Canadian Association of MAiD Assessors and Providers
Association canadienne des évaluateurs et prestataires de l'AMM

Clinical Considerations for Advance Requests for MAiD

December 2024

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Canadian Association of MAiD Assessors and Providers (CAMAP)

The Canadian Association of MAiD Assessors and Providers (CAMAP) is the unique association of professionals involved in the delivery of medical assistance in dying (MAiD) care in Canada. Founded in 2016, the mission is to support MAiD professionals in their work, educate the health care community about MAiD, and provide leadership on determining standards and guidelines in MAiD practice. CAMAP members strive to achieve the highest level of care for our patients and to model this care for a national and international audience. CAMAP works with governments in Canada at all levels, provincial medical and nursing regulatory bodies, national medical and nursing colleges, national professional groups, medical and nursing colleagues, and national organizations supporting MAiD.

Process

Clinical Considerations for Advance Requests for Medical Assistance in Dying (MAiD) was first drafted by the CAMAP Advance Requests Working Group. This Working Group included experts in MAiD assessments/provision, MAiD care coordination, advance care planning, palliative care, the ethical and legal aspects of MAiD, and advance requests. In July 2024, a draft was released to national stakeholders and expert readers for consultation. Following this consultation period, the Executive Director of CAMAP requested that the Working Group reconvene to review and incorporate feedback.This review was completed in October 2024. The resultant final draft was then submitted for final approval by the CAMAP Board of Directors for publication on the CAMAP website. It is a working document and will be amended to reflect legislative and regulatory developments and best practices as experience is gained in the provision of MAiD under advance requests. On October 30, the province of Quebec implemented their provincial regime for advance requests for MAiD. For full details on Quebec's provincial implementation, please access the appropriate government resources. In early 2025, CAMAP plans to review this document to ensure that it appropriately reflects the implementation of advance requests in the province of Quebec.

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Introduction

As Canada navigates the evolving landscape of Medical Assistance in Dying (MAiD), the potential (federal) and actual (Quebec) introduction of advance requests represents a pivotal development in end-of-life care. The Quebec National Assembly has amended its MAiD legislation to permit advance requests in some circumstances. The federal Special Joint Committee on MAiD (AMAD) has also recommended that the Criminal Code of Canada be amended to permit advance requests in some circumstances. Despite the fact that advance requests for MAiD are not permitted under the federal Criminal Code, in accordance with provincial prosecutorial charging guidelines, practitioners who provide MAiD in Quebec in accordance with the provincial law will not be prosecuted.[1]

In response to the second AMAD report, in April 2023, CAMAP formed the Advance Requests Working Group (hereafter referred to as the Working Group). The primary task of the Working Group was to develop this document to inform CAMAP and relevant stakeholders regarding the clinical considerations associated with the potential introduction of advance requests as recommended by AMAD.

In this document, CAMAP does not take a position on what the law with respect to advance requests should be. Rather, it seeks to bring clinical experience and expertise to the question of the feasibility of implementing the advance requests legislation as passed (Quebec) or recommended (AMAD). This includes offering commentary on the issues addressed in the legislation and AMAD recommendation as well as identifying issues on which they were silent but, from a clinical perspective, in order to maximize the realization of the objectives of the legislation, should be addressed.

First, we lay out the terminology used in the document and describe the legal background. Then we cover the major issues associated with an advance request for MAiD. In each subsection, we set out the position taken on the issue by the legislation/recommendations and explore the relevant clinical considerations. This includes identification of clinical challenges associated with particular policy positions taken and/or issues about which positions have not been taken.

This document is not an advocacy document. It is not advocating for advance requests for MAiD. Rather, it aims to contribute considerations that could underpin the establishment of an advance request framework that would meet the objectives as established by the policy-makers in their legislation/recommendations. To meet this goal, clinical input at the stage of design/implementation is essential.

Terminology

There has been a confusing array of terminology used in discussing various types of requests and consents for MAiD that are drafted in advance of loss of the capacity to make decisions with respect to MAiD. Some words and phrases are already in use in the Criminal Code; where that is the case, this document will use these terminology and definitions. Some expressions are part of the public discourse but not (yet) in the Criminal Code. Where that is the case, a definition for the purposes of this document is provided.

*"**Capacity**"* is a complex concept and a full exploration is outside the scope of this document. Its meaning is well-established in law – simply, the capacity to understand and appreciate the nature and consequences of the decision to be made. It is time specific (i.e., must be at the time of the making of the decision) and is specific to the decision to be made (i.e., a person may have capacity for making a decision about where to live but not whether to have a complex surgery). For the purposes of brevity in this document, when the term "*capacity*" is used, it is in reference to the person's decision-making capacity for decisions regarding MAiD; specifically, whether or not the person has the capacity to refuse or consent to MAiD and to make an advance request for MAiD. Further, when the term "*incapacity*" is used, it is in reference to a person's lack of decision-making capacity for decisions regarding MAiD.

- It should be noted that capability is part of the definition of grievous and irremediable condition (advance state of irreversible decline in capability). Capability within the context of grievous and irremediable condition is commonly interpreted as the person's ability to perform important functions (e.g., walking, talking, eating, socializing, etc.) whereas capacity refers to cognitive function being the ability to understand and appreciate information. For further information regarding capacity and capability please see CAMAP's relevant guidance documents and the Canadian MAiD Curriculum.

"***Advance request"*** for MAiD refers to a request for MAiD made by a person *before all of the eligibility criteria for MAiD,* as defined by the Criminal Code, *are met.*

*"**Advance consent**"* for MAiD refers to a consent given before *the loss of capacity to consent to receiving MAiD*. Advance consent for MAiD is legal in Canada only through one of two mechanisms: a "final consent – waiver" and "advance consent – failed self-administration."

> *"**Final consent – waiver**"* is a mechanism that allows for the waiving of the requirement that express consent be given by the person immediately prior to the provision of MAiD. This is commonly referred to as a waiver of final consent. A waiver of final consent may only be acted upon when all of the following are true:
>
> - the person's natural death has become reasonably foreseeable;

- all of the other procedural requirements for a valid waiver of final consent, as set out in s.241.2(3.2) of the Criminal Code, have been met;
- the person has lost capacity; prior to losing capacity, the person met all of the eligibility criteria.[2]

"***Advance consent – failed self-administration***" is a mechanism that allows for the waiving of the requirement that express consent be given by the person immediately prior to the provision of MAiD in the specific context of a failed self-administration (i.e., the person has self-administered the oral medications but has not died within a specified time period). An advance consent - failed self-administration agreement may only be acted upon when all of the following are true:

- prior to losing capacity, the person met all of the eligibility criteria;
- the person self-administered MAiD but has not died within a specified time period and has lost capacity;
- all of the other procedural requirements for a valid advance consent – failed self-administration set out in s.241.2 (3.5) of the Criminal Code have been met.

Note, under advance consent, all eligibility criteria must be met before the person loses capacity. By contrast, under an advance request, MAiD may be provided even if some of the eligibility criteria were not met until after the loss of capacity.

To reduce any potential confusion about related terminology, we offer the following additional definitions:

"***Advance directive***" is an umbrella term that refers to a person's wishes with respect to health care and personal care that are made before the loss of capacity to make such decisions. These are sometimes colloquially known as "living wills," "durable powers of attorney for health care," and "proxy directives." In Canada, advance directives are regulated by provincial/territorial legislation and common law and cannot include a request for MAiD.

"***Advance care planning***" is an umbrella term covering the elements of a comprehensive and ongoing process of reflection and conversation about future care between a person, their family/friends, healthcare providers, and caregivers. It focuses on understanding the values and wishes of an individual which will then inform care decisions in the future.

Advance directives, waivers of final consent, advance consent for failed self-administration, and (if legal) advance requests for MAiD can all fit together as part of a larger advance care planning conversation (where appropriate).

Legal Background

In 2016, the legislative framework for MAiD was introduced in Canada through Bill C-14.[3] This legislation required that immediately before providing MAiD, the provider had to ensure that the person receiving MAiD maintained capacity to consent to MAiD and offer the person an opportunity to withdraw their request; this requirement effectively prohibited advance requests for MAiD. In 2021, Parliament passed Bill C-7 which included what is commonly referred to as "Audrey's Amendment."[4] This amendment created an exception to the requirement of obtaining express consent immediately prior to the provision of MAiD through the introduction of a waiver of final consent. This created the opportunity for the provision of MAiD for persons who had lost capacity to consent to MAiD, so long as they had consented to MAiD and met all criteria and safeguards for MAiD *prior to losing capacity*. Full details on waivers of final consent can be found in CAMAP's associated Guidance Document. Bill C-7 also established a process through which a person could receive clinician-administered MAiD after a failed self-administration, another scenario where a person could receive MAiD after having lost capacity. On June 2, 2022, Senator Wallin introduced Bill S-248, which, if accepted, would amend the federal Criminal Code to permit advance requests for MAiD. Given its lack of progress through the parliamentary processes, it seems highly unlikely that this bill will proceed, therefore this document focuses on AMAD's recommendations and Quebec's legislation.

In February 2023, the Second Report of the Special Joint Committee on MAiD (AMAD) was released.[5] The report provided three specific recommendations with respect to advance requests:

Recommendation 21

That the Government of Canada amend the Criminal Code to allow for advance requests following a diagnosis of a serious and incurable medical condition, disease, or disorder (sic) leading to incapacity.

Recommendation 22

That the Government of Canada work with provinces and territories, regulatory authorities, provincial and territorial law societies and stakeholders to adopt the necessary safeguards for advance requests.

Recommendation 23

That the Government of Canada work with the provinces and territories and regulatory authorities to develop a framework for interprovincial recognition of advance requests.

Throughout the remainder of this document, these specific recommendations will be referred to as “AMAD’s recommendations,” whereas reference to the “AMAD report” refers to the discussion within the body of that report.[6]

The AMAD report does acknowledge potential risks, however, none of these risks were deemed sufficient to prevent the implementation of advance requests in Canada. The risks can generally be characterized as concerns for consideration, such as:

- The need for specific support for people with dementia,
- Difficulties in interpreting an advance request,
- Logistical concerns with administering MAiD for a conscious person who lacks capacity,
- The need for safeguards to protect, while also empowering, vulnerable persons.[7]

To help deal with these concerns, the AMAD report made note of the following possible safeguards:

- An advance request should be made after a diagnosis is present,
- The advance request ought to document objective criteria for intolerable suffering, such as being bedridden or not being able to recognize family members,
- The patient should ensure their wishes are known to family and healthcare providers,
- The advance request ought to be periodically reaffirmed,
- There should be a central, national repository where such advance requests can be registered,
- Patients should have access to healthcare supports to make a well-informed decision.[8]

It is worth noting that the report does not officially *recommend* these safeguards. Instead, the report recommends changes to the *Criminal Code* so that advance requests are legal with an understanding that the provinces and territories will be the ones developing standards and safeguards for the implementation of advance requests into practice.

In June 2023, Quebec passed Bill 11, which expands MAiD eligibility and formalizes the process for advance requests.[9] This legislative update enables individuals with serious and incurable illnesses leading to incapacity to make advance requests for MAiD. Furthermore, from March 7, 2024, those with significant disabilities due to serious physical impairments are also eligible (excluding those with mental disorders, except for neurocognitive disorders). In September 2024, the Director of Public Prosecutions issued charging guidelines indicating that clinicians who provide MAiD in accordance with the Quebec legislation will not be prosecuted under the federal Criminal Code. The changes with respect to advance requests will be in force as of October 30, 2024.[10]

In sum, advance requests are currently prohibited by the Criminal Code of Canada. Clinicians who provide MAiD under an advance request in accordance with the Quebec legislation will not be subject to prosecution under the Criminal Code. For full details regarding the implementation of advance requests in Quebec, please see the appropriate government resources. Practitioners in Quebec ought to be aware of and follow the legislative provisions regarding advance requests in their province, and practitioners outside of Quebec should not be incorporating advance requests into their practice prior to changes being made to the federal legislation.

Eligibility Criteria - Who May Draft an Advance Request for MAiD?

Requirement of a Serious & Incurable Diagnosis Leading to Incapacity

While both the Quebec legislation and AMAD's recommendations require a diagnosis leading to incapacity, there is a slight variation on what that diagnosis must be. In Quebec, there must be a diagnosis of a serious and incurable *illness* leading to incapacity. By contrast, AMAD's recommendations indicate that there must be a diagnosis of a serious and incurable *medical condition, disease, or disorder* leading to incapacity.

It must be noted that, in Quebec, the eligibility criteria for MAiD when a person maintains capacity (i.e., a contemporaneous request) is broader than eligibility criteria under an advance request: under a contemporaneous request, the eligibility criteria include "serious and incurable illness"[11] or "serious physical impairment causing significant and enduring disabilities"[12] but only "serious and incurable illness"[13] under an advance request. The criteria are also different between AMAD's recommendations ("condition, disease, or disorder")[14] and the current eligibility criterion for MAiD ("illness, disease, or disability")[15]. It is unclear what to make of these differences and whether they were intentional or not.

The Working Group notes that if the AMAD recommendations are followed verbatim, clinicians will require guidance from the federal government as to what is meant by terms like "condition, disease, or disorder" as these are not clearly distinguishable terms, nor do they have clear clinical definitions. For the sake of brevity, this document will use the umbrella term "serious and incurable *diagnosis* leading to incapacity" to capture the various terms used in AMAD's recommendations (condition, disease, or disorder), Quebec legislation (illness), and federal legislation (illness, disease, or disability).

Beyond this potential for terminological confusion at the clinical level, there are additional clinical considerations.

While a person would have to have a serious and incurable diagnosis prior to drafting an advance request, AMAD's recommendations do not indicate that the initial serious and incurable diagnosis leading to incapacity *must* contribute to the person's eventual eligibility for MAiD after a loss of capacity. For clarity, a person could develop a new serious and incurable diagnosis that causes their eventual loss of capacity, advanced state of irreversible decline in capability, or intolerable suffering, and thereby meet the eligibility for MAiD as outlined in their advance request. This aligns with current practice for MAiD assessments not involving advance requests. It is standard of care for MAiD assessors to consider new and overlapping diagnoses when determining eligibility for MAiD in persons with capacity.

The role of an advance request for MAiD would be for situations in which a person loses capacity to consent. Amongst the possible conditions that could lead to a loss of capacity there are two broad categories: progressive, predictable conditions, such as neurodegenerative diseases; and, sudden, unpredictable conditions, like severe strokes or accidents. Given that the Quebec legislation and AMAD's recommendations require an advance request be drafted after a diagnosis is given/received, advance requests would be largely restricted to only persons with progressive, predictable conditions.

It is worth noting that polls continue to indicate that most Canadians support advance requests for MAiD prior to a diagnosis (e.g., in anticipation of potential sudden, unpredictable conditions).[16] In regard to this ongoing support, the Working Group did consider the clinical feasibility of implementing advance requests prior to diagnosis, and came to a consensus that, under certain conditions, a clinically feasible protocol could be developed to support the implementation of advance requests in the absence of a specific diagnosis and therefore could accommodate requests due to sudden, unpredictable conditions that would lead to a loss of capacity, such as stroke or traumatic head injury. However, following the Quebec legislation and AMAD's recommendations, for the remainder of this document, we consider only advance requests made after a diagnosis and therefore, largely restricted to progressive, predictable conditions.

Mature Minors

The Quebec legislation specifies that a person must be 18 years of age or older to draft an advance request. This is in line with current Quebec and federal MAiD legislation. However, the AMAD recommendations include expanding MAiD to mature minors. This document does not provide any analysis specific to advance requests for mature minors.

Mental Disorder/Illness as Sole Underlying Medical Condition

Under current Quebec legislation, a mental disorder other than a neurocognitive disorder is not considered an illness for the purposes of eligibility for MAiD. Under the current federal MAiD legislation, until March 2027, a mental illness cannot be considered a serious and incurable illness, disease, or disability for the purposes of eligibility for MAiD. This document does not provide any analysis specific to advance requests for persons with mental disorder/illness as a sole underlying medical condition.

Who Can/Should Be Involved in the Drafting of an Advance Request?

Trusted Third Person

Under the Quebec legislation, the person drafting the advance request (hereafter referred to as the requestor) may designate a “trusted third person” whom they entrust with the following responsibilities:

> (1) notify a health or social services professional who provides care to the patient due to their illness where the trusted third person believes
>
> > (a) the patient is exhibiting the clinical manifestations related to their illness that are described in the request; or
> >
> > (b) the patient is experiencing enduring and unbearable physical or psychological suffering; and
>
> (2) when the patient has become incapable of giving consent to care, notify any health or social services professional who provides care to the patient due to their illness of the existence of the request, or remind such a professional of its existence.[17]

In Quebec, the requestor may also designate in the request a second trusted third person who, if the first trusted third person is prevented from acting, refuses, or neglects to do so, replaces that trusted third person. A trusted third person must be 18 or older and be capable of giving consent. It is worth noting that the Quebec legislation does not *require* the designation of a trusted third person.

AMAD’s recommendations do not mention a trusted third person. The Working Group identified three possible options regarding the involvement of a trusted third person and identified the following clinical considerations to be taken into account in future federal policy-making:

1) Permit an optional trusted third person as outlined in Quebec: Having a trusted third person would provide the requestor with added confidence that their advance request will be upheld. However, there may be a risk that individuals assigned the role of trusted third person may experience the responsibility as a burden. There is also a risk that the healthcare team may think that they have no authority or responsibility to prompt the request for assessment if a trusted third person is named in the advance request.
2) Require the requestor to name a mandatory trusted third person: Having a trusted third person would provide the requestor with added confidence that their advance request will be upheld. However, requiring a mandatory third person would potentially

discriminate against requestors who lack a person in their life who could assume the role of trusted third person.

3) Take no position as regards to trusted third person: This has the advantage of ensuring that all involved may maintain a degree of responsibility to monitor the patient. However, this may also dilute responsibility such that no single individual among family, friends, and the healthcare team takes action to prompt the request for assessment. It also does not reassure the requester there is someone specific who will ensure their request for assessment gets prompted. Further, this option may lead to an expectation that the healthcare team is responsible for prompting the request for assessment. Consideration should be given to the potential burden this would place on the healthcare team.

A full analysis of who can prompt the request for assessment is outlined later in this document (see section “Assessments Under an Advance Request,” subsection “Prompting a Request for a MAiD Assessment Under an Advance Request”).

Substitute Decision Maker (SDM)

Substitute decision-makers have no decision-making authority in relation to MAiD under current federal legislation, or within either an advance request under the Quebec legislation or AMAD’s recommendations. From a clinical perspective, it would be helpful for implementation guidance to make clear that an SDM does not have any decision-making authority with respect to MAiD.

The requestor may choose to have their SDM and trusted third person (if legislation suggests one is advised) be one and the same person, or different people. The advantages of having the same person in both these roles (SDM and trusted third person) are that the person would be involved in multiple aspects of advance care planning and hopefully this would allow a greater understanding of the requestor’s wishes. The advantages of having different people in these roles are that it maintains role clarity and may help prevent misunderstanding of the respective responsibilities. A full exploration of this decision is beyond the scope of this document and depends largely on the requestor’s personal circumstances.

Professional Healthcare Support

The Quebec legislation requires the involvement of professional support during the drafting of the advance request. The Quebec legislation requires that this support be provided by a Competent Professional who is defined further as a physician or specialized nurse practitioner.

AMAD’s recommendations do not require the involvement of professional support. However, the report associated with AMAD’s recommendations does include some discussion of potential safeguards and amongst these there is mention of the inclusion of healthcare supports to assist the requestor in making a well-informed decision.

To make a well-informed decision regarding an advance request for MAiD, the requestor must have sufficient understanding of their diagnosis, prognosis, the range of potential illness trajectories, and the therapeutic treatment options and their consequences. If the person lacks this understanding, it is not possible to make a well-informed decision, and this may give rise to future difficulties in implementing the advance request if the person's condition progresses in a trajectory that was not considered during the drafting of the advance request. It is worth noting that a well-informed decision will also allow for a well-drafted advance request. As outlined in the subsequent section, the clinical feasibility of implementing advance requests relies almost entirely on how well the advance request is drafted. If the requestor is well-informed then they are far better equipped to draft a high-quality advance request that clearly outlines their wishes regarding MAiD in all probable illness trajectories. The professional healthcare support at this stage of the process not only assists the requestor in making a well-informed decision, but also in documenting their decision within the advance request in such a way as to facilitate the enactment of that decision after the person has lost capacity.

There exists a range of potential healthcare supports that may assist the requestor in making a well-informed decision; all have their own advantages and disadvantages. The following could facilitate the drafting of high-quality advance requests:

- Be a member of a relevant regulated healthcare-related profession. This may include, but is not limited to, physicians, nurse practitioners, registered nurses, or social workers.
- Have expertise in the diagnoses most likely associated with advance requests for MAiD (ex. progressive, predictable conditions, such as neurodegenerative diseases) including the potential illness trajectories or have the means to collaborate with relevant experts when needed.
- Have experience and training in advance care planning and MAiD.
- Have undertaken some additional training in advance requests for MAiD. This could take the form of a new module associated with the Canadian MAiD curriculum, or training offered by other recognized organizations such as professional associations or regulatory bodies.

These features of potential healthcare supports need to be balanced against human resource considerations. Drafting an advance request properly will be a very time intensive process. In jurisdictions where advance requests for MAiD are currently permitted, the total number of MAiD provisions under advance requests are low. However, the number of people who draft an advance request is, relatively, quite high (approximately 7% of people over the age of 20 in the Netherlands).[18] Therefore, the demand on professional healthcare support for drafting an advance request is likely to be quite high in Canada as well, even if very few result in an actual MAiD provision via an advance request. Therefore, the human resource demand may not be feasible if only nurse practitioners and physicians are permitted to provide healthcare support for drafting an advance request, as is the requirement in Quebec.

Of note, both Quebec legislation and the suggested safeguard outlined by AMAD rule out the option of non-healthcare professionals. Notably, lawyers or paralegal services would not meet the standard.

Legislation, regulation, and policy should reflect the importance of health human resources in the implementation of advance requests for MAiD. Given the critical nature of this consideration, the Working Group encourages policy-makers to pay special attention to this issue as the clinical impact of decisions in this space will be significant.

What information Should be Included in an Advance Request?

Objectively Assessable Criteria

The Quebec legislation requires that the advance request must describe in detail the "clinical manifestations related to their illness" for MAiD to proceed.[19] These "clinical manifestations" must "be observable by a competent professional who would have to observe those manifestations before administering medical aid in dying."[20]

While the AMAD recommendations do not mention what should be included in an advance request, the associated report does suggest that the advance request ought to document objective criteria for intolerable suffering: "Many witnesses spoke about the importance of very clear, observable criteria that a person would need to set out in an advance request for MAiD, such as not being able to recognize one's family members, being bedridden, or not being able to eat, that would constitute their intolerable suffering."[21]

Given that the person being assessed for MAiD under an advance request will lack capacity, objectively assessable criteria/indicators for subjectively-defined suffering would facilitate the MAiD assessor's ability to detect the presence or absence of suffering. However, there is ambiguity in the wording of the Quebec legislation regarding what constitutes "observes". Clarity on what constitutes "observable" would be helpful for the MAiD assessor. For example, does the MAiD assessor have to be physically present and literally observe the manifestation happening directly in front of them, or can the MAiD assessor observe that the manifestation is present by reviewing reliable documentation including test results and reports on behaviour.

Values, Wishes, & Goals of Care

When thinking about how to successfully implement advance requests for MAiD, consideration of best practices in advance care planning may be helpful. Advance care planning is most successful when discussions and documentation include an individual's values, wishes, and goals of care in respect of their own self-identified quality of life. Both Quebec and AMAD suggest inclusion of objectively assessable criteria by which to measure subjectively-defined suffering which will help to facilitate the future MAiD assessment under an advance request. However, incorporating further context, as is often done in quality advance care planning, can provide the rationale behind the stipulated objectively assessable criteria, along with an understanding of suffering, as defined by the requestor, considering the entirety of their experience, including physical, emotional, and existential factors. This approach allows for adaptability when addressing both predictable and unpredictable courses of illness.

Standardized Templates

Standardized templates could be of assistance for a requestor to help draft an advance request where they can follow a series of options for identifying what they believe would qualify as intolerable suffering as defined by them. Quebec has created a standardized form that will be mandatory in Quebec. If advance requests become permissible in other parts of Canada, the Quebec form could be a useful starting point and CAMAP could be consulted in the development of standardized templates for advance requests.

Reviewing, Reaffirming, Modifying, and Withdrawing an Advance Request

Reviewing & Reaffirming

In Quebec, an early version of Bill 11 included a requirement for the competent professional to remind the requester of the existence of the advance request at regular intervals. However, this was removed, and the final Quebec legislation provides no requirement for review, update, or reaffirmation of the advance request once it has been drafted. AMAD's recommendations provide no mention of any requirement for reaffirming the advance request. However, the associated report does suggest that the advance request ought to be periodically reaffirmed.

The requirement to reaffirm the advance request does pose some advantages and disadvantages for the feasibility of the clinical implementation of advance requests. When assessing an incapable person for MAiD under an advance request, the MAiD assessor's main challenge is determining if the then-capable person wanted MAiD to be provided under the current circumstances. The longer the time period between when the advance request was drafted and when the person is being assessed for MAiD, the greater the chances the MAiD assessor may feel uncertain about what the then-capable person's wishes may have been about the current situation. If this time interval is long, the MAiD assessor may be concerned that the person may have changed their mind during the interim period, forgotten they drafted the advance request, or may have not appropriately predicted the trajectory of their illness. By mandating review, updates, or reaffirmation of the advance request, these potential uncertainties are decreased. However, review and reaffirmation of an advance request does create increased burden on the requestor and the healthcare supports. For example, repeated capacity assessments to ensure that the requestor maintains capacity to review their advance request would be onerous.

Given that AMAD has suggested (but not formally recommended) periodically reviewing the advance request, there are three potential options worth considering:

1) Mandatory review at a set interval: In Belgium, an advance request is only valid for 5 years but is renewable.[22] The advantage of requiring renewal at a set interval increases the chances that the advance request is in line with the requestor's wishes immediately prior to loss of capacity. However, nullification of an advance request that had not been renewed has the potential to discriminate against certain populations.
2) Recommended review at a set interval: In Luxembourg, the person will be sent a request for confirmation of the advance request every 5 years. However, the person is not obliged to confirm and the advance request for MAiD will hold without a time limit.[22] This avoids the potential concern regarding discrimination against persons who may face barriers to meeting the requirements of a mandatory renewal.

3) Recommended review with no specific time interval: In the Netherlands, there is no time limit to the advance request, but it is suggested that it be updated regularly with no specific designation of a time frame. This provides more flexibility, however, the loss of a fixed time interval also removes the specific prompt that would come with an option such as is done in Luxembourg.

If no specific time frame is set, the MAiD assessor may rely on the rate of clinical progression; for example, once the person reaches the moderate stages of their condition, the time between reaffirmations of the advance request may shorten if their cognitive abilities are changing more rapidly. For clarity, reaffirmation and rescindment of the advance request can only occur while the person maintains capacity to make decisions regarding MAiD. Once they have lost capacity in this regard, reaffirmation and rescindment are not possible. More frequent reaffirmation may help to facilitate the MAiD assessment as it provides the MAiD assessor more confidence that the advance request accurately depicts the wishes of the requestor just prior to losing capacity. However, these advantages need to be balanced with the resources required to maintain ongoing reaffirmation.

Modifying & Withdrawing

Under the Quebec legislation, "a patient who is capable of giving consent to care may, at any time, withdraw their advance request by means of the form prescribed by the Minister." Also, "A patient who wishes to withdraw their request must be assisted by a competent professional. After the form has been signed, the competent professional dates and countersigns the form to attest that the patient is capable of giving consent to care. The professional must make sure that the request is removed, as soon as possible, from the register…" AMAD's recommendations do not include withdrawal or modification but the associated report does suggest establishing a registry for advance requests, which could then entail a similar process for withdrawal.[23]

It is worth considering the clinical scenario where a requestor has expressed a desire to withdraw their request but has not been able to go through the formal process outlined in the Quebec legislation. The requirement for a competent professional (MD/NP) could create a barrier to withdrawing the advance request. If the federal government puts forward legislation following AMAD's recommendations, it is worth considering if any reliable record of a rescindment ought to qualify to rescind the request, including a verbal conversation with the trusted third person, SDM, family or friend, so long as the person had capacity at the time that they expressed the rescindment.

Under Quebec legislation, "A patient may modify an advance request only by making a new advance request by one of the methods specified in section 29.8. The new advance request replaces the previous one as soon as it is recorded… in the register."[24]

The AMAD recommendations make no specific mention of modification of an advance request. If advance requests are not modified in a consistent fashion, MAiD assessors may face difficulty in determining which version of the advance request to follow. MAiD assessors would require clear guidance on what qualifies as a valid modification of an advance request.

Assessments Under an Advance Request

Clinicians will need clear guidance on the assessments required for MAiD under advance requests. It will be important to:

1) Be clear precisely what needs to be assessed at the various stages in the process and who is required and authorized to make such assessments;

2) Who and how assessments are prompted once the requestor has lost capacity; and

3) Understand the complexity of assessing enduring and intolerable suffering in a person who has lost capacity.

Stages of Assessments

There are three critical stages in the process of MAiD under an advance request. First, an assessment will need to be conducted to ensure that the person seeking to make an advance request meets the eligibility criteria for making such a request. For example, under the Quebec legislation the requestor must, "suffer from a serious and incurable illness leading to incapacity to give consent to care."[25] AMAD recommended that advance requests can only be made "following a diagnosis of a serious and incurable medical condition, disease, or disorder leading to incapacity."[26] In Quebec, this determination must be made by a physician or nurse practitioner. AMAD makes no specific recommendation as regards who determines if the person has a "serious and incurable medical condition, disease, or disorder leading to incapacity." For the remainder of this document, this will be referred to as the "assessment for eligibility to draft an advance request."

Second, an assessment will need to be made at the point at which the trusted third person or someone else seeks to prompt action on the request (as described in the next section). This is the point at which the assessor will need to determine whether the person has lost capacity. If they have not lost capacity, then MAiD can only proceed through a contemporaneous request for MAiD. If they have lost capacity, then they would proceed to the third stage of assessment to determine if they meet criteria for MAiD under an advance request. For the remainder of this document, this will be referred to as the "capacity assessment." Neither the Quebec legislation, nor AMAD's recommendations make any specific mention of who performs this capacity assessment.

Third, an assessment will need to be made to determine whether the conditions for providing MAiD under an advance request have been met. There is further discussion of this type of assessment below. For the remainder of this document, this will be referred to as the "MAiD assessment." Under the Quebec legislation, this MAiD assessment must be conducted by two competent professionals (MD/NP). AMAD does not provide a specific recommendation in this regard.

The eligibility criteria for **drafting** an advance request (e.g., after a diagnosis with a serious and incurable medical condition) are a matter of public policy. From a clinical feasibility perspective, what is essential is that legislation is clear on what the criteria are, who is authorized to complete the assessments, and whether one or two independent assessors are required.

It makes sense that the second stage will rest on a capacity assessment. Any legislation should make clear whether that assessment can be conducted by only one, or must be conducted by two, independent assessors. It should also make clear who is authorized to complete such an assessment (e.g., only physicians and nurse practitioners or other healthcare professionals providing support to the person drafting their advance request as described above).

The conditions for **providing** MAiD under an advance request (e.g., in an advanced state of irreversible decline in capability and experiencing enduring and intolerable suffering) are also a matter of public policy. Again, from a clinical feasibility perspective, what is essential is that legislation is clear on what the conditions are, who is authorized to complete the assessments, and whether one or two independent assessors are required.

Prompting a Request for a MAiD Assessment Under an Advance Request

Before the second and third stages of assessment are performed, the request for these assessments must be "prompted." When the requestor initially sets out to draft an advance request, this will prompt the initial assessment to see if they are eligible to draft an advance request. However, once they have lost capacity, it seems unlikely that the requestor, themselves, will be able to prompt the request to assess their capacity and subsequent assessment to determine if they are eligible for MAiD under their advance request.

Under the Quebec legislation, prompting the request for a MAiD assessment under an advance request is the primary responsibility of a designated trusted third person, however, the request for assessment may also be prompted by the healthcare team. The legislation does not prohibit any friend, family member, or close associate from suggesting that the MAiD assessment be requested, however, only the healthcare team or trusted third person can put forward the formal request for the MAiD assessment to occur, which should only be done when they feel that the criteria outlined in the advance request may be met. While this may place the healthcare team as gatekeeper to MAiD assessment, this also prevents overburdening MAiD assessor human resources with unnecessary capacity and MAiD assessment requests. However, it is recognized that there have been instances where healthcare teams have created barriers to MAiD referrals due to issues of conscientious objection to MAiD. AMAD's recommendations do not make specific mention of who should have the ability to prompt the request for MAiD assessment. Further, having the healthcare team be the only prompt for the advance request could also lead to concerns that an advance request would not be respected because there is the possibility that healthcare team members may be reluctant to go through the challenges associated with going against the opinions of opposing family, friends, or other associates. If the healthcare team holds any responsibility for prompting the request for MAiD assessment, appropriate

support would be required to enable the healthcare team to fulfill this expectation. Balancing resource utilization with access and protection of the vulnerable should be important considerations for future policy-makers.

Assessing Suffering

Enduring and intolerable suffering will likely be the most significant component of a MAiD assessment as to whether the conditions for providing MAiD under an advance request are met.

Under current federal legislation for MAiD in requestors with capacity, suffering is entirely defined by the requestor: "Enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable."[27] If this criterion is to be used in any federal legislation regarding advance requests, the MAiD assessor will be very reliant on the quality of the description of suffering laid out in the advance request. If sufficient information is not incorporated into the advance request, the MAiD assessor will face a clinically difficult scenario: Given that the person is incapable of making decisions regarding MAiD, they are also highly unlikely to be able to provide the assessor with the requisite information to determine the nature of enduring physical or psychological suffering that *is intolerable to them.* Nor will they be able to explain to the assessor which relieving conditions that *they consider acceptable*. Therefore, for a MAiD assessment to occur under an advance request, it is imperative that the advance request has clearly spelled out objectively assessable indicators that the MAiD assessors can look to when attempting to determine if the requestor is experiencing intolerable suffering, as defined by the person when previously capable. As mentioned above, template checklists on standardized forms can assist the requestor to outline the objectively assessable criteria that they feel would be evidence of suffering that is intolerable *to the requestor*. However, template checklists may not reflect the nuances required in certain situations.

The Quebec legislation on advance requests requires that the requestor has described clinical manifestations of suffering in the advance request: "29.1. (*c*) be exhibiting, on a recurring basis, the clinical manifestations related to their illness that they described in the request;" but also provides this additional requirement:[28]

> 29.1. (*d*) ii. that gives a competent professional cause to believe, based on the information at their disposal and according to their clinical judgment, that the patient is experiencing enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable.[29]

This incorporates the MAiD assessor's perspective of what constitutes suffering. Each clinical situation will present differently and could be interpreted differently based on the individual assessor. In some situations, a person will be able to actively participate in the self-assessment of their suffering, even if they have lost capacity. In other situations, however, this assessment will have to be based solely on the observations of the healthcare team where there will no

doubt be varying interpretations between different professionals as to what does and does not constitute suffering. Aside from Quebec, MAiD assessments in Canada have been reliant on the requestor's definition of suffering and to incorporate this additional perspective from the assessors will require a dramatic shift to how Canadian MAiD assessments are performed.

However, the incorporation of the contemporaneous evidence of suffering from the MAiD assessor's perspective may avoid situations when the requestor asserts that they are not suffering, even though they exhibit the clinical manifestations described in the advance request. Many MAiD providers have expressed discomfort at the prospect of providing MAiD to a person lacking capacity who appears content but has met the criteria laid out in their advance request. It is worth noting that no MAiD provider would be compelled to provide MAiD in a clinical scenario they are not comfortable with.

Irreversible Unconsciousness and Intolerable Suffering

The relationship between an irreversible state of unconsciousness and intolerable suffering raises challenges. MAiD assessors and providers may feel more comfortable providing MAiD to an unconscious patient under an advance request with specific direction and protection from legislation or regulation.

While AMAD did not make specific recommendations on how to deal with unconsciousness, the AMAD report does read with a clear intention that advance requests would be available to both conscious and unconscious persons. Therefore, the Working Group anticipates that any federal legislation that may proceed from the AMAD recommendations will provide allowance for provision of MAiD to unconscious requestors. If the federal government wishes to allow for advance requests to be enacted for persons who are unconscious, a clinically feasible protocol for MAiD assessments under an advance request would only be possible if the legislation is drafted in a fashion that makes it clear that provision of MAiD to persons in a state of irreversible unconsciousness is legally permissible.

Assessments that Deem the Person Currently Ineligible

Under Quebec legislation, "An advance request does not lapse because a competent professional has concluded that medical aid in dying cannot be administered, unless that conclusion results from the refusal expressed by the patient to receive such aid" (see the section on refusal below).[30]

AMAD's recommendations do not indicate what should happen to an advance request if a person is deemed ineligible. If MAiD clinicians follow best practices in advance care planning in general, if a requestor undergoes an assessment for MAiD under an advance request and is found not to meet the criteria at that time, this outcome should not nullify the advance request. If maintaining alignment with similar protocols in medicine, such advance requests would remain valid and there can be a re-assessment in the future, at which point the requestor's eligibility can

be re-evaluated by the MAiD assessors based on any changes in their condition or circumstances. In this context, MAiD assessors would play a crucial role not only in determining current eligibility, but also in advising requestors and their families on the specific criteria and conditions to monitor going forward should a requestor be determined currently ineligible.

Provision of MAiD Under an Advance Request

Neither the Quebec legislation nor AMAD's recommendations provide substantial guidance surrounding the actual provision of medication for MAiD under an advance request. The Working Group has flagged a number of areas that will need to be considered for clinically feasible implementation of advance requests. As Quebec moves forwards with advance requests over the next year, many of these areas may be addressed by regulations and clinical guidance documents; if so, this document will be updated to reflect these. For now, the following discussion is guided primarily by review of advance requests in other jurisdictions, best practice in MAiD when a requestor has capacity, and the few areas of guidance that do exist in Quebec legislation and the Report from AMAD.

Preparation for the Administration of MAiD

Current MAiD provisions are done primarily when a requestor has capacity, with the provision of MAiD under a waiver of final consent and advance consent for failed self-administration being the only exceptions. Drawing from best practices for MAiD provisions under a waiver of final consent, the Working Group would note that it is important for all relevant stakeholders (the requestor, family, friends, etc.) to be aware that MAiD is not guaranteed after the person has lost capacity. Further, MAiD providers, the healthcare team, and any friends or family who are present to understand the current cognitive limitations of the person who is to receive MAiD under an advance request. Given their lack of cognitive capacity to make decisions regarding MAiD, it is possible that any attempt to explain the proposed procedure will not be understood by the person who is to receive MAiD as they are likely to comprehend only portions of any complex information that is communicated to them and may interpret the information in a very different manner than intended, such as in a very negative and distressing fashion. Therefore, any communications with the person should be done with a comprehensive and compassionate understanding of the person's current limited cognitive capacities. In many cases, pre-sedating the person with medications such as benzodiazepines may be warranted to avoid potential behaviours that may result from misunderstanding.

Neither the Quebec legislation, nor AMAD's recommendations mention the use of pre-sedation. In the Netherlands, there was a 2020 Supreme Court ruling surrounding an advance request for MAiD where pre-sedation was one of the important elements of the case and the Supreme Court deemed that pre-sedation was completely appropriate for the use in MAiD under an advance request (known as an advance directive for voluntary euthanasia in the Netherlands).[31] Prior to this case, there was no clear guidance on the issue of pre-sedation. MAiD providers will face challenges in providing MAiD under an advance request if there is no clear guidance surrounding the use of pre-sedation. This guidance would be very helpful both to provide consistent practice and also to provide protection for the MAiD providers and could take the form of legislation, regulation, and/or clinical guidance documents.

Refusal

Refusal under an advance request poses considerable challenges for MAiD assessors and providers. AMAD's formal recommendations do not include expressions of refusal. However, within the report, there is mention that "while any conscious refusal or resistance should be respected, unconscious resistance could be addressed by including in the advance request direction about what action a clinician is to take, or not take, if there are signs of resistance."[32] It is worth noting that federal legislation does stipulate that demonstrations of refusal through "words, sounds or gestures" should be respected under waivers of final consent even when the person lacks capacity.[33] It also clarified that "[f]or greater certainty, involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance."[34] In order to support MAiD clinicians, any future federal legislation, regulation, or clinical guidance should take special care regarding the issue of demonstrations of refusal.

Under the Quebec legislation: "Any refusal to receive medical aid in dying expressed by the patient must be respected and it is prohibited to disregard it in any manner. If the patient is exhibiting behavioural symptoms resulting from their medical state, such as resistance to care, the competent professional must, based on the information at their disposal and according to their clinical judgment, rule out the possibility that the patient is refusing to receive medical aid in dying."[35] Having clear guidance does support MAiD providers, however, this approach to refusals may also cause some clinical challenges. Similar challenges would be met if the federal government moves ahead with MAiD and adopts a similar approach to refusals as is required under waivers of final consent. Some of these potential clinical challenges are listed below:

1) The MAiD provider may face difficulty in determining if a requestor's refusal is specific to MAiD or simply an overall expression of refusal of any care. At times, many people who lack capacity may refuse all (or most) care. Determining if the current expression of refusal is part of a larger tendency towards refusal of all care or if the refusal is specific to MAiD will be a challenge for MAiD providers.
2) The MAiD provider may experience moral distress if the MAiD legislation takes the position that an incapable person can override an advance request for MAiD by demonstrating refusal and the province/territory the person is in does not allow an incapable person to override an advance directive to withhold life-sustaining interventions (e.g., An incapable person may express refusal to MAiD and then MAiD would not proceed. However, if that same person may have an advance directive to stop eating and drinking but if they request food, the advance directive would hold and they would not be given food.).

As noted above, there are also advantages to having clear guidance to respect demonstrations/expressions of refusal made by the incapable person:

1) Where the determination of suffering is difficult and the MAiD assessor is uncertain if the requestor meets criteria, an expression of refusal for MAiD would take the decision surrounding eligibility out of the assessor's hands.
2) It is feasible that an incapable person may demonstrate many things that are at odds with the advance request for MAiD. For example, the incapable person may meet the criteria for suffering as described in an advance request but may also express that they are not suffering, or even that they are happy. If the incapable person is expressing that they are happy, then they may also express refusal.

Post-Advance Request MAiD Care: Support for Families and Healthcare Teams

The Working Group recognizes the potential additional distress that families and healthcare teams may experience with MAiD provision under an advance request. Family or staff may have been caring for the person for a significant period of time and may feel that the person is not suffering from their perspective. Likewise, families and healthcare teams may experience distress if the incapable person is denied MAiD. The family or staff may continue caring for an incapable person who they feel is suffering and would have wanted MAiD. It will be important for staff to have the opportunity to debrief and share their potentially conflicting emotions about a MAiD provision or denial for someone who has lost cognitive capacity. The development of new resources may be needed to help families and healthcare teams cope with the special circumstances surrounding MAiD and advance requests.

Documentation & Registry

Quebec's legislation requires advance requests to be kept on a provincial register kept by the Minister in accordance with subparagraph 5 of the second paragraph of section 521 of the Act respecting health services and social services (chapter S-4.2). As noted above, AMAD made a formal recommendation "That the Government of Canada work with the provinces and territories and regulatory authorities to develop a framework for interprovincial recognition of advance requests" which is intended to provide guidance as to the documentation required and the possibility of a federal registry, or at a minimum a method for communication between provincial/territorial registries.[36]

Documentation

Best practices regarding documentation ought to be considered when outlining how to successfully implement advance requests for MAiD. As noted above, clear, consistent, and in-depth documentation of the requestor's wishes are essential to enact the request as they desired. Standardized tools can support the requestor and the assisting health professional to document all aspects required to best support the request in the future and to create consistency for MAiD providers.

Registry

An establishment of either a national or provincial/territorial advance request for MAiD registry could facilitate consistency in a variety of ways and support clinicians to better understand the goals of care of the requestor. A registry could contain the written advance request for MAiD, as well as collateral information to aid in the interpretation of said request. Collateral information could include personal or legal documents, audio or video recordings, or pictures. Registries could also be an online repository for advance care planning more broadly, while recognizing that advance directives are provincially/territorially legislated.

Health care teams could check the registry at appropriate times (e.g., admission to hospital for a person lacking capacity or a significant change in condition). When considering the risks inherent in creating and maintaining a registry, the Working Group encourages this to be examined while also examining the clinical benefits requestors, families, and health care providers could gain from a consistent means to store and refer to advance requests.

It is worth noting that the Quebec legislation seems to indicate that a requestor would have to have the Quebec form within the Quebec register in order to receive MAiD in Quebec.

In order to achieve interprovincial recognition of advance requests, as recommended by AMAD, the government could establish provincial/territorial registries that are connected or a federal registry.

From a clinical perspective, a provincial/territorial registry has a number of advantages and disadvantages that are worth considering:

- Reflect the provincial administration of healthcare and thereby support the housing of advance request documents in accordance with provincial/territorial laws and regulation, increasing requestor useability;
- Include in-depth provincial/territorial resources or considerations supporting the requestor when creating an advance request for MAiD or an advance care plan;
- Create variability within the registries;
- Potentially create inequity in access to MAiD through advance requests between provinces/territories;
- MAiD assessors and providers have noted that many people move provinces when facing the end of life. Quite often this is to live with family or other supports who can assist them through the final stages of their disease process. If provincial/territorial registries are not properly interfaced, requestors could face issues of having to register with multiple registries or face the unfortunate scenario where their advance request was not upheld due to registration issues.

From a clinical perspective, a federal registry has a number of advantages and disadvantages that are worth considering:

- Standard documentation across the country which would thereby support harmonization of care;
- Establish the ability to register an advance request for all Canadians;
- Could be built to interface with the Canadian MAiD Data Collection Portal;
- Would have to be connected with provincial/territorial information systems such that awareness and access is feasible for all healthcare providers who may be serving patients who may have advance requests.

Conclusion

In summary, this document has outlined the critical clinical considerations for implementing an advance request regime for MAiD in Canada. As legislation surrounding MAiD continues to evolve, this document will be updated to reflect new legal developments and emerging best practices. The fluid nature of medical and legal landscapes necessitates ongoing revision and dialogue to address any gaps or new challenges that arise. This commitment ensures that the document remains a relevant and reliable resource for healthcare professionals and policymakers. CAMAP is available for consultation on the clinical feasibility for any legislation, regulation, or clinical guidance relevant to advance requests.

When considering implementation for advance requests for MAiD, it is worth reflecting on advance care planning more broadly. Many of the pitfalls that could pertain to advance requests for MAiD also apply to advance directives and advance care planning. If Canada moves forward with the implementation of advance requests for MAiD, there will be an opportunity to remedy the shortcomings in how advance care planning is done in Canada more broadly. Advance requests for MAiD should prompt a broader conversation regarding high quality advance care planning, encompassing all aspects of future healthcare decisions. This holistic approach not only honours the values and wishes of requestors but also facilitates clearer communication and decision-making among requestors, their families, and healthcare providers.

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