CONGRESS OF
ABORIGINAL PEOPLES

FINAL REPORT

PALLIATIVE END-OF-LIFE CARE & MEDICAL ASSISTANCE IN DYING

The Congress of Aboriginal Peoples (CAP)

abo-peoples.org | July, 2024

CAP acknowledges the support of Health Canada

Health Canada
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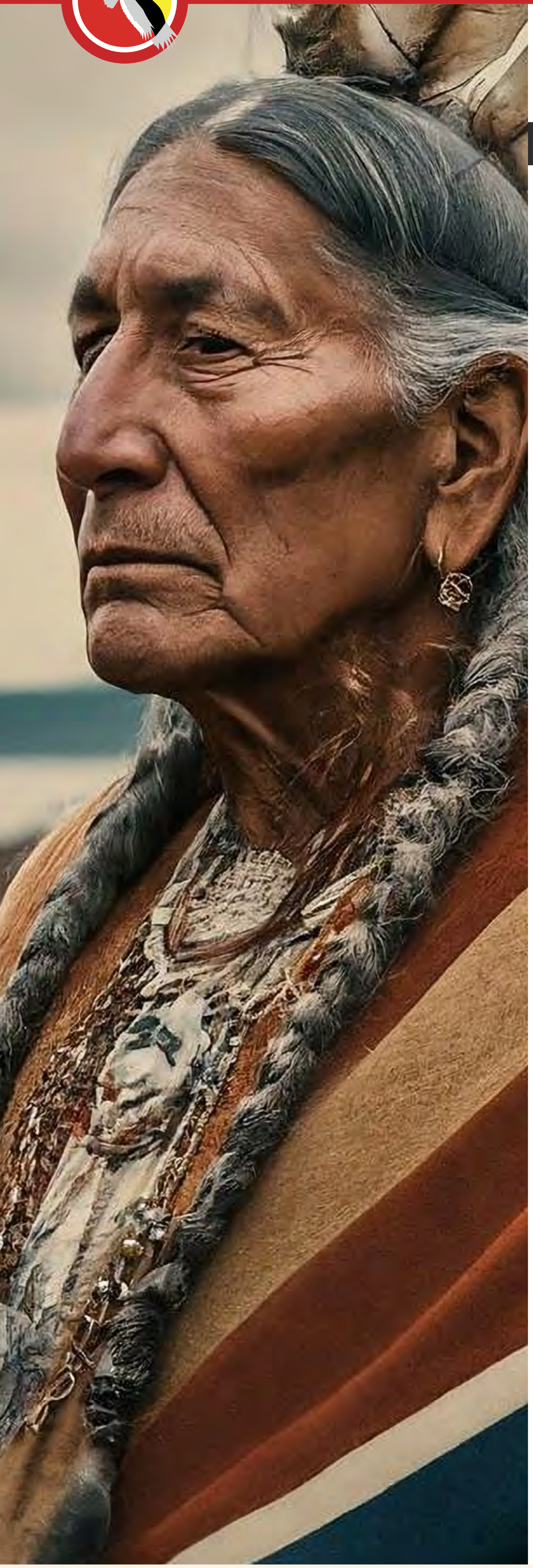


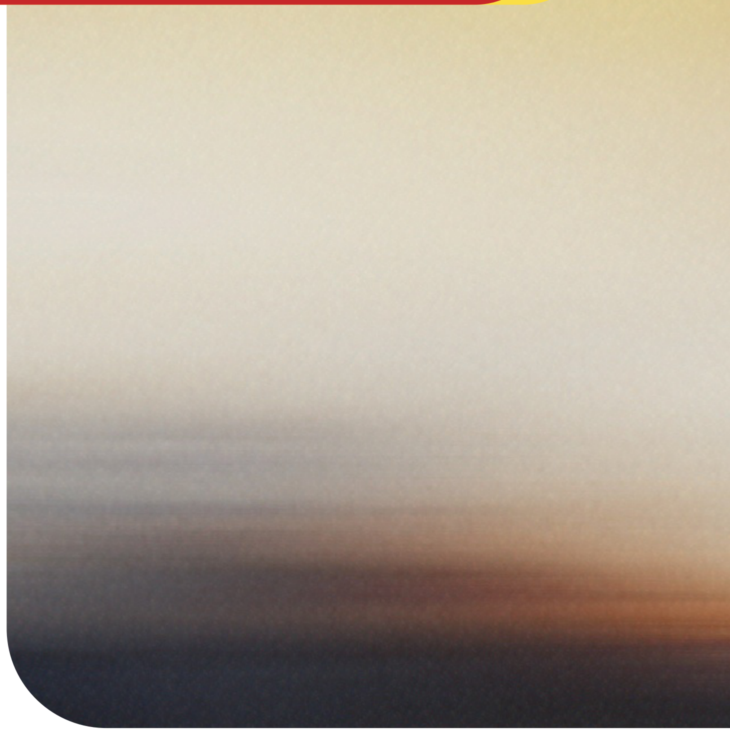
① SECTION ONE

BACKGROUND

The Congress of Aboriginal People's Palliative End-Of-Life Care (PEOLC) and Medical Assistance in Dying (MAID) project was conducted in 2023 – 2024, with the following objectives in mind:

- **To strengthen our partnership** with Health Canada to support our capacity and ability to establish a process to co-develop a distinctions-based, Indigenous palliative care framework. This work would include utilizing expert technicians in the End-of-Life care space and to work with Indigenous Knowledge keepers to be able to provide input based on Indigenous ways of knowing and to support a two-eyed seeing approach. Two-Eyed Seeing refers to learning to see from one eye with Indigenous ways of knowing and from the other with Western ways of knowing and to using both of these eyes together.

- **In conjunction with our work** on PEOLC we will also engage with our community to feed into policy considerations around MAID. CAP will engage their constituency to get input on issues of culture, community practice, anti-Indigenous racism, access to palliative care and others. This work will be done in collaboration with the department to help to inform the "What We Heard report" scheduled for end of the 2024 fiscal.



CONTEXT

The need for Indigenous peoples across Canada to have equal access to high quality Palliative End-Of-Life Care (PEOLC) and Medical Assistance in Dying (MAID) has been stipulated in both the Truth and Reconciliation Commission of Canada's Calls to Action as well as in the United Nations Declaration on the Rights of Indigenous People.

Truth and Reconciliation Commission of Canada Calls to Action

- **TRC call to action #22.** We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.

- **TRC call to action #23.** We call upon all levels of government to:
  - I. Increase the number of Aboriginal professionals working in the health-care field.
  - II. Ensure the retention of Aboriginal health-care providers in Aboriginal communities.
  - III. Provide cultural competency training for all health-care professionals.

- **TRC call to action #24.** We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.

United Nations Declaration on the Rights of Indigenous Peoples

UNDRIP's declaration establishes a comprehensive international framework of minimum standards for the survival, dignity and well-being of the Indigenous Peoples of the world. Regarding Indigenous approaches to palliative and end-of-life care, notable articles include:

Article 7(1): Indigenous individuals have the rights to life, physical and mental integrity, liberty, and security of person.

Article 21(1): Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions, including inter alia, in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security.

Article 23: Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

Article 24(2): Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.

UNDRIP's declaration establishes a comprehensive international framework of minimum standards for the survival, dignity and well-being of the Indigenous Peoples of the world.

FROM OUR ELDERS & KNOWLEDGE KEEPERS

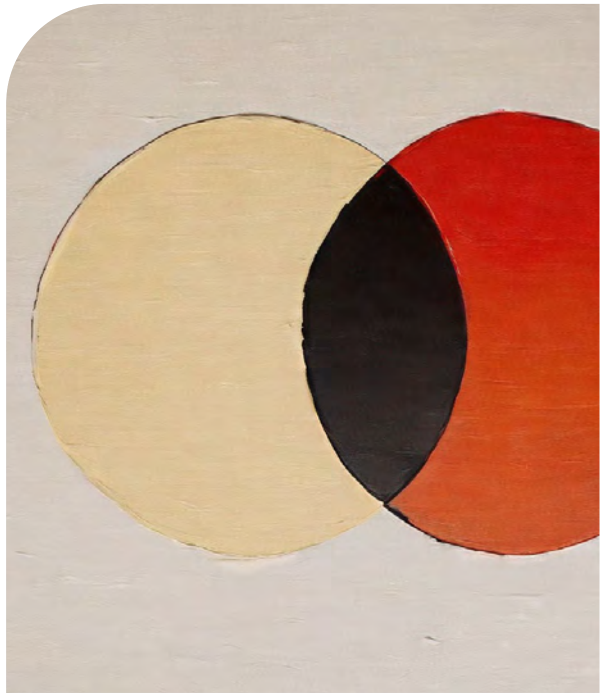
Engagements with Elders and Knowledge Keepers occurred over the summer and into early Fall 2023. One of the salient points made by many was that the Indigenous perspective on PEOLC and MAID should be around our policy development and our needs first and foremost, not by an external, non-Indigenous stakeholder. If Health Canada is asking for our opinion and our input on PEOLC and MAID, then they need to mean it. CAP needs to make sure that our input is part of the policy and incorporated and reflected in a way where CAP's constituents know that their voices are actually being heard and respected. Most importantly, CAP and its constituents should have been consulted at the very beginning to determine Indigenous PEOLC and MAID priorities. What follows is some of the rich feedback received through that engagement process:

- The healthcare system cannot just do carte blanche for everyone.
- Awful things can and will happen, and too much trauma could happen.
- Too much programming and practice is within the framework of western medical approaches and attitudes. But for Indigenous people, everything is grounded in ceremony. Our ancestors are with us all the times and they guide the whole process. For healthcare practitioners, it's hard to understand that 'space' because they need to understand the spiritual space of the other person.
- We need to learn from one another and from other cultures too.
- For CAP, it is important to speak to the community. It is difficult at this point as there's not a full understating of what PEOLC and MAID are.
- We all need to remember that PEOLC, MAID, death, dying, etc., will bring fear to many due to lack of understanding. There's always the question of 'what's the good way to go'? As such, we need to open up space in our communities for this discussion because as soon as you say PEOLC, there's a 'pushing away' due to opening up so many feelings of loss, grief and fear.
- There are some good practices. For example, Manitoba has been a leader in PEOLC and Indigenous space. In The Pas, staff have been educated on best practices for delivering PEOLC to Indigenous people. Hospitals invite family members in and provides care, services and space for the individual and their family. Elders and Indigenous liaison staff are employed, providing a connection for Indigenous patients and family members. Elders, grandmothers and grandfathers are also there. Medicines are there, including Medicine bags. There, Indigenous Elders can offer teachings. This type of programming, people and processes need to be available across the country.
- The Issue of racism still prevails and impacts PEOLC services for Indigenous people.
- The Elders asked to go back to community and bring back the teachings for the health system to utilize. Our

communities are so used to being research done to them and then when we ask for results, nothing happens.

- Everyone needs to be in the same space when an individual is in PEOLC. These are important conversations that the medical staff and others making decisions need to be in the same space and facing those experiencing PEOLC. Indigenous patients in PEOLC and their families need to have a voice. We can help them be in that space in an easier way.
- Indigenous teachings and care should be incorporated into medical and nursing schools/colleges so we can share our traditional ways – i.e., lodges and other spaces where our teachings and our concerns are and can be expressed.
- We need to remember that our traditional ways have saved our old people and that many old people now believe that MAID is equal to taking a life. Some Indigenous people denounce MAID because from their perspective it's wrong to take a life.
- Elders, teachers and healers need to lead our communities on issues such as PEOLC and MAID. They have to bring that back to the community.
- The old people are siting right now and holding all the energy. We need to go to them, sit with them in their space. This will have a life of its own and evolve with the energy it has. It will evolve as the good energy is with them. This discussion on PEOLC and MAID is just the beginning as there is still too much to do. We need to open that space and give the people their voice.
- We have been given the opportunity right now to open this space and dialogue so It's important for us to just do it, let it grow.
- We need to use ceremony as the basis of everything around PEOLC and MAID.
- It's hard because everyone has a different culture, a different tribe. Many are still affected by residential and/or day school. Many Indigenous people are afraid to ask for a more traditional ceremony. Sometimes they're met with empathy and understanding, sometimes with indifference.
- Being able to offer or open to suggestions or even just a cultural understanding and awareness that things are done differently within our culture is important. Sometimes families don't know how to bring that up. Healthcare profession being able to ask the questions to help families is needed.
- Because of intergenerational trauma, many Indigenous people are afraid to embrace or include indigenous ceremony as part of their PEOLC journey.
- We need to gather Elders from each region – gather experiences but also gather direction/ guidance on process, remembering however that many of our Elders are still working through their own intergenerational trauma. Everyone's healing journey in a different space. CAP could put a call out to see who would be interested, including a call out to mental health – trauma informed care, etc., as they're trained in this area. The more people we have involved, the more people who can offer support. It will be important for many to be included in this process. Elders can have a say withing their capacity, health care providers can offer a different knowledge as well. If people need help with power of attorney for example, they need people who knows about this and other end-of-life issues. For example, if people need help to explain a Will - what's in it, what's missing, etc., pulling the appropriate together will help a lot of people at a vulnerable time.
- The Canadian health care system is broken, there's not enough helpers and not enough supports to go around. This plays a part on a person's mental health. If they don't think they're going to get the help they need then why bother. Indigenous people are already dealing with so much trauma so there's a potential risk that some Indigenous people may choose to end their life because they're tired of fighting and don't see anything else to do. In some ways, the broader Indigenous community and individuals are not providing the right care, information, or culturally appropriate help that those struggling with a mental health issue need.
- As Indigenous people and nations, too many are unwell. Reconciliation, being able to go through and have a healing journey in a way that you're healing in a good way takes time and effort. "Unless you're willing to see the hurt and face the trauma and go through the trauma in a good way, I worry about our people. I don't want MAID a reason to end their life".
- Indigenous people and communities need access to Indigenous-led and run healing lodges that deal with mental health, trauma and the disconnect by many Indigenous people from their culture to truly work with people to get to the root of the issue in order to move forward. Services and programming need to last until the person's needs are met and they get the help they need. Need time to form that relationship, that trust, before they're going to open up. Therefore, service providers need to invest that time because if they don't, the program won't be successful (need at least a year-long program/service).
- It's all too common for government to throw money at people, but they don't offer the supports and services – i.e., cultural components, to actually heal and move on. And for Health Canada and the healthcare system to make change, making sure that Indigenous people are included in policy making is paramount.

> **Everything for us is a circle and at the center is the fire. Things are refined and come back. When a community's own people can bring back our teachings around death and dying, it will be a safe space – but communities need to decide this.**



FROM OUR YOUTH

The following highlights key recommendations brought forward by CAP's National Youth Council. Overall, the Council provided recommendations aim at addressing cultural differences, ensure community care, and provide culturally safe support during end-of-life processes:

- Importance of Elders protocol: Consider how Elders are treated and engaged with throughout the process of MAID and palliative care, including through provision of culturally safe care for Elders and emphasizing the importance of navigators for Elders.
- Increase number of Indigenous Health Care Providers.
- Role of Community: Consideration of community-wide impact from MAID, community involvement in the process and need for scaled up grief supports for community.
- Establish Indigenous navigator positions within hospitals and healthcare settings with the primary responsibility of helping Indigenous people navigate the palliative care and MAID processes. The role of navigators includes liaising with hospital staff, explaining cultural differences in end-of-life care, providing technical support, and supporting families and communities after death. Navigators also act as advocates and provide comfort in potentially unfamiliar health care spaces.

> **Spiritual and cultural practices & MAID: Identified need for integration of spiritual and cultural practices within the process of MAID and into Western medical spaces.**

- MAID Setting: Engage to understand more about impacts of MAID Settings. The setting in which MAID occurs is an essential consideration to ensure culturally safe care, community care during the process and after death, address challenges in accessing rural and remote areas, respect Indigenous spiritual and cultural practices, and provide appropriate supports.
- Guidelines/checklists required for health care providers to reflect considerations and protocols when caring for Indigenous people, their families, and communities, at the end-of-life.
- Need for training for Heath care professional on historical and present-day injustices Indigenous Peoples have faced, continuing inequities, cultural and spiritual needs of Indigenous Peoples.
- MAID education: More education on MAID is needed for people to understand it, which may reduce perception that it is cowardly and/or conflation with suicide.
- Support for End-of-Life Care: A support team for palliative care and MAID is recommended.
- MAID options: Increase awareness and accessibility of self-administered MAID options, as some Indigenous people may view it differently from doctor-assisted MAID.

HEALTHCARE PRACTITIONER & KEY STAKEHOLDER SURVEY:
SUMMARY REPORT

The purpose of this survey was to gather input from healthcare professionals on the delivery of Palliative End-Of-Life Care (PEOLC) and Medical Assistance in Dying (MAID) medical and support services to Indigenous people and family members. Survey questions also probed the level of knowledge and previous engagement respondents have had providing end-of-life care and support to Indigenous individuals and their families. Results from the survey will be incorporated into CAP's final *What We Heard* report on PEOLC and MAID to help inform Health Canada about health professionals' gaps in knowledge about Indigenous people as well as gaps in end-of-life care medical service delivery to off-reserve Indigenous people requiring or requesting end-of-life care. A total of 16 responses were received from 4 provinces (Saskatchewan, Ontario, New Brunswick, and Nova Scotia). The respondents who identified their role within the organization were mostly involved in Palliative Care as family support, nurse, nurse manager, financial support, community support, and social worker. They would provide information and referrals to patients requesting MAID but did not practice the procedure. Some were managers with no direct patient contact. One of the nine respondents identified as a MAID assessor.

Approximately half of respondents had delivered services and/or support to Indigenous patients. The others either had not or were unaware of the patient's racial identity. Those who were aware of a patient's Indigenous identity learned either directly from the patient (in person or on an intake/referral form) or a family member.

The type of care provided to Indigenous patients varied, primarily based on the direction provided by either the patient or the family/community. Support could be indirect, such as linking patients to local resources, an Indigenous Coordinator, or an Elder. Some provided more direct support such as providing space for smudging or other ceremony such as food preparation or an end-or-life ritual. Where direct support was available, the patient and family were involved in guiding the process as much as possible. Only one respondent indicated having specific training through an Indigenous Cultural Safety Course.

Several respondents had some prior knowledge of Indigenous perspectives on death and dying before providing care to an Indigenous patient. They provided valuable insight into the positive ways that they acknowledge Indigenous perspectives on death and dying, as well as their interest and willingness to learn more these practices through training and working closely with surrounding communities in order to deliver more culturally informed medical services and supports. As much as possible, they would accommodate a patient's desire to use traditional medicines, meditation, and connection to nature There was recognition that not every Indigenous person has the same traditional values, so treatment was adapted on a case-by-case basis.

> **“**
> **In their final comments respondents emphasized the need to be open and honest throughout the process and consider varied cultural approaches to grief and loss.**

Respondents acknowledged their overall lack of knowledge regarding the needs of Indigenous patients and their family over the course of the end-of-life journey. They also noted the need for end-of-life medical services to be more informed about and inclusive of Indigenous peoples and cultures to ensure such medical services can adequately address end-of-life medical and social (family-specific) support needs.

Wide-ranging input was provided on how services and approaches to services and programming of end-of-life care for Indigenous patients and their family members can be improved. These included developing better understanding of the culture, in particular Indigenous communities' stand on MAID. This could be accomplished in part by embracing a "two-eyed seeing" approach which utilizes Traditional knowledge alongside Western knowledge as well as providing education opportunities for staff and collaborations with local Indigenous communities and Elders. One respondent felt very fortunate to have access to a fulltime Indigenous Patient Navigator who acts as an advocate, educator and support to patients and families. Others acknowledged the need for dedicated cultural support personnel.

Respondents also identified the need for the medical profession to better understand the historical context of health care delivery to Indigenous people in Canada, as well as the need for the profession to be more informed on the cultural practices, traditional teachings and individual health needs of the many unique Indigenous cultures across the country. Some of the issues mentioned included Generational Trauma, lack of trust in the healthcare system, and the individual's level of desire to include culture and tradition into their journey. Many Indigenous people were raised in Western Christianity and MAID can cause spiritual distress for family and the community. Having a safe space to disclose personal values and providing a private space in hospital or community to have ceremony if wanted is necessary. It is important to ask what the patient wants and who should be there at what time in the process. Finally, medical professionals need to embrace a holistic approach to care that recognizes the interconnectedness of physical, mental, emotional, and spiritual well-being.

In their final comments, respondents emphasized the need to be open and honest throughout the process and consider varied cultural approaches to grief and loss. Healthcare providers must be respectful and non-judgemental about patient choices, regardless of their personal beliefs. This is also true of community members and Elders who have concerns that the current risk of suicide in Indigenous communities will be increased with the introduction of MAID, especially if mental health is approved as the sole underlying reason. Despite the challenges, respondents felt that their work was rewarding.

> **“**
> **"It's been our honor when we are able to provide such care"**
>
> (HEALTHCARE PROVIDER)

② SECTION TWO

PALLIATIVE END OF LIFE CARE

What is Palliative End of Life Care? (PEOLC)

Palliative End of Life Care actually encompasses two areas of health care which are very closely connected;

Palliative care sometimes referred to as "comfort care" is a process from diagnosis to end-of-life in relieving symptoms (pain and discomfort) and improving the quality of life for people with life-limiting illnesses (i.e., cancer, dementia, heart disease, heart failure, HIV/AIDS, kidney failure, progressive neurological conditions). Palliative care includes physical, emotional, mental, and spiritual support and focuses on the whole person and their families. Palliative Care may also be offered alongside other treatments which may be attempting to cure an illness or to prolong life, and to people whose life expectancy may be unknown.

End-of-life care focuses on increasing care and meeting the goals of people within their last hours, days, weeks, or months of life. End-of-life care also includes supporting the families and loved ones of the patient through the illness journey and after death and is part of palliative care.

When is palliative care provided?

- It can be offered from the time of diagnosis of an advanced or life-limiting illness and can continue to the point of death.
- It can be provided along side treatment plans such as chemotherapy.
- Palliative care can be provided without being enrolled in a specific palliative care program.
- Grief support is an important part of palliative care which can and should be provided along side of palliative services. In most cases grief support continues for the family even after a patient's death.

Who provides palliative care?

- Palliative care can be delivered by physicians, psychologists, nurse practitioners, nurses, social workers, spiritual care providers, physio and occupational therapists, respiratory therapists, music and art therapists, grief specialists, children's grief specialists, child life specialists and play therapists, dieticians, pharmacists, paramedics, home care aides, personal support workers, and others.
- Many large urban centres have palliative care teams, which include a variety of members listed above, who have advanced training in palliative care.
- The needs of the person who is ill and their family, and the services that are available in their area, determine which healthcare providers may be involved in providing care.
- A large portion of palliative care is provided by family and other unpaid caregivers.

Where is palliative care provided?

① **Palliative care at home** is an option chosen by many for comfort and convenience. Remaining at home however depends on a number of factors including:

- The kind of care required.
- Whether the family or other caregivers are available and prepared to provide care.
- The services available in your area to support care in the home, such as home care training, a health facility near you and equipment. NOTE: Transfer to a health facility may eventually be required if there is a significant change in circumstances.

② **Hospice** is a facility that provides palliative care in a home-like setting. Hospices may also provide short-term respite care, some in-home programs and grief support. Eligibility for admission would greatly depend on the level of care need vs the level of care available at the particular hospice facility. While hospice facilities are often the preferred choice for many individuals it is important to note that there are not nearly enough hospices available to meet the demand and they are seldom found in rural and remote areas. Additionally, hospice care isn't always covered by the public health system so families may have to pay for services out of pocket where private insurance is unavailable.

③ **Hospitals** can also provide palliative care in any unit or section of their facilities including the general ward, a cancer ward or even the emergency room. Some hospitals, especially in larger centers may have a specialized palliative care unit or beds available to admitted patients. These units may offer a more home-like environment but are not generally able to facilitate long term stays.

PEOLC programs and services

In ideal situations, palliative care is provided by a team of healthcare and service providers specializing in various fields which may be impacting the patient. In these cases, support is provided from the early stages of illness through to death regardless of where the patient has been receiving care, at home, in hospice or in a hospital.

In the vast majority of our communities however "ideal" is rarely the reality. In those communities it can be considerably more difficult to gather all the necessary resources to care for our loved ones. It is important to note however that all Canadian provinces and territories have some form of Palliative End of Life Care services available. To have an idea of what services and supports may be available in your area, you can review the Canadian Virtual Hospice map:

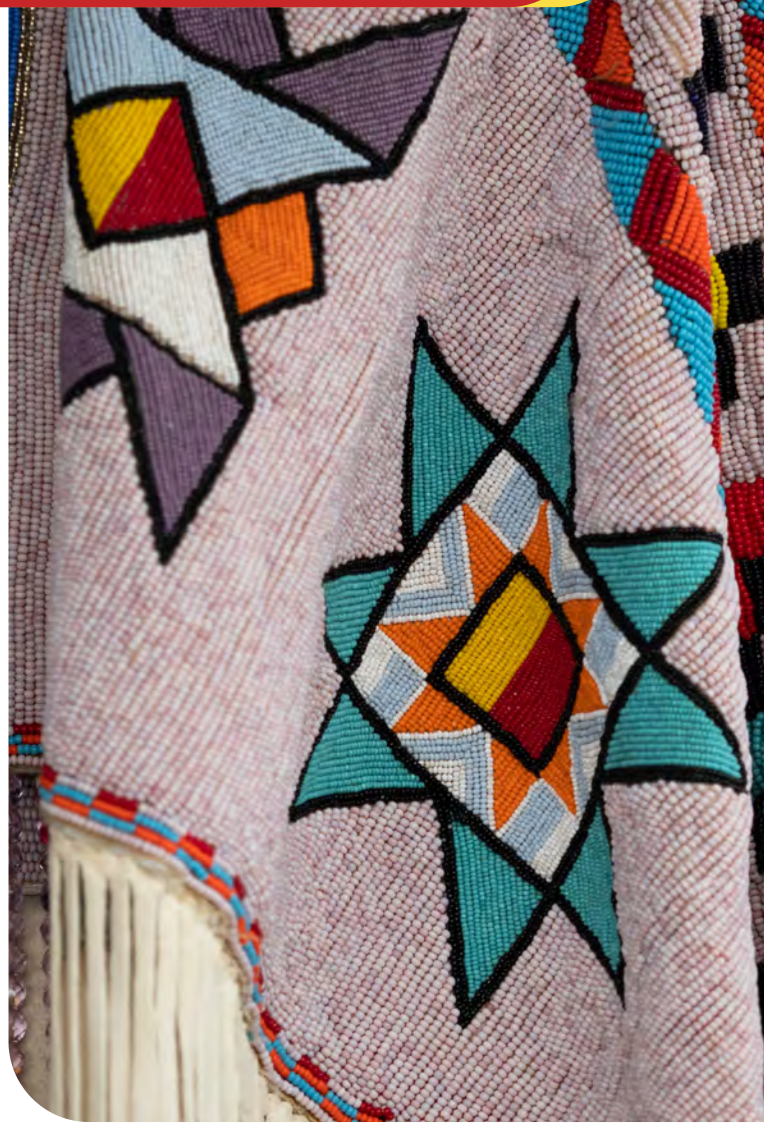
CANADIAN VIRTUAL HOSPICE MAP

Support Services

Many communities have not-for-profit hospice, palliative care, or caregiving organizations that provide a variety of supports. These supports may include education and training programs, visiting and caregiver support, or access to medical supplies & specialized equipment to name a few. Again, the Canadian Virtual Hospice map is a valuable resource to learn about support services available in your area.

Respite Programs

Respite care provides temporary relief for a primary caregiver, enabling them to take a much-needed break from the demands of providing at home care for a loved one. Respite care can take place in your own home, at day-care centers, or at residential facilities that offer overnight stays.



End of Life Doulas (Death Doula)

Historically, communities and villages relied heavily on their Healers, Shaman or Elders for their health and spiritual wellbeing. These individuals typically held a high position within the community and were greatly respected. Their roles involved teaching respect for the earth & the animals, caring for the sick and infirm, assisting with births, supporting new mothers as well as guiding individuals in their final days of life in this world and crossing over to the next (death).

The onset of the Modern Era & the Industrial Revolution brought with them colonization and attempts to wipe out Indigenous Peoples and their way of life. This Era's "advancements" in medicine combined with the affects of colonization meant this form of community-based care was nearly lost.

In recent years however the value derived from including community-based supports into the larger health care equation is being realized once again. The growing popularity of this form community based, or layperson care seems to have begun with revitalization efforts in the field of "Midwife" care which has expanded to include Birth Duolas.

In 2001, the New York University Medical Centre's Department of Social Services engaged with the 'Doula to Accompany and Comfort Program', a grass roots initiative run by volunteers. The engagement aimed to explore the social, psychological, and spiritual needs of individuals at risk of isolation during the dying process. End of Life Doula (EOLD) programs are still relatively rare in institutional settings, but they are experiencing steady growth within independent community-based settings.

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Community Feedback

National gatherings with CAP PTO constituents in attendance were held in March 2023 and March 2024. Participants engaged in guided discussions to determine their level of knowledge and understanding of Palliative and End of Life Care in their communities. The results of those discussions, captured below, clearly demonstrate the importance of PEOLC within Indigenous communities and provide valuable insights on how services could be improved.

Q1: Do you know how to access information on PEOLC in your area?

- There are many service providers for PEOLC in Alberta. There are many Indigenous cultures in Edmonton so they should be accounted for through this medical care service.
- Maybe through family doctor.
- Googling and basic awareness of palliative care centres. Have to rely on healthcare providers to have this information.
- No, nothing available specifically for Indigenous peoples.
- If you had a family doctor you could get that information from there. Shortage of doctors to get the information.
- There are no doctors on the island, even for initial assessments so it's often too late.
- Don't really think about it until in comes into your life.
- Hospital or clinic.
- Both grandparents went into Palliative Care in Goose Bay. When on the coast, you have to go into Goose Bay.
- Long term care rather than specifically palliative.
- Some people just refuse any type of medical intervention – fear of the health care system.
- No adequate health care in Black Tickle
- Have to travel sometimes by dog team or snowmobile.
- Yes, in CLSCs, hospitals, doctors explain to the family, CHSLDs, health clinics, private residences and home care. The doctors come to the house to explain processus.

> **Accessing regular healthcare is currently quite difficult and not really knowing how to access the PEOLC other than googling or going to ER or information desk in ER.**

Q2: How could access to and delivery of Palliative End-Of-Life Care be improved in your area?

- It is hard to say because of inconsistency across the provinces.
- Digital charting accessible across various service providers would help.
- Services/programming need to start before they can be improved.
- Community information sessions provided on regular basis for families and individuals; Access to home palliative care; every hospital regardless of size should have a palliative care unit; Follow up with family receiving in-home supports; if no space in hospital, should receive same care at home.
- Options to be at home to receive care; gives patient the ability to make decision
- Having Indigenous knowledge in healthcare
- Ensuring Indigenous language speakers and/or material is available
- Could be culturally responsive/sensitive.
- In Truro, had to wait in the ER hallway for a room
- Ensure Indigenous people know what their rights are in hospitals.
- Advocate for people in hospital and ensure proper care is provided.
- Need to build trust.
- Provide the resources, give a safe space closer to home for access to PEOLC so people can avoid going to the hospital.
- Need to invest in places like long-term care for indigenous persons in our area.
- Create Holistic/care palliative community care area for our people.
- There are few if any healthcare forms that ask for your consideration or about identity (i.e., are you indigenous, or what are your needs).
- People assume palliative care means imminent death, so more education for the general population is needed.
- Ensure the cultural piece is there as there are multiple Indigenous groups.
- Make space more comfortable, less institutional.
- Improve ability to be cared for at home, in your own community, or make the transition to the city easier and more cultural. For example, in one instance an Innu tent was set up outside the hospital for the patient and family.
- Have Indigenous Patient Navigators
- Raising awareness, more support for acceptance of the situation. NAQ is seeking information to inform members of the community since many don't feel comfortable seeking information.
- More knowledge of the various Nations and traditions to better inform and respect end-of-life ceremonies
- Not growing up with culture it can be difficult to ask for the services you need – more education needs to be provided to health care workers on Residential Schools & the 60's Scoop and the damage and disconnect these have caused to many Indigenous people
- Preventing racism in the health care system needs a lot more work
- There is a lack of resources and staffing in the health systems. They don't have the

time or energy to provide what is needed by patients and/or family members.

- Need to train more Indigenous healthcare providers
- Suggestions to accommodate Indigenous Peoples:
  - Costs are a barrier, i.e., travel for clients – adequate transportation for clients from home to centre; having financial assistance for those who need it to help cover the cost of an ambulance, etc.
  - Having adequate spaces for families (i.e., sleeping accommodation for families traveling to visit and places for smudging)
- Protocol after death are important and healthcare professionals need to give the time/space for families to do these for example, washing of patient's body, the family should be able to lead or at least participate in this process

Q3: What do existing PEOLC services look like in your community?

- **Truro, NS** - I'm not aware of anything specific for off-reserve Indigenous peoples. I did have an experience based in nursing home and the care was exceptional for family and patient.
- **Manitoba** – context, mother passed away, the nurse knew individual's mother was going to die and nurse told relative to make her peace with her mother as the mother would likely pass away overnight. The nurse stayed until individual's mother passed away.
- More information on End-of-Life options needs to be discussed openly and in various forums.
- Nothing, other than the services provided at the hospital with an open room for everyone to gather. Family members that can access the room, it has a tv, but nothing outside of that.
- **Fredericton NB** - PEOLC was delivered in the community through Hospice and it was 'fabulous'. They were able to do cultural ceremonies & practices and the space was easily accessible.
- **Saint John NB** - Nothing Indigenous specific. Public service delivered at hospital and some home care, but not much for PEOLC. Posters accepting Indigenous practices and ceremonies in the hospital were displayed, but participant didn't know anything more about the actual program/service.
- **Shelbourne NS** - A nursing home had a separate room to access for end-of-life care, but there is no home care available.
- **Stratford ON** - has an Indigenous Liaison that speaks the language, there's space with a large room, food is provide and there is a shower and participants can stay from beginning to end of the PEOLC process.

> **"They need to have the Indigenous liaison that speaks the language with the space, and that's where the shift would start."**

Q4: In your opinion, what needs are most important at end-of-life?

- The direct needs of the patient and then the family.
- For patients: whatever the patient wants; access to family members as much as they want; favorite foods; have pets close by; to be able to wear their own clothes; be as comfortable as possible. Most important, to have their wishes and beliefs respected.
- For the family: to be kept well informed and update; access to adequate facilities like beds, showers, kitchens; a gathering space for visiting relatives; access to cultural or religious supports.

Q5: How can these needs be met?

- End of Life Care plans, Power of Attorney, Living Wills are all resources that could be used to help ensure our end of life needs and wished are known.
- End of life Navigators or Doulas that have palliative specialization would go a long way in ensuring that the patient's and family's needs are met.

Q6: Do existing services include adequate cultural components and supports specific to Indigenous People?

- This very much depends on where you live or where you are receiving care. While some communities have made a lot of effort to support Indigenous people, sadly most have not.

- A lot of places don't want to deal with that, but some will.
- In most places today it is up to the patient to request cultural supports as a part of their care plans. If the patient cannot do so themselves, it would fall to a family member to make the request.
- No, there is only one Indigenous healthcare provider in in our area.
- Not so much: Indigenous families have to do the work themselves; General services not tailored to Indigenous Peoples.
- Increasing the training for indigenous folks to be trained in those roles and then utilizing empty space to provide end of life care space relevant to the cultures and its needs.
- Smoke-free policies often complicates smudging. Ontario made accommodation to their policy for smudging
- Five years to take smudging into the jails. We shouldn't have to fight years to get stuff.

> **Death Doulas - helping train community members and healthcare providers in preparing individuals, families, and communities for death.**

- Yes, they do. Hospitals raise awareness in hospitals to know the customs and culture of each.
- Indigenous people are treated on the same equal footing, the only thing would be to be better informed about the cultural ceremonies.
- Need to advocate for a role that will work with the staff at the higher level in the health regions/authorities to support awareness of different Indigenous peoples' needs
- Having culturally safe rooms in hospitals, hospice, etc. Making chapel spaces non-denominational, into spiritual spaces.
- Changing the conversations on death to be about transitioning, going home, celebrating, etc. It is the colonial views that say death is bad and scary and that we shouldn't talk about it
- Need to share and hear more stories (both legends and contemporary experiences). The facts and reports will never reach our community members.
- Written, video, audio stories need to be shared, not "What We Heard" reports.
- Palliative rooms need to have glass/windows so to help increase connection to the natural world
- People need access to art, not just visual but also music and textiles and stories and movement/dance
- Ability to pick-up/access medicines (ie bundles of sage, sweetgrass, tobacco etc.)
- In many cultures death is a celebration of someone passing on to the next stage of their spirit journey and colonialism has brought in this finite belief that they are gone forever and we mourn their passing and not celebrate their graduation.

Q7: What could cultural components (of PEOLC) look like?

- Own space, own building (close to hospital with resources).
- Things like smudging and drumming should be allowed and common practice.
- Patient's bed arranged in proper direction.
- Ability to open the room's window so the soul can leave when ready.
- Patient and family can bring their own cultural items into the room (their own drum with them, healing blanket, gifts).
- Ability to allow pets into room.
- In house Elders at all facilities.
- Develop intake processes that directly include questions around indigenous identity and or cultural requirements/needs.

> **Meetings like this are a good start. It is always important to acknowledging the difficulty of the topic, and to acknowledge and respect the different opinions and beliefs of the people gathering.**

Q8: What should be done to raise awareness about PEOLC in your communities?

- Need to have a team of people who can start/create the conversations. Can not be one way, information should be "provided" as well.
- No access to mental health counselor/nurse – fears; the conversation starts well, but after it's over, the services aren't available for everyone, so these topics can be difficult.
- Need to build awareness of PEOLC overall – need a marketing campaign.
- More discussion and more information on PEOLC – i.e., brochures in doctor's offices.
- Planning in advance needs to be promoted more.
- Funding to hire awareness coordinators within the PTO. Part of the funding should go to hire navigators to assist families.
- Grief counsellors and therapists to support the family.

RECOMMENDED ACTIONS

1. **Priority of addressing Indigenous spiritual and cultural needs.** Cultural components of PEOLC delivery need to be both patient-centred and region/territory-specific to respect Indigenous person's unique culture, teachings and traditions. Health care practitioner' knowledge of Indigenous culture and community' membership or affiliation is key to effectively and appropriately providing safe and comprehensive PEOLC care to Indigenous patients and support for family members.

    - **Indigenous spiritual and cultural needs** should be a priority in an Indigenous focussed palliative and end of life care framework. In the urban environment, Indigenous spirituality is a diverse and complex process because of the forces of colonization and assimilation. Most importantly, Indigenous understandings of spirituality are different than many beliefs in mainstream communities. In urban Indigenous culture, spirituality is still viewed as important in promoting health and wellness and essential in the end-of-life process. For urban Indigenous peoples who have suffered trauma as a result of residential school experiences, their culture and spirituality can be a key foundational strength. Participants spoke to the importance of respect for Indigenous spiritual practices in upholding end of life traditions and ceremonies. Key informants spoke to the number of legal barriers that interfere with traditional Indigenous health care and that more work will be required to address legal complexities since hospices are required to follow the BC Health Care Act.

    - **Culturally appropriate care** for one group of urban First Nations may not be the same for others. While traditional knowledge protocols and processes differ from nation to nation, key informants spoke to commonalities in Indigenous culture and traditions which are deeply rooted: a wholistic viewpoint of health and well-being; use of traditional medicines and foods; use of Indigenous languages; use of traditional knowledge holders; and maintaining family connections, culture, spirit and identity. Key informants emphasized the importance of Indigenous culture in the planning, quality, appropriateness, and delivery of palliative and end of life care.

2. **Training and education for healthcare professionals and support staff** is necessary to understand Indigenous histories, cultures, practices, and approaches to death and dying, and to subsequently develop and provide the medical services and protocols towards providing culturally appropriate, trauma informed PEOLC.

    - **Importance of high quality**, culturally safe, trauma-informed palliative, and end of life care and that the goal of seamless service delivery must reflect the diversity of Indigenous values, customs, and beliefs. Engagement participants were supportive of training for Indigenous patient navigators to assist caregivers, palliative clients, and their families. These navigators can play a key role in bridging relations between traditional

Indigenous practices and mainstream health and palliative and end of life care services. Engagement participants frequently referenced the blunt fact that culturally safe, trauma-informed palliative and end of life care services are not accessible for urban Indigenous peoples and the existing system is complex and inadequate.

- **Non-Indigenous caregivers and health care providers** involved in palliative and end of life care for Indigenous peoples must be educated and trained in Indigenous history and culture. Participants also supported the provision of cultural sensitivity training for non-Indigenous palliative care workers with the goal of culturally safe, trauma informed care for Indigenous peoples. Key informants spoke about the lack of funding for cultural competency training for non-Indigenous caregivers and health care providers. Key informants emphasized the importance of improving patient outcomes by employing an Indigenous palliative and end of life care team potentially made up of various professions including physicians, registered nurses, nurse practitioners, traditional healers, patient navigators, personal support workers, mental health workers, occupational therapists, and social workers.
- **Nurses or health care providers** do not get much support after having to be present at a death or administer the medication in the End-of-Life process. A lot of them rely on each other for support. But there are no assisted supports from Health Canada afterwards. At times a debrief is needed for the health provider.
- **Tools used in the delivery of PEOLC** such as the "Seniors Assessment Screening Tool" are not culturally informed. Treatments based on this tool are not personalized and no personalized context is included in the care plan. She also noted that this tool often separates a patient's physical needs from their psychological needs, rather than integrating them.
- **Workshops** devoted to effective communication should be provided to all healthcare staff, including doctors and administrators (e.g., health care workers should be trained to ask the patient what they need, to listen carefully, and to do their best to ensure that the need is met through collaboration with communities, families, and other healthcare providers).
- **Anti-bias training** should be provided to all healthcare workers providing palliative care, to ensure that they are able to put aside their own beliefs aside when working with patients and families.
- **Training for Indigenous cultural awareness/sensitivity needs** to be provided to all healthcare workers, including administrative and policy-making staff. This training should reflect the diversity of Indigenous peoples on PEI (e.g., Mi'kmaq, Cree, Inuit, Métis, off-reserve, non-status, etc.).
- **Frontline palliative care staff** also need to be trained in how to advocate for the patient with the family (i.e., that families do not try to influence the patient's requests).

③ **Development of Indigenous-led** palliative care homes or Elder Centres.

- **Need for palliative care homes** or Elders' centres.
- **More information is needed regarding homecare services** that are available (cleaning, food preparation, etc. versus medical care, providing medications, etc.). The patient's needs should be at the forefront, rather than having a limited list of things available for people to choose from (i.e., find ways to provide the patient with what they need/ask for).
- **The patient's rights, wants, and wishes** should take precedence above all others — including care homes rules and regulations. For example, if a person wants to smoke, they should be able to do so; provisions should be made in the care home to make this possible.

④ **Need for reform of healthcare institutions and practice** to acknowledge and deliver culturally-appropriate care to Indigenous patients accessing PEOLC and adequate supports for family members:

- **Pathways/workflows for communication** among and within departments should be created or improved. This will reduce the silo effect and ensure patients and families understand their options for PEOLC.
- **Healthcare institutes need to increase supports** for and communication of culturally appropriate spaces available to patients / families. Some participants noted that dedicated "prayer rooms" or similarly named spaces still maintain a Christian influence, and do not reflect Indigenous cultural teachings. Further efforts should be taken to Indigenize as much space as possible within the institutions.
- **Healthcare institutes should maintain a list of contact information** for local Indigenous communities and organizations to rapidly respond to requests from Indigenous patients/families (i.e., patient requests for an Elder or smudging ceremony). Likewise, internal policies and procedures of healthcare institutes should make every effort to accommodate such spiritual and medicinal requests from Indigenous patients, even if such requests may contradict existing policies and procedures (i.e., no smoking policies).
- **Healthcare institutes, in partnership with post-secondary educational institutes**, should strive for broader Indigenous representation amongst the healthcare labour workforce, and in particular in positions of seniority and leadership. Each healthcare institute should identify at least one Indigenous employee to act as a navigator / liaison to work closely with Indigenous patients, families, and the broader Indigenous community on PEI.
- **Communication between the healthcare provider and the patient / family** should be clearer regarding the range of culturally appropriate care that is available.

- **Conversations** about end-of-life care should be normalized in all healthcare settings and with/by all healthcare providers, including doctors providing a diagnosis. All healthcare providers should communicate with patients to ascertain what they want/need at different stages at their end-of-life journey.
- **Culturally appropriate care** needs to be normalized in the health system and can start with requiring healthcare providers to have a clearer understanding of what "culturally appropriate" means (i.e., the emotional and spiritual dimensions of what is being done and why). As well, regarding Indigenous cultural components, these should be patient-specific, as each Indigenous person's culture has different teachings and traditions, depending on the territory/land base.

5 **Better support and information sharing** needed to help the family understand the process and the importance of respecting their loved one's PEOLC journey as well as their loved one's wishes:

- **There should be something in the Act to support the families**. It is not only the person it is happening to, but also the effect it leaves on the immediate family. The families definitely need to have some kind of support. Two things should be included, one to support the family and the other to protect the family that must make the decision for a loved one against legal repercussions or other members of the family.
- **Need for care for the family**, because having a nurse come in to give the patient a bath, etc., can provide family with time to take a break for self-care. She also noted that PEOLC can contribute in an important way to the family's grieving process.

6 **More support is needed around helping the family understand the process and what the patient wants**; the family also needs to be encouraged to respect the patient's boundaries (i.e., the family should not influence or interfere with their loved one's end-of-life needs/requests). Healthcare staff should be trained in having these discussions with the family.

7 **Information about advance care planning**, palliative care, and home care services should be publicized more broadly and clearly. These could either be delivered by Health PEI staff or an educational/information packet provided to community organizations that they could share/present to their community members. Emphasis should be placed on the eligibility criteria for accessing PEOLC supports (i.e., not just patients with specific illnesses like cancer, and that PEOLC can be accessed as soon as a diagnosis is received).

RESOURCES

Quality palliative care respects people's culture traditions and spirituality. In honour of National Indigenous Day, Canadian Virtual Hospice has launched *Coming full circle: Planning for your care*. This booklet was developed by Indigenous Peoples to ensure their choices for future health care are heard and respected.

Quality palliative care helps you honour your culture, spirituality, and traditions. *At Living my Culture*, people from various cultures share their stories and wisdom about living with serious illness, end of life and grief to support others.

First Nations perspectives:	*https://livingmyculture.ca/culture/first-nations*
Inuit perspectives:	*https://livingmyculture.ca/culture/inuit*
Métis perspectives:	*https://livingmyculture.ca/culture/m%C3%A9tis*

3 SECTION THREE

MEDICAL ASSISTANCE IN DYING

What is Medical Assistance in Dying? (MAID)

Medical assistance in dying (MAID) sometimes referred to as "Assisted Death" is the process by which eligible individuals seek and obtain medical help to end their life. MAID has been a legal option for Canadians since 2016 and while much controversy continues to exist regarding MAID advocates assert that providing MAID as an option is about compassion and the fundamental rights of an individual.

An individual's **Eligibility** to access MAID is determined based on the evaluation of two independent health care professionals, often referred to as MAID Assessors. Through this evaluation process applicants must meet ***all*** of the following criteria:

- Be eligible for government funded health care in Canada.
- Be at least 18 years of age or older and have decision-making capacity.
- Have a grievous and irremediable medical condition.
- Make a voluntary request for MAID that was not the result of external pressure.
- Give informed consent to receive MAID after receiving, reviewing, and understanding all relevant information required to make the decision, including diagnosis and possible treatment options.

To be considered as having a ***grievous and irremediable medical condition***, the applicant must meet **all** of the following criteria.
The patient must:

- Have a serious illness, disease, or disability.
- Be in an advanced state of decline that **cannot** be reversed.
- Experience unbearable physical or mental suffering from their illness, disease, disability, or state of decline that **cannot** be relieved in a manner acceptable to them.

Currently there are two methods in which MAID can be administered in Canada.

Method 1
involves a physician or nurse practitioner directly administers a substance that causes death, such as an injection of a drug. This is sometimes called clinician-administered medical assistance in dying.

Method 2
A physician or nurse practitioner provides or prescribes a drug that the eligible person takes themselves, in order to bring about their own death. This is sometimes called self-administered medical assistance in dying.

> **An individual's Eligibility to access MAID is determined based on the evaluation of two independent health care professionals.**

MAID – THE STEPS INVOLVED

STEP 1 **Patient Written Request.**

STEP 2 **Patient Eligibility Assessment.**

STEP 3 **Referral to Providing Practitioner.**

STEP 4 **Mandatory Period of Reflection.**

STEP 5 **Provision of MAID**
OR
Self-Administration of MAID Medication.

Making a request

All Canadians, regardless of where they live, can request MAID if eligible. The initial step for the patient to talk with their physician or nurse practitioner and discuss options related to their circumstances and their possible interest in accessing MAID services. How and where this medical service will be offered is determined by:

- medical institutions
- provinces and territories
- the organizations that regulate health professionals.

The patient may have to meet other requirements; their health care provider can tell them more about those requirements. Due to differences in accessing MAID across provinces and territories in Canada, if the patient does not have a regular doctor or nurse practitioner, there may be a central coordination service that can answer questions.

It is important to note that some provinces and territories may have a specific request form for individuals to complete.

Making a written request

Anyone considering MAID must sign a written request that says they want to have a medically assisted death. The request must include:

- a signature confirming the patient's request for medical assistance in dying. If the patient can't write, another adult can sign the request on their behalf under their clear direction. This adult must:
    - be at least 18 years of age
    - understand what it means to request medical assistance in dying
    - not benefit from the patient's death (for example, they must not be an heir to their estate)
- a written request must be signed and dated before an independent witness who must also sign and date the request

It is important to note that some provinces and territories may have a specific request form for individuals to complete. Such forms are primarily accessed from a person's health care provider or their provincial or territorial government website.

Advance consent in cases of self-administered MAID

Persons requesting MAID can make a written arrangement with their health care practitioner so that they can administer MAID in the event of failed self-administration. This arrangement allows for clinician-administered MAID if there are complications during self-administration that cause a person's loss of decision-making capacity but not their death. This means that an individual's medical practitioner must be present at the time that they self-administer the medications.

Requesting MAID When Natural Death Is Not Reasonably Foreseeable

If the medical practitioners assessing someone's request for MAID determine that their death is not reasonably foreseeable, there are extra safeguards that must be met before MAID can be provided:

- One of the 2 medical practitioners who provides an assessment must have expertise in the medical condition that is causing unbearable suffering.
    - If neither of them have this expertise, another practitioner with expertise in the medical condition must be consulted during the assessment process.
- The patient must be informed of available means to relieve their suffering, and offered consultations with professionals who provide services including, where appropriate:
    - palliative care
    - community services
    - counselling services
    - mental health and disability support services
- The patient and their practitioners must have discussed reasonable and available means to relieve their suffering, and all agree that those means have been seriously considered.
- The eligibility assessment must take a minimum of 90 days, unless the assessments have been completed sooner and the patient is at immediate risk of losing capacity to consent.

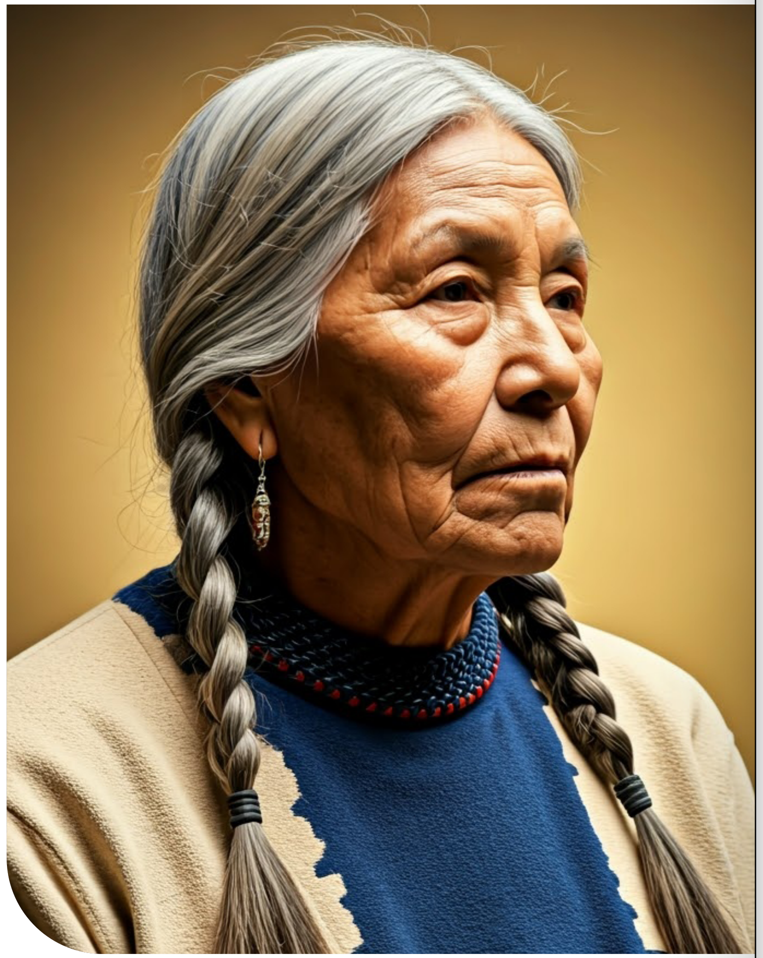
- Immediately before medical assistance in dying is received, the practitioner must:
    - give the patient an opportunity to withdraw their request
    - ensure that the patient gives express consent to receive medical assistance in dying.

It's important to note that not all health care providers are comfortable with or providing MAID. Federal legislation does not force any healthcare practitioner to provide or help to provide MAID. Provincial and territorial governments are responsible for determining how and where to provide health care services and they may also make policies around where MAID can take place (they cannot permit actions that are prohibited under the Criminal Code).

Mental Illness and MAID

Under the law passed in March 2021, Canadians whose only medical condition is a mental illness and who would otherwise meet all eligibility criteria, were not eligible for MAID. This restriction was to be lifted by March 31, 2024, however on January 29, 2024 the Government of Canada said they would be requesting a further extension to allow time for provinces, territories and MAID assessors and providers to be fully ready to address the complex issues associated with mental illness those requesting MAID based solely on suffering from a mental illness.

It's important to note that not all health care providers are comfortable with or providing MAID.



INDIGENOUS & OTHER STAKEHOLDER' OBSERVATIONS ON MAID

Medical Assistance in Dying is a highly contentious issue. Many, such as Dr. Rod McCormick, Professor and Research Chair in Indigenous Health and director of All My Relations, an Indigenous research centre based at Thompson Rivers University believe that MAID is especially problematic for Indigenous peoples who he states "are overrepresented at every stage of the health-care system, including that of premature deaths. This may all seem overly dramatic to you, but do we really need yet another path to death?" He especially did not want to see the eligibility criteria changed to include mental health as the sole underlying cause. Others felt that for some mental health conditions that did not respond to treatment, patients may resort to dangerous methods to end their life if MAID is not accessible.

Those in the Indigenous community who had concerns about MAID referenced colonial practices that created an innate distrust of health care systems as well as limited access to health care in remote and rural areas. They suggested that improving access to health care, including mental health, and cultural training for medical practitioners should be considered first. It was also noted that some Indigenous languages do not have words for some of the terms in MAID law. Finally, as Indigenous views on death and dying are substantively different than colonial understandings, consultation with Elders and Knowledge Keepers is necessary to ensure MAID processes are culturally safe and appropriate.

Community Feedback

National gatherings with CAP PTO constituents in attendance were held in March 2023 and March 2024. Participants engaged in guided discussions to determine their level of knowledge and understanding of Medical Assistance in Dying in their communities. The results of those discussions, captured below, clearly demonstrate the importance of more discussion on MAID, serious concerns about mental health as the sole underlying cause, and ways communication and service could be improved.

Q1: What do you think are the most important things to consider before discussing MAID within your community?

Most people do not want to discuss MAID so it would have to be approached in the right way. The first consideration is ensuring appropriate supports are in place, such as presenters who are knowledgeable, written resources participants can take home, and Elders, healers, and/or counsellors in place during the discussion and available afterwards. Many Indigenous communities are Christianized and equate MAID with suicide. The people leading the discussion need to understand Indigenous cultures and ways of knowing as well as the history of colonization so they can be sensitive to issues that may come up.

Q2 2023: When you think about MAID, what are your main concerns?

People need to be educated as many do not understand MAID. They need direct contact with care providers rather than pamphlets. The stringent process may be too much for some to cope with or understand. On the other hand, some may see it as a solution to problems that might be fixed with other treatments.

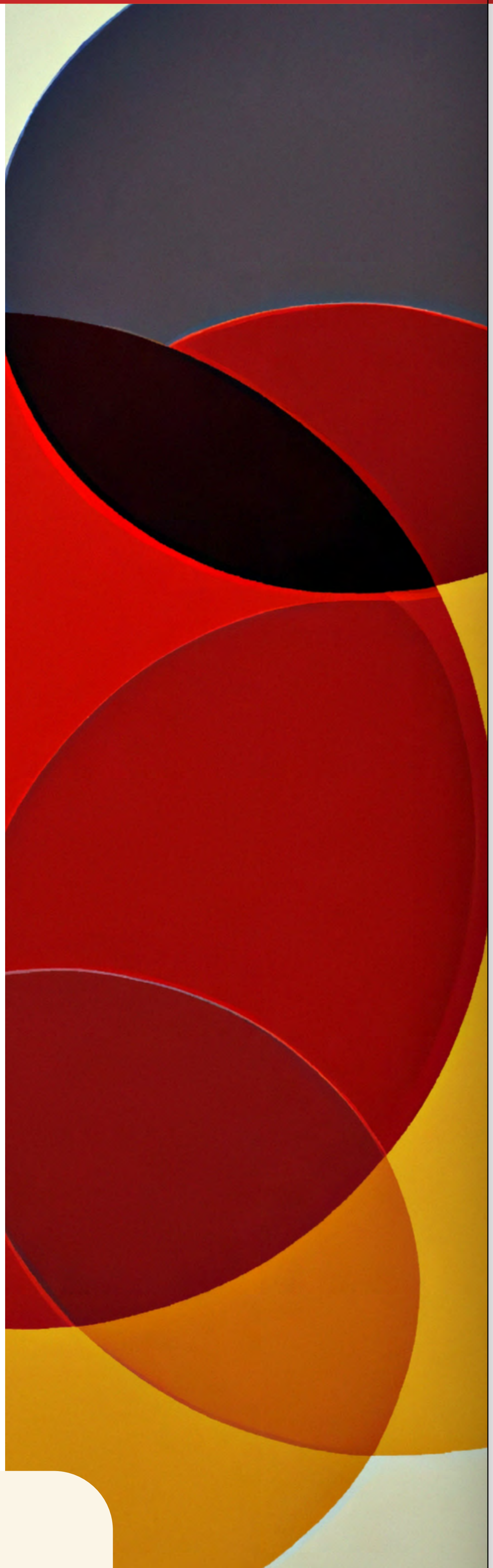
A person accessing MAID is not obligated to include their family in the decision-making process. This can cause confusion, hurt, and misunderstanding. There are also questions about whether Indigenous people want assistance in dying. It may not be culturally accepted in some Indigenous communities – traditions and customs may not support MAID. the possibility that if family members are aware, they may attempt to interfere with the patient's wishes. This can create tension within the family. In an indigenous community, a fear may be that someone would use it as almost a revenge mechanism.

Q3 2023: How could the MAID process be structured to support the individual prepare for their journey to the spirit world?

MAID can be a very individual decision – if a person wants it that is their decision to be respected. Open discussion about the decision and the process is important. The process is not accessible everywhere so improving accessibility would be a factor. Arranging supports needed along a clear timeframe would also help.

Q1 2024: Do you know how to access information on MAID in your area?

There is insufficient information readily available. Perhaps this is because it is still relatively new to us, or because people in the Indigenous community are not interested in learning. Having information available in PTO offices and other gathering places would be beneficial. One PTO had a representative make a presentation but did not provide feedback. Some provinces, such as Nova Scotia, have a dedicated 3rd party phone number to connect to services.



Q2 2024: Do you feel you have a sufficient understanding of who is eligible for MAID?

None of the participants expressed confidence in their understanding of MAID as they did not feel there is information accessible. They also expressed discomfort in discussing it while admitting that it should be talked about. There were concerns about how to approach the subject, and with whom. Other concerns included questions about how to ensure that MAID is not used as a relief plan, how to ensure that prescribed medications do not get out into the street, how to ensure the applicant has sufficient supports, and is the process covered by medical insurance? In essence, this question generated more questions than answers. It was suggested that more information sessions were required and should include storytelling. Narrative therapy and sharing circles could be used to help people understand the decision.

Q3 2024: When considering Mental Health Disorders as the sole underlying health condition of a MAID application, what do you feel are the most important factors to consider?

Most participants were against allowing mental health as the sole underlying health condition. They felt that the issues leading to negative mental health conditions are not fully explored – things like intergenerational trauma, addictions, lack of mental health care, outside influences such as housing, income, and other social determinants of health. They also expressed concerns about the patient's capacity to make such a decision, the challenges of diagnosing a mental health disorder, and the concept that mental health care and knowledge is continually evolving.

Participants also acknowledged how difficult it is to see a family member lost in mental anguish, admitting that the end of suffering might be considered. It is important to look at the duration of the mental illness and steps that have been taken to deal with it.

Past experience with the health care system creates an aura of suspicion around this issue. Without proper monitoring, it could become another way to commit genocide of Indigenous people.

> **"From the time of colonization, Canada has been making Indigenous people sick, and now it wants to help them die."**

Mental health is a very challenging diagnosis and there may be repercussions for patients using it as a cause for MAID. For example, one participant expressed concern that making such a request could be taken as an indication of the wish to self harm, resulting in institutionalization.

There are many different Nations, each with its own traditional beliefs around death and dying. People need access to Elders and cultural understanding rather than just working with a medical professional.

RECOMMENDED ACTIONS

1. **MAID requires outreach and engagement** with an extensive range of Indigenous peoples and organizations
   - Meaningful consultation must be respectful of the diversity of Indigenous peoples and the wide range of experiences, values, cultures, practices, and use of traditional laws and in the context of historical and intergenerational trauma. MAID practitioners as well as the broader healthcare system need to be aware of and prepared to discuss the implications of MAID with Indigenous patients as ending one's life goes against some Indigenous' traditional teachings.

2. Ensure that safeguards for MAID, including witness requirements, eligibility criteria, consent, and waiver of final consent are infused with Indigenous culture and traditions.
   - Ensure that all MAID request documents are available in plain language. Documents should also be available in Indigenous languages. Ensure that consent documents and processes take into consideration the low literacy and comprehension skills of some Indigenous patients.

3. **Family and MAID practitioners work together** to ensure cultural needs are met throughout their loved one's journey.
   - Family members should be around the dying individual and able to conduct traditional ceremonies for death.

4. **Ensure that training and education are seen as critical components** in the provision of culturally safe services and supports that respect Indigenous customs, values, and beliefs.
   a) Increase the number of Indigenous health care professionals working in end-of-life care and MAID.
   b) Incorporate traditional knowledge into training and education concerning MAID.
   c) Increase education and training for Indigenous patient navigators working with health care providers in the area of MAID.
   d) Provide cultural competency training for non-Indigenous health care professionals working in end of life care and MAID.
   e) Increase education and training for non-Indigenous health care professionals to support respectful relations with Indigenous peoples seeking MAID.
   f) Provide cultural sensitivity training materials for Indigenous and non-Indigenous health care professionals working in MAID.
   g) Ensure that Indigenous health care professionals involved in the implementation of MAID understand the relevant laws, policies and protocols.

5. **Provincial Health Ministries and Health Canada** make concerted efforts to engage in earlier consultations/engagement sessions with Indigenous peoples.
   - Many constituents reiterated that both PEOLC and MAID legislation and frameworks are/were drafted years prior to any engagement with Indigenous people, leaving them feeling that many decisions had already been made on their behalf without their consent. Indigenous people have the right to be involved from the beginning of process on any decision that would impact them. This is guaranteed by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Further, funding should also be made available for year-round engagements, as opposed to singular engagement sessions.

6. **Provincial palliative care strategies/action plans** should be created that ensure PEOLC is patient-led and centred from the moment a person or a family member identifies the need for assistance.
   - Also, within such a strategy/action plan, there should be provisions and steps to expand the range of homecare services offered (i.e., not just for administering medications) and to ensure that homecare workers are well matched to the patient and their needs (including needs specific to culture, gender, etc.). Strategies/action plans should aim to reduce (ideally remove) all barriers to culturally appropriate care (e.g., smudging should be allowed in any Health PEI site, including but not limited to all spaces where palliative care is provided, such as long-term care homes).

CONCLUSION PEOLC AND MAID

Palliative End-of-Life Care (PEOLC) and Medical Assistance in Dying (MAID) are challenging and contentious issues. Both invoke strong feelings and, often, a reluctance to discuss. Some suggest that this is the result of colonial thinking about death and dying as an ending rather than a continuation of a journey which is the way it is in many Indigenous cultures.

Palliative care is more commonly understood and accepted. However, there is a general consensus that the care is not always accessible, especially in rural or remote communities. Ideally, PEOLC would be provided in the patient's home if not accessible in a medical centre, but there are not many options for that either. This can result in a patient having to spend their last hours/days/weeks/months far away from home and family.

There is very little Indigenization of PEOLC regardless of where it is offered. Indigenous patients need the comfort of their culture during the final stages of life. This could mean Indigenous art, music, healing blankets, or the ability to practice ceremony such as drumming and smudging as well as access to Elders and traditional healers. While some of this is available in some health centres, it was felt that the best solution would be Indigenous-led facilities.

Medical Assistance in Dying evoked primarily negative comments in group discussions. Many felt that there is just not enough information publicly available for them understand the process. Additionally, MAID raised many questions around eligibility, family involvement, and cultural acceptability. The strongest reaction was to the concept of mental health as the sole underlying cause for MAID. Most felt that mental health is affected by so many other factors in a person's life and that all of these factors must be addressed first. Some associated MAID with suicide, others with genocide – seeing it as a way for Canada to eliminate Indigenous peoples.

> **Education and communication are central to ensuring that Indigenous patients receive care in a safe and appropriate manner.**

More Indigenous health care providers should be trained to work with Indigenous patients through these processes. Health care providers need in-depth education on Indigenous ways of knowing and the colonial history of Indigenous peoples. The people need wider access to information on both PEOLC and MAID, delivered using culturally acceptable methods such as sharing circles or storytelling. Patients need to have opportunity to communicate their needs and practitioners need to take the time to fully explain what is going on.

Finally, with both PEOLC and MAID, participants in this project felt that the consultation was "too little, too late". Decisions had been made, protocols and practices established, and Acts passed with minimal or no consultation with Indigenous peoples.

RESOURCES

As the leading defender of Canadians' end-of-life rights, we at *Dying With Dignity Canada* have a role to play in ensuring fair access to palliative care. Through our Support Program, we educate Canadians and their families about palliative care and where to find it.

Understanding Medical Assistance in Dying (MAID) – online (and downloadable) toolkit for individuals considering MAID and their families.

https://www.virtualhospice.ca/maid/media/yafpybhp/maid-individuals-and-families.pdf

Videos by individuals and families who chose MAID:

https://www.virtualhospice.ca/maid/#programs-and-services

CONGRESS OF
ABORIGINAL PEOPLES

FINAL REPORT

PALLIATIVE END-OF-LIFE CARE & MEDICAL ASSISTANCE IN DYING

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