

Medical Assistance in Dying (MAiD): A Shared Journey

A Resource for Individuals and Families



Interior Health
MAiD Coordination Centre

c/o Community Health Services Centre 505 Doyle Avenue

Kelowna, BC VIY 0C5

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At Interior Health (IH) we recognize that the decision to request medical assistance in dying is very personal and will be experienced differently by individuals, families, and loved ones. The intent of this resource is to share information and ideas you may wish to consider as you proceed along your journey.

When thinking about the end of your life and about saying goodbye to those you love, you may feel a deep sense of grief and sadness. You have put a great deal of thought into your decision to explore a medically assisted death.

You may wish to discuss a medically assisted death with your family doctor or nurse practitioner. You may find that your family doctor or nurse practitioner does not wish to be involved in MAiD. If this is the case, they have a duty to refer you to another medical professional to support you. They may also direct you to contact the IH MAiD Coordination Centre to receive further information about how to start the process.

You are also welcome to call the IH MAiD Coordination Centre directly without previous discussion with your family doctor or nurse practitioner.

How You can Request MAiD

If you would like to start a formal request for MAiD you must complete the BC Ministry of Health's **Patient Request Record** (form 1632). You can submit the form to your family doctor, nurse practitioner, a member of your health care team or fax it directly to the IH MAiD Coordination Centre at 250-469-7066. You can go to any IH health care facility and request assistance to fax the form. You can also mail your completed form to:

IH MAiD Coordination Centre c/o Community Health Services Centre 505 Doyle Avenue Kelowna, BC VIY 0C5

The Patient Request Record is available to the general public and can be found at:

- BC Ministry of Health Website https://www2.gov.bc.ca/assets/gov/health/forms/1632fil.pdf
- Interior Health Website <u>https://www.interiorhealth.ca/YourCare/MAiD/Pages/default.aspx</u>
- IH MAiD Coordination Centre by calling 250.469.7073 or 1.844.469.7073 directly or by emailing MAiD@interiorhealth.ca.

How to Complete a Patient Request Record

To meet the legal requirements to complete the Patient Request Record, you and your two independent witnesses must sign and date this form. If you are physically unable to sign the Patient Request Record, a proxy may sign on your behalf and under your expressed direction.

You/Proxy and your two independent witnesses must be together to sign the form on the same day and at the same time.

Your independent witnesses and/or proxy can be any person who is at least 18 years of age and who understands the nature of the request, unless they:

- know or believe that they are a beneficiary of your Will (this includes family members and in-laws);
- know or believe that they would receive a financial or other material benefit resulting from your death;
- are an owner or operator of any health care facility where you live or are being treated; or
- are directly involved in providing health care services or personal care to you (for example, a staff member in a facility or another individual providing care to you).

If you are having difficulty finding an independent witness or proxy to sign the Patient Request Record you can contact Dying with Dignity Canada (DWDC) at 1-800-495-6156 or witnessing@dyingwithdignity.ca for support.

For assistance on how to complete the Patient Request Record please refer to the *Instructions* for Completion found on the BC Ministry of Health website: https://www2.gov.bc.ca/assets/gov/health/forms/1632 instructions.pdf.

You can also contact the IH MAiD Coordination Centre for any questions related to your Patient Request Record.

Please be aware that you can withdraw your request at any time.

What happens once my formal Patient Request Record is received by the Interior Health MAiD Coordination Centre?

- We (the IH MAiD Coordination Centre) will call you or your preferred contact and/or care facility to let them know we have received your Patient Request Record. If you do not want us to contact your family doctor/nurse practitioner or your preferred contact and/or care facility please write this on your form or advise us directly by telephone or email.
- We will notify you if there are any errors or missing information on your submitted Patient Request Record.
- You will require two independent assessments to determine your eligibility for MAiD. If
 one of the assessments has not already been completed by your family doctor or nurse
 practitioner, we will find two MAiD Assessors to complete this step. One of the MAiD
 Assessors will also serve as the MAiD Prescriber who will support you in planning and
 completing the medically assisted death.
- We will ask your family doctor or nurse practitioner if they are willing to be one of your assessors, unless you ask us not to contact them.
- The two MAiD Assessors will contact you directly to set up separate appointments to
 meet with you to determine if you are eligible for a medically assisted death. One of these
 assessments could be completed by video/Skype/FaceTime (telehealth) if desired or
 required. A registered nurse must be present during a telehealth assessment. The IH MAiD
 Coordination Centre will assist with these arrangements.
- Home visits to complete the assessments may be an option, if needed.
- If you are eligible for MAiD, you and your MAiD Prescriber will discuss if and when you would like to proceed with a medically assisted death.
- During your discussion with your MAiD Prescriber, you may request support from a health care professional to be present during the medically assisted death, e.g. nurse, social worker, spiritual support, etc.
- If a MAiD Prescriber requests a MAiD Nurse to support the medically assisted death, the IH MAiD Coordination Centre will make the necessary arrangements. The nurse will contact you for any needed assessments and preparations for the MAiD procedure.
- Note that MAiD Assessors and Prescribers are also referred to as MAiD Providers.

- An approved MAiD request can be put on hold for as long as you wish. A Patient Request
 Record and assessments do not expire. However, you must be able to provide informed
 consent immediately before the medically assisted death. There may be circumstances
 where the MAiD Prescriber requires a reassessment of your eligibility.
- If one of the MAiD Assessors advises you that you are not legally eligible for MAiD, you may ask for another opinion (another assessment).
- If you are assessed as not being eligible for MAiD, the MAiD Providers (assessor and prescriber) will discuss this assessment independently with you, including:
 - the reason for this decision
 - other available health care options
 - options for re-assessment if there is a likelihood that you will become eligible in the future
 - the option to seek another opinion (another assessment)
 - the option to submit a new Patient Request Record in the future if you develop a grievous and irremediable medical condition.

Of note, 98% of all individuals pursuing MAiD will utilize supports from the IH MAiD Coordination Centre. However, a doctor or nurse practitioner can legally complete assessments and make arrangements without the involvement of the IH MAiD Coordination Centre.

'Period of Reflection'

There is a legal requirement for a 10 clear day waiting period between the date you sign your Patient Request Record (Day zero) and the first day you may be eligible to receive MAiD (Day 11 or later). This time is formally referred to as the 'Period of Reflection' and is meant to ensure you have time to carefully consider your decision. There may be medical circumstances where you could be eligible for the 10 clear day period to be shortened, i.e. eligible for an 'expedited provision'. This will be decided by the two MAiD Assessors in discussion with you.

A medically assisted death is not required to take place at the end of the 10 clear day waiting period. You decide when you are ready.



Planning for a medically assisted death

When thinking about the day of your medically assisted death, many thoughts, feelings and ideas may come to mind about how you would like the day to proceed. There are a number of possibilities that can be included on the day of your medically assisted death, and there isn't a particular way that the day must proceed. Each medically assisted death is unique to the individual and their family and focuses on what is most meaningful for you. You may wish to consider:

- Focusing on the people and activities you enjoy most.
- Thinking about who you would like to see and any special places you might want to visit, or special things you might want to do if you are able.
- Tackling difficult decisions or talking about difficult subjects may resolve anxiety and can contribute to your peace of mind.

- Taking care of any legal concerns such as your Will, estate planning, life insurance or any other advance care planning activities.
- Contacting a funeral home to make arrangements that are meaningful for you. Be sure to notify a trusted loved one of your arrangements to ensure your wishes are followed after your medically assisted death.
- Speaking with your loved ones about your wishes regarding any social media accounts you
 may have.
- Thinking about what memories or stories you want to share (highlights, achievements, regrets, etc.).
- Arranging mementos, letters, or gifts you may wish to leave for family, friends and loved ones.
- Seeking spiritual, religious, social work or counselling support for you or your loved ones.
 Those close to you may experience anticipatory grief; talk with each other and/or a professional if needed.
- Planning some private time with those who mean the most to you so that the preparations do not overwhelm you.
- Talking to your loved ones and friends about where and when you would like your medically
 assisted death to take place and any individuals and/or pets you would like to have present.
- Thinking about what you need or would like on the day before your medically assisted death; perhaps quiet time with your closest loved ones, or a big celebration with friends and family.
- Thinking about whether you would like specific music, cultural, and religious rituals, and/or have special belongings, or wear something important to you during your medically assisted death.

You may choose complete privacy throughout the planning and procedure of MAiD and only discuss your medically assisted death with your MAiD Providers.

Many people have questions about the MAiD procedure itself and what they can expect to experience. For example, medications and their effects, pain management, will I become incontinent, how long will the procedure take, etc. You are welcome to discuss any and all questions with your MAiD Providers and/or the IH MAiD Coordination Centre.

If you wish to consider making an organ donation

Organ donation may be possible following a medically assisted death. If you are interested in further information regarding possible organ donation, please discuss this with your family doctor/nurse practitioner or MAiD Provider and/or <u>BCTransplant</u> services.

If you are under 75 and wish to consider making an eye donation, please discuss this with your family doctor/nurse practitioner or MAiD Provider and contact the Eye Bank of British Columbia.

If Your Loved One has Requested MAiD

When a family member or close friend has requested MAiD, it is common to experience a wide range of feelings and reactions. Even if you are supporting their choice, it is normal to have conflicting thoughts and emotions. You may not always know what to say or do, and that's okay. This is a natural part of anticipatory grief and adjusting to loss.

Remember that your views are based on your personal beliefs and life experiences which may not be the same as those of your loved one. If you are strongly against this decision, it may be helpful to find other people or professionals who can listen and provide support to you. In the time leading up to your loved one's medically assisted death it may help to consider the following:

- Acknowledging the decision for medically assisted death and inviting a conversation with your loved one.
- Listening with compassion and an open mind.
- Avoiding repeated questions about their decision.
- Thinking about how you would like to spend time with your loved one.
- Reflecting on important things to do or see together (intimacy, socializing, sharing stories, travel).
- Thinking about what is important to say to each other (words of love, forgiveness, thanks, encouragement and understanding).
- Sharing things you would like each other to know that you may not have already talked about.
- Offering practical support to your loved one (meals and housekeeping, pet care, errands, paperwork, organizing caregivers, funeral arrangements, insurance and legal matters).
- As a family member or friend, thinking about what **you** need and who can provide emotional or practical support to you during this time.
- Planning what you can do for your own self-care (e.g. exercising; mindfulness; spending time with family, friends, pets; eating and sleeping regularly; writing in a journal, etc.).

On the Day of MAiD

Times of great love and togetherness may be mixed with times of deep sadness and despair. Plan to take time and space as you need. Be patient and generous with yourself and your loved ones. If your original plans no longer feel 'right', allow yourself to revise the plan as needed and able.

- Please have government issued identification available for the MAiD Providers to confirm your identity when they arrive.
- You may eat or drink anything you wish. If you have any restrictions due to risks of choking, please consider this carefully in your decisions.
- You do not need to withhold any of your medications, including pain medications.
- You may wish to see or speak with certain people or pets if they are not going to be with you.
- Prepare any significant or special items you want to wear or have with you.
- Have someone prepare the space ahead of time with enough seats, and any other special arrangements you want such as music, candles, any meaningful meals etc.
- If MAiD is to take place at home, if possible, find a separate space with a table or counter where the MAiD Provider can prepare the medications.
- If a MAiD Nurse is supporting your medically assisted death, they will typically arrive 30-60 minutes before the MAiD Provider arrives to start an IV(s) for the medications (you need an IV even if you have chosen to take the medications by mouth). If the nurse is coming to your home they will call you to make arrangements in advance.
- Inform the MAiD Provider and MAiD Nurse when they arrive of any special rituals or events that you would like honoured either before, during or after your medically assisted death.

Most of the time people who receive a medically assisted death fall asleep and lose consciousness quickly after receiving or taking the medication, and the timing of death can vary from minutes (if given into a vein) to hours (if taken by mouth). There may be breathing changes such as deep breaths and snoring. Loss of bowel or bladder control is rare. Once the person appears to be sleeping they are comfortable until death.

You have the right to change your mind right up until the moment before the medications are given or taken. You can either withdraw your request completely or change it to a later date.

Preparing for when the medication is administered (given or taken)

When the MAiD Provider arrives, typically 30 minutes ahead of time, they will confirm that you wish to proceed. You will be given medication through the IV or orally (as prearranged) to cause sedation, loss of consciousness, coma, and death.

If you are a loved one who will be present for a medically assisted death

Each person will have their own individual experience upon witnessing a medically assisted death. Some who have chosen to be present may leave the room afterwards, while others will want to stay for some period of time.

There is no 'correct' response. You may have a variety of emotions including feeling anxious, angry, relieved, sad, calm or restless. These responses are natural; consider sitting comfortably, focus on your breathing and/or be aware of whatever it is that you're feeling.

Immediately after the medically assisted death

- The MAiD Provider will confirm death and complete a Medical Certification of Death using the government issued identification provided. The Medical Certification of Death will be provided for the family or designated person to provide to the funeral home. The funeral home typically handles the registration of the death with vital statistics which results in the issuing of the **death certificate** required to settle legal affairs and apply for benefits. For more information on obtaining a death certificate please speak with your funeral director or refer to "A Death in Your Family" handbook found in the Resource section at the end of this booklet.
- The Medical Certificate of Death will identify medical assistance in dying (MAiD) as the primary cause of death, followed by the underlying illness or disease that the individual was diagnosed with.
- The MAiD Provider and/or the MAiD Nurse usually leave within 30 minutes.
- The MAiD Prescriber or MAiD Nurse will remove any medical devices.
- If a MAiD Nurse is involved they may stay longer to support your loved ones as needed.
- When everyone is ready, the funeral home can be contacted to collect the body according to any pre-arrangements. Timelines vary according to different situations or care settings.
- Please refer to the end of this booklet for grief and bereavement resources. The MAiD Nurse may be able to provide you with additional resources in your area.

Grief and Bereavement

Grief and bereavement following a medically assisted death can be very similar to grief and bereavement following a natural death due to typical illness progression or age. How you feel will depend a lot on how you arrived at this moment, and will be unique to you.

Your grief will depend on your relationship to the person who died; the death of a close family member or friend may feel differently than that of a more distant relation. The nature of your connection may shape the way you feel as well. You may continue to carry conflicted feelings about your loved one and their planned death.

How long was your loved one ill? How much of your time went into caregiving? How well supported did you feel during the illness and MAiD journey, and how well supported do you feel now? These are all questions that can shape how you grieve no matter how your loved one died.

It's important to know there is no "right" way to feel after the death of someone you care about. Grief can be a rollercoaster of feelings affecting not just your emotions, but affecting how you feel in your body too, from how you sleep, to how you respond to stress, to your energy level in general. Many people say grieving takes up more energy than they ever expected. Be patient and gentle, and give yourself time...

Research shows that, on average, grief experiences are similar between medically assisted and non-medically assisted deaths. However, your experience may vary greatly depending on the kind of support you received before, during and after the medically assisted death. There are a few considerations for how your grief may unfold that are specific to MAiD. For example, your grief may be made easier if you and the people and professionals around you, felt similarly about the choice of your loved one to use medical assistance in dying. But, if you or the people around you were ambivalent or conflicted about MAiD, you may experience some feelings that surprise you, such as anger and disappointment with your loved one. This is normal. You may find it helpful to express these feelings through writing, art, and conversation.

Talking with others when you are mourning may be helpful. There is always the chance you will hear negative comments about MAiD. Use your discretion to determine how you speak and what you share with people about your loved one and their death.

You may consider joining a general bereavement or grief support group, or choose to seek individual bereavement or grief counseling.

People say one of the positive aspects of a MAiD death...

... is that they had time to talk through important issues with the loved one's circle of family and friends, to tell stories, resolve conflicts, celebrate and appreciate the person prior to their death. These activities are part of what is called "anticipatory grief" and they may help prepare you for your grief following your loved one's death.

People also say that knowing their loved one is free from suffering can make the death feel like a relief. A sense of relief can be a very natural reaction after a medically assisted death.

If you or your loved one would like to provide feedback....

At Interior Health we know that the decision to request a medically assisted death is a deeply personal choice. We are committed to improving the quality of care for individuals receiving a medically assisted death, and their loved ones. If you or your loved ones would like to provide feedback during any part of your journey you are welcome to contact the IH MAiD Coordination Centre at I-844-469-7073 or the IH Patient Care Quality Office at I-877-IHA-2001 (I-877-442-2001).



Grief and Bereavement Resources

BC Bereavement Helpline is a resource for people to find bereavement support within their own community.

http://bcbh.ca/

Phone: I-877-779-2223

Bridge C-14, the Ottawa-based organization that supports families experiencing a MAiD death; offers online support forums that provide you with connections to others with potentially similar concerns.

https://www.bridgec-14.org/

Canadian Virtual Hospice "Ask a Professional" is a resource that offers a way to submit questions to health care providers, including grief counsellors. http://www.virtualhospice.ca

Compassionate Friends is a peer support group for parents who have experienced the death of a child (of any age).

www.tcfcanada.net

Coping with Grief - HealthLink BC

https://www.healthlinkbc.ca/health-topics/aa122213#tp16402

Dying with Dignity Canada offers phone-based counselling support. <u>www.dyingwithdignity.ca</u>

Grief and Grieving - HealthLink BC Overview

https://www.healthlinkbc.ca/health-topics/hw164282#aa128831

Grief in Times of Celebration - The Empty Spot

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/ Emotional+Health/Grief+in+Times+of+Celebration_+The+Empty+Spot.aspx

Grief Work – Virtual Hospice

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Emotional+Health/Grief+Work.aspx

Grieving and Treatment - HealthLink BC

https://www.healthlinkbc.ca/health-topics/hw164282#aa128899

KidsGrief.ca is an interactive network of information and support for parents and caregivers supporting bereaved children and youth. www.kidsgrief.ca

Learning Through Loss offers grief and loss education and supportive programs for youth. www.learningthroughloss.org

Victoria Hospice provides booklets and pamphlets about many aspects of grief and bereavement. You can access them online at: https://victoriahospice.org/how-we-can-help/bereavement-services/

Youthspace.ca is a community of volunteers available to support youth via text, chat, forum and email counselling.

www.youthspace.ca

Video Resources

CAMAP Canada: Medical Assistance in Dying

https://youtu.be/8VDPANp4-k0

WebMD: Dying on Your Own Terms

https://www.webmd.com/cancer/video/medically-assisted-death

Additional Resources

"A Death in Your Family" is an online handbook designed to support people who want to know what to do when a loved one dies. This resource includes, but is not limited to: information on funeral arrangements, registering a death and where to find support. https://www.peopleslawschool.ca/publications/death-your-family

BC Transplant

http://www.transplant.bc.ca/

Eye Bank of British Columbia

http://eyebankofbc.ca/eye-donation/

Gibson Smith, Carolyn & Leake, J. (Handout). (April, 2019):

So Now What? Grief and bereavement following MAiD.

https://www.carolyngibsonsmith.com/writing-and-resources/2019/3/27/so-now-what-grief-and-bereavement-following-maid

Interior Health MAiD Web Page

https://www.interiorhealth.ca/YourCare/MAiD/Pages/default.aspx

MAiD: A Guide to Support Patients and Families. (Handout). (2019-04-23). (Available from VIHA or Victoria Hospice, Victoria, BC, Canada) https://www.islandhealth.ca/sites/default/files/2019-05/maid-bereavement-guide-patients-families.pdf

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