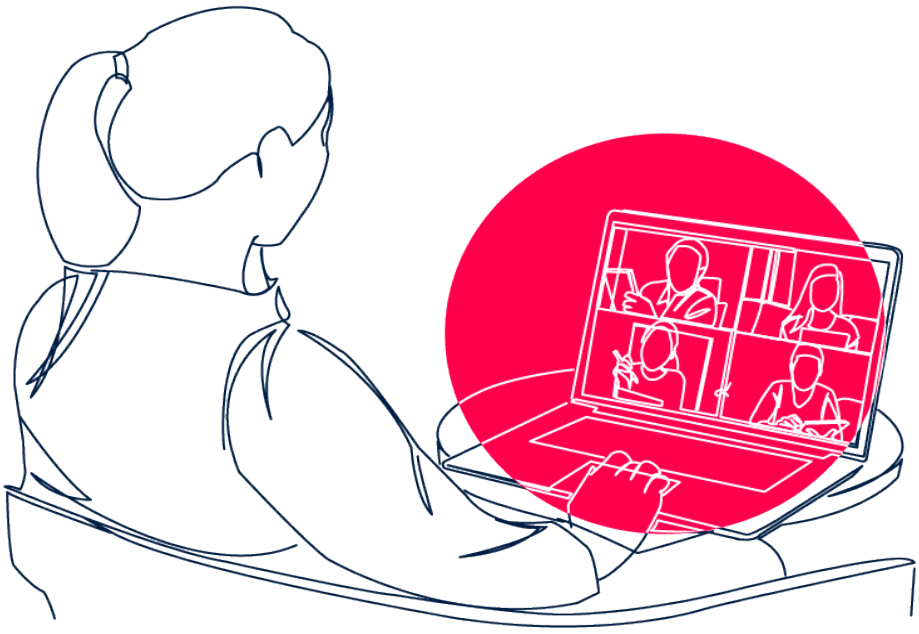

Discussing MAiD: Compassionate Conversations in End-of-Life Care

RESOURCES

1.50 MOC Section 1, Mainpro+ Tuesday, November 1, 2022

THE UNIVERSITY OF BRITISH COLUMBIA
Continuing Professional Development
Faculty of Medicine

IMP PEP
Island Medical Program
Physician Education Program

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Discussing MAiD: Compassionate Conversations in End-of-Life Care

Nov 1, 2022 | 1730–1900 PT

Q&A: Slido.com #maid-nov1

THE UNIVERSITY OF BRITISH COLUMBIA
Continuing Professional Development
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LEARNING OBJECTIVES

After attending this webinar you will:

1. Increase confidence and competence when talking about dying.
2. Introduce community and palliative care options, advance care directives and medical assistance in dying (MAiD) at various points in a patient's journey.
3. Identify barriers and tools to engaging in these discussions.
4. Provide resources about end-of-life and MAiD to patients and families.

QUIZ TIME / Q&A

Go to **Slido.com**

#maid-nov1

Up vote with

DISCLOSURES

Name	Disclosure
Nancy Humber	I have nothing to declare.
Sarah Jesshope	I have nothing to declare.
Janet Kusler	Board of Directors, Canadian Association of MAiD Assessors and Providers.
Christopher Morrow	I have nothing to declare.
Chelsea Peddle	Advisory Committee of Bridge C-14; Speaker for Dying with Dignity conference.
Amanda Proznick	I have nothing to declare.
Tracy Tresoor	I have nothing to declare.
Konia Trouton	Vice President, Canadian Association of MAiD Assessors and Providers.
Tracy McConnell	I have nothing to declare.

TOPICS COVERED

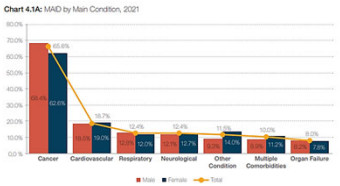
- MAiD statistics
- Patient story
- MAiD options and process, including family involvement
- Tools to introduce and support end-of-life conversations

Please note that handouts and resources will be emailed to you.

WHAT IS MAiD?
MEDICAL ASSISTANCE iN DYING

- Exception to Canada's Criminal Code as of February 2016
- MAiD provides eligible people the option to end their life with the assistance of a physician or nurse practitioner.

REASONS PEOPLE HAVE MAiD IN CANADA AND THE NETHERLANDS



Netherlands 2021 Report:[2]

Table 7: Netherlands Summary Comparison 2020 and 2021

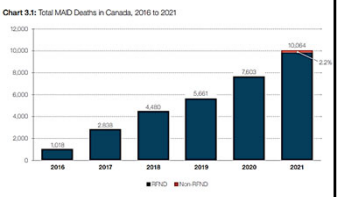
	2021		2020	
Total Deaths, all causes	170839	101%	168566	111%
Euthanasia Deaths	7666	4.5%	6938	4.1%
Euthanasia deaths, underlying disease	n	%	n	%
Cancer	4694	61.1%	4480	64.6%
Neuro system: MS, ALS, Parkinson	501	6.5%	458	6.6%
Cardiovascular	349	4.6%	286	4.1%
Lung disease	237	3.1%	209	3.0%
Combination of disorders	307	4.0%	235	3.4%
Dementia Total	215	2.8%	170	2.5%
Dementia-Early stage	209	2.7%	168	2.4%
Dementia-Advanced stage	6	0.1%	2	0.0%
Mental Illness (Psychiatric disorders)	115	1.5%	88	1.3%
Accumulation of age disorders	1053	13.7%	896	12.3%
Other conditions	205	2.7%	156	2.2%

Assistance to die is legal in other countries, not only in Canada. There are some differences in who qualifies. Countries are: Netherlands, Luxembourg, Belgium, Switzerland, Spain, Chile, New Zealand and some US states.

TYPES OF MAiD, AND FREQUENCY OF USE

Clinician-administered medical assistance in dying
- Clinician who approved request prescribes medication
- Clinician brings, administers IV medication and certifies death
- MOST COMMON OPTION

Self-administered medical assistance in dying
- Clinician who approved request prescribes medication
- Clinician brings, observes drinking, and certifies death
- CLINICIAN MUST BE PRESENT UNTIL DEATH



MAiD UPTAKE IN CANADA AND BC

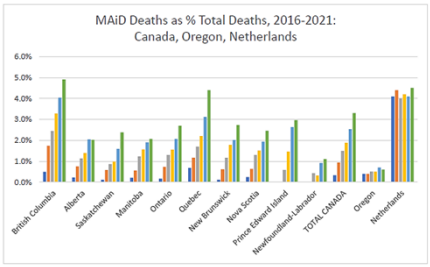


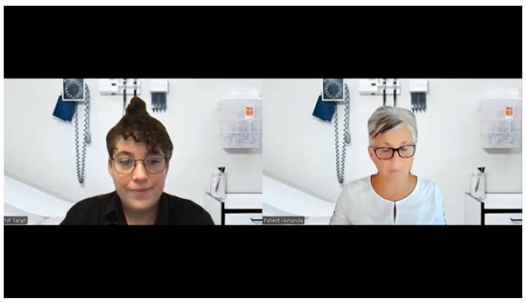
Figure 1: Adapted from Health Canada Data in Table 3.1 of 3rd Annual Report. Oregon and Netherlands are added for comparison.

ELIGIBILITY CRITERIA

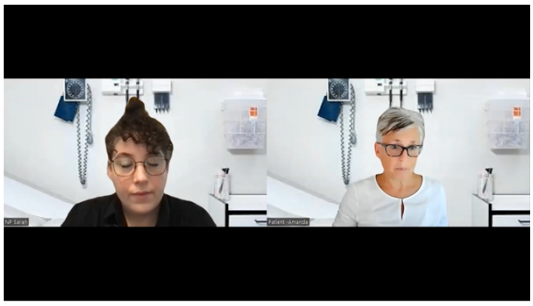
1. Adult (18 years)
2. Eligible Canadian government funded health services (no tourists)
3. Voluntary request, not result external pressure
4. **Grievous & irremediable medical condition** (later in presentation)
5. Capable of making medical decisions (informed consent after review all options including palliative care)

Only a physician or nurse practitioner can determine if the person is eligible.

MEET AMANDA



AMANDA AND HER NP



GOALS OF CARE AND SERIOUS ILLNESS

We're going to apply the approach but here is the full course:

For further information and resources on SERIOUS ILLNESS CONVERSATIONS, visit

- https://www.ariadnelabs.org/serious-illness-care/
- https://bc-cpc.ca/wp-content/uploads/2020/03/SICG-Tri-fold-for-HCP-3.0-hour-CME.pdf

What could the NP have done to begin the serious illness and end of life goals of care conversation in this visit?

Go to **Slido.com**

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ROLE OF HEALTH CARE PROFESSIONAL

- Explore all suffering (physical, psychological, existential) and losses.
- Explore current care plan & goals of care.
- Ensure person is aware of all care options, including MAiD.
- Consider the psychosocial needs of the person and their family or support persons.
- Provide information including Request for MAiD form, instructions and brochure. If uncomfortable doing so, please refer to a colleague who will.
- Consider notifying MAiD Care Coordination Services in your area.
- Notify the Primary Care Provider (GP/NP) or Most Responsible Provider (MRP) with person's consent.

WHY HAVE GOALS OF CARE DISCUSSIONS OFTEN?

- People may prioritize *quality* of life more than *length* of life
- Goals might change throughout their life
- Clinicians may not routinely inquire, yet need to align treatment options
- Learning *how* to ask will make it easier to align your care

WHAT ARE PEOPLE SEEKING FROM THEIR HCP?

- Diagnosis
- Trajectory of their illness
- Prognosis
- Options for care and treatment at each stage
- Concurrence of information (ensuring nothing is missed)

Discussions like this early and often will provide foundation for decision-making and improve therapeutic alliance.

WHY DOES DISCUSSING GOALS HELP?

- Aligns clinician and patient/caregiver efforts
- Empowering patient to be in charge of decision-making
- Better coping by patient and family/caregiver
- Eased burden of decision-making
- Fewer hospitalizations/reduced health care costs
- Earlier use of hospice/palliative services
- Improved bereavement outcomes

IS THERE EVIDENCE THAT DISCUSSING GOALS IS HARMFUL?

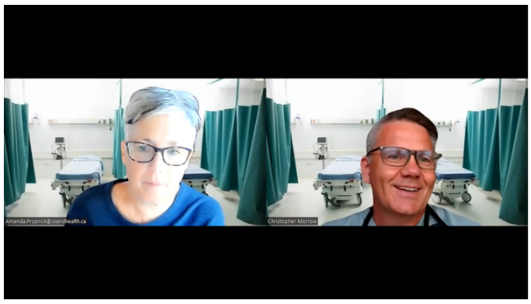
- If we aggressively treat illness against patient wishes, it harms patient and their caregivers.
- Average time from discussion of end-of-life preferences to death is short (33 days), and often in hospital (55%), when insufficient time to incorporate to other planning.

Reference: Heyland DK, Barwich D, Pichora D, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. JAMA Internal Medicine. 2013;173(9):778-787. doi:10.1001/jamainternmed.2013.180

WAYS TO ASK…

- What is your understanding of your disability, illness or injury?
- What do you think is likely to be ahead for you? (in time, or in function)
- I want to share with you my understanding of where we're at

AMANDA IN THE ER



WHEN DO PEOPLE REVISE AND REVIEW CARE?

- Diagnosed with a grievous illness that has no cure
- Need increased level of care or a move to assisted care
- Exhausted/failed in ways to reverse or manage suffering
- Suffering because they believe the burden on their family is too high
- Recurrent hospitalizations and/or ER visits

AMANDA IN THE ER

What else could Tracy have said to make this a more comprehensive conversation about end-of-life care?

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ARE DNR ORDERS THE SAME AS GOALS OF CARE?

- "Do Not Resuscitate" (DNR) is a subset of the goals.
- Like goals of care, they need to be reviewed and revised.
- DNR is more about REACTIVE crisis management, planning "in case" something happens.
- Goals of care are PROACTIVE, planning best options for the future, when it may seem bleak.
- Goals of care may help patients feel more in control of the future, and their options so they can live with a better quality of life.

AREN'T THESE DISCUSSIONS HAPPENING ANYWAY?

- I talk about CODE status, isn't this enough?
- Don't patients talk to their GP/primary care provider about that?
- I review even more detail - the MOST status - isn't this about goals?
- If my patient has a clear DNR, why should I reopen that talk?

All clinicians have the responsibility to support people with end-of-life options, including palliative care and MAiD.

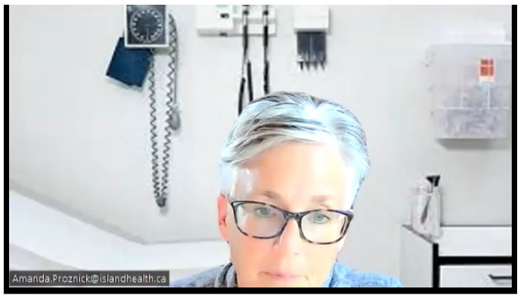
AMANDA AS AN IN-PATIENT

A GOOD DEATH

1. Relief from physical pain and other physical symptoms
2. Effective communication and relationship with health-care providers
3. Performance of cultural, religious, or other spiritual rituals
4. Relief from emotional distress or other forms of psychological suffering
5. Autonomy with regards to treatment-related decision-making
6. Dying in the preferred place
7. Life not being prolonged unnecessarily
8. Awareness of the deep significance of what is happening
9. Emotional support from family and friends
10. Not being a burden on anyone
11. The right to terminate one's life

Zaman M, Mohapatra A, Espinal-Arango S, Jadad A. What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. *Lancet Healthy Longevity*. 2021; 2: e593-e600

AMANDA WITH HER NP



EXPLORATION OF MAiD

- We do not need to be afraid of this.
- We are mainly exploring expressed **expectations and understanding of dying:**
  - There are differences between ***ready* to die** vs ***wanting* to die** vs **wanting *help* to die.**
  - It is appropriate and expected to let patients know MAiD is legal and available even if they don't bring it up.

Providing information is not the same as recommending.

POSSIBLE OPENING COMMENTS ABOUT MAiD

"I can see this topic is uncomfortable. It's normal that these conversations can make people feel sad or angry. These conversations are to ensure our loved one's care team can learn how to best support them in their end of life wishes."

"You sound like you are pondering big questions about your future and the care you would like. There are many options to consider including palliative care, hospice, and MAiD. Would you like information about any/all of these?"

"Knowing you are nearing the end of life, tell me what is important to you and how you would like to spend the time you have left?"

See handout for more suggestions.

GRIEVOUS + IRREMEDIABLE CONDITION

MUST HAVE ***ALL*** OF THE FOLLOWING:

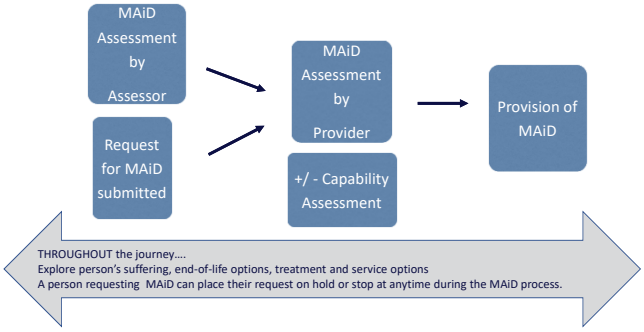
1. A serious and incurable illness, disease or disability*
2. An advanced state of irreversible decline in capability/function
3. An enduring suffering (physical and/or psychological) that is intolerable and which cannot be relieved *by any means acceptable to the patient*

*Note: In Quebec, person must have a serious **disease***

- *Those with illness or serious condition are NOT eligible in Quebec.*

The person does not need to have a fatal or terminal condition to be eligible for MAiD.

COMPONENTS OF MAiD



TWO MAiD TRACKS

Death is reasonably foreseeable → **Track 1 safeguards**

Death is NOT reasonably foreseeable → **Track 2 safeguards**

Safeguards are implemented to ensure vulnerable people are protected.

DON'T CLINICIANS HAVE TO BE TRAINED FOR MAiD?

- Nurses and nurse practitioners require additional education and training for aiding, assessing and providing MAiD.
- Physicians must have appropriate qualifications to establish that a patient meets the criteria for MAID.
  - All physicians, if they assess patients, should be able to assess for eligibility for MAiD.
- For physicians who administer MAiD, additional technical knowledge and competency is required
- If a MD or NP is assessing and/or providing MAiD within a health care facility, they may need special privileges.

BEST PRACTICES IN DISCUSSING MAiD

For more information, education and support, visit or join CAMAP, the Canadian Association for MAiD Assessors and Providers:
https://camapcanada.ca/join-camap

Watch for the national curriculum on Best Practices for Assessing and Providing MAiD, to be available in Spring 2023.

KINDNESS AND AUTHENTICITY – HELPFUL PHRASES

- I hope the next year will go well, but I worry about…
- I wish we didn't need to review this, but I worry that if we don't…
- I hope that we don't come to this, but I worry that…
- I wish things were different, but I worry that this is not likely
- I wonder if there are things you can do
- I know you may not want to discuss where this might lead, but if you have that information, it might help you be more informed

USE A "**REFLECTIVE PAUSE**" IN PATIENT ENCOUNTERS

- Idea of deep listening, not rushing the conversation.
- Reflect on each request, but don't delay an assessment, if requested.
- Introduce the concept of MAiD followed by some basic written information allowing the patient time to reflect till next visit.
- Each patient's needs are so different, so allow for clarification.
- Can provide the information without any need for confirmation.
- Meet with people who are asking for MAiD on two (or more) occasions to clarify and ensure that is the intent.

ALLOW A TRANSITION FROM FEARS TO STRENGTHS

- What is most important to you if your health gets worse?
- What are the biggest fears and worries?
- What are you willing to live with/without as things change?
- What gives you strength as you think about your health?
- How much does your family know about your priorities?

SUMMARIZING AND EXPRESS SUPPORT

- Summarize their goals and priorities
- Recommend next steps/referral or obtaining more information
- Ensure steps align with goals (check in with patient)
- Affirm ongoing commitment to review and revise
- Document conversation
- Obtain consent to share with other HCP if appropriate

FAMILY INVOLVEMENT

- Encourage the patient to think about the role they would like their family members to play
- It is not mandatory to involve the family, it's the patient's decision
  - *While we encourage family and close friends to be involved in MAiD conversations, you may choose to include them as much or as little as you like.*
- Being involved may help family members cope with the patient's decision and say goodbye

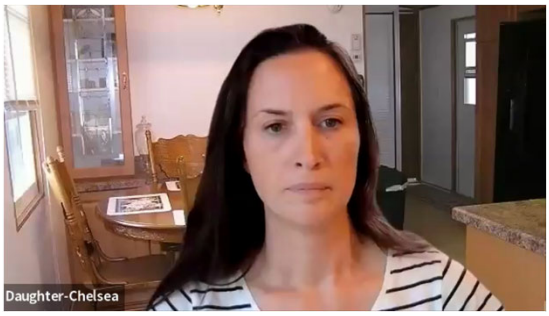
FAMILY INVOLVEMENT - WHEN THERE IS DISAGREEMENT

- Family members may not support patient's decision, see it as giving up, or conversely, family caregiver wants info about MAiD while patient does not.
- Cultural considerations: individualistic medical system, collectivist culture considerations etc.

FAMILY INVOLVEMENT - WHEN THERE IS DISAGREEMENT

- Acknowledge cultural/systems context that is not well-skilled in grief and loss
- View family as "the patient," validate all feelings
- Encourage members to articulate the perspective of the person choosing MAiD as well as their own feelings
- Talk to dissenting members separately
- Offer information and links to other resources, esp. (anticipatory) grief support. Engage supportive religious advisor if religious objections involved.
- Prepare for/hold space for a lack of resolution

AMANDA WITH HER DAUGHTER



THE COMPLETE PATH

Patients and their families may want information about other important milestones on the MAiD path and ways to prepare beyond the MAiD application and approval process:

- How will I know when I'm ready to set the date? What do I need to consider when picking a date (e.g., provider's schedule)?
- Where can I have MAiD (location options)?
- How can I prepare my death so it's easier for my family?
- How do I prepare emotionally?
- How do I talk with children about MAiD/what role can they play?
- What happens on the day of?
- What happens after?

WHAT WORDS DO YOU USE TO INDICATE YOUR **DESIRE TO UNDERSTAND**

- **If** you would like more information, I can provide you with it.
- Continually asking "what other questions can I answer for you?"
- **Why** do you want assistance to die?
- What are your **values and hopes** for this stage of your life?
- Do you **worry** you will be a burden on your family?
- Has **anyone else** suggested MAiD to you and if so, why?
- Our (doctor/NP/hospitalist) can provide further information, **would you like** to speak with them?
- If you or your family have any questions you would like answered, write them down before our next meeting

WHAT WORDS DO YOU USE TO INDICATE **NON-COERCION**?

- **Some people** who have medical conditions like yours choose to explore the option of medical assistance in dying. *Is this the type of thing that you would want to learn more about?*
- In Canada, there are **options** available for end of life care...
- Assisted death is **legal** in Canada for people who meet the eligibility requirements
- It is my **duty** to present all the available options of care to you so you can make the most informed decision possible. I am here to provide information and support your decision making, but it is important that you know that it would be **your decision** to make.
- This is would be YOUR choice, it is not a choice that can be made by anyone else.
  - We encourage your family to be involved in these conversations if you're comfortable with this.
- You could **change your mind** at any time, even right before the medication is administered

WHAT NON-VERBAL TECHNIQUES DO YOU USE TO INDICATE NON-COERCION?

- Communicating non-coercion **isn't just about the words**, it's about their **presence** with the patient, their accessibility, thoughtfully responding to every question, using trauma-informed practice.
- When patients feel **heard and seen**, **valued and engaged** in the process, will feel like they are in control and can make the decision that is best for themselves.
- Not **rushed**, meeting in a **home** where patient is comfortable/on their turf.
- **Energy** is calm and grounded, speaking **clearly** and at a **pace** to absorb info
- Asking if there were any **other** family or friends to be there, and to think about questions **beforehand** that we'd like answered.

What are some of the emotions you feel when having these end-of-life conversations?

Go to **Slido.com**

#maid-nov1

RESPONDING TO EMOTIONS

Allow silence to allow time for patient/family to process.
Don't feel like you have to fix it.

Name it, acknowledge it, and explore it.

- You seem surprised. Tell me about what you were expecting.
- You seem really upset. Tell me more about what you're feeling.
- It's hard to hear that. Can you tell me what you're thinking?

THINGS TO AVOID

GETTING SIDETRACKED WITH EMOTION

- Stopping conversation
- Deferring conversation
- Leaving the room
- Becoming defensive
- Becoming angry in response
- Responding dismissively or disingenuously
- Falsely reassuring

DELAYING THE DISCUSSION ABOUT PROGNOSIS CAN BE HARMFUL

- People will seek information elsewhere
- Increase in anger or hostility to you, if not raised
- increase in patient and loved one's anxiety and suffering
- Reduced ability to plan and alter expectations
- Reduced quality of life
- Loss of therapeutic alliance
- Increased risk of patient seeking alternative care or dangerous methods
- Death is not necessarily a failure of treatment

COMMON MISTAKES AND PITFALLS

- Providing artificial reassurance, when there are few or no options, and when things truly are going to get worse, not better
- Talking more than your patient
- Not allowing for silence
- Addressing the emotions/responding to the anger/fear/hostility
  - Getting side-tracked with emotion
- Trying to solve problems.

The focus is to clarify GOALS – the patient's goals.

RESOURCES

"TALKING ABOUT DEATH" RESOURCES

- Canadian Virtual Hospice: https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- Dying with Dignity Bereavement Counselling: https://www.dyingwithdignity.ca/bereavement_counselling
- Bridge C-14 (peer-to-peer support): https://www.bridgec-14.org/
- Refer to your local Health Authority and Hospice Society

MAID RESOURCES

Federal & Provincial Guidelines:
Government of Canada
BC Ministry of Health

Professional Colleges & Associations:
College of Nurses and Midwives
College of Social Workers
College of Pharmacists
College of Physicians & Surgeons
College of Speech & Hearing Health Professionals
Canadian Association of Spiritual Care
Canadian Association of MAiD Assessors and Providers

RESOURCES

Provincial or regional health website
- https://www.islandhealth.ca/learn-about-health/medical-assistance-dying/medical-assistance-dying
- https://www.cpsbc.ca/

Canadian Association of MAiD Assessors and Providers (CAMAP)
- https://www.camapcanada.ca

Dying with Dignity Canada
- https://www.dyingwithdignity.ca

MAiD INTRODUCTORY PHRASES & CONVERSATION STARTERS

- "You sound like you are pondering big questions about your future and the care you would like. There are many options to consider including palliative care, hospice, and MAiD. Would you like information about any/all of these?"
- "I'm hoping to understand how your health is affecting how you see the future. Is this something you want to discuss more? What you can hope and expect realistically. "
- "We've talked a lot about some of your chronic health issues and explored ways to manage them. What we haven't explored is what you have as goals – can you tell me more about that?"
- "Knowing you are nearing the end of life, tell me what is important to you and how you would like to spend the time you have left?"
- "I can see this topic is uncomfortable. It's normal that these conversations can make people feel sad or angry. These conversations are to ensure our loved one's care team can learn how to best support them in their end-of-life wishes."
- "It sounds like these repeated trips to the hospital are really affecting your quality of life. Sometimes people wish to shift from life-prolonging treatment to focus on comfort and quality of life. Would you want to talk more about this today?"
- "Some people who are frail and suffering from medical conditions similar to yours want to learn more about medically assisted death. Is this an option you would like to learn more about?"
- "Overall, patients very rarely are angry about having these conversations. Conversely, they are relieved and often want to talk more about treatments that support quality of life and end-of-life options."
- "I have talked with your specialist and understand that there are no further treatments planned. What is important to you now and how can I and your care team help with your end-of-life goals and wishes?"
- "You seem frustrated with your care team, not wanting to participate in physio or take your medications. Would you like to talk more about your quality of life now and how we can best support the things that are really important to you?"

RESOURCES

Talking about Death

- Canadian Virtual Hospice: https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- Dying with Dignity Bereavement Counselling: https://www.dyingwithdignity.ca/bereavement_counselling
- Bridge C-14 (peer-to-peer support): https://www.bridgec-14.org/
- Ariadne Labs: https://www.ariadnelabs.org/serious-illness-care/
- BC CPC: https://bc-cpc.ca/wp-content/uploads/2020/03/SICG-Tri-fold-for-HCP-3.0-hour-CME.pdf
- Refer to your local Health Authority and Hospice Society

MAiD Resources

Federal & Provincial Guidelines:

- Government of Canada
- BC Ministry of Health

Professional Colleges & Associations:

- College of Nurses and Midwives
- College of Social Workers
- College of Pharmacists
- College of Physicians & Surgeons
- College of Speech & Hearing Health Professionals
- Canadian Association of Spiritual Care

Provincial/regional health website:

- https://www.islandhealth.ca/learn-about-health/medical-assistance-dying/medical-assistance-dying
- https://www.cpsbc.ca/

Canadian Association of MAiD Assessors and Providers (CAMAP):

- https://www.camapcanada.ca

Dying with Dignity Canada

- https://www.dyingwithdignity.ca

Cultural Humility

- Living My Culture: http://livingmyculture.ca/culture/
- Cancer Care Ontario: https://www.cancercareontario.ca/en/guidelines-advice/treatment-modality/palliative-care/toolkit-aboriginal-communities
- Caring for the Terminally Ill: Honouring the Choices of the People: https://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/Honouring-the-Choices.pdf