

Engaging in End of Life Conversations with Patients and Families: A Four Part Series

Part One: General Exploration of End of Life Options

We receive training and build skills throughout our careers that allow us to engage with patients in conversations with the hope of building trusted therapeutic relationships. It is through these trusted relationships that we are able to provide information and important linkages which assist patients with decision making throughout the health care continuum, including at the end of life. Supporting patients, during the serious and emotional conversations which are required, and allowing them to explore their thoughts and feelings and their unique values without fear of judgment is what supports the delivery of high quality care.

Further to our skills and training, we have the ability to empathize with, and to advocate for, the needs and wishes of our patients while holding true to our own values. And, most importantly, we are highly skilled listeners. Listening carefully to the nature of the patient's questions, concerns and wishes help us connect our patients and their families to the services that most appropriately fit their unique needs and wishes, and support their personal values.

Despite all this, we have long known that conversations about end-of-life care can be very difficult for our patients, their families and for ourselves. Now that medical assistance in dying is part of our new health care reality, our skills, training and ability to empathize, advocate and to listen will be a challenge now more than ever.

Preparing Yourself: Enhancing knowledge, exploring emotions

The recent decriminalization of medical assistance in dying has challenged the values of many health care providers and has led to uncertainty about roles. This uncertainty has made some health care providers apprehensive to engage in conversations with patients. Equally challenging is knowledge of, and being able to appropriately discuss, other end of life care options that may be relevant in the context of each individual patient.

Before we can engage in conversations with patients and families about health care choices, we first need to educate ourselves about what options are available. This is no different for end of life care choices. And, of equal importance, is our own need to explore and acknowledge our feelings about those options. To address this struggle, we suggest that the first step to developing the skills you need to have for these important conversations about end of life care with patients and families, which may include medical assistance in dying, is to enhance your knowledge and explore your emotions.

Purpose of this Document

This document is the first in a series of four and is intended to help health care providers foster existing and develop new therapeutic relationships with patients at the end of their life. The document was developed by health care providers for health care providers and provides examples of language and suggested dialogue that are meant to help you to begin to formulate your response to inquiries.

Resources for Self-Exploration

A health care provider's exploration of their personal and professional values is a key component to supporting the therapeutic relationship. Our willingness to listen carefully, empathize with, and support our patients is vitally important to support informed decision making.

The resources listed below are designed to guide health care providers through an exercise to explore how you and others feel about providing information about assisted death and other end of life options. It is important to recognize that AHS has a policy in place to support individual choice, and that protects providers from being pressured to participate against their conscience. Doing this self-exploration work in advance will help to prepare you to support the patient and family in a direction that meets their needs and still honours your values.

1. Medical Assistance in Dying: Values-Based Self-Assessment Tool for Health Care Providers including Physicians and NPs) **Link to tool:** <http://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-self-assessment-tool.pdf>. The purpose of this self-assessment tool is to:
 - Support individuals to clarify or deepen their understanding of their own ethical perspective on medical assistance in dying;
 - Provide individuals with a language with which they can better convey their perspective to others; and
 - Enable individuals to further understand other perspectives.
2. Healing the Divide: A Health Care Provider's Relational Approach to Medical Assistance in Dying Discourse. **Link to the document:** <http://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-healing-the-divide.pdf>. The purpose of the Healing the Divide document is to:
 - Acknowledge how the use of language could impact team relationships—language could promote divisiveness or it could bridge differences; and
 - Foster intentional use of non-divisive language and honoring of diversity in MAID related discussions.

This document is optimally used in conjunction with the Values Self-Assessment tool.

How is this Four Part Series organized?

We acknowledge and trust that many health care providers may already have a tested dialogue and language style. This four part series has been developed to support patients, families and providers to work together to explore end of life options as described below:

- **Part One: General exploration of end of life options.**
- **Part Two: Suitability of requested options.**
- **Part Three: Informed decision making.**
- **Part Four: Moving forward with decisions.**

It is important to recognize that this document is not intended to be a script for health care providers. It simply contains shared experiences and examples of past dialogue and language used successfully by our colleagues when engaging in conversations about sensitive issues.

One of the ways health care providers learn is to share their experiences. We hope that the information provided below will be helpful to you as you construct a dialogue and language style that will work for you and the patients and families for whom you care. The document also includes communication tips and suggestions about supportive language choices.

Part One: General exploration of end of life options

Mr. Brown is a 59 year old married, retired firefighter. He was admitted to your unit two days ago due to increasing shortness of breath. Mr. Brown is in the later stages of his illness and has been diagnosed as palliative but still has good functional status and enjoys time with his family.

He has 2 children (ages 19 and 23) and prior to admission to your medicine unit, he resided with his wife in their own home in a rural community. The patient is described as 'old school' and has a social history of 'yelling' and being 'demanding' of his wife. He has maximum palliative homecare and his wife is demonstrating behaviors consistent with caregiver burnout. They cannot afford to hire private caregivers.

James, a health care professional, has been working on the medicine unit for approximately 6 years in his professional capacity. James has heard some rumblings about medical assistance in dying in the news, but until today had never really thought about it. James is not aware of the processes AHS has in place to manage inquiries from patients regarding end of life care options, which now includes medical assistance in dying.

Today, during James' morning interactions with the patient, Mr. Brown twice made a shooting gesture to his head and stated he 'might as well die'. He denies any suicidal ideation and depression has not been part of his history, however he notes that he contemplated 'going to Montreal where physicians could help me die (laughing) and then you would be out of a job'.

James enters Mr. Brown's room to offer him care. Mr. Brown says to James that he does not want the care James is offering and states, "I wish this was all over with and I want to talk to my doctor about ending it all." **What should James say to Mr. Brown now?**

Considerations

- Take time to explore the nature of the request and clarify the patient's intention.
- Is there urgency around the need to address the symptoms that may be influencing the request?
- Consider what action(s) should be taken and inform the patient's MRHP (most responsible health practitioner) of the patient's comments.

Examples of Dialogue and Language provided by Health Care Professionals

A. Non-participating provider language

- *I want to do everything I can to work with you and provide you with the best care I can offer. If you are in agreement, I will be asking my colleagues to continue this discussion with you on medical assistance in dying with as much continuity as we can provide.*

B. Participating provider language

- *You've mentioned several times that you are wishing it were all over.*

○ <i>We haven't talked about this before....please tell me more</i>
○ <i>Can you tell me why you wish your life to end?</i>
○ <i>Can you tell me about the things that frighten or concern you the most right now?</i>
○ <i>Some people make this statement when they're feeling down; then when circumstances change they feel differently. What do you think things might look like tomorrow? Do you feel depressed or down? Could this be part of the reason for the request? We should explore fully so that we can find ways to support you and treat your symptom.</i>
○ <i>Some people feel they are a burden to others as their condition worsens and they require more help from family or friends. Do you ever feel this way?</i>
○ <i>What do you expect will happen without medical assistance in dying? (Understanding and expectations of the illness; expectation of what dying will be like) Can you share with me what you're thinking in that regard?</i>
○ <i>Who else knows that you have expressed this wish to end your life?</i>
○ <i>If I understand you clearly, you are interested in more information about accessing medical assistance in dying to end your life in the near future. OR</i> ○ <i>if I have this correctly, you are wanting more information about medical assistance in dying unless your situation improves...symptoms or otherwise?</i>
○ <i>Thank you for being honest with me about your desire to helping me to understand your perspective about your wishes to die. It sounds like you have thought about this a lot. As this is the first discussion you and I have had about this topic, I need some time to consult with the team/consider your options/reflect on where we go from here, with your consent. There are many options that would help respect your dignity.</i>

Suggested Next Steps

What should James do after talking to the patient? *Enhance knowledge and explore emotions*

- Go to AHS webpage for information, review regulator advice and any applicable practice standards, seek professional advice: www.AHS.ca/MAID
 - Inform himself about the legislation and the AHS policy
 - Understand his role as a health care provider – seek advice from his professional regulator
- Explore personal and professional values: <http://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-self-assessment-tool.pdf>
- Speak with an ethics staff member, a spiritual care staff member or his manager, trusted colleague
- Build awareness about how the use of language could impact team relationships: <http://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-healing-the-divide.pdf>

Who on the collaborative care team should James speak to?

- James should discuss the patient's comments with the Charge Nurse and/or his manager/supervisor. It is important that the patient's MRHP (most responsible health practitioner) is made aware of the patient's comments
- It is also important that palliative care options are reviewed with patient and appropriate referrals are made and that patients are aware of the complimentary role of these services

What linkages to services could be meaningful to the patient at this time?

- Ensure the most appropriate members of the collaborative care team are involved in the patient's exploration
- Consider creating linkages to spiritual care and ethics services
- Consider creating or renewing linkages to palliative care services. Reviewing these options with patient and facilitating appropriate referrals are crucial
- Consider facilitating linkages to the most appropriate member of the collaborative care team to review the Advance Care Planning/ Goals of Care Designation Policy with the patient and family as appropriate. (Previous Goals of Care should be reviewed and accompanying documentation should be added to the patient's health care record)

What behaviours are required?

- Do not make judgments - judgments made by health care practitioners may affect the therapeutic relationship, limit choices and lead to premature decisions
- Be empathetic - remember that empathizing is not the same thing as agreeing
- Listen carefully - attempt to understand the nature of the request (If the patient is seeking general information about medical assistance in dying offer dialogue and/or direct them to resources. (www.AHS.ca/MAID or Health Link 811))
- If you are a non-participating practitioner (i.e. you do not participate in medical assistance in dying activities due to reasons of conscience or other personal reasons) use verbal and body language that is neutral in tone

Additional Communication Considerations

If providing more focused dialogue consider proceeding with:

- Ask open-ended questions in a calm and non-judgmental manner to elicit:
 - Specific information about the type of request being made
 - The underlying causes for the request
- Use silence appropriately; do not rush to fill gaps in the conversation
- Sit quietly through patient (and family if present) tearful episodes
- End the discussion by letting the patient know this is the first discussion of others to follow; ensure shared understanding of next steps
- Seek agreement to have ongoing discussions to check understanding and whether concerns and expectations have changed
- Document and advise other team members participation
- Encourage the patient to discuss their request with family members and other important people in his/her life Inform patient of the process for alternative providers to continue the process for this discussion for those providers who are non-participating

In Conclusion

The tips in Part One of this series are intended to assist health care professionals to support patients and families in the general exploration of end of life options. If you feel this is not providing you with the skills needed, speak to your manager, ask a colleague for help, seek further readings on the topic, etc. Please watch for the release of the following documents in the coming weeks:

- Part Two: Suitability of requested options;
- Part Three: Informed decision making;
- Part Four: Moving forward with decisions.

Feedback

Your ongoing feedback is important to us so please feel free to offer your suggestions and share your experiences as you engage in end of life discussions. The more we share and learn the better able we are to support those we serve and each other. MAID.CareTeam@ahs.ca