive MAiD. The 10-day period may be shortened if the dying person's death and/or loss of capacity for consent is imminent. (Mandatory reflection periods vary by jurisdiction. In Oregon for example, two requests must be made, separated by a 15-day waiting period.)

The person pursuing MAiD must understand that they have the right to withdraw their request at any time. At the time, the person receives the prescription for the medication, the HCP or care team will advise the person and any other appropriate people (e.g., family members) about what to expect and will provide specific instructions for self-administration of the medication (if applicable).

Know and Be Clear about the Terms Used in Your Jurisdiction

It is important that, as a PSW, you clearly understand the meaning of the terms used in your jurisdiction. These are some guiding questions for you to consider:

1. Is it legal for a physician/nurse practitioner to directly end a person's life, at the person's explicit request?
2. Is it legal for a physician/nurse practitioner to prescribe life-ending medications to a person, at their explicit request, to be taken later and in a different place?
3. If one or both of the above practices are legal, what criteria determine whether a person qualifies for MAiD?
    a. Does the person need to be at the "end of life" and if so, how is this determined?
    b. Does the person need to be "suffering unbearably" and if so, how is this determined?
4. What does the relevant legislation say, if anything, about involvement of other members of the health care team (e.g., PSWs) in MAiD?
5. What does the local or provincial regulatory authority say about PSWs' involvement in MAiD?

Reasons for Requesting MAiD

The primary value underpinning the MAiD movement is the autonomy of the person. As a guiding value for health policy, respect for autonomy establishes a person's right to decide what happens to their own body in situations of health and illness, including through the dying process and at the time of death. This means that the person's own preferences are what matters when deciding the appropriate course of action in health care decision making. The interests of other parties, including the government, HCPs, or even members of the person's family, are important, but they cannot override what the person has chosen. The following quotations from people who want the option to choose MAiD highlight their desire for autonomy:

> *I want to be in control of my life as long as I can, I don't want doctors and nurses controlling me...when I get to the [point] where I really can't cope anymore, where my quality of life is totally gone, I will tell my husband I want a really good day out with the kids, which is how he'll know that when I go to bed that night I won't wake up the next morning.*

(Chapple et al., 2006)

> *I spent a month in the hospice...So I have seen what happens at the end and, if I could avoid it happening to me, I would, simple as that…if somebody was brave enough to help me, I'd be grateful to them. It's almost nonsense we can't decide what to do with our life at the end, isn't it? Why should a judge be able to say, no, I can't kill myself if I want to?*
>
> (Chapple et al., 2006)

Another value that motivates the MAiD movement is relief of suffering. Proponents of this movement seek to provide people at the end of life with an option to avoid what could be intolerable suffering—to create end of life experiences that are consistent with values that are most important to them. Some people fear that values such as dignity, self-reliance, and bodily integrity will be undermined by the physical and cognitive deteriorations associated with the dying process.

Although the desire for autonomy and relief of suffering do motivate some people's interest in MAiD, it is important to understand what this interest is all about. A desire for *choice* to end one's own life in a situation of terminal illness is not the same thing as having *already decided* to die. Gloria Taylor, a public advocate in Canada for MAiD, was the first Canadian to be allowed to end her life through MAiD, before national laws changed. After her death, which was *not* by means of MAiD, her family said that they were grateful that Gloria was given the solace of knowing that she had a choice about how and when she would die, enabling her "to live her final days free from the fear that she would become trapped in a body that had failed her" (BCCLA, 2012). Data from Oregon, where physician-assisted death (the term used in the United States) has been legal for 20 years, substantiates the idea that while some people are comforted by having the option of physician-assisted death, they do not necessarily choose to die this way, even after being provided with the ability to do so (see "The Oregon Experience" section in this document).

While some people will express interest in receiving information about MAiD and want to have conversations with their family and HCPs about this option, that does not necessarily mean each person has decided that MAiD is right for them.

The Oregon Experience

Data from Oregon collected since physician-assisted death was legalized there in 1997 indicates that of those people who request and receive a prescription for life-ending medication, 60% of them use the medication, while 40% do not.

In Oregon in 2016, 204 new prescriptions for life-ending medication were issued, and 133 deaths occurred due to ingesting life-ending medication (including 19 prescriptions from previous years). This means that the death rate attributed to physician-assisted death in Oregon was 37.2 per 10,000 total deaths, that is, only 0.372% of deaths are attributed to physician-assisted death.

(Oregon Public Health, 2017)

MAiD and the Principles of Hospice Palliative Care

Definitions of hospice palliative care, for example, the World Health Organization's definition, clearly state that hospice palliative care neither hastens nor delays death, and that death is a natural phenomenon. Because MAiD deliberately hastens death, some people in the hospice palliative care community maintain that MAiD contradicts the principles of hospice palliative care.

Currently, there is still a perception that hospice palliative care is only for people who are dying imminently and that involvement with such care will hasten death. Therefore, many people in the hospice palliative care community are concerned that if hospice palliative care programs were to provide MAiD, the mistaken perceptions and beliefs about hospice palliative care services would increase.

The definition of hospice palliative care suggests that the person and the family are the focus of care, that care should be individualized, and that the goal of care is to reduce suffering. If, for any reason, hospice palliative care is not available to the dying person, or if symptom management has not been effective, MAiD may seem the best way to address the person's unique needs and reduce their suffering.

Some hospice palliative care programs have policies that clearly indicate that they do not support or provide MAiD, while other programs have developed specialized teams to respond to requests for it. Other programs have policies that are somewhere in between.

As individuals, PSWs have beliefs, values, and ethical assumptions about MAiD that affect their desire and willingness to participate in discussions about it. One person may believe that life is sacred and that MAiD is terminating a life and therefore is not ethical, while another person may believe that the person requesting MAiD is a competent adult and has the right to decide how and when they want to die.

All these influences contribute to the stress PSWs experience as they determine how to respond to requests for MAiD.

Responding to a Person's Request for MAiD

A dying person interested in MAiD may say to you,

> *I want to know about medical assistance in dying.*
>
> *I want to die.*
>
> *I have had enough! Can someone just give me a pill?*
>
> *I want medical assistance in dying.*

While these statements reflect a range of emotions and can mean many different things, it is most important that you first respond with compassion and empathy, and then clarify what the dying person means. You can offer compassion and empathy by sitting in silence and providing appropriate touch. The essence of compassion, and of hospice palliative care, is to be with a person in their suffering, to walk with them on difficult pathways, and to convey empathy, warmth, and acceptance along the journey. This is a time for nonjudgmental presence, no matter what your personal beliefs are about MAiD.

When it is appropriate to ask questions, you might clarify the person's meaning by asking questions such as these, or adaptations of them:

> *Can you tell me more about what is happening, what you are wanting [thinking] about?*
>
> *Do you want to talk for a bit?*
>
> *Can I clarify what it is that you are asking for?*

Asking open-ended questions will help clarify the person's needs and interest in MAiD. Whether the person is seeking more information about MAiD or wanting to access it, the next steps for the PSW include recording the request and reporting to the nurse and health care team. The policies and guidelines relating to MAiD and legal policies of your professional college/organization or work setting will identify how to proceed

The role of the health care team is to address the needs of the dying person and help the person make decisions based on their own values, goals, and circumstances.

When a person wants to explore the option of MAiD, remember that it is more often the unbearable suffering, which includes both physical factors (e.g., pain) and psychosocial factors (e.g., perceptions of dignity), that lead a person to consider MAiD. The team will want to reflect on some critically important questions such as these:

- What suffering is this person experiencing that they feel is intolerable?
- Are there palliative care options that might help minimize suffering? Specifically,
    - Is this person receiving optimal pain and symptom management?
    - Is this person receiving the necessary psychological, social, and spiritual support from an appropriately trained interprofessional care team?
    - Has the health care team done everything possible to provide dignity-conserving care?

The PSW's Role in MAiD

As a PSW, you work closely with the dying person and their family. You may experience strong emotions when engaging with a person who expresses a desire to die and may find the intensity of the experience difficult. You may be concerned about the well-being of the dying person's family members. You may find that the interprofessional dynamics of your work setting are such that you need to advocate for the dying person's wishes for MAiD so that the rest of the care team understands those wishes and takes them seriously. Conversely, you may have personal moral objections to some or all aspects of caring for people who request MAiD.

One thing is certain: the therapeutic relationship that you develop with the dying person is unique and can be a source of important insights that need to be a part of collaborative interprofessional decision making (Wright and Brajtman, 2011).

The exercise that follows is provided to help you reflect on your beliefs, assumptions, and values. Self-reflection will help you become more comfortable in responding in an ethical way when you care for someone who wants to talk about or who requests a hastened death.

Reflective Exercise Exploring Beliefs about Medical Assistance in Dying

This exercise is designed to help you clarify your beliefs and feelings about participating in MAiD. The care process relating to MAiD is complex. Below is a list of activities that PSWs may participate in as part of the MAiD process. Consider how comfortable you would be doing each activity. Identify where on the continuum you would place yourself for each activity.

1. Responding to a request from a person you are caring for about the possibility of MAiD as a care option

2. Responding to a request from the family of a person you are caring for about the possibility of MAiD as a care option
3. Discussing a person's request for MAiD with interprofessional colleagues, including physicians/nurse practitioner
4. Supporting family members after a person dies by means of MAiD

After completing the exercise, consider the activities that make you feel *uncomfortable*. Explore, through journaling or in dialogue with a friend or colleague, whether your discomfort comes from a *professional* or a *moral* stance. Consider the following:

- **If you are uncomfortable having an open dialogue** with a dying person about the possibility of MAiD, is this because you lack confidence in your knowledge and skills to have these conversations, or because you have an ethical objection to the idea of MAiD as a care option?
- **If you believe MAiD is not ethical**, investigate your organization's policies and find out whether they include a policy for employees who have a moral objection to MAiD. Consider other ways you can contribute to your team.
- **If you are unsure of what you believe** and are not comfortable in supporting MAiD for any reason, consider your needs for education, support, and skill development, and seek continuing education in the areas you identify.
- **If you support MAiD**, you may also want to identify areas in which you want to further your education and skill development. Consider ways you can contribute to the well-being of the health care team, and how you might offer empathy and support to team members who do and those who do not participate in offering MAiD. You may want to volunteer to respond to requests for MAiD, and provide information and counseling supports.

The results of the preceding reflective exercise may help you to clarify your current level of comfort with respect to engaging in the care of people who might request MAiD, and to identify directions for your professional development.

It is important to involve yourself in dialogue with other members of the health care team about what the dying people you care for experience and what you can do to support them. If you practice in a jurisdiction where MAiD is legal, ensure that your organization has a policy that delineates clearly the nurse's role in responding to requests for MAiD, and in participating or not participating in the care of dying people who request MAiD.

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