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Expert Report and Briefing Note on Assisted Dying

Part I: My Qualifications:

I am a medical doctor licenced in Canada since 1990. My undergraduate BSc and MD were obtained at Queen's University in Kingston Ontario in 1986 and 1990 respectively. I completed a family medicine residency program in Alberta, at University of Calgary in 1992, and then completed a MPH at Harvard in 1994. I have been affiliated with various universities to teach and mentor medical trainees and currently hold the following clinical teaching positions; University of Calgary (Clinical Assistant Professor 1992-present), University of British Columbia (Clinical Professor 2015-present), University of Toronto (Clinical Lecturer 2023- present). I have been involved in research initiatives, as well as the development of new practice in health care- as a clinical epidemiologist, educator and clinician. I have worked across Canada, in Ontario, New Brunswick, Nunavut, Alberta and BC.

I have been involved in Assisted Dying practice in Canada since 2016. I attended the International Right to Die Federation meeting in the Netherlands in May 2016 as a physician to consider whether this was an area that I could reasonably incorporate. I recognized I had the skill set to assess patients for eligibility: in my many years of experience as a family physician focussed on Women's Health and abortion care, I was continually assessing both capacity and voluntariness. In this field, it is paramount that there is no coercion and fulsome consideration of options by a competent patient. I had a good understanding of administrative reporting responsibilities and oversight, as I ran a government funded surgical facility and had experience in the Ministry of Health as Director of Population Health in Nunavut (one of the Canadian territories) and nationally, with Health Canada as Chief of the Reproductive Health Bureau in the Laboratory Centre for Disease Control. I also volunteered for a number of years on boards and committees of the College of Family Physicians of BC and of Canada (at the provincial and national levels), and with the national and

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international Physicians for the Prevention of Nuclear War. These organizations gave me the skill set and experience to co-found a national organization in Canada focussed on Medical Assistance in Dying (MAiD); CAMAP- the Canadian Association of MAiD Assessors and Providers. I served on the board from our establishment in 2017-2021, and then from 2022-present as the Vice President (2021/22). I am the current President of CAMAP. In this regard, I am the chief spokesperson, and responsible for the executive director, who has a staff of 3 full time, and 3 part time staff.

In the first few years within CAMAP, I worked to develop guidelines and educational events for physicians and nurse practitioners across Canada. I co-developed the first training course in Assisted Dying, co-led several on-line case sharing webinars, and was on the first planning committees for what has become annual the national conferences on MAiD. I was able to successfully get accreditation through the College of Family Physicians of Canada for the first educational events- case sharing webinars, spring and fall virtual symposia, an in-person workshop on Assessing and Providing MAiD, and a confidential on-line forum for members of CAMAP to share and inquire about the correct interpretation of the law.

Since 2016, I have also been active as a clinician, assessing and providing an assisted death to those that meet the criteria and decide to pursue that outcome. I have provided assistance in hospital, in hospice, in long term care, in nursing homes, in retirement residences, in private homes, and in the outdoors. I have worked in BC, Alberta and Ontario in thisfield, as I am licenced in all 3 jurisdictions. Each province and territory in Canada has different health systems, and have varying degrees of support for the assisted dying process, as well as different reporting mechanisms.

My complete CV is attached, for your reference.

Part II: My instructions for the preparation of this Expert Report

I have been instructed by Adams & Adams, Attorneys on behalf of DignitySA to address a number of questions on the position of medical assistance in dying in Canada.

Part III: My expert opinion on key questions

Part III a) ***What is the current regime regarding assisted dying in Canada?***

Assisted Dying in Canada was legalized in 2016, as an exemption of the Criminal Code and following a Supreme Court Decision. The Supreme Court Decision, also called the Carter Decision was made in 2015, required review by parliament to enact legislation. This legislation, called **Bill C-14** spelled out the criteria under which a person may be found eligible for an assisted death, and included:

- Resident of Canada (eligible for Canadian Health insurance)
- Over the age of 18
- With a grievous and irremediable condition, further specified as:
    - having a serious and incurable illness, disease or disability
    - being in an advanced state of irreversible decline in capability
    - experiencing intolerable suffering that cannot be relieved in ways the person accepts

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- And furthermore, to be on a trajectory towards death- know that death is reasonably foreseeable.
- Have capacity to consider and make this decision
- Demonstrate voluntariness or lack of coercion

The legislation in Canada was amended in 2021, as a result of another Supreme Court appeal by plaintiffs who met all the criteria but did not have a reasonably foreseeable death, or reasonably predictable death from their disability and decline. The plaintiffs had an incurable disability. Parliament was instructed to amend the legislation, and the result was **Bill C-7**, under which we practice today. There were 3 additional amendments to Bill C-14 with the new legislation, that added safeguards and removed a barrier to access.

Today, the legislation designates specific safeguards which are discussed in more detail in Part IIId) below.

Part III b) ***In Canada, who is accessing medical assistance in dying and in what circumstances?***

The details about who accesses and receives MAiD in Canada are publicly available. This is a fully insured health care service, and data is collected on insured services. In addition, MAiD is an exemption to the criminal code and practitioners are required to report to ensure that all safeguards are met to protect public safety, and document that the criteria are all fully met when assessing and providing assistance to die. Failure to report results in loss of license and jail time. Annual reports are made public.

Detailed reporting on MAiD in Canada was implemented in 2017, by a collaborative initiative from the national Justice Ministry (Justice Canada) and the Health Ministry (Health Canada). Reporting is required, and obligatory, following each and every assisted death. A robust and detailed national report is released in the fall of every year, reporting on data from the prior years. Data from 2023 is located in the 5th Annual Report on MAiD.[Fifth Annual Report on Medical Assistance in Dying in Canada, 2023 - Canada.ca]

In 2023, 15343 Canadians had an assisted death, or 4% of all deaths that year. The vast majority, 64% of people, who access MAiD have cancer. The average age is 78, and the most common location is the private residence of the person. 96% of people who had MAiD identified as Caucasian. 51% were men, and 49% were women.

Although MAiD can be provided to people with a condition and decline that is not leading to death (death is not reasonably foreseeable), only 4.1% of all those receiving MAiD in 2023 had this experience. MAiD is mainly used by people with a terminal condition.

There are 2200 unique practitioners who provided the 15343 deaths in 2023. 89 (4.1%) of that group of practitioners provided MAiD over 30 times in the year, meaning that they likely have a very focussed practice in this domain, but it is rare. MAiD is mainly provided by physicians (94.5%0 but can also be done by nurse practitioners (Nurses with a Master's Degree in clinical work). Of the 2200 practitioner that provided MAiD in 2023, 1830 (85.5%) provided assistance 1-10 times that year.

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MAiD is typically provided in the same places many people die naturally; in the home (37.8%) in hospital (32.7%), or in palliative care (21.8%). Increasingly fewer facilities maintain a conscientious objection to MAiD in the premises, so while some people still need to be transferred to an alternative location for the assessment and/or provision, this is less often, but nevertheless distressing. Patients requesting MAiD are suffering already, and are in an advanced state of decline in capability, so that a transfer compounds their problems.

Part IIIc) ***How, practically, does medical assistance in dying work in practice? In this regard, please explain the practical process from start to finish, including the administering of the lethal medical and the effect that this has on a patient's body and mind.***

In practice, MAiD is initiated by the patient. They convey a deliberate or specific request to their health care provider who is required to then take action. The person's request may also take the form of a written request on a government developed form, which is available on-line and differs in each province and territory, because Health Care is under the management and responsibility of the province and territory, though the legislation is national. The deliberate request requires the person to attest that they have been told they have a serious illness, disease or disability; that they are currently in an advanced state of irreversible decline in capability and that they are suffering intolerably.

Occasionally, this request is put forward verbally by the person's spouse, or other family member, from a level of concern for their loved one and with their consent. However, it is incumbent on the clinician receiving the request that they verify it is the person's explicit request and not the wish of a loved one. The request must be made in writing before MAiD is performed, and in most cases, is done prior to any MAiD assessment. The request must be witnessed by someone who will not benefit from the person's death, so deliberately excludes family members. Criteria for the witness of a MAiD request are defined by federal legislation.

Once having made this deliberate request, the patient's primary physician or nurse practitioner may make a first deliberate assessment of eligibility, if they are comfortable and trained in doing so. This requires a specific form is completed, but also a narrative that clearly documents that the person understands their serious illness, disease or disability, that they can describe or demonstrate the advanced state of decline, and the irreversibility of that decline, and most importantly, that they have suffering which they have tried without success to reasonably address and improve, but find that the suffering is now intolerable and unrelieved. Through this process, the clinician is usually able to address if capacity is intact or not. The person must understand their condition and the options, appreciate the consequences of any action they request or pursue, reason between the options at hand and communicate a choice. If the person does not have capacity, or capacity is in question, a formal assessment of capacity is required. If capacity is not intact, the request for MAID is denied. Similarly, if the illness, disease of disability is curable, or if the decline is not advanced or is reversible, or if there are other reasonable means to manage suffering, including palliative care and disability supports, then the request for MAiD is declined, and the person is found not eligible, or not eligible now.

If a person is determined eligible by a first assessment, then a second independent assessment is required. This may be done by the first assessor seeking another clinician to do this. However, the clincians cannot coerce on another, cannot be supervising the other person, and must not be influenced by the determination of the other. They are required to be independent. In most cases, a regional or

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provincial level coordination team has been established. These coordination teams, run by administrators and nurses, have a listing of clinicians who have voluntarily offered to lend their time and expertise to MAiD assessments. The coordination team will contact by email one or more persons on the list to assess any person who submits a formal request.

Each of the 2 assessments usually occur on different dates and ideally in person. During the pandemic, virtual assessments were more common, and in most situations now, at least one of the assessments is in person. The persistence of virtual assessments (by video and voice) were established also to allow for increased access in a large and sparsely populated country.

Following the 2 assessments, if found eligible by both clinicians, the patient may proceed to plan their assisted death. One of the 2 assessors is required to work with the patient to choreograph and plan the provision of MAiD. That person must liaise with the pharmacy and demonstrate that the legal criteria has been met. The prescription is very specific and both the IV sequence and the oral medication are pre-determined by the College of Pharmacy in each jurisdiction, though they are almost identical in each province and territory in Canada. Pharmacists are not required to participate, and undergo some training to ensure they understand the legislative requirements.

The practitioner administering the medications has several obligations. That person must pick up the medication- not the patient or a designated family member. Moments before the IV is started or the oral medication is given, a final opportunity to withdraw the request is required. The clinician must offer every chance for the person to opt out. In some provinces, this involves a final signature from the person. The clinician must arrange for IV start and ensure that a funeral home is identified to pick up the body following the provision of MAiD. The practitioner must return all unused medication within 72 hours and provide documentation of the timing and amount administered. The practitioner is responsible to prepare and provide the death certificate, and complete mandatory reporting within 30 days of the death [ref: Reporting requirements under the Regulations Amending the Regulations for the Monitoring of Medical Assistance in Dying: Guidance document - Canada.ca]

The person dying will decide on the number and identity of people attending, which typically includes close family members, possibly a spiritual person, and/or close friends. The required attendee from the health care team is the MAiD assessor who has agreed to provide. A nurse may accompany them.

Medications are administered intravenously by the practitioner, as this is the most common route in Canada. Even if the oral medication is used, the practitioner must remain until death occurs. In the case of oral MAiD, this may be up to an hour, though the person is required to agree to completion with IV, if the oral medication is ineffective in leading to death in a certain time. If the IV method is used, the clinician also has a back up dose in case of IV failure, or insufficient dose. The IV method has become the usual method in Canada, because it has as predictable effectiveness, has complete efficacy and no suffering. The same protocol is used across the country, and is effectively an overdose of the sequence of medications used in a prolonged general anesthetic; midazolam (a sedative), propofol (coma inducing) and rocuronium (neuromuscular blocker). The person experiences a deep and profound sleep within 2-3 minutes of the midazolam, and then feels nothing. The observers notice breathing become shallow and then usually stop during the propofol administration. There is no choking, gasping or panic experienced or observed. While the end result is a respiratory arrest, there is no distress seen or felt. When the sequence is used on people who

subsequently donate lungs for transplant, no effects of drowing are noted. In natural death, final stages are either cardiac cessation or respiratory arrest.

Oral medication has gained little traction in Canada. It was thought to make the option of MAiD more accessible to those in rural and remote areas, but the strict oversight and concern for public safety has led legislators and clinicians to conclude that oral medication should be obtained and given to the patient only by the practitioner, who must observe the effects until death occurs. Therefore, a practitioner must be present, and the patient cannot hold onto a lethal dose in a private location for an indefinite time period. In the limited experience with 2 protocols (secobarbital being one and a mix of morphine, chloral hydrate and phenobarbital being the other) the time to death ranges from 30 minutes to well over an hour. Because patients must agree to final completion by IV in the event of delay or ineffectiveness, about 50% of the time, IV was used to complete the process. Clinically, because patients must be in an advanced state of decline and have intolerable suffering, they may be unable to hold the flask or drink without vomiting a total 125ml of a bitter medication.

Following the death by MAiD, the practitioner must complete a death certificate. The funeral home is alerted prior to the provider leaving the location. Condolences are offered, and the provider leaves. The provider is required to immediately return unused medication to the pharmacy with a document of the type, timing and amount of medication used. Mandatory reporting to the province or directly to the national reporting system is made within 24 hours of the death. Documentation on the provision is also required as these more fulsome records may be requested once the mandatory reporting papers are reviewed by the oversight body in that jurisdiction.

Part IIId) ***What are the safeguards and mechanisms in place to guard against abuse in the context of requests for medical assistance in dying? Have these been manageable to follow or implement in clinical practice?***

Safeguards for MAiD start with the request. It is required that the person submit in writing before MAiD occurs that they have a grievous and irremediable condition (the 3 points include an incurable illness, disease or disability, an advanced state of decline in capability, and intolerable suffering). They also must attest that they have considered means to address their suffering and have opted independently and without coercion for an assisted death. This written request is signed by a person who will not benefit from the death, including the 2 assessors. With Bill C14 from 2016-2021, 2 witnesses were required and for some patients that was difficult, because with the nature of the illness and the isolation, they did not have access to friends or volunteers willing to do this. Bill C-7 advises only one required witness. It is important to note that no substitute decision makers, no power of attorney, no executor or other person can speak or sign on the person's behalf to request MAiD.

The second safeguard is having 2 independent and qualified health practitioners (either medical practitioner (physician) or nurse practitioner). This safeguards any possible collusion between a single practitioner and the patient, and ensures transparency in the process whereby a patient is found eligible under the law, with the required criteria. In practice, this is made possible in some regions by efforts of the MAiD coordination unit supporting training and education of family physicians and specialists on an annual basis, so that more clinicians are trained to be able to provide one of the 2 required assessments for their patients, whom they know better than a separate consultant. In other areas both of the 2 assessments are arranged by a provincial list, or by electronic referral to practitioners who have self declared that they are willing and trained to provide an assessment and provide the MAiD if the person

is found eligible. This process works better in some regions than others, leading to a slight variation in the uptake and completed request for MAiD across Canada, from 2% in some areas to 10% in others.

Each of the 2 assessing practitioners must ensure that the requestor meets the required eligibility criteria specified in the law. It is not merely that a person asks for assistance to die, and the practitioner provides assistance- there is not a general right to die in Canada, but a right to have assistance ONLY when certain criteria are in place.

Another safeguard is the repeated instruction and option for the requestor/patient to withdraw from the process and from the assessment or provision at any time. This includes withdrawing their request at the time of administration of the substance.

A further safeguard is in place when the person's death is not reasonably foreseeable. That person is required to wait a minimum of 90 days from the start of the first assessment until the assisted death can take place. The delay enforces reflection and additional opportunities to determine alternative and additional means to relieve suffering. For this type of assessment (called Track 2), the assessors must also consult an additional practitioner who has explicit expertise in the incurable illness, disease or disability. If one of the 2 main assessors has that expertise, no consult is required. The specialist must provide evidence about the natural trajectory of the condition, and the means to relieve any associated decline and/or suffering. Those means must be offered to the person, and both assessors must be content that the person has reasonably explored and/or given adequate consideration to these alternatives. These safeguards ensure that the person is thoroughly assessed by practitioners who know the condition and have time to offer alternatives and improve quality of life. Extended time for reflection and consideration helps ensure that MAiD is not a rushed decision.

Additional safeguards include the mandatory clarification about the consideration of disability supports and palliative care, so that all requestors/patients are provided the option to consider and experience any social, logistic and medical supports to improve quality of life and reduce suffering.

Another safeguard occurs at the time of the provision of an assisted death, because informed consent is required immediately before provision. In some provinces, this is done in writing, and others it is verbal, but it is explicit. In 2021, with Bill C-7, there was a formal Waiver of Final Consent made possible. This allows for one specific practitioner to have a commitment with one defined patient for an assisted death on a specific date in the not-too-distant future, even if the person has lost capacity by that date. This option was put in place for those with a high risk of imminent loss of capacity through disease process or medication requirements, and is not frequently used (only in 594 of 15343 cases in 2023), though is often considered and put in place to reduce anxiety where the fear of loss of capacity may be a cause of suffering.

The safeguards are not difficult to follow, but require time and diligence on the part of the requestor/patient, and the practitioner to ensure every detail is in place. Two national initiatives help with this:

- The Model Practice Standards for MAiD was released in March 2023, to make some details of assessing and providing MAiD more explicit, particularly in challenging cases and can be obtained on the following government website: <Model Practice Standard for Medical Assistance in Dying (MAID) - Canada.ca>

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- The Canadian MAiD Curriculum was released in the fall 2023. This robust 7-part curriculum was developed through input from a variety of perspectives including expert clinicians, the College of Nursing, the Canadian College of Family Physicians and the Royal College of Physicians and Surgeons. It also benefitted from People with Lived Experience (Patients or Families) and Indigenous Organizations. Targeted to nurse practitioners and physicians, the entire curriculum takes 81 hours to complete, including 27 hours of self study and 54 hours of workshops and reflective practice. For 3 years, it is free of charge to those clinicians through a contribution agreement to CAMAP from Health Canada. Information about the curriculum is on the following website: < Canadian MAiD Curriculum - CAMAP | ACEPA>

These initiatives help train and guide practitioners in the correct application of the law and the safeguards. Guidance documents are also available on the CAMAP website, developed by experts with a great deal of experience in application of the law to clinical practice.

Part IIIe) ***What difficulties, if any, are experienced in practice in relation to the eligibility or qualifying criteria for accessing assisted dying in Canada?***

There are few difficulties in practice relating to the eligibility criteria in most cases. Much of the time the incurable illness is well identified (cancer, organ failure) and specialists have been involved in helping cure the condition or at least make the remaining life more tolerable through palliative care. In most cases, the illness leads to an advanced state of irreversible decline, and that is when most people seek MAiD- near the end when death is reasonably foreseeable and suffering is a mix of the increasing demands on family, machines, medication and supports which rob the person of dignity and the ability to do anything for themselves.

Over the 8 years of MAiD legalization in Canada, the Canadian Association of MAiD Assessors and Providers (CAMAP) has created Guidance documents on where interpretation of the legislation is less clear to clinicians. These are freely available to clinicians and to the public on our website. [CAMAP Publications and Guidelines - CAMAP | ACEPA] The first document was to better define the clinical meaning of "death is reasonably foreseeable". This can be more complex to determine when an illness, disease or disability has a slower trajectory toward death, such as MS, motor neuron disease or frailty.

When legislation permitted MAiD for persons whose death was not reasonably foreseeable, additional clinical terms needed exploration. This included the definition of "incurable", when the disability or illness was complex, such as a rare neurological disorder. It also required clinicians to explore chronic pain, and the origin- which can be the cause of intolerable suffering, but are ill defined in clinical terms.

Other challenges making an assessment complex were not necessarily clinical, but more social in nature. Some people struggle with non supportive family members, having a spiritual or religious community that was actively blocking information, or being placed in a publicly funded facility that had objections to MAiD assessments. These social difficulties are discussed by clinicians in confidential forums and in case sharing webinars so that they have an opportunity to see how others resolved, or addressed these situations.

Some challenges have been logistical in nature, arising from institutional barriers or policies. This may include a person declining while being assessed, and admitted to a facility where the assessor has

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no privileges to work- necessitating the re-start of the process and assessment. It includes challenges of obtaining the medications off hours or on a weekend, when the family can all come to be with their loved ones, but a pharmacist is not available to prepare and release the medication. It may include challenges with IV access in the community, or lack of a speech language pathologist when the disease affects communication (stroke or injury). These logistical barriers are also discussed and those practitioners who have agreed to assess and provide have worked at a community and regional level on an ongoing basis to ensure good care and a dignified experience for the people who seek an assisted death.

Part III f) ***What are your views on the legal alternatives to assisted dying – conventional suicide, withdrawing or withholding of life-sustaining treatment or artificial feeding, voluntary starvation – from an assessment of:***

f 1) the ease or difficulty with which a person may exercise these alternatives, and the consequences if the person does not manage;

Desire to commit suicide and request for MAiD are not the same. People who plan to, and succeed at suicide are often depressed, and having major psychiatric troubles with the only realistic solution in their minds to be self harm and suicide. People with suicidal ideation often benefit from intensive therapy and medication. People who plan to commit suicide do this alone, don't often discuss the plan with others, and are isolated. Ensuring that people have the best supports- medical and pharmacological- is part of the assessment for an assisted death. Assessors must ensure that a requestor/person's request to die with assistance is not clouded by untreated depression.

People who want to die with assistance are suffering, but also are in an advanced and irreversible state of decline and with an incurable illness. People in that state may have a reactive depression, a reasonable feeling of hopelessness with their condition. They want to have help to end the suffering they are experiencing, and cannot be relieved. They discuss their goals of care with others and consider assistance to die, versus an inevitable natural death that is unavoidable in most cases.

There is a specific teaching module on MAiD and Mental Health, with a focus on suicide, in the Canadian MAiD Curriculum.

Withdrawing or withholding life-sustaining treatment or artificial feeding is always an option and is used in some countries where MAiD is not legal and not an option. Part of the withholding or withdrawing of life sustaining treatments is already in place when a person has a "Do Not Resuscitate" (DNR) order. The DNR is about withholding treatment, and the health care team, the family- in particular the designated Power of Attorney- generally respects a person's wish for non-heroic measures, particularly at the end of life.

DNR orders and a plan for MAiD co-exist in many cases. People who plan to die with assistance logically do not want any measures to keep them alive with excessive interventions. As an example, someone with end stage heart disease may opt to have a DNR so that they do not experience defibrillation and a few days in Intensive Care, prolonging an already poor-quality existence. That same person may want MAiD so that they can die with

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dignity, perhaps in a hospital bed, but surrounded by loved ones- saying final goodbyes and "I love you" to their spouse, children and grandchildren. With assistance, they believe they leave a positive memory of their last moments behind, where they were in control and able to attend their own celebration of a life well lived. However, having the DNR order in place assures that even if nature takes its course quickly, their wish to accept the inevitable without additional medical treatment is ensured. It's the next best thing, in their mind, to an assisted death.

f 2) the effect of these alternatives on the body, mind and suffering of the patient;

Voluntary Stopping of Eating and Drinking is termed VSED in global medical literature, and detailed on websites for Assisted Dying <Voluntarily Stopping Eating and Drinking - Compassion & Choices>. It is voluntary starvation and some people try this, or succeed at this when the option of assisted death is not possible. The option differs from person to person, but after a few days, they become increasingly weak and tired, and sleepy. They can no longer move without assistance, and experience dizziness suddenly. With more sleeping, they become less mentally alert and eventually slip into a coma. Dehydration affects the kidneys are heart, and these eventually stop working. Most people require support from health care workers, and may be in hospice.

The increasing loss of mental acuity and will required to persist with VSED makes it different from MAiD. Even though this is possible in Canada, very few people pursue this- the numbers are not known. People who choose an assisted death do not experience additional suffering from starvation, and no additional loss of mental acuity.

Suicide leads to suffering by the patient, but even more so, complex bereavement by the family and loved ones left behind. They may dwell on the cause and consequences for generations.

Withdrawal or withholding of medical interventions can play a role, and co-exist with a plan for an assisted death. In practice, it is sometimes difficult for family and loved ones to decide collectively on whether to stop antibiotics, dialysis, cardiac medications, and/or a respirator. Such decisions place an enormous burden on those left behind. Medical Assistance in Dying is always the wish, choice and decision of one person- the requestor and the person who dies. They can opt out at any time, and are explicitly *not* to be coerced or influenced by others.

f 3) the timing and nature of death; and

Death from suicide is not predictable, and may be unsuccessful. No medical professional can advise or support this initiative. It may occur from lethal shooting, lethal knife wounds, hanging, drowning suffocation or lethal combination of medications. All are painful, require some skill and planning, and are most often secret. In many communities, families left behind may be

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shunned and troubled, trying to grapple with the cause, motivation and sense of unexpected loss.
Death from VSED may be prolonged, over a few weeks. The person gradually slips into a coma, but the exact timing is not predictable. Death occurs from kidney failure, and/or multi-system organ failure. Families and loved ones may be able to support the person through these times, but may be aware of suffering in the process.

Death from withdrawal or withholding of life supporting measures does not necessarily lead to a predictable death. It can be reassuring to families and loved ones to be able to respect a specific DNR order that the person has in place, and it can be helpful to have discussions with a healthcare team to stop unnecessary treatment when it will not result in any greater quality of life. DNR orders and plans often co-exist with MAiD. One is an explicit non-intervention, and the other is a specific intervention.

f 4) any other relevant factor that you have experienced in practice.

In my experience, if a person/requestor is depressed and this is affecting their logical review of their health status, I engage a psychiatrist and/or mental health worker. I explain that I would like them to give a few months trial to treatment options and then re-assess if that helps their experience of suffering. I slow the process down, and in some cases this helps. People may withdraw the request for an assisted death.

In my experience, I talk about the options of withholding care (DNR) and withdrawing care at the same time as an assisted death. It is all part of the discussion of goals of care- and helps to situate why an assisted death may be preferred (or not) rather than a natural death. It helps align the family considerations as well, because they are involved in the considerations of options, which may change over time. Also included in these goals of care discussions (or Advanced Care Planning) are discussions of funerals, estate plans, involvement of spiritual or religious community and other aspects of death. An open conversation with the person/requestor and their family as part of the decision-making process is required, and usually helpful to all.

Part III g) How does a patient's death experience when a patient uses medical assistance in dying differ from a patient's death experience in the alternatives above, if at all?

MAiD deaths in Canada are mainly from IV administration of a series of medications. The IV can be started by a nurse earlier in the day, or by the clinician administering the medications. Typically a longer tubing is used so the practitioner can be a few feet away from the patient, allowing family members and loved ones to gather close. Before beginning, the person must give explicit consent to receive the medications and tells the practitioner when to start.

The series of medications used for MAiD in Canada (IV form) are similar to those used in a major operation. The person becomes drowsy from the midazolam over 1-2 minutes and then is given propofol, to initiate a coma. One in a non- rousable coma, which takes 3-5 minutes, the person stops breathing, and a final medication is given, to stop muscular contraction (rocuronium).

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Death appears peaceful, and loved ones are near. There is no gasping or choking. There are no involuntary movements or seizures. There is no loss of bladder or bowel control- no loss of bodily fluids. It is quick- just a few minutes, predictable, and successful.

People dying with assistance can be on an armchair, on a couch, in bed, outdoors or in hospital. It allows for flexibility to say final farewells and celebrate their final moments in an alert state, with loved ones.

Part III h) In your opinion, should there be any difference between the assessment of capacity in the above circumstances and the assessment of capacity for purposes of medical assistance in dying? Is there any difference in practice when assessing the capacity of a patient seeking medical assistance in dying compared to when a patient chooses one of the alternatives above?

Capacity is assessed for MAiD in every case. The person/requestor must have the capacity to understand the information, appreciate the alternatives, reason logically between the various alternatives and communicate a choice. This sequence is taught to assessors, but usually very evident to an experienced health care practitioner when capacity is in question, or not present.

Withholding and withdrawing care may not involve an assessment of capacity. While many people have a DNR order in place and may discuss their goals of care with family, others may not. In that situation, it is the power of attorney or next of kin who will make the decision, in concert with the medical team, about the aggressiveness of interventions.

VSED requires the full participation and determination of a consenting person, though capacity is not usually formally assessed. It may be with the help of a team, but it must be explicitly clear that this is not facilitating suicide, or aiding in murder- both of which are criminal activities in most countries. It is withholding care with the explicit and ongoing direction of the person.

Part III i) Do you consider there to be a conflict between your ethical and professional duties as a medical professional and providing medical assistance in dying? Please explain your answer.

I do not feel there is conflict between my ethical and professional duties as a health care provider. I believe that my role is to explain the natural course of any illness, disease or disability to a patient, to the best of my ability. Once explained, my next duty is to explore all the alternatives to care, and explain these in a way the patient understands. I must take into account the person's own goals of care, and understand what constitutes quality of life from their point of view. I understand that my role is to care always, to cure sometimes and to relieve suffering.

Death is a part of life, and something that we all will experience. My professional duty is to ensure that people have access to options that delay death, when and if appropriate for them. There will always come a time when medical care, and interventions are not enough, and death is inevitable. While medical care can delay death, it should additionally improve quality of life, even if only for a short time.

With the advent of MAiD in Canada, I have noticed that families and individuals are more open to discussing what death may look like for them, both a natural death and one with assistance. Even people in the early stages of illness want to understand the trajectory, and discuss what options are not

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consistent with their idea of quality of life. I have also noticed that death is less of a taboo or hidden subject, but one that can be planned for and re-framed as a celebration of life. MAiD generally occurs within a short time of the natural end, so it does not seem jarring.

Part III j) ***Is palliative care a true alternative to medical assistance in dying?***

Palliative care is a complement, not an alternative, to MAiD. At the end stages of many diseases, illnesses or disabilities, palliative care can provide relief of suffering and improved experience of death. The most common integration of palliative care at end of life is in cases of cancer, and end stage organ disease. Palliative care involves a holistic approach to the illness experience, and may be nursing care, medication use, wound care- but also psycho-spiritual care and support. It can be done at the home or in a hospice, and it is a team approach.

I have learned an enormous amount about palliative care and the approaches since I have been assessing and providing MAiD. I am not formally trained in palliative care, though was involved in some electives in family practice residency training. Some colleagues who provide MAiD are also palliative care specialists, and find that they can easily integrate both approaches.

MAiD is an alternative that many people/patients keep in mind while they are experiencing palliative care. An assisted death may be what the person wants- on a particular day, with particular people, but while awaiting that time/hour, they will experience and be cared for by the palliative team. This is common.

- What are the underlying objectives of palliative care?
    - 24.10.2 What does palliative care entail?

See above.

- What medications are utilised in palliative care and what effect do these have on the patient's illness, suffering and/or quality of life?

Palliative care can use medications to ease suffering. This will depend on the type of symptoms the person has, but may include pain medications (narcotics or other), anti-psychotics (if hallucinating), drying agents (for excessive secretions), steroids (to reduce swelling), sedatives (for anxiety). Palliative care may also include terminal sedation, a series of strong sedatives and narcotics used when someone is "actively dying" and in the final stages but visibly suffering from inability to breathe, or excessive pain.

People who have MAiD after, or while, experiencing palliative care choose this because of the increasing sedation by some medications. They do not want to be groggy, sedated, or unaware of their surroundings, even though it helps with breathing, anxiety or pain. They want as many alert moments as possible to appreciate their surroundings, and their loved ones.

Some people may find that palliative care is not enough. Despite best efforts, not all pain can be eliminated. Not all sense of suffocation and drowning from lung disease/cancer can be reduced. Not all worry about repeated bowel obstruction can be stopped. These are the reasons that MAiD can complement the good care from palliation.

- What are the primary benefits of palliative care?

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Palliative care is a necessary option that those requesting MAiD must explore. Assessors for MAiD must ensure that all options are explained to the patient, and that a palliative referral is put in place or seriously considered.

The benefits of a multi-disciplinary and team approach to the end stage of any illness, disease or disability is fabulous. Different perspectives, and the use of a multi-modal care plan can really help many people. Palliative care reduces suffering, and improves the quality of those last several weeks.

- What are the limits of palliative care?

The limits of palliative care are listed above.

In addition, not all care facilities have a good palliative care team, and rural communities with limited resources or access to care may not have the multi-modal approach in bigger centres. Since MAiD has been an option in Canada, the need for and improvements to palliative care have increased.

Palliative care may not be an option when the person has a non-terminal condition, or when the condition is slower and chronic, such as MS or Parkingson's disease, that slowly rob a person of the ability to move, stand, or talk.

- Can palliative care ease or erase, entirely, a patient's suffering, and to what extent?

Palliative care measures ease suffering, and temporarily eliminate some suffering. However, the flip-side to the treatment may be increases in sedation, confusion and other side effects. Benefits are temporary, and death is expected following management from palliative care.

Palliative care is a management approach to end of life. It is employed usually when the end of life is expected, and there is no known, or acceptable alternative to cure. Cure is not expected when palliative care is initiated.

Part III j) ***How can, or do, palliative care services and assisted dying work together in practice? How has this been done in Canada?***

In many locations in Canada, MAiD occurs on the palliative care ward in hospital, or while someone is experiencing palliative care at home. According to the 5th Annual Report on MAiD (Health Canada), 75% of people having an assisted death experienced palliative care. Most of these people had palliative care for over a month.

Over the first few years, there was a building of trust in most health care facilities between the palliative care team and the practitioners who stepped forward voluntarily to assess and provide MAiD. Sometimes, these were the same people- who already knew how to ease suffering from palliative care and discuss goals of care at end of life. In other places, the clinicians came to work together.

In the beginning, there was an assumption that palliative care practitioners would be the ones assessing and providing MAiD. While this is sometimes the case, in my experience, it is often helpful to keep these roles separate. The palliative care team manages the patient throughout, and the

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final step – death- is a decision of the competent patient, about whether they want assistance or not.

Part III k) ***With respect to the three most "common" terminal illnesses that result in patients seeking medical assistance in dying, please describe – to the extent that it falls within your expertise:***

Cancer is overwhelmingly the most common underlying medical condition that leads to a completed request for MAiD. In each annual report in Canada from data in 2018-2023, cancer is the incurable disease for 60-65%. Other incurable illnesses, diseases and disabilities are 10-19% each- and include cardiovascular, respiratory, neurological and 'other', typically multiple conditions. Therefore, these other disease categories are similar in frequency to the 4 main types of cancer leading to an assisted death; lung, colorectal, hematologic and pancreatic.

- K1) the nature of the particular disease and its usual natural progression, including its foreseeable effects on a patient's body, mind and pain;

Lung cancer, as the leading cause of death, naturally progresses by increased weakness and fatigue, so overwhelming that simple tasks such as raising a spoon to the mouth are a great effort. People with lung cancer who request and receive MAiD are typically bedbound, and with home oxygen. Speaking to loved ones becomes increasingly a struggle, and they live in constant fear of battling to breathe. They also fear metastatic disease to the brain. This is also a similar fear and experience for those with progressive chronic obstructive pulmonary disease, or COPD, the most common of the terminal respiratory diseases.

Colorectal cancer, as the next leading underlying disease, is a long progressive course. Many of the people with this condition have experienced surgery, removing primary lesions. They have experienced chemotherapy for early metastatic disease, and likely radiation therapy for targeted metastatic lesions. Their last few years is often fraught with medical appointments and fear of disease progression. Some people with metastatic disease request MAiD early in the course of treatment, when it is metastatic. They may be stable for some months, but eventually run the risk of bowel obstruction from tumor blocking the intestine, liver failure from metastases, or severe intestinal bleeding. Bowel obstruction is intensely painful, may lead to rupture and is frequently accompanied by intractable nausea and vomiting.

Hematologic cancers, such as leukemia, are also slowly progressive. At the end stage, people with advanced hematologic cancer are dependant on transfusions to keep them alive. In lay terms, they lack red cells for oxygen and energy, white cells to fight infection and the right amount of platelets to keep the blood the correct consistency- neither too thick or too thin. At some point in care, the transfusion stops being effective, and people would naturally die because the organs fail- the heart, the brain, the kidneys in particular. Many of these people request MAiD as they become weaker and the time between transfusions is too short, or they experience side effects of extreme itching or fever- they also become too weak to get to a facility for care, and it seems pointless to many, as death is inevitable.

- K2) the inevitable outcome of such terminal illness based on current medical or scientific knowledge;

The inevitable outcome for the patients with cancer is natural death, and this is likely to occur at home while having home support or hospice care, or in hospital, likely in a palliative care ward.

- K3) the ability of palliative care to eradicate or ease suffering as the disease progresses;

Palliative care is a vital component of care for people with end stage cancer. When active treatment (surgery, chemotherapy, immunotherapy and radiation) becomes ineffective, they are referred for palliative care, and symptom management, as death is the expected result. Palliative care is very effective and used by 75% of people who received MAiD in Canada. We do not have the data on whether all of the people with cancer (63%) include most of those that received palliative care, but I suspect this is likely.

People with cancer who have palliative care seek MAiD because of the poor quality of life in the last few weeks, and because of the experience of uncontrolled symptoms. In particular, these include severe shortness of breath (lung cancer and respiratory illness, or even heart failure), and bowel obstruction. It also includes brain effects- delirium and coma- that accompany brain metastases from cancer, brain cancer, and the side effects of some palliative medications.

- K4) the different options available to a patient where assisted dying is not an option, and the effect of these on the patient's suffering, pain, body, mind and quality of life; and

In places where MAiD is not an option, suicide is not likely an option. People with end stage cancer, or end stage heart and respiratory disease are much too weak to try an overdose, drowning, gun shot or any other possible measure. They are surrounded by care workers and family, usually.

VSED is likely not an option, thought this may be a possible unexpected activity, particularly with bowel cancer, when obstruction seems inevitable. Many people with end stage cancer or end stage heart and lung disease are too weak to eat, and they stop having the strength to drink. Care workers often help to keep lips moist with sponges, and keep these people comfortable. It is not the deliberate decision of a person to die this way, but an inevitable withdrawing of care and support.

Withdrawing and withholding treatment are common ways that people with cancer experience. Death is not the result of withdrawing food and liquid, because death is inevitable. However, it may be most kind to the loved one to stop intravenous management, to stop dialysis, to stop transfusions and unnecessary transfers out of the home, and even out of the bed. If care causes, or appears to cause, undue suffering, the person and/or the family will agree with care workers that is best to stop. People want their loved ones to die in as much comfort as they can provide.

- K5) what it means for a patient in the above circumstances to be able to access medical assistance in dying.

Being able to access MAiD gives people back some dignity and some control. Without the overwhelming preoccupying fear of dying with discomfort and in a coma, they can focus any remaining energy on their loved ones. They can determine who they want to see, and what they want to say to those they love. They are at peace because they do not need to fear the mechanism of death. They are at ease because they can control how much suffering, and for how long. They can direct their care and regain bodily autonomy, at a time when this autonomy may appear to be taken away from them by the unexpected and prolonged ravages of disease, illness and disability. They feel restored for some time- and rather than being an invalid, they are again the independent person they have known themselves to be

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throughout life. They die as they have lived- making a choice that fits for them, and declining other options.

Part III l) ***From the above, is there, in your view, a commonality in illnesses (their progression, suffering experienced, ability to ease suffering) that most commonly lead to requests for assisted dying?***

There is a commonality in some of the experiences of illness of persons who seek MAiD. It is not necessarily the separately defined illness, but the effect of the illness, disease and/or disability on people's ability to function. The label of the disease or illness does not give the full picture, but it is the effect of the illness on function, and the experience of illness as suffering.

It is helpful that in Canada there are 3 aspects to the term "grievous and irremediable condition". After naming the incurable illness, disease or disability, the Assessing Practitioner must define and understand decline, and this is common in my experience. This is noted in the 5th Annual Report on MAiD and states "The most frequently cited indicator of irreversible decline in capability reported by practitioners was an inability of the person to do most or all activities of daily living – or ADL- (e.g., feeding, bathing and toileting oneself), or instrumental activities of daily living- or IADL- (e.g., managing finances, meal preparation, managing medications). This was followed by persistent significant fatigue or weakness, and chronic pain.".

This is true in my experience. Most people can tolerate some reduction in ability to do IADL, and it may be a relief- to stop meal preparation, finances or medication. However, to some, this is an unacceptable situation particularly if one lives alone, and has been very proud of the independence in managing all that. Loss of IADL may mean moving to a home, which some find unacceptable. Loss of ADL, in distinction, is something that people tolerate for a short time, for example, post hip surgery- but not for prolonged periods or years, with no end in sight. When one is finally bed bound, and not able to toilet, feed themselves, death is foreseeable and quality of life is extremely poor. Many people requesting MAiD are at this point, or close to this point.

The 3rd aspect to "grievous and irremediable condition" is suffering. This is not an objective measure- it is not something a health care provider can identify and correctly label. It is not something that a loved one may know with complete certainty. The experience of an illness, disease and disability can differ from person to person- some people can tolerate the last months of lung cancer knowing they are completely dependant on oxygen, and can never move outside of the home, because transfer to a vehicle takes too much energy. Others would find it intolerable to never see the sky, feel the wind, smell the flowers, let alone drive a car. Suffering depends on a cumulation of what is familiar to that person- when it is robbed forever, it is to suffer. Suffering is affected by fear of the future and of the unknown- which can be affected by life experience of the experience of death and illness in the past. Inquiring about suffering and ensuring suffering is intolerable, is a vital part of the MAiD inquiry. Sometimes, we can find suitable ways to relieve suffering, and the MAiD request is put on hold, or withdrawn.

Part III m) ***How is conscientious objection handled in Canada. In particular, may medical professionals conscientiously object to providing, or assisting in providing, medical assistance in dying and, if so, do they have any referral or other duties.***

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Practitioners who assess and/or provide MAiD so do voluntarily. There is no role where it is a required part of the job or the position. Over the 8 years of MAiD in Canada, a few programs have opted to hire RN or Nurse Practitioner to manage triage phone calls and case coordination. The NP may also be the main MAiD Assessor in that region. However, this full time job as an assessor is rare.

Most practitioners who provide MAiD in Canada are family physicians. Some add this to their practice, doing an assessment once a week, or once a month on top of regular practice. Others are semi-retired and do assessments when able.

The essential component of MAiD assessment is to have a regional or provincial listing of those practitioners who are willing to assess and provide MAiD, so that the public and other health care providers can reach out for a consultation, without barrier.

There is a duty for an effective referral. This means that practitioners who do not believe in assisted dying, or are unwilling or unable to assess a patient must refer to someone who can.

Effective referral ensures that all people with Canadian health insurance and over 18 can access an assessment for MAiD without barrier. It is a health care option that all can use or consider. It is not unlike abortion care, where it is a health care option for all, but not all practitioners will participate in providing.

Part III n) ***To the extent that you are of the view that there is anything further which falls within your expertise that in your view ought to be addressed in your expert report, please do so.***

I believe I have summarized my experience, my knowledge and my understanding of MAiD in Canada.

If we were establishing MAiD in Canada anew, I would change only a few aspects;

1) Establish a care coordination unit at a regional level. This was some months or a few years in coming to several regions. This is very helpful, as the public and/or patients, have many question about process, what to expect, what the law involves. They want to know ahead of time what it is all about, not because they want it now, but they may want it in future. Care coordination is also key for practitioners who may need to follow several patient's trajectory with the illness and throughout palliative care. During that time, families and others have questions and concerns, that are general in nature. Care coordination is needed for IV starts, for helping with funeral, organ donation, social work and nursing support and care for those who are not found eligible.
2) Establish a good training program for clinicians. Our national Canadian MAiD Curriculum was only finalized in 2023, and would have been helpful early on. Early versions were available, but not developed by practitioners who planned to provide MAiD, and not benefitting from international experience, or from those who work in end of life care.

Signed: **Konia Trouton** Date: 28th December 2024

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Konia J Trouton
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Education

1983 Lester B Pearson College of the Pacific United World College IB Program
1986 Queen's University BSc Chemistry (Hons)
1990 Queen's University MD
1992 University of Calgary Family Practice Residency (CCFP)
1994 Harvard University MPH
1998 Fellow of the College of Family Physicians (FCFP)
2015 Promoted to Clinical Professor, Department of Family Practice UBC, UVIC, and U of C
2024 Clinical Lecturer, Department of Community and Family Medicine, University of Toronto

Awards

1983 Full Scholarship for Lester B Pearson College
1986 Provincial Entrance Scholarship for Queen's University (4 year award)
1986 Terry Fox Humanitarian Award (4 year award)
1993 Sir James Lougheed Scholarship for post graduate work in public health (for Harvard)
2003 Clinical Investigator Award (3 year award) UBC
2005 Residency Teaching Award UVIC
2007 Family Practice Research Award UBC
2009 BCMA Clinic Award of Excellence
2018 Clinical Teaching Award UVIC Family Practice Program
2021 Christopher Tietze Humanitarian Award (shared with partner Dawn Fowler)
2022 Enhanced Skills Gender & Sexual Health Preceptor Award, UBC
2023 Federation of Medical Women of Canada's Reproductive Health Award

Employment

2024-current MAiD Clinician, Department of Anesthesia and Pain Management, University Health Network, Toronto
2023- current Clinical Associate, Department of Gynecology, Women's College Hospital, Toronto
2022-current Deputy Medical Director, Women's Care Clinic (abortion services), North York Ontario
2022-current Community MAiD assessor, Greater Toronto area
2016-2022 Medical Director and founder, Westcoast Assisted Dying (MAiD assessments and provision)
2003-2022 Medical Director and founder, Vancouver Island Women's Clinic
1992-1998 and 2006-2023 staff physician, Kensington Clinic (abortion services) Calgary
2004-2008 Kelowna Women's Clinic staff physician
2001-2003 staff physician in Vancouver; Willow clinic (medication abortion, MVA and IUD clinics), Everywoman's Health Clinic (surgical abortion care to 16 weeks), Elizabeth Bagshaw Clinic (surgical abortion care to 16 weeks), BC Women's Hospital CARE program (surgical abortion clinic to 20 weeks), Sexual Assault Program Vancouver General Hospital
2002-2003 Medical Director (for maternity leave), Everywoman's Health Clinic, Vancouver
1996-2006 Women's Care Clinic physician, Toronto (weekly fly in till 1999, then monthly till 2006)
1999-2001 Director of Population Health, Department of Health, Government of Nunavut
Deputy Chief Medical Officer of Health, Government of Nunavut
1996-1999 Medical Epidemiologist, Reproductive and Child Health Bureau, LCDC, Health Canada, Ottawa (0.8FTE)
1996-1999 Morgentaler Clinic staff physician Fredericton NB (Bi-weekly clinic, fly in)
Morgentaler Clinic staff physician Toronto (weekly fly in)
Sault Ste Marie clinic physician for abortion care (monthly fly in)

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1994-1996	Clinical teaching practice, on faculty with University of Calgary Hospitalist, Foothills Hospital, Rocky View Hospital, Calgary General Hospital (ICU, CCU)

Volunteer Activities

2026	Choose Wisely Canada initiative, Women's College Hospital
2025-present	Canadian MAID Journal Editorial Committee member
2017-2026	Canadian Association of MAID Assessors and Providers (CAMAP) co-founder and member, Board of Directors. Board president 2023-2025
2021-2025	CAMAP Curriculum Development Committee, and co-chair of two Working Groups
2019-2021	SOGC Scientific Planning Committee for Annual Scientific Conference
2018-2021	National Abortion Federation (NAF) Canada conference Planning Committee
2016-2024	Clinician Advisory Committee, Dying with Dignity Canada
2006-2014	Member, then Chair of Gender & Equity Committee, CFPC
2004-2014	Member, Board of Directors CFPC (as BCCFP executive, then Committee chair)
2006-2010	BC representative for Canadian Federation of Sexual Health
2005-2008	Medical Director and board member, Island Sexual Health Society
2000-2007	Board Member and then Board President of BC College of Family Physicians
1988-2000	Board Member and then Board President of CPPNW, now Physicians for Global Survival
1992-1996	Board Member and then Secretary, International Physicians for Prevention of Nuclear War (IPPNW)

Teaching

2016-present	MAID teaching- lead of scientific planning committee for monthly MAID webinars, annual CAMAP MAID conference, CAMAP "Providing MAID" course and Canadian MAiD Curriculum
2022-present	Late abortion training for gynecology residents, Women's College Hospital
2020-2025	Contraceptive Implant training and LARC curriculum development, CCRN and UBC
2000-2025	*Family Medicine Residency program* UBC on MAID, unplanned pregnancy, sexual assault, contraception and miscarriage management *Medical students* at the Island Medical Program, as above Family Medicine Forum; IUD training and since 2016, addition of MAID training Women's health clinic mentorship training (ob-gyn/family practice, NP, RN and RM students)
2003-2020	Leading workshops on medication abortion for NAF Canada and SOGC, managing abortion complications, and safe 2nd trimester abortion care for NAF at the international fall and spring meetings
1996-2000	Clinical Assistant Professor University of Ottawa. Established R3 in Population Health for Family Practice Residents
1994-1996	Assistant Professor University of Calgary Faculty development and clinical teaching for family practice program

Publications

Available on request- topics include MAID, IUC care and abortion care

References

Available on request

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Available on request

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