2024

MAiD Death Review Committee Report 2024 – 1

Waivers of Final Consent

Ministry of the Solicitor General | Office of the Chief Coroner

BACKGROUND

Under the *Coroners Act*, physicians and nurse practitioners who provide Medical Assistance in Dying (MAiD) are required to notify the Office of the Chief Coroner (OCC) of the death and provide relevant information to support MAiD death review, oversight, and Health Canada mandatory reporting requirements. Ontario has an established team of highly skilled nurse coroner investigators (MAiD Review Team) who retrospectively review every reported MAiD death in Ontario. A structured feedback approach for practitioners is followed to respond to concerns with statutory requirements, regulatory policies, and/or professional practice when identified during the review process. Further investigation is undertaken as required in accordance with the *Coroners Act* and with the Chief Coroner. The majority of reported MAiD deaths in 2024 (N=4,356 or 88% of all MAiD deaths) reviewed by the MAiD Review Team were evaluated to have met all legislative requirements, with no additional complexities identified requiring further evaluation. Approximately 602 MAiD deaths in 2024 required further in-depth review (N=321) or went on to require an investigation (N=281).[1]

Reflecting the more mature state of MAiD practice, in January of 2023, the OCC modernized its approach to MAiD death review and oversight. Through the modernization process, the OCC review and oversight approach has continued to evolve to include, when indicated, enhanced expert review to respond to increasing social and systemic complexities within the contexts and circumstances surrounding MAiD legislation, practice, and care. Ontario is the first province in Canada to develop a multi-disciplinary expert death review committee to provide enhanced evaluation of MAiD deaths and to explore end-of-life complexities that have systemic and practice implications. Ontario continues to be a leader in high-quality and innovative MAiD death oversight and review.

The MAiD Death Review Committee (MDRC) was established in January of 2024. The committee is comprised of 16 members from across multiple disciplines (law, ethics, medicine, social work, nursing, mental health and disability experts, and a member of the public) who bring a diverse background of expertise in providing advisory support to MAiD oversight in Ontario.

The MDRC seeks to provide recommendations and guidance that may inform the practice of MAiD through the evaluation and discussion of topics, themes, and trends identified by the MAiD Review Team (MRT).

[1] Preliminary overview of 2024 data. A small number of MRT reviews are pending final review outcomes.

Committee Aim

The MDRC provides multidisciplinary expert review of MAiD deaths in Ontario with legislative, practice, health, social, and/or intersectional complexities identified through the oversight and review process. MDRC members review and evaluate the contextual circumstances that impact MAiD and inform the ecology of care for persons, families, and communities. MDRC members review relevant MAiD trends, topics, or issues and offer insights, perspectives, or interpretations and assist in formulating recommendations to inform system improvements (e.g., education of MAiD practitioners, review of regulatory body policies) with a goal to support quality practice and the safety of patients and MAiD practitioners.

Acknowledging there is public discourse regarding MAiD, the MDRC is committed to increasing public transparency of the MAiD oversight and review process through the dissemination of reports.

Acknowledgement of Persons, Families, and Communities

The MDRC acknowledges the deaths of persons who have experienced profound suffering at end-of-life. We acknowledge the losses to partners, families, close relations, and communities.

During the death review process, the OCC protects the personal biographies of the persons who have accessed MAiD. In this report, while some personal information was included for a small number of MAiD deaths, efforts were taken to maintain privacy for persons and their families by sharing only the necessary details and circumstances of their death to support understanding of the issues explored. When we identified that a person's particular circumstance may be identifiable to a person's close relations, we have made efforts to inform their next of kin. We are respectful to the persons whose aspects of their lives are shared in the information presented.

In alignment with the OCC's motto to "speak for the dead to protect the living", the MDRC approaches this important work to learn from each MAiD death. By examining these deaths and presenting this information, we aim to support continued improvement for how MAiD is provided in the province of Ontario.

Acknowledgement of MAiD Practitioners

We extend recognition to clinicians who provide dignified care to persons who have requested MAiD. We respect the clinicians who commit to on-going learning and integrate evolving MAiD practice improvements into their approaches to care. We also acknowledge that clinicians are navigating care for persons accessing MAiD within the limitations of our health and social systems. We further recognize that the OCC MAiD

oversight process is an additional step in the provision of MAiD; we are appreciative of the important role of clinicians in the Ontario MAiD oversight process.

Approach to MDRC Review

Through the OCC MAiD death review process, we have observed that only a small number of MAiD deaths in Ontario have identified concerns. MAiD deaths illustrative of specific circumstances, identified during review by the MRT, are provided to the Committee. The Committee review approach is to gain understanding of the circumstances of the deaths and any issues arising, with the goal to inform improvements to MAiD care. While the circumstances of the deaths reviewed are not representative of most MAiD deaths, the themes identified during the review are not uncommon within the MAiD review process and likely have implications for emerging MAiD practice. The deaths selected are chosen for the ability to generate discussion, thought, and considerations for practice improvement. Reporting of the review discussions is largely focused on identifying areas where there may be opportunities to prompt such improvements.

These deaths are intended to initiate discussions around areas of MAiD practice and encourage practitioners, policymakers, and other stakeholders to explore the issues presented that are relevant to their scope of decision-making. We have selected topics and deaths that depict circumstances that often represent divergence from typical practice and thereby allow new and possibly emerging practice concepts to be evaluated.

Practice considerations and recommendations may have varying levels of transferability to broader MAiD practice and policy. Some practice considerations raised by the Committee should be considered by care teams integral to the delivery of healthcare, more generally (e.g., primary care, mental health services, specialty care teams). Moreover, all persons experiencing profound suffering would likely benefit from improved access to comprehensive care which may require investments in health and social systems to meet the rising expectations of MAiD practices.

Approach to MDRC Report

The Committee reports include, where possible and appropriate, a diversity of thought and perspectives from committee members. Statements do not reflect the views of individual members. We did not aim to establish consensus – we recognize that MAiD practice in Ontario is evolving and may benefit from this varied discourse. Committee member opinion, in favor of or in opposition to, a particular recommendation or discussion point or idea, were not collated or counted and we have employed qualifiers such as “few, some, many, and most” to acknowledge the extent of support by committee members. We do not intend for these qualifiers to reflect the validity of some

of these statements – some members of the Committee offer more unique expertise and may prompt the reader to consider differing perspectives. Moreover, a variety of statements included in this report may have varying significance for different stakeholders.

Recommendations provided in the report have been informed by and developed from the Committee's written and verbal discussions. Recommendations are addressed to the organizations that are believed to be positioned to effect change and support MAiD practice and policy. The recommendations are specifically provided and disseminated by the OCC accompanied by a request for a response from the recipient.

Ontario

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INTRODUCTION

The enactment of Bill C-7 in March of 2021 created two sets of safeguards to access Medical Assistance in Dying (MAiD): track one [Track 1] – for persons with reasonably foreseeable natural deaths [RFND] and track two [Track 2] – for persons with non-reasonably foreseeable natural deaths [NRFND]).

The Criminal Code of Canada has established safeguards that must be met before a MAiD practitioner may proceed with providing a medically assisted death. One such safeguard is that the person has an opportunity to withdraw their request and the person must give express consent prior to the administration of the medications that will cause their death. For persons with RFNDs [Track 1], the Parliament of Canada introduced the option for a MAiD provider and a requestor to enter into a written arrangement to waive this final consent [hereby termed 'waiver' or 'WoFC']. This waiver must be completed prior to the person losing capacity to consent to MAiD, and is submitted to additional procedural requirements. The purpose of the legislative change was to enable persons who are determined to be at risk for a loss of capacity to arrange for advanced consent, possibly avoiding a decision to end their life sooner than they would want[i].

In their explanatory note, the Parliament of Canada presented that this "advanced consent arrangement" would be available where the "individual has been assessed and approved for MAiD in accordance with the applicable safeguards and has indicated their preferred date for the procedure"[i]. Bill C-7 includes additional safeguards that MAiD practitioners must follow: the person must be informed of their risk for losing capacity to give final consent and must have a written arrangement with the MAiD provider. In the arrangement, the person consents in advance to receive MAiD on a specified day, and the provider agrees to provide MAiD in accordance with the arrangement if the person has lost capacity to consent. However, the advance consent is invalidated, and the MAiD practitioner will not be able to administer the substances that would cause their death, if the person illustrates verbal or behavioural signs of refusal or resistance.

The MAiD Review Team (MRT) has identified that the interpretation and evaluation of the required safeguards for persons who have accessed MAiD with a written arrangement to waive final consent has presented some opportunities for practice learnings and raises some concerns about the application of legislation. As such, cases were purposively selected across three themes that reflect relevant issues identified through Ontario's review and oversight mandate, including:

- distinguishing a WoFC from an advance request to receive MAiD,
- determining a loss of capacity prior to invoking a WoFC, and
- considerations for the completion of a written arrangement to waive final consent.

Terminology

For the purpose of this MDRC report, the following definitions inform the presentation of the Committee's discussions.

Advance Request: The Government of Canada defines an advance request for MAiD as "a request made by an individual who still has the capacity to make decisions, before they are eligible or want to receive it. The intent is that MAID be provided in the future after they have lost the capacity to consent and when certain conditions that they specify in their request are met"[ii].

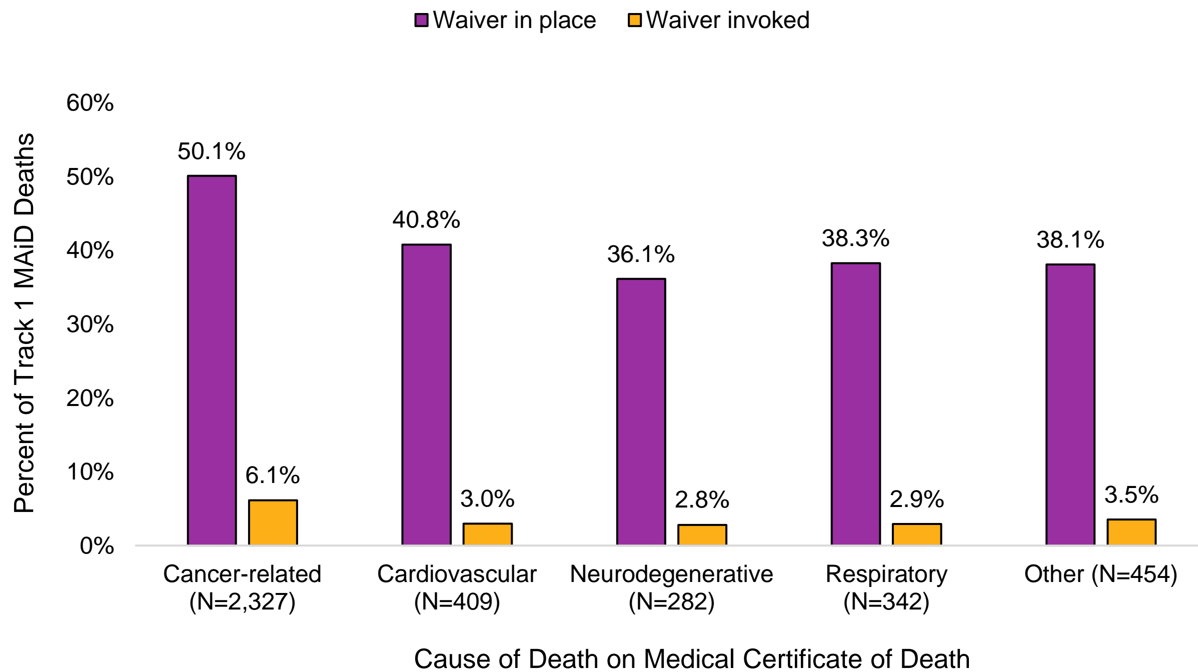
Waiver of Final Consent: Bill C-7 legislation defines the parameters for final consent waiver as "an arrangement in writing with a medical practitioner or nurse practitioner that permits that [practitioner] to administer a substance to cause their death on a specified day" in the event that they lose capacity prior to the day agreed upon (Subsection 3.2 (a)(ii)(iv)). This arrangement must be completed while the person still has decision making capacity and is capable to consent to recieving medical assistance in dying. It permits the practitioner to proceed, waiving the requirement for final consent prior to a substance being administered (Subsection 3.2 (a)).

TOPIC OVERVIEW

Due to changes to Health Canada's mandatory reporting and Ontario's reporting structure, data collection informing use of waivers of final consent has evolved. Prior to 2023, additional data was available on the number of WoFCs arranged, irrespective of whether the waiver was invoked. These data illustrate that in Ontario, in 2022, based on 3,814 Track 1 (RFND) MAiD deaths, 1,739 (45.6%) recipients had a waiver of final consent in place; however, only 189 recipients had a waiver invoked (10.9% of those with a waiver and 5.0% of all Track 1 MAiD deaths).

Persons with a waiver arranged and/or invoked in 2022 much more frequently had cancer as the cause of death (6.1% of those with a cancer diagnosis invoked WoFCs; Figure 1). Persons with neurodegenerative causes of death, including multiple sclerosis, Parkinson's disease, and amyotrophic lateral sclerosis, less frequently had a waiver in place and/or invoked waivers of final consent (36.1% had a WoFC in place; 2.8% of WoFCs invoked).

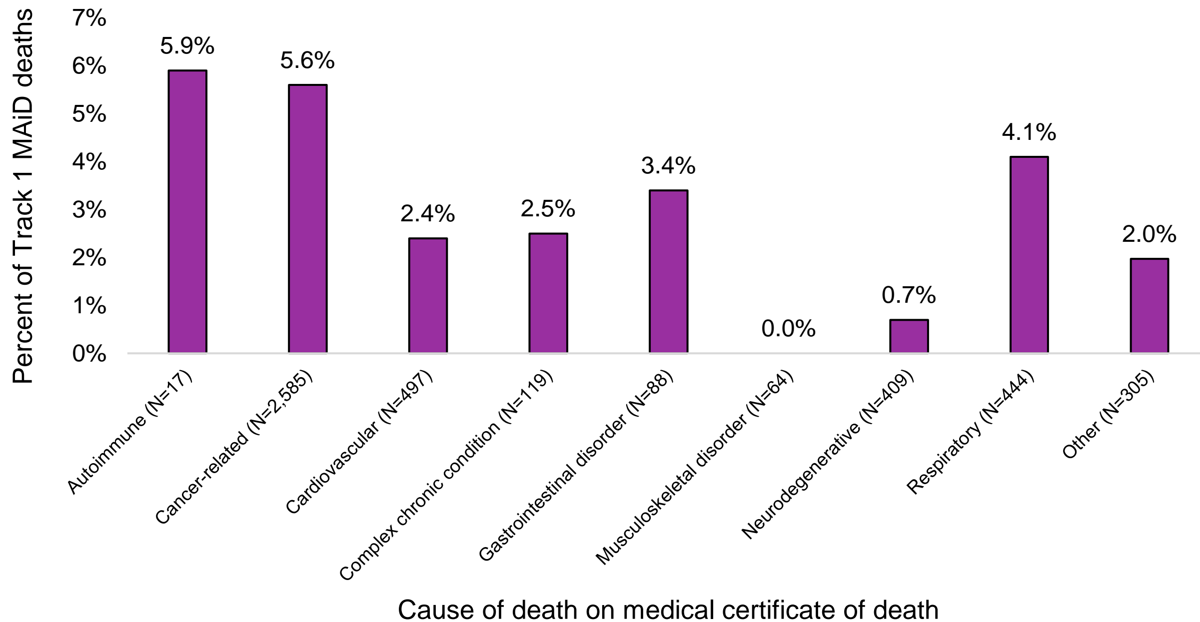
Figure 1. Proportion of Track 1 MAiD Deaths Where a Waiver of Final Consent was In Place and Invoked, by Cause of Death on the Medical Certificate of Death, 2022



Beginning in 2023, arising from changes to Health Canada's mandatory reporting requirements, the OCC only required MAiD providers to report when a WoFC was invoked. In 2023, 190 (4.2%) of the 4,528 Track 1 MAiD deaths had a waiver invoked. This finding is slightly lower than the 5.0% (N=189) invoked in 2022.

When proportions of deaths with waivers invoked in 2023 were examined across cause of death, cancer remained the most common condition for which a waiver was invoked (Figure 2).

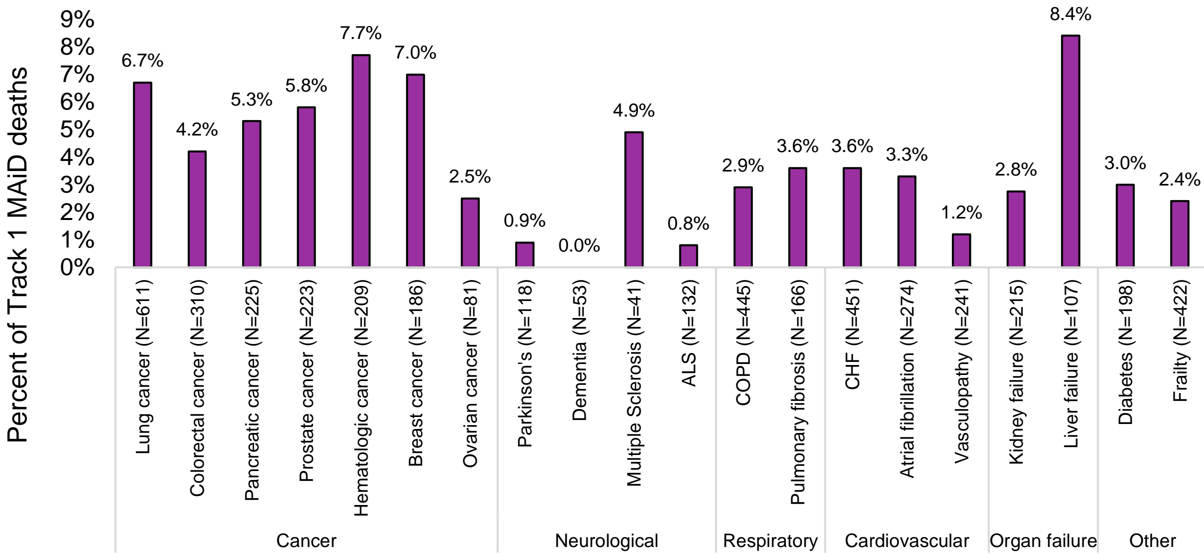
Figure 2. Proportion of Track 1 MAiD Deaths Where a Waiver of Final Consent was Invoked, by Cause of Death on the Medical Certificate of Death, 2023



When WoFCs are examined in relation to the MAiD recipients' serious and incurable diseases[2], persons with liver failure had a waiver invoked most frequently, followed by persons diagnosed with three specific cancer diagnoses – hematologic, breast, and lung cancers (Figure 3). No MAiD recipient with a diagnosis of dementia had a waiver of final consent invoked.

[2] Conditions are not mutually exclusive. Totals do not add up to 100%.

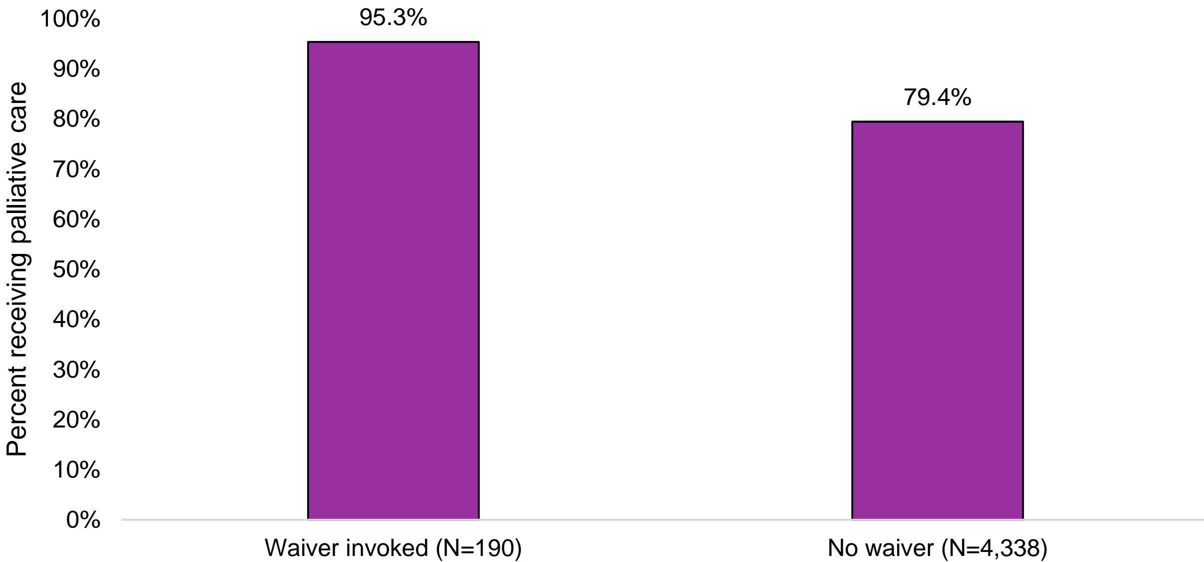
Figure 3. Proportion of Track 1 MAiD Deaths with a Waiver of Final Consent Invoked, by Serious and Incurable Condition, 2023



The following analyses explored characteristics of persons who accessed MAiD with a RFND and invoked a waiver, compared to persons who accessed MAiD without invoking a waiver.

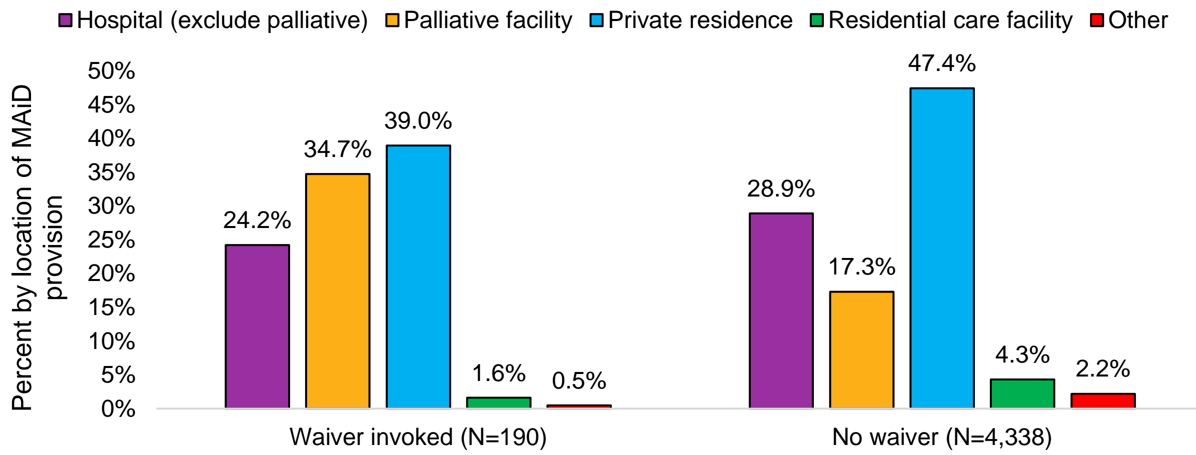
Figure 4 demonstrates that a larger proportion of persons with a waiver invoked had received palliative care (95%, N=181), compared to just under 80% (N=3,445) of persons with no invoked waiver.

Figure 4. Proportion of Persons Receiving Palliative Care, by Waiver of Final Consent, 2023



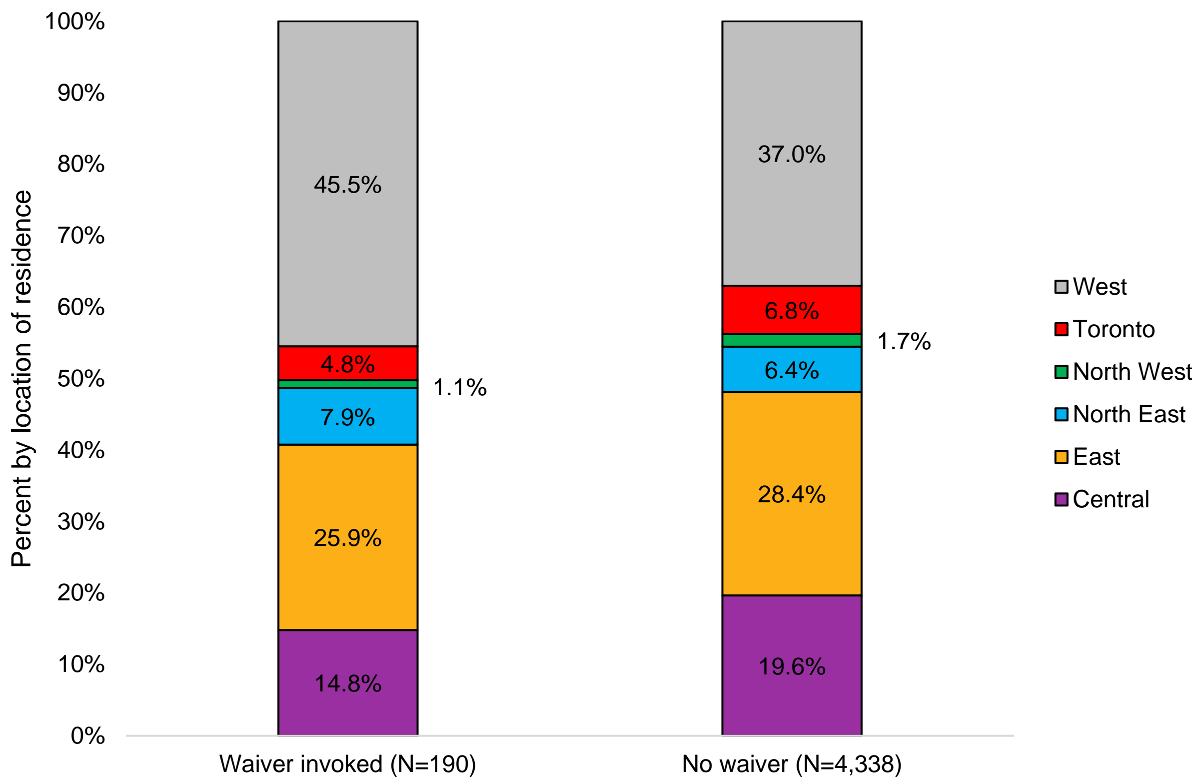
The large proportion of those with an invoked WoFC who received palliative care is also aligned with the location of death (Figure 5). The provision of MAiD for more than one third of persons with an invoked waiver occurred in a palliative care facility. When compared to persons who did not arrange a WoFC, persons with an invoked waiver less frequently had their provision occur in a private residence, which includes retirement homes, or in a residential care facility, such as long-term care homes.

Figure 5. Proportion of Track 1 MAiD Deaths by Location of Provision and Invoked Status of Waiver of Final Consent, 2023



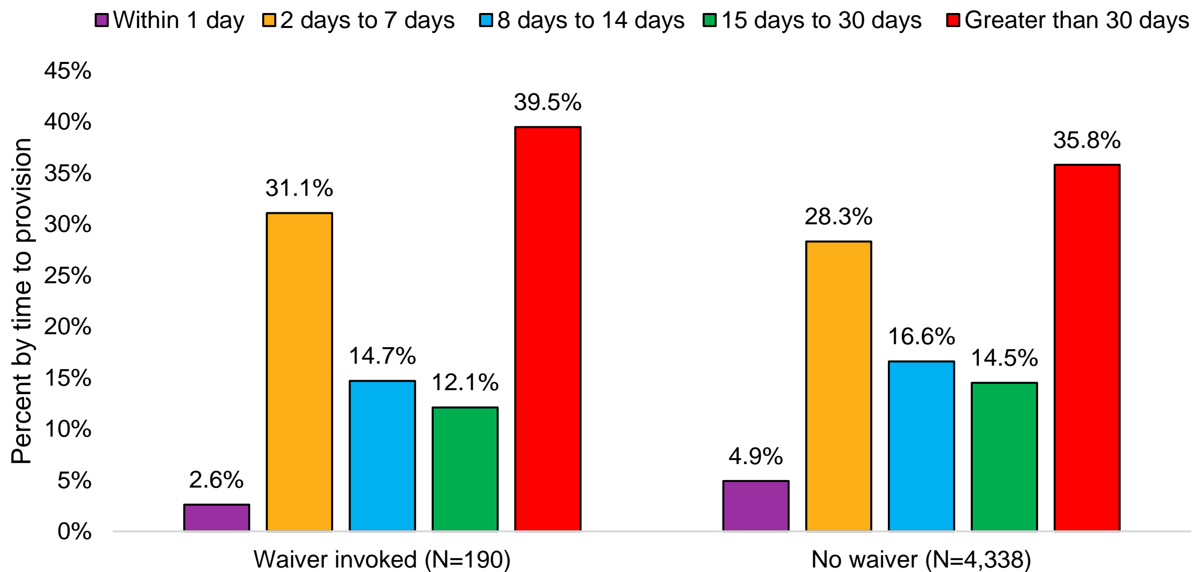
Regionally, similar patterns were observed when comparing persons with a waiver invoked and persons without a waiver invoked (Figure 6). Persons who accessed MAiD with an invoked waiver more frequently resided in the West region of Ontario, and less frequently resided in the Central region.

Figure 6. Proportion of Track 1 MAiD Deaths with a Waiver of Final Consent Invoked, by Region, 2023



The time period between a person's written/verbal request date and the date of provision was evaluated (Figure 7). Overall, the time from written/verbal request date to provision was similar for persons who accessed MAiD with or without an invoked waiver. However, persons accessing MAiD either the same day or next day of their request (see MDRC Report 2024.4) less frequently accessed MAiD with an invoked waiver.

Figure 7. Proportion of Track 1 MAiD Deaths with Number of Days Between MAiD Request and Provision, by Waiver of Final Consent, 2023



COMMITTEE REVIEW

The following case summaries illustrate relevant considerations when entering into an arrangement in writing to waive final consent.

Differentiating a Waiver of Final Consent from an Advance Request

CASE 1A

Case Overview

[Note: In the eligibility assessment process provided, Mr. A was first assessed by an intended provider (Assessor One). He was subsquently assessed by his family medicine practitioner (Assessor Two). Lastly, a third assessor became involved (Assessor Three) who was the eventual provider of MAiD.]

Mr. A was an older male diagnosed with a major neurocognitive disorder of Alzheimer's disease or mixed (Alzheimer's disease and vascular) etiology. He also presented with parkinsonian symptoms.

Mr. A initiated the process of MAiD due to his experience of cognitive and functional decline. He was distressed by his short-term memory loss. He also required assistance with some basic activities of daily living (ADLs). Mr. A described suffering related to

anticipatory fear of admission to long-term care; however, he also described that he was continuing to enjoy his quality of life at the time of his request for MAiD.

During his initial assessment of eligiblity for MAiD (completed by Assessor One), Mr. A demonstrated cognitive capabilities to provide decisional capacity. He experienced suffering due to current and future anticipatory suffering of dependency. Mr. A was determined by this assessor to meet eligibility criteria for a reasonably foreseeable natural death (RFND) due to the diagnosis of a terminal illness, additional comorbidities, and his presentation of functional decline.

During this initial assessment for MAiD, Mr. A was advised by Assessor One of his risk for loss of capacity due to cognitive decline. Mr. A completed a written arrangement to waive final consent with Assessor One. He selected a provision date 3.5 years in advance. In addition to waiving final consent to receive MAiD when he lost decisional capacity, Mr. A outlined additional conditions for which MAiD could be provided: inability to verbally communicate, inability to respond to verbal or physical prompts, reduced cognitive awareness of his environment and social surroundings, developing urinary and fecal incontinence, inability to sit unsupported, difficulty eating or swallowing, and/or uncontrollable bodily tremors. Mr. A and Assessor One had an understanding that one or more of these conditions were likely to be met prior to the identified provision date (3.5 years in advance).

Approximately a month and a half following the initial assessment, Mr. A’s family medicine practitioner (Assessor Two) completed a second assessment. Assessor Two opined that Mr. A’s death was not reasonably foreseeable due to their evaluation of limited functional decline. Assessor Two found Mr. A. eligible via Track 2 safeguards. Assessor Two also identified that Mr. A did not want to access MAiD in the short-term – rather he indicated that his wish was to identify a provision date far in advance.

Two months later, a third assessment was completed by Assessor Three who would eventually be the MAiD provider. Assessor Three determined that Mr. A met eligibility for Track 1 safeguards for a RFND. The WoFC completed by Assessor One was then also signed by Assessor Three, the MAiD provider.

Unfortunately, less than a year following assessments, Mr. A suffered a fall and required hospitalization. He had a possible delirium (increased confusion, hallucinations, agitation, falls, and a rapid decline in function)[3]. He required sedation and symptom management. Mr. A’s spouse arranged for the MAiD provider (Assessor Three) to be

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[3]A discussion of the finding of capacity is outside the scope of this report. However, some MDRC members raised concerns about capacity to consent. A brief discussion of this issue is included in the report. The MDRC will formulate additional recommendations for capacity evaluations in a future report.

contacted through the provincial care coordination service. Assessor One declined further follow-up.

Prior to the provision, Mr. A reportedly demonstrated a period of cognitive improvement. The MAiD provider (Assessor Three) determined Mr. A to have the cognitive capabilities to provide final consent[3], and an assisted death occurred. The WoFC was not invoked[4].

Discussion

Current legislation (Bill C-7) allows for final consent to be waived for persons whose death is reasonably foreseeable; however, legislation does not permit advance requests for MAiD. This difference between advance consent by waiver and an advance request is not outlined in legislation. Moreover, there is no legislative guidance on the duration of a WoFC. As such, several MDRC members felt that these areas in practice are a challenge for MAiD practitioners to navigate. Some other members presented that clinicians involved in MAiD have shared their emerging approaches and practices.

Evaluating Eligibility and Entering into an Arrangement to Waive Final Consent

The Department of Justice understands MAiD legislation to require that a person has been assessed and found eligible for MAiD prior to entering into a waiver of final consent[iii]. [*Note: The specific language of the Criminal Code indicates only that the person must meet all eligibility criteria before losing their capacity to consent, not before entering into a waiver arrangement.*]

Most MDRC members framed their discussions with the Department of Justice's presentation of legislation – a MAiD provider must confirm eligibility for MAiD and determine that a requestor's death is reasonably foreseeable (Track 1 safeguards), prior to evaluating and communicating a risk for a loss of capacity and entering into a WoFC. In alignment with the law and with guidance provided by the Canadian Medical Protective Association (2024), many MDRC members advised that the waiver should not be applied to future circumstances of eligibility (i.e., confirming at a later date, after the WoFC is in place, that the person has an irreversible decline in capability or intolerable suffering). Most members opined that such an approach would constitute an advance request.

Most MDRC members agreed that a WoFC with a provision date identified more than 3.5 years in advance raised concerns that this approach represented an advance request for MAiD. In particular, MDRC members were concerned that the prolonged timeline for the proposed provision date selected by Mr. A brought into question the MAiD practitioners' assessments of eligibility, particularly whether all criteria for a

[4] MDRC discussions of possible contraventions to MAiD legislation are for educational purposes.

grievous and irremediable condition and the determination of a reasonably foreseeable natural death were met prior to entering into a WoFC.

Many MDRC members identified that Mr. A's suffering may not have been intolerable if he was willing to endure several more years of suffering. In contrast, a few members offered that the determination of intolerable suffering could have been met at the time of MAiD eligibility assessment due to Mr. A's expressed experience of anticipatory suffering related to his fear of dependency and cognitive decline. Some members disagreed with the interpretation that fear of future loss of capacity may constitute intolerable suffering. Most MDRC members also aligned with Health Canada's guidance that the intended purpose of a WoFC was for circumstances where a person is experiencing enduring and intolerable suffering in the present and therefore, seeking MAiD in the short-term to relieve their suffering.

Some members discussed whether Mr. A met the criteria for irreversible decline at the time of assessment. The family medicine practitioner (second assessor) indicated a similar perspective. Some members discussed that establishing a trajectory of decline over multiple visits, particularly when assessing a person with dementia, may have aided in determining eligibility and provided opportunity to inform Mr. A of the nature of his decline and his risk for losing capacity. Some MDRC members offered perspective that the MAiD practitioner could have considered monitoring functional decline over multiple follow-up visits. With such an approach, the prolonged duration of time included in the WoFC that Mr. A had in place may not have been required (as a waiver would not be arranged until irreversible decline was confirmed). A few members expressed, in response, the concern that repeatedly bringing up MAiD to a person may unduly induce their decision to access MAiD. Some members also questioned whether the RFND criterion applied and noted that the family physician opined that he did not have a RFND.

Specifying a Provision Date and Use of Additional Terms

MDRC members discussed the complexities of a WoFC in a person with dementia, particularly related to an unpredictive trajectory towards a loss of capacity. Most members interpreted Mr. A to have aligned his WoFC with certain conditions, associated with his anticipated dementia trajectory, rather than a specific date. MDRC members referred to the inclusion of conditions such as a future loss of cognitive capabilities and multiple criteria reflecting a future state of physical decline (e.g., difficulty eating or swallowing) as examples. These members also could not identify from the available documentation that Mr. A selected a provision date with the intent of accessing MAiD in the short term.

Bill C-7 states that a requestor and a MAiD provider must enter into a waiver of final consent for a specified date for the provision of MAiD. Most MDRC members aligned with an interpretation of legislation that following confirmation of Track 1 eligibility for MAiD, the date of provision should be directly guided by the person accessing MAiD, with a readiness to access MAiD in the short-term (potentially three-to-six months). A few members discussed that Track 2 safeguards require persons to live with intolerable suffering for a minimum 90-day assessment period, so selecting a provision date within a reasonable range of this timeframe may be an acceptable practice.

Most MDRC members offered perspectives that there should be auditable documentation of the requestor's decision and rationale for selecting a provision date. Some MDRC members offered opinions that the use of a WoFC was not intended to include additional terms (e.g., specific cognitive communicative or physical losses), apart from a loss of capacity, to identify when the provision of MAiD should occur. Other members asserted that the WoFC is an appropriate document in which to record some of the specific variables that are discussed elsewhere in this report (e.g., deferring the provision date until family can visit).

Prolonged Waivers and Potential Impact to Caregivers

Some MDRC members presented that there are additional complexities that may need to be navigated when the provision date identified on a WoFC is prolonged. Specifically, family members' involvement may change over time, and therefore understanding of the arrangement between the MAiD provider and requestor may be unknown to the family members involved at the time. A prolonged specified provision date may introduce family distress. Family members may have difficulty understanding the arrangement to waive final consent for MAiD if regular follow-up, discussion, and review of the arrangement does not occur over time. A few members brought up that caregiver burnout may influence their perspective of when MAiD should be provided.

Conversely, a few MDRC members identified that waivers with a longer duration may be reassuring to family members, particularily to avoid the administrative and care burdens of repeat MAiD follow-ups. In these circumstances, the additional terms may be explicitly discussed with family to ensure they are aware of when and how to connect with the provider if the requestor's circumstances appear to be changing.

Finding of Capacity for Decision-Making

A WoFC is only invoked when a requestor has lost capacity to provide final consent. In the case of Mr. A, the waiver was not invoked because the MAiD provider considered that the patient had capacity for decision-making. Several members raised concern, however, that the evaluation performed to determine capacity for decision-making was unclear. Mr. A had experienced a probable delirium in-hospital. The MAiD provider did

not provide detailed documentation of the measures taken to evaluate underlying and potentially reversible causes of the delirium. Members offered perspective that MAiD practitioners should carefully consider clinical circumstances that may potentially influence capacity, and the approaches to ensuring capacity to provide informed consent have been met.

Practice Considerations

- A WoFC should not be used as a proxy for an advance request. All MDRC members agree that the intended use for a WoFC is for a provision date selected within a reasonable period (in alignment with some communities of practice, some MDRC members suggest a provision date identified within a 3-to-6-month period).
- It is important for MAiD providers to include documentation in their records of clinical decisions, where appropriate, when entering into an arrangement in writing for a WoFC, such as:
  - evaluation of risk for loss of capacity and communication with requestor regarding same, and
  - rationale for the selected provision date (e.g., requestor selected the closest available provision date, requestor wanting to celebrate a particular milestone, requestor wanting to facilitate family visits).
- Recognizing there is limited government guidance that informs the determination of a provision timeframe for a WoFC, MAiD practitioners would benefit from considering the following areas if a requestor wishes to select an extended provision date:
  - eligibility determination, particularly whether the criteria for intolerable suffering and advanced decline have been met prior to arranging a WoFC,
  - evolving end-of-life goals-of-care requiring re-assessment, and
  - increased involvement of persons involved in the requester’s care to remember and understand the terms of the WoFC and identify a potential loss of capacity to the MAiD provider.
- During an extended MAiD process (i.e., person requests MAiD in earlier stages of their illness trajectory), MAiD practitioners may decide to defer entering into a WOFC arrangement, if clinically appropriate, until later stages of the illness trajectory (when readiness to access MAiD in the short-term is identified).

Evaluating Capacity to Invoke a Waiver

CASE 1B

Case Overview

Mr. B was an older male in his 70s diagnosed with a major neurocognitive disorder of Alzheimer's etiology. He was in the moderate stage of cognitive decline. Mr. B was assessed and determined to be eligible for MAiD. A WoFC was arranged identifying a MAiD provision date six months later.

In the days leading up to the selected provision date, Mr. B's spouse contacted the MAiD provider to advise of increased confusion. The MAiD provider made arrangements to schedule the provision of MAiD.

Prior to the provision of MAiD, the MAiD practitioner determined, based upon information shared by the spouse (during previous telephone contact) and brief observation (i.e., loss of recognition of the MAiD provider), that Mr. B was incapable of providing final consent for MAiD. There was no verbal interaction documented with Mr. B to determine his level of cognitive understanding or to determine his ability to engage in decision-making. The MAiD provider reported that he did not want to elicit agitation in Mr.B as a consequence of not understanding the purpose of the interaction.

During the procedural aspects of the provision (e.g., establishing intravenous access), there were no signs of verbal or physical refusals. The WoFC was invoked, and the provision of MAiD was completed.

Discussion

MDRC members acknowledged that an evaluation of capacity prior to the provision of MAiD is a legislative requirement – a loss of capacity is required to invoke a waiver of final consent. As such, MDRC members advised that the determination of a loss of capacity should be documented, with some members recommending that the MAiD provider should include, more specifically, comprehensive documentation of their capacity evaluation. A few members brought forward discussion of a study of capacity evaluations in the context of MAiD for mental illness in another jurisdiction[iv], where documented global judgements of capacity[5] were often accepted by review committees and may reflect a normative position. Some other members discussed that this study of capacity evaluations could be viewed as raising concerns about the weakness of capacity assessments completed by practitioners in the study's jurisdiction. Based on this interpretation, these members offered perspectives that these findings may indicate a need for guidance on approaches to completing capacity evaluations for the purposes of MAiD.

MDRC members discussed that there is no legislative requirement for how to evaluate or determine capacity, or loss thereof. Many MDRC members discussed that healthcare

[5] Confirmatory statement of capacity, rather than addressing specific capacity criteria (e.g., demonstrating understanding and appreciation)

professionals are expected to have the knowledge, skill, and expertise within their regulated professional practice to determine a person's decisional capacity. As such, a few MDRC members identified the need to maintain MAiD practitioners' autonomy of practice. These members discussed that MAiD practitioners are responsible for upholding quality care[v] within their practice and providing specific practice guidance may create barriers for persons accessing MAiD. Furthermore, some members opined that evaluating capacity requires a flexible approach that is responsive to a person's capabilities in order to provide them with the best opportunity to appreciate and understand their choice for MAiD. Other members disagreed with this suggestion and raised concerns that the capacity evaluation skills of health care providers may be overstated. Particularly in the context of MAiD, comprehensive and structured capacity assessments should be required.[vi]

Some MDRC members acknowledged that knowledge of a requestor's clinical history and diagnoses, clinical observation, and obtaining collateral history of cognitive progression from a family member can represent an appropriate approach to determining a loss of capacity. A few members offered that more comprehensively evaluating capacity in Mr. B's circumstance would not have offered additional benefit to the person or family. These MDRC members deduced that Mr. B did not recognize the MAiD provider, and as such, was unable to identify that there was a decision (i.e., final consent for MAiD) to be made.

A few MDRC members aligned with guidance from the Convention on the Rights of Persons with Disabilities[vii] directing that, when possible, opportunity for active engagement in decision-making, including for persons with cognitive disability, should be provided. These members discussed that an opportunity to engage in final decision-making should be offered, even if there is belief that the person proceeding with MAiD may not be able to provide final consent. These members discussed that a possible approach, in alignment with this convention, would be to directly communicate and explain the healthcare being provided (i.e., provision of MAiD), creating an opportunity for the person potentially proceeding with MAiD to agree or disagree with the healthcare provided. Some MDRC members with experience providing MAiD identified that this approach presents additional ethical challenges, including the possibility of a person verbalizing refusal due to their limited cognitive capabilities, and thereby positioning the MAiD practitioner to be unable to uphold the person's decision to waive final consent and access MAiD. These concerns may suggest further uses for the 'additional terms' option in the WoFC to capture the potential clinical circumstances for which MAiD may be provided. In contrast, some MDRC members offered perspective that the use of a WoFC for a person with dementia presented unique and complex considerations that may not be aligned with the intended utility of a WoFC.

A few members discussed whether an approach to evaluation of capacity should include assessing whether the loss of capacity is reversible. For persons with dementia, such as Mr. B, these members discussed the consideration that the change in his cognitive capabilities could have been attributed to a reversible cause, such as a delirium, rather than illustrative of progressive cognitive and functional decline. These members, aligned with perspectives of maximizing decisional autonomy to provide final consent, suggested that differentiating between reversible versus irreversible causes of loss of capacity may be an important consideration when formulating a decision to invoke a WoFC.

Practice Considerations

- MAiD providers to recognize the importance of documenting their approach and evaluation of capacity prior to invoking a waiver of final consent. To support their evaluation for loss of capacity, MAiD practitioners may want to consider documenting the clinical reason for the loss of capacity (e.g., end-of-life loss of consciousness, cognitive decline associated with illness).

Components of a Written Arrangement

Case Overviews

Three deaths were reviewed where components of the arrangement to waive final consent raised concerns.

CASE 1C

Mr. C was a male in his 80s with metastatic lung cancer. He was bedbound with cachexia, had severe shortness of breath requiring supplemental oxygen, and was dependent for activities of daily living. Mr. C did not want to experience a “slow death”. He requested a WoFC, with a selected provision date two weeks later. The WoFC was signed and initialed by Mr. C, but not by the MAiD provider. Mr. C lost capacity to consent prior to his selected provision date. The WoFC was enacted in accordance to these terms; MAiD was provided. Upon review, the MRT identified that the written arrangement did not include the signature of the provider.

CASE 1D

Mr. D was a male in his 70s. He was diagnosed with metastatic urothelial cancer. He was cachectic and mainly bedbound. Mr. D reported profound pain, refractory to palliative pain management. He was experiencing some drowsiness. As such, a WoFC was completed with the provider with a provision date selected four days in advance. To facilitate a family visit, Mr. D deferred his provision past the date present on the WoFC.

The day after the scheduled provision, the provider completed a telephone follow-up. Reportedly, capacity was confirmed during this interaction. The requestor identified his intent to have MAiD the following day. The MAiD provider documented the interaction and changed and initialed the date on the existing written arrangement (a new waiver was not completed with the requestor's signatures or dates). The following day, Mr. D had lost capacity to provide final consent. The existing waiver was enacted (with the changed date).

CASE 1E

Mrs. E was a female in her 70s. She was diagnosed with metastatic cancer. She required hospitalization at end-of-life due to advanced care needs. Mrs. E was in profound pain. The MAiD provider identified that Mrs. E was at risk of losing capacity. As such, a WoFC with a provision date for two days later was selected. Due to severe pain, Mrs. E could not sit up and sign the WoFC. The requestor's adult child signed the WoFC on her behalf. Upon review, the MRT raised concerns regarding the lack of independence of the adult child signing the waiver. The signer was confirmed to be a financial beneficiary.

Discussion

MDRC members acknowledged that there is limited legislative guidance outlining the details of the arrangement in writing to waive final consent. As such, some members presented that the arrangement could be any written form provided it meets the basic legal requirements, such as specifying a provision date. Also, most members opined that none of the presented circumstances illustrated contravention to current legislative safeguards (Bill C-7). Some members advocated that defining additional requirements for completing a WoFC may be beneficial for MAiD practice.

A few MDRC members discussed that focusing on the components of the written arrangement may unintentionally amount to weak documentation of the informed consent process to waive final consent. A clinical tool (i.e., such as Clinician Aid D) emphasizes the structural components of a written arrangement (i.e., confirming consent, specifying the date of provision, confirming agreement with signatures and dates); however, such clinical aids and guidance do not prompt MAiD practitioners to attend to more complex end-of-life circumstances and considerations for navigating a waiver of final consent. These MDRC members presented that the emphasis for MAiD quality care and practices should be placed on clinical documentation (not completion of a form) outlining the process of obtaining informed consent to waive final consent and the approach to navigating MAiD care in alignment with the arrangement agreed upon between the MAiD provider and requestor (e.g., How will the MAiD provider be alerted if capacity is lost?; Who will be involved in facilitating the provider's access to the

requestor to provide MAiD?; What will be the alternate plan of care if the terms of the WoFC cannot be upheld?).

Considerations for the Written Arrangement

Most MDRC members agreed that given the exceptional medico-legal practice of waiving consent, MAiD practitoners should consider comprehensive documentation practices when completing a written arrangement for this purpose, reflecting the profound responsibility of this practice. Each case presented additional considerations for practitioners when completing a written arrangement to waive final consent.

CASE 1C

Most MDRC members indicated that a signed and dated WoFC is best aligned with standard legal documentation procedures to illustrate agreement to the terms of an arrangement. These members encouraged MAiD practitioners to attend to their documentation and ensure the WoFC is signed and dated by the MAiD provider and requestor.

CASE 1D

All MDRC members acknowledged the important role of the provider to prioritize and facilitate family involvement in the MAiD process. A few members offered perspective that these circumstances are an example of how structured documents (i.e., Clinician Aid D1) may complicate and potentially limit MAiD practitioners' clinical flexibility to attend to complex human needs at end-of-life. These members offered perspective that ongoing documentation of the arrangement to waive final consent may better reflect evolving circumstances.

Most MDRC members discussed that the terms of a written arrangement outline the conditions for which final consent is waived. Most members opined that changing one term of the arrangement, particularly a detail such as the date of the provision, may change acceptance of the remaining terms of the written arrangement. Therefore, these members opined that completing a new waiver was required. In addition, MDRC members acknowledged Health Canada's (2023) guidance that a new written arrangement to waive final consent should be completed if the provision date passes. Most members expressed views that a passed provision date expires the term of the arrangement, voiding the written arrangement to waive final consent. A few members opined that changing a provision date on a waiver is legislatively permitted, and has limited relation to practice.

CASE 1E

Some MDRC members discussed that informed consent is critical to the MAiD process, for adhering to legislative eligibility and safeguards, and for the provision of MAiD. A few MDRC members with legal expertise advised that informed consent is the basis for the exemption for MAiD to the Criminal Code of Canada. Accordingly, most MDRC members suggested that MAiD providers should ensure that obtaining consent to waive final consent is not unduly influenced by another person, or could be perceived to be influenced (e.g., potential influence of financial motivations of a family member or caregiver fatigue or burnout). A safeguard requirement for an independent authorized signer is not currently legislatively required when entering into a written arrangement for a WoFC; however, many MDRC members encouraged the use of an independent third-party signer when the requestor is unable to sign the WoFC. This approach may protect the MAiD provider from concerns about voluntariness when entering a written arrangement with the requestor to waive final consent.

Practice Considerations

- MDRC members encourage MAiD practitioners to enhance their clinical documentation of obtaining informed consent to waive final consent. MAiD practitioners should consider documenting, with specificity, the discussion with the requestor for how to proceed with the provision of MAiD.
- MAiD providers are also encouraged to consider the following when entering into an arrangement in writing to waive final consent:
  - The use of the provincial Clinician Aid D. The arrangement in writing serves to protect both the provider and requestor by outlining the terms for waiving final consent. Available provincial documents aid in meeting the required legislative safeguards and provide guidance on the structure of a written arrangement to waive final consent.
  - MAiD practitioners should follow guidance from CAMAP (2024) that a WoFC should include the signatures and dates of all parties (i.e., MAiD provider and requestor).
  - MAiD practitioners to follow guidance from Health Canada (2023) that a WoFC is invalid after the identified date for provision is past.
  - MAiD practitioners to consider that changing the date of a provision on a WoFC does not necessarily confer acceptance to all additional terms of the arrangement. Many MDRC members recommend completing a new WoFC with the requestor when there are any significant updates to the terms of the written arrangement. This is also in alignment with Health Canada’s guidance.
  - MAiD practitioners to take into consideration that the use of individuals to sign a WoFC on behalf of the requestor, who do not fulfill the legal definition for an independent signer within other MAiD safeguards, could raise concerns regarding the voluntariness of the requestor’s consent to waive final consent.

In such circumstances, use of an independent third-party signer may be prudent.

SUMMARY

Most MDRC members acknowledged that waiving consent in healthcare is an exceptional medico-legal practice. As such, most MDRC members recognized the profound responsibility of care and practice MAiD practitioners must navigate with persons accessing MAiD. CAMAP has released practice guidance to MAiD practitioners for approaching WoFCs. In addition, many MDRC members indicated that there would be benefit for further clarifications and guidance of legislative interpretations and applications including: determining the approach for obtaining consent to waive final consent, formulating a written document/record detailing the arrangement, and how to distinguish a waiver of final consent from an advance request for MAiD.

Informed Consent to Waive Final Consent

Some members presented that a priority should be to develop guidance that assists MAiD practitioners with navigating situations in which entering into a WoFC presents particular complexities. This guidance would focus on the development of an approach to care that attends to requestors' end-of-life care decisions, involves family and other healthcare professionals, and considers integration of the WoFC with end-of-life care. For many MDRC members, review of these MAiD deaths informed the following considerations:

- The need to establish regular follow-up and care within the MAiD process, particularly when death is not imminent, to monitor cognitive and functional decline to inform decisions for MAiD (e.g., determine when a person is at a significant risk for loss of capacity to inform the need for a WoFC).
- The need to integrate and consider MAiD care and decisions within a comprehensive understanding of a requestor's values, end-of-life goals and functional trajectory when arranging a WoFC.
- The need to determine and document a plan of care and involve family or persons close to the requestor and/or involved healthcare professionals (e.g., palliative care providers) to facilitate their understanding of - and engagement in - the MAiD process. For example, involved family members or healthcare professionals may have an integral role in recognizing a change in cognition and subsequently following an established plan of care to inform the involved MAiD provider of such a change.
- The need to establish alternate end-of-life care options should the MAiD provider not be able to provide MAiD (e.g., requestor illustrates signs of refusal or MAiD provider is not available).

Some MDRC members discussed that establishing and documenting a plan of care is an integral component of obtaining informed consent with the requestor to waive final consent. These MDRC members offered perspective that informed consent should be comprehensively documented and/or reflected in the terms of the arrangement to waive final consent.

Formulating a Written Arrangement and Additional Documentation

Most MDRC members agreed that given the exceptional medico-legal practice of waiving consent, MAiD practitioners should attend to the procedural aspects of entering into a written arrangement to waive final consent. Many MDRC members recommended using a standardized document (i.e., Ontario's Clinician Aid D) to facilitate comprehensive completion of a written arrangement. To potentially reduce legal risk, some MDRC members suggested following legal approaches to documentation when completing the WoFC to confirm agreement to the terms of the arrangement: including initialing of conditions, signatures and dates of the MAiD provider and requestor; considering involvement of an independent[6] third-party signer if the requestor is unable to sign; and completing a new written arrangement to reflect significant changes to the terms of the arrangement.

Most MDRC members recommended that MAiD practitioners attend to comprehensive documentation when providing MAiD care and navigating the WoFC process. First, members suggested documenting each legislative safeguard for entering into a waiver of final consent, including: confirmation of eligibility; evaluation and discussion of risk for loss of capacity; requestor's rationale for selecting the date of provision; determination of loss of capacity prior to invoking the waiver; and confirming an absence of signs of refusal. Additionally, MDRC members recommended documenting the clinical discussion of obtaining consent from the requestor to enter into a written arrangement to waive final consent.

Considerations for Distinguishing a Waiver of Final Consent from an Advance Request

Given the current public discourse regarding legislative amendments to permit advance requests, MDRC perspectives and learnings were collated to inform this relevant topic. In particular, government, regulators, and professional associations should be aware that MAiD practitioners may require clearer guidance to differentiate within their practice the use of a waiver of final consent from an advance request.

Many MDRC members interpreted a sequential application of the WoFC legislative safeguards, and as such, suggest that the MAiD practitioner should confirm,

[6] The signer should not benefit financially or otherwise from the person's death.

communicate, and document eligibility for MAiD prior to evaluating a risk for loss of capacity and entering into a written arrangement to waive final consent. This approach to practice would ensure that eligibility criteria related to the ability to make health care decisions is confirmed prior to the person's anticipated loss of capacity, a legislative requirement. Moreover, in alignment with professional guidance, this approach reduces the perception that the eligibility for MAiD is being applied to future circumstances or conditions, an approach more in-keeping with an advance request.

A few MDRC members proposed that a potential mechanism for distinguishing a waiver of final consent from an advance request is determining the source of end-of-life decision-making. Most MDRC members aligned with the perspective that the requestor should wish to access MAiD in the short-term and select a provision date accordingly. This process is directed by the requestor, giving 'permission[viii]' to the MAiD provider to proceed with MAiD in the absence of decisional-capability to provide final consent. The MAiD practitioner obtains informed consent to waive final consent, mutually agreeing to a written arrangement, and receives direction from the requestor to establish a date of provision. In contrast, an advance request typically relies on external persons (e.g., substitute decision-maker and MAiD provider) to decide whether the terms and conditions of the advance request are met.

The following table may be helpful to distinguish a waiver of final consent from an advance request.

Table 1. Potential Considerations for Distinguishing Between a Waiver of Final Consent and an Advance Request

Waiver of Final Consent	**Advance Request (Note: Advance requests are not legally permitted)**
The person meets all legislative criteria prior to arranging a WoFC, including intolerable suffering	The person, in conjunction with experts, establishes what findings would objectively constitute that they meet legislative criteria in the future
Self-directed process: Provision date identified by the patient exclusively	Development of the advance request is directed by the requestor. The timing of the provision is facilitated by others (e.g., family and MAiD provider), in accordance with the terms and conditions of the advance request
Decision-making to access MAiD is self-directed	

RECOMMENDATIONS

1. To Health Canada:

1.1 Health Canada (HC) to consider the issues presented in this MDRC report to inform and expand on legislative guidance provided to MAiD practitioners for entering into an arrangement in writing to waive final consent.

1.2 HC to consider providing guidance to MAiD practitioners for:

- differentiating a waiver of final consent from an advance request, and
- evaluating capacity, considering different clinical parameters and presentations (e.g., reversible causes, decreased level of consciousness, decline in cognitive capabilities), for the determination of invoking a waiver.

1.3 HC, in collaboration with the Department of Justice, to consider the issues presented in this report in their national consultation for advance requests for MAiD.

1.4 HC, in collaboration with the Department of Justice, to consider revising MAiD legislation to clarify safeguards for the use of a WoFC (i.e., requirements for the written arrangement, clarity for distinguishing a WoFC from an advance request).

2. To Ontario Ministry of Health:

2.1 The Ontario Ministry of Health (MOH) to consider revising the OHIP Fee Schedule to provide a compensation framework for the enhanced role of providing comprehensive and on-going assessment and care within the MAiD process (e.g., regular follow-up to inform end-of-life decisions [need for WoFC]).

2.2 The MOH to consider the issues reviewed in this report to inform the development of provincial guidance or policy outlining an approach for formulating and documenting an 'arrangement in writing' to waive final consent (e.g., British Columbia's Instruction for Completion). This may require changes to the Clinician Aid D1 (Waiver of Final Consent for RFND) document.

2.3 The Centre for Effective Practice (CEP) via MOH to consider the issues presented in this report to inform potential change to their Track 1 RFND Resource Tool to include the evaluation of capacity, and possible related considerations (e.g., determination of cause of loss of capacity), as part of the

stepwise approach to entering into a written arrangement to waive final consent for MAiD.

3. **To College of Physicians and Surgeons of Ontario and College of Nurses of Ontario:**

3.1 The College of Physicians and Surgeons of Ontario (CPSO) and the College of Nurses of Ontario (CNO) to consider employing this MDRC report to inform practice guidance for entering into a written arrangement to waive final consent for the provision of MAiD.

3.2 CPSO and CNO to consider employing this MDRC report to inform practice guidance for obtaining and documenting advance consent to waive final consent and for evaluating capacity prior to invoking a waiver of final consent.

4. **To Canadian Medical Protection Association and Canadian Nurses Protective Society:**

4.1 To the Canadian Medical Protection Association (CMPA) and Canadian Nurses Protective Society (CNPS) to consider employing this MDRC report to inform medico-legal information, resources, and advice provided to MAiD practitioners.

Ontario

RESOURCES

Consider the following resources to inform MAiD practice:

Health Canada: Implementing the Framework

CAMAP: Guidance on the Waiver of Final Consent

CMPA: The Continuing Evolution of Medical Assistance in Dying

Please contact occ.deathreviewcommittees@ontario.ca to request additional MDRC reports.

APPENDIX

Table 1A. Number and Proportion of Track 1 MAiD Deaths Where a Waiver of Final Consent was In Place and Invoked, by Cause of Death on the Medical Certificate of Death, 2022

Cause of death	Number with a waiver in place	Percent with a waiver in place	Number with a waiver invoked	Percent with a waiver invoked
Cancer-related (N=2,327)	1,166	50.1%	143	6.1%
Cardiovascular (N=409)	167	40.8%	12	3.0%
Neurodegenerative (N=282)	102	36.1%	8	2.8%
Respiratory (N=342)	131	38.3%	10	2.9%
Other (N=454)	173	38.1%	16	3.5%

Table 2A. Number and Proportion of Track 1 MAiD Deaths Where a Waiver of Final Consent was Invoked, by Cause of Death on the Medical Certificate of Death, 2023

Cause of death	Number with a waiver invoked	Percent with a waiver invoked
Autoimmune (N=17)	1	5.9%
Cancer-related (N=2,585)	144	5.6%
Cardiovascular (N=497)	12	2.4%
Complex chronic condition (N=119)	3	2.5%
Gastrointestinal disorder (N=88)	3	3.4%
Musculoskeletal disorder (N=64)	0	0.0%
Neurodegenerative (N=409)	3	0.7%
Respiratory (N=444)	18	4.1%
Other (N=305)	6	2.0%

Table 3. Number and Proportion of Track 1 MAiD Deaths with a Waiver of Final Consent Invoked, by Serious and Incurable Condition, 2023

Serious and Incurable Diseases		Number with a waiver invoked	Percent with a waiver invoked
Cancer	Lung cancer (N=611)	41	6.7%
	Colorectal cancer (N=310)	13	4.2%
	Pancreatic cancer (N=225)	12	5.3%
	Prostate cancer (N=223)	13	5.8%
	Hematologic cancer (N=209)	16	7.7%
	Breast cancer (N=186)	13	7.0%
	Ovarian cancer (N=81)	2	2.5%
Neurological	Parkinson's (N=118)	1	0.9%
	Dementia (N=53)	0	0.0%
	Multiple Sclerosis (N=41)	2	4.9%
	ALS (N=132)	1	0.8%
Respiratory	COPD (N=445)	13	2.9%
	Pulmonary fibrosis (N=166)	6	3.6%
Cardiovascular	CHF (N=451)	16	3.6%
	Atrial fibrillation (N=274)	9	3.3%
	Vasculopathy (N=241)	3	1.2%
Organ failure	Kidney failure (N=215)	6	2.8%
	Liver failure (N=107)	9	8.4%
Other	Diabetes (N=198)	6	3.0%
	Frailty (N=422)	10	2.4%

Table 4. Characteristics of Track 1 MAiD Deaths with a Waiver of Final Consent Invoked and Not Invoked, 2023

Characteristics of MAiD recipients	Number with a waiver invoked (N=190)	Percent with a waiver invoked	Number with no waiver invoked (N=4,338)	Percent with no waiver invoked
Received palliative care	181	95.3%	3,445	79.4%
Number of days between request and provision				
Within 1 day	5	2.6%	214	4.9%
2 days to 7 days	59	31.1%	1,226	28.3%
8 days to 14 days	28	14.7%	718	16.6%
15 days to 30 days	23	12.1%	627	14.5%
Greater than 30 days	75	39.5%	1,553	35.8%
Location of provision				
Hospital (exclude palliative)	46	24.2%	1,254	28.9%
Palliative facility	66	34.7%	749	17.3%
Private residence	74	38.9%	2,054	47.3%
Residential care facility	3	1.6%	187	4.3%
Other	1	0.5%	94	2.2%
Region of residence				
Central	28	14.8%	839	19.6%
East	49	25.9%	1,215	28.4%
North East	15	7.9%	273	6.4%
North West	2	1.1%	74	1.7%
Toronto	9	4.8%	289	6.8%
West	86	45.5%	1,582	37.0%

Ontario

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