



Dying With Dignity

It's your life. It's your choice.

END-OF-LIFE CHOICES

YOUR LIFE

YOUR DECISIONS

www.dyingwithdignity.ca

Dying With Dignity Canada

Who We Are

Mission: Improve quality of dying and expand end-of-life options in Canada

Advocating for:

- expanded end-of-life choices to help Canadians avoid unwanted suffering
- patient-centered Medical Aid in Dying (MAID) reflecting the spirit of Carter v. Canada
- patient rights, including protection for vulnerable Canadians, and access to MAID

Supporting health care providers and patients

Educating about Advance Care Planning and MAID

"Every story has a beginning, a middle, and an end.

The more we participate in writing the ending of our own story, the more satisfied we are with the arc of our life."

C. Conger "Through the Dark Forest" 2014

CHOICES NEAR END-OF-LIFE

- Allowing dying to take its natural course
- Suicide
- Ceasing or not starting life-maintaining treatments eg. dialysis, chemotherapy
- VSED – voluntary stopping eating and drinking
- Palliative care
- Palliative Sedation
- Medical Assistance in Dying



“Talking about dying won’t kill you”





DEFINITION OF PALLIATIVE CARE

- Health Canada has adopted the World Health Organization's (WHO) definition of palliative care
- Palliative care is an approach that improves the quality of life of persons and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

<http://www.who.int/cancer/palliative/definition/en>

PALLIATIVE CARE

- Affirms life and regards dying as a normal process
- Provides relief from pain and other distressing symptoms
- Is best started early in the course of illness: along with other therapies intended to manage symptoms, such as chemotherapy or radiation and includes other investigations to better understand/manage distressing complications
- Intends to neither hasten nor postpone death
- Integrates the psychological and spiritual aspects of care, allowing patients to live as well as possible until death
- Utilizes a team approach to address the needs of the patient and family to cope during the illness with counselling and bereavement
- May enhance quality of life and have a positive influence on the experience of the illness

COMPLEMENTARY THERAPIES

- Aromatherapy
- Massage therapy
- Meditation
- Acupuncture
- Guided imagery
- Music therapy
- Naturopathic medicine
- Yoga
- Pet therapy



CRITERIA FOR HOME PALLIATIVE CARE

- Must have a life-limiting illness which is actively progressing and requires symptom management and /or end of life care Prognosis has been discussed with patient/POA
- PPS (Palliative Performance Scale) $\leq 50\%$
- Must have a LHIN Palliative Care Coordinator and a chart in the home
- Must have adequate support to be maintained at home, at least initially
- Must have a signed MD or NP referral

PALLIATIVE CARE AND MAID CO-EXIST

- Facilities that are MAID providers offer palliative care and MAiD which co-exist in respectful harmony
- At the community level(LHIN), the community care coordinator is responsible for both in-home palliative care and MAiD
- Objecting facilities do not allow MAiD on site but do allow formal written requests. However, they eventually require a patient transfer
- There are ongoing discussions with the palliative care community that indicate perspectives are changing as patients may now receive MAiD in some hospices.

Christina Sinding

- *“I hope the CHPCA and CSPCP will be able to lower the walls and build bridges with MAiD organizations that are possible to build; bridges support knowledge and skills development among practioners and foster conversations in families and communities, in vital spaces shared between palliative care and MAiD, where so many of us want to live and die.”*



COMMUNITY RESOURCES

- Community Deathcare Ottawa – a collective of practitioners who support dying and death care in the National Capital Region.
<http://communitydeathcareottawa.com>
- Death Doula Ottawa – integrated end of life care.
www.deathdoulaottawa.ca
- The Ottawa Hospital/Champlain Hospice Palliative Care Program – Journey Through End of Life (guide for family and friends)
https://champlainpalliative.ca/wp-content/uploads/2019/05/Journey-Through-End-of-Life-Booklet_rev-2019-04-03_EN.pdf
- Anne E. DeButte, Grief's Abyss Finding Your Pathway To Peace –
www.understandinggrief.com
- Private nursing services such as Nurse On Board and At Home Hospice – experienced RN's ensuring a proactive approach to healthcare www.NurseOnBoard.ca and www.athomehospice.com

MEDICAL ASSISTANCE IN DYING (MAID)



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They paved the
way



Challenging Canada's Criminal Code – Section 241

Criminal Code - Section 241:

Everyone who counsels, aids, or abets a person to commit suicide is guilty of an indictable offense & liable to imprisonment for a term not exceeding 14 years.

February 2015: Supreme Court of Canada unanimous ruling in **Carter** decision “decriminalized physician assisted death for **competent** Canadians with a **grievous and irremediable** medical condition (including an illness, disease or disability) that causes **enduring suffering that is intolerable to the individual.**”

June 2016 - Bill C-14 (amending criminal code to allow MAID) received Royal Assent. Protects conscientious objectors as well as physicians & nurse practitioners from prosecution if providing MAID, healthcare team assisting, or individuals helping person self-administering MAID

MAiD in Canada - by the numbers

Since MAiD legislation came into effect,
13,000+ assisted deaths

(=1.89% of all deaths recorded across the country, feb2020)

As of September 2020:

- 6059 in Ontario
- 493 in Ottawa
- 43% in hospital
- 47% in private home
- 63% with cancer diagnosis

Medical Assistance in Dying (MAID)

In Canada, two types of MAID are allowed:

1. A physician or nurse practitioner can directly administer a substance that causes the death of the person who has requested it, and
2. A physician or nurse practitioner can give or prescribe to a patient a substance that they can self-administer to cause their own death.

Medical Assistance in Dying (MAID)

Criteria:

Under MAID legislation, 2 **independent health care professionals** need to evaluate an individual in order to determine whether he/she qualifies for MAID. To qualify, an individual must be competent, 18 years or older and meet all the following four **eligibility criteria**:

1. Have a serious and incurable illness, disease, or disability
2. Be in an advanced state of irreversible decline in capability
3. Endure physical or psychological suffering that is intolerable to them
4. Their natural death has become reasonably foreseeable *

Patients must also be capable of providing **informed consent** at the time that MAID is provided.*

The Process for MAiD

- Patient makes initial inquiry for MAiD to physician or NP
(must have grievous & irremediable condition)
- Patient makes written request before 2 independent witnesses
(Clinician Form A)
- Physician orNP #1: - assesses individual against criteria for MAiD
 - reminds patient they can rescind request any time
- Physician orNP #2: - confirms that patient meets eligibility criteria
- 10-day reflection period (can be reduced if patient may die or lose capacity)
- Physician/NP informs pharmacist that prescribed substance is for MAiD
- Confirmation of wishes
(@MAiD, physician/NP must give patient opportunity to rescind/document consent)
- Certification of death - physician must notify coroner
 - nurse investigator follows up with provider, family member

Planning for MAiD

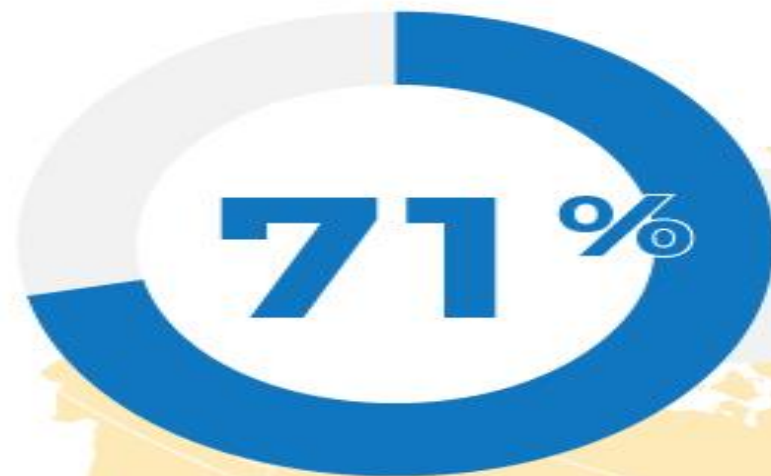
- Schedule day/time with provider
- Make arrangements with funeral home
- Who will be present on the day? (close family, pet)
- Plans for the day (music, time alone with family)
- Pre-plans (family visit, living wake, favorite meals/activity)
- Where will the MAiD procedure occur?
- Privacy (if in seniors' residence, quiet, no cellphones)
- Understand that once the procedure starts, person will fall asleep, then into a coma (death happens quickly & peacefully)
- What to do after (contact coroner, funeral home, gather family members)
- Grieving (Bereaved Families Ottawa, a peer support group)



COURAGEOUS
INDIVIDUALS

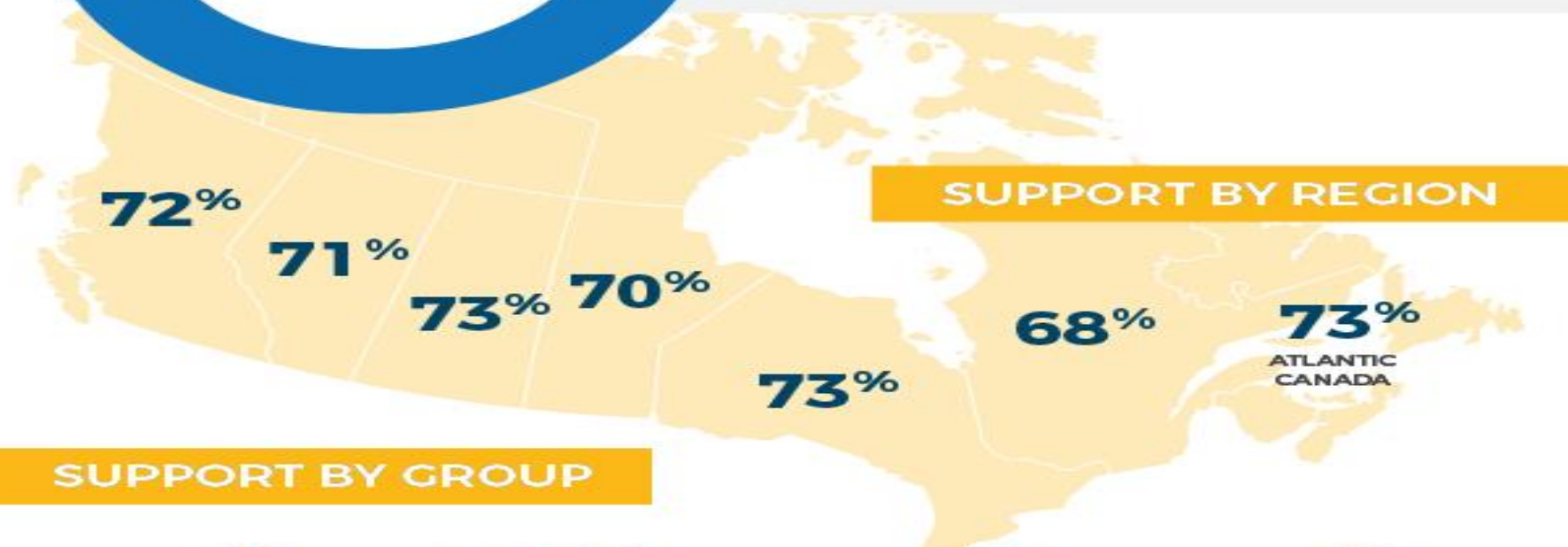
CREATE
IMPROVED
ACCESS





OF CANADIANS

support removing the "reasonably foreseeable" requirement from the federal assisted-dying law.*



SUPPORT BY GROUP



CHRONIC PHYSICAL /
MENTAL CONDITIONS
& DISABILITY



55+ YEARS OF AGE



CATHOLIC



HEALTHCARE
PROVIDER

*Those respondents who said they "somewhat support" or "strongly support" to the following statement: "Do you support or oppose removing the 'reasonably foreseeable' requirement from the federal assisted-dying law?" Ipsos survey, February 2020. Result is considered accurate to within +/- 4 percentage points, 19 times out of 20.



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85%

OF CANADIANS

support medical assistance in dying for patients who meet all the criteria, have been approved for medical assistance in dying and who are competent at the time of the request, but who lose competency before the procedure can be carried out.*



SUPPORT BY REGION

SUPPORT BY GROUP

84%



CHRONIC PHYSICAL /
MENTAL CONDITIONS
& DISABILITY

91%



55+ YEARS OF AGE

86%



CATHOLIC

82%



HEALTHCARE
PROVIDER

*Those respondents who said they "somewhat support" or "strongly support" to the following statement: "Would you support or oppose medical assistance in dying for patients who meet all the criteria, have been approved for medical assistance in dying and who are competent at the time of the request, but who lose competency before the procedure can be carried out?" Ipsos survey.



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Proposed Changes & Review

Government tabled amendments to MAiD legislation
(as per Bill C-7 – likely by Dec-2020)

“Natural death reasonably foreseeable” – 2-track process:

1. suffering and expected to die (NDRF)
2. suffering and not expected to die (ND not RF)

“Assessed & Approved” – waiver of final consent (per Audrey)

Exclusions:

- ❖ advance requests, mature minors, mental illness

“Last Rights”

Connecting the space between Palliative Care and MAiD

In some middle of the night moment... [the] lyrics from the song, “The Water is Wide” came to my mind...

... we gave her a boat. Her family, and her family doctor, and the MAiD coordinator and assessors and provider, gave her a boat....

My Mom received excellent palliative care before, during and following her request for MAiD; palliative care and MAiD unfolded easily and gracefully together.

Christina Sinding, June 2020

Professor, School of Social Work and
Department of Health, Aging & Society,
McMaster University

Healthy Debate, Opinions, 7/10/2020

[\[https://healthydebate.ca/opinions/palliative-care-and-maid\]](https://healthydebate.ca/opinions/palliative-care-and-maid)



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Patient-Centred End-of-Life Care

- MAiD is about expanding choices
- MAiD is not in competition with palliative care
- They can be complementary in a patient-centred approach to the end-of-life care

Getting Information

[**www.dyingwithdignity.ca**](http://www.dyingwithdignity.ca)

Offers information about:

- advanced care planning
 - knowing & defending your rights
 - getting support
 - voicing your choice
 - sharing your stories
 - advocacy, updates & events
 - issues relating to end of life choices
- and much more.....

Thank you

Questions



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Changes to Eligibility Criteria

Person has “grievous and irremediable medical condition”, meaning all of the following criteria:

- serious and incurable illness, disease or disability;
 - in an advanced state of irreversible decline in capability; and
 - has enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.
- (reasonable foreseeability of natural death criterion repealed)**

For purposes of MAID eligibility, a mental illness is **not** a “serious and incurable illness, disease or disability” **(new)**.

Natural Death IS reasonably foreseeable

Changes to Safeguards

- Patient must make a written request that must be witnessed and signed by **one** independent witness (**eased safeguard**).
- A paid personal or health care worker can be an independent witness (**eased safeguard**).
- **(10-day reflection period safeguard removed)**

Ongoing Requirements:

- 2 independent practitioners must confirm all eligibility criteria.
- Person must be informed that they can withdraw request at any time, by any means
- Immediately before MAID is provided, person must be given opportunity to withdraw consent, and must confirm consent to receive MAID, **except if waived (consent is given in advance)**.

Natural Death IS reasonably foreseeable

Waiver of Consent

A Waiver may allow MAiD to persons unable to consent at time of MAiD if:

- Natural death is reasonably foreseeable
- Assessed as eligible and MAiD has been scheduled
- At risk of losing decision-making capacity
- Practitioner agrees to provide MAiD on the scheduled day if patient loses capacity (or earlier, after loss of capacity, if agreed)
- Written consent to receive MAiD on the scheduled day (if no longer able to consent on that day)

Note:

- If the person has capacity to consent on the day of MAiD procedure, the practitioner must give the person the opportunity to withdraw their request and ensure that the person gives express consent to receive MAiD
- If the person has lost capacity to consent on the day of MAiD procedure, the practitioner can provide MAiD on the basis of the consent given earlier
- Consent given in advance is invalidated if the person demonstrates, by words or gestures, refusal or resistance to the administration of MAiD at the time of the procedure.

Natural Death is NOT reasonably foreseeable

Changes to Safeguards:

- Patient must make a written request witnessed and signed by 1 independent witness (**vs 2 IWs**)
- **A paid personal or health care worker can be an IW**
- 2 independent practitioners must confirm all eligibility criteria
- **1 of the practitioners must have expertise** in the condition causing the suffering
- Person must be advised that they can withdraw request at any time, by any means
- **90-day assessment period** (possibly less if loss of capacity is imminent)
- **Clarification of informed consent:**
 - Person must be informed of counselling, mental health supports, disability supports, community services and palliative care, and be offered consultation with relevant professionals, as available and applicable
 - Practitioners agree with the person that they have discussed and considered reasonable means to alleviate suffering
- **Confirmation of wishes:**
 - just prior to MAiD, person must be given opportunity to withdraw consent
 - person must confirm consent to receive MAiD