Guidance on the Use of a Waiver of Final Consent

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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

Guidance on the Use of a Waiver of Final Consent was first drafted by the CAMAP Working Group on waivers of final consent. This Working Group included experts in MAiD assessment/provision, ethics, and the legal aspects of MAiD. Work began with the collection and review of all provincial/territorial forms for a waiver of final consent, standards of practice or guidance documents regarding the use of a waiver, the content of the Canadian MAiD Curriculum, and relevant previous discussions/issues raised on CAMAP's online community of practice (forum). An initial draft was sent to expert readers for consultation and feedback, and once considered and modified, a second draft was sent to the CAMAP Board of Directors for feedback and permission for wider release. A third draft was released to a wide range of national stakeholders for consultation and comment. Following this consultation period, all feedback was compiled and considered by the Working Group, and further amendments were made. The resultant document was re-submitted to the CAMAP Board of Directors for review, and approval was granted for publication on the CAMAP website. It is a working document and will be amended to reflect any legislative and regulatory developments as well as experience in the use of waivers of final consent.

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Terminology

There has been a confusing array of terminology used in discussing various types of requests and consents for MAiD being given in advance of loss of capacity. Some words and phrases are already in use in the Criminal Code. Where that is the case, this document will use the terminology and definitions from the Criminal Code. 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.

"***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 requests for MAiD are not currently legally permissible in Canada.

*"**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, in the form of a written agreement, that allows for the waiving of the requirement that express consent be given by the person immediately prior to the provision of MAiD. A final consent waiver is not a request for MAiD, it is a tool to provide an advance consent under specific circumstances.

  A final consent – waiver may only be acted upon when all of the following are true:
  - the person's natural death has become reasonably foreseeable
  - prior to losing capacity to consent to MAiD, the person met all of the eligibility criteria and satisfied all procedural safeguards
  - the person has lost capacity to consent to MAiD
  - all of the other procedural safeguards for a valid "final consent - waiver", as set out in s.241.2(3.2) of the Criminal Code[1], have been met

  Common parlance is to refer to this mechanism as a "waiver of final consent", or "a waiver", and we will do so in this document.

- "***Advance consent – failed self-administration***"[2] is a mechanism, in the form of a written agreement, 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 to consent to MAiD, the person met all of the eligibility criteria and satisfied all procedural safeguards
  - the person self-administered MAiD but has not died within a specified time period and has lost capacity to consent to MAiD
  - all of the other procedural safeguards for a valid advance consent – failed self-administration set out in s.241.2 (3.5) of the Criminal Code[1] have been met

To reduce any potential confusion with similar 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". Advance directives are regulated at the provincial/territorial level. In Canada, advance directives are not currently permitted to 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 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 advance requests for MAiD, once implemented in Quebec and if made legal in the rest of Canada, could all be part of a larger advance care planning conversation.

For the purposes of this document:

- "***capacity***" means "the capacity to consent to MAiD". This is an abbreviation used throughout this document (except when quoting the legislation) for the sake of brevity
- *"**agreement**"* means the written agreement referred to in legislation as a "written arrangement", which is either the final consent-waiver or the advance consent- failed self administration.

Background

When the legal framework for MAiD was introduced in Canada through Bill C-14, it required that immediately before providing MAiD, the provider had to offer the person an opportunity to withdraw their request and ensure that they gave express consent to receive medical assistance in dying.[3]

One consequence of this requirement was that some individuals chose to access MAiD earlier than they might have wanted, for fear of losing capacity and thus becoming ineligible for MAiD. This situation came to the public's attention most poignantly through the case of Audrey Parker, a 57-year-old woman from Nova Scotia with breast cancer.[4] In March 2021, Parliament passed what is commonly referred to as "Audrey's Amendment" to create an exception to the requirement of obtaining express consent immediately prior to the provision of MAiD. This exception was implemented via the introduction of a final consent-waiver.

Applying categorical legal language to the variety and complexity of medical conditions and circumstances is challenging. There has been a variable evolution in practice with respect to the use of waivers of final consent, prompting CAMAP to develop this guidance document.

This document reviews what is permitted, what is best practice, and explores what must be done to account for exceptional circumstances. CAMAP recommends that each situation be assessed and carried out on a case by case basis, but always within the law, sensitive to jurisdictional variances, and keeping in mind the best practice guidance reviewed and outlined in this guidance document.

In all cases, clinicians are reminded that the purpose of a waiver of final consent is to protect access to MAiD provision for those already eligible for MAiD prior to their loss of capacity, and it is not to be used as an advance request for MAiD in the future.

This is a working document and will be amended to reflect any legislative and regulatory developments, as well as evolving experience, in the use of waivers of final consent.

Waivers of Final Consent: Clinical Implementation and Best Practices

A waiver of final consent is a written agreement that allows the clinician to provide MAiD on or before a specified date if the person loses capacity for any reason (e.g., increased analgesia requirements, illness progression, fall/head trauma). This exception to the requirement for express consent immediately prior to the administration of medication must be arranged with a person before they lose capacity.

A person can enter into a waiver agreement if the following requirements are met:

- their natural death has become reasonably foreseeable
- they are at risk of losing capacity to consent to MAiD
- they have been informed of that risk by the clinician

In addition, according to federal legislation:

- the written agreement exists between the person and the provider for MAiD and states MAiD is to be provided on a specified date,
- the person consents in the written agreement to the provision of MAiD on or before the specified date if they lose capacity prior to that date

Legislation does not preclude additional stipulations to proceeding after loss of capacity from being added as part of the agreement (e.g., “If I lose capacity prior to the specified date, I want to allow the time necessary (to a maximum of 5 days) for my daughter to arrive from California, and then proceed with MAiD as soon as possible”), but in all cases, the assisted death must occur on or before the date for provision specified in the waiver agreement.

MAiD can proceed under a waiver agreement only if:

- the person has lost capacity
- the person met all of the eligibility criteria and satisfied all of the procedural safeguards (apart from final express consent) prior to the loss of capacity
- the person does not demonstrate resistance or refusal at the procedure (The legislation notes that involuntary words, sounds, or gestures made in response to contact do not equal refusal or resistance).
- the MAiD provider administers the substance in accordance with the terms of the written agreement.

CAMAP recommends that when invoking a waiver, each of these elements are clearly documented.

Determining whether or not a person’s natural death has become reasonably foreseeable is the responsibility of the MAiD provider.[5, 6]

Because capacity is task-specific, some people may have the capacity to consent to MAiD but not the capacity to understand and agree to the more complex concept of a waiver of final consent. In such a circumstance, a person may not enter into a waiver agreement.

Entering into a waiver agreement need not be delayed until the completion of a second assessment. However, the waiver is *only valid for use if prior to the loss of capacity*, the person has been found eligible by two independent clinicians and all procedural safeguards (except giving express consent immediately prior to administration of MAiD) have been satisfied.

There are specific logistical considerations pertaining to completing and invoking a waiver of final consent.

Setting a date

Understanding that they are always free to change their mind, in order to enter into a waiver of final consent, a person must nonetheless be willing to set a date for their MAiD provision. It must also be true that they are at risk of losing capacity prior to the date specified in the agreement and that they have been advised of this risk. It should be made clear that this agreement states that if the person loses capacity on or before the specified date, they have requested and consented to proceed with MAiD.

If the agreed upon date arrives while the person still retains capacity, the waiver of final consent cannot be used. That is, they will have to be asked for express consent which they may give or deny. If they chose not to proceed but still want to do so at a later date, they may specify a new date for provision and enter into a new waiver.

A waiver of final consent has one specific provision date and, while it can be used before this date if the person has lost capacity, it cannot be used once the date has passed. If MAiD has not occurred by this date, a new waiver may only be established if the person retains or regains capacity. Health Canada guidance suggests that any change in date requires a new written agreement, not just a date change on an older agreement.[6]

There may be some value in reviewing a person's wishes prior to the specified date, rather than waiting for the exact date itself, so as to avoid any inadvertent lapse of access to MAiD via a waiver.

Provision prior to the specified date

While federal legislation requires that the waiver specifies a date for the provision of MAiD, it allows for provision on an earlier date if:

- the person loses capacity before the specified date
- the person was found fully eligible for MAiD prior to their loss of capacity
- the person consented to provision on or before the specified date in the written waiver agreement
- any other conditions stipulated by the person regarding when to proceed, after loss of capacity, have been met.

Inclusion and implementation of additional stipulations

Although loss of capacity will permit invocation of a waiver, some people may request specific additional stipulations be added to the agreement.

Any conversation around a possible waiver of final consent provides an important opportunity to clarify the meaning of the waiver for both the person and their family/friends, for example by asking if there are any conditions in which the person would NOT want to proceed with MAiD as soon as possible once they had lost capacity (e.g., they wish for a delay of the procedure until certain family/friends are able to say goodbye, or they may wish to require contemporaneous evidence of suffering). If stipulations are added, the person and family/friends must understand that if these stipulations cannot be met (e.g., a family member is unable to travel to be present) the provider cannot proceed with MAiD. Therefore, CAMAP recommends that when stipulations are added, the person considers qualifying those stipulations to permit some flexibility, provided that doing so is still in keeping with the wishes of the person (e.g., adding the words, "when possible" or "if possible" such as "I want my brother, Jim, in attendance, if possible").

The absence of additional stipulations provides an opportunity to stress that there is a mutual understanding by the person and their family/friends that the person is saying that in ANY circumstances in which they lose capacity before the specified date, they want MAiD to proceed as soon as it can be arranged.

It may be appropriate at this time to discuss reasonable expectations about how long it may take to respond to apparent incapacity and to discuss the importance of a palliative care plan to keep the person comfortable until the provider has the opportunity to assess capacity and provide MAiD if appropriate.

- Are contemporary signs of suffering required at a MAiD procedure?

This is not required by the law governing MAiD. With respect to invoking and proceeding on the basis of a waiver of final consent, the person must have met all eligibility criteria and safeguards prior to losing capacity, and there is no requirement to repeat the assessment of eligibility at the time MAiD is provided. If the person is unconscious or has otherwise become incapable of providing consent and the waiver is invoked, the law requires only that the person does not refuse or resist the provision of MAiD. It does not require the provider to reconfirm or assert that the person is still suffering physically or psychologically at the time of provision.

Transferability of a waiver

Common practice is to establish a waiver between 1 person and 1 provider. However, federal legislation does not prohibit the use of alternative practitioners named within the same agreement (for example, in case the intended practitioner is unavailable). This practice is common in several provinces/territories.

What is important is that the waiver is transferable *only* to an alternate provider who is named in the agreement and who has conducted an independent eligibility assessment prior to the loss of capacity, discussed a possible waiver with the person, and agreed to enter into such an agreement with them. This can essentially be thought of as multiple waiver agreements compiled into one document.

Health Canada guidance similarly reminds clinicians that in all cases, the practitioner who provides MAiD must:[6]

1. have personally assessed the person and found them eligible for MAiD while the person still retained capacity to provide informed consent
2. personally ensure that all safeguards have been satisfied
3. be named in the written arrangement
4. have agreed to enter into the arrangement with the person

When providing MAiD as an alternatively named provider, it is recommended that the practitioner document all of the above to have occurred.

Signatories

Federal legislation does not require that the written arrangement for a waiver of final consent be signed and/or dated by either the person or the practitioner. It therefore makes no mention of the potential use of signature proxies or witnesses to the written arrangement.

Provinces, territories, and professional regulatory bodies have established a diversity of guidance for written arrangements for the waiver of final consent that may include:

- requirements for both the person and the provider to sign the written agreement
- whether a signature proxy for the person can sign on their behalf

CAMAP recommends that both the person and the provider(s) sign all waiver of final consent agreements. In case of any question of the actions taken by a provider in the care of a person who has lost the ability to consent, the provider will always be best served to have had a signed written agreement with the person.

Best practice is to have the person sign the form personally, in person with the provider, and then return the form to the provider for documentation purposes. In the circumstance when a person is physically unable to provide a signature (e.g., cannot write due to illness or disability), CAMAP recommends allowing and obtaining a proxy's signature. This proxy is not a substitute decision maker or authorized to consent to MAiD on behalf of the person, only to provide a signature on behalf of the capable and consenting person. Some jurisdictions have requirements for who this proxy may/may not be, and CAMAP advises practitioners to be aware of any local restrictions.

If necessary, these events may happen virtually.[7, 8]

If signatures are not possible for some reason, a verbal agreement to the written arrangement with the provider could suffice as legislation does not require signatures. Obtaining a video recording of the person providing oral consent to the written agreement could be considered. Documenting why the person could not sign is strongly encouraged. Whether signed or not, clinicians are reminded that federal legislation requires a written agreement be prepared outlining the arrangement between a person and provider.

CAMAP does not support the routine use of a witness to any of these signatures. Such an additional burden is seen as an obstacle rather than a proven safeguard. However, in some cases (e.g., where a person with a physical disability may make an inconsistent or uninterpretable mark, or if concern of a possible legal challenge to the validity of a signature) obtaining a witness may have some probative value for the benefit of both the provider and/or the person.

Documenting which family members/friends were present for any discussion or decisions about the agreement will be helpful and is strongly recommended whenever possible.

Nothing in law precludes a person from asynchronously signing the agreement and having the provider sign it at another time. However, if this is done, CAMAP recommends strong documentation, such as including reasons as to why asynchronous documentation was deemed necessary.

Where multiple providers may be listed on a single document, providing physical signatures may not be feasible. As noted previously, signatures are not required by legislation. However, any named providers must be aware of and agree to enter into the agreement outlined in the waiver of final consent. When invoking a waiver, an alternatively named provider should document that they were aware of and had agreed to enter into the agreement and had personally assessed the person as fully eligible before the person lost capacity.

Regardless of these best practice recommendations, MAiD practitioners should be aware of and follow any guidance specific to their own jurisdiction of practice.

Permission vs. obligation

According to federal law, a waiver of final consent *permits* the provider to administer MAiD under specific circumstances (the loss of capacity in a person already found fully eligible for MAiD and having met all safeguards, plus any other stipulations having been established). However, it *does not obligate* the provider to provide MAiD, nor does it impose any legal duty to proceed. (For example, when a person loses capacity, death may be imminent, and the provider may not be able to arrange a provision before natural death intercedes).

One way of explaining this to patients and families is that the waiver is “like a permission slip, not a binding contract.” It is good practice to document such explanations.

Refusal of MAiD

Even if a valid waiver of final consent exists, a MAiD provision cannot proceed if the person demonstrates “by words, sounds or gestures, refusal to have the substance administered or resistance to its administration.”[9] For greater clarity, a person may have lost the capacity to consent to MAiD, but they always retain the legal ability to refuse its administration.

Legislation clarifies that “involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance.”[9] This means any reactions to touch, restraint, or discomfort during the establishment of IV access (e.g., twitching or physical

recoiling from contact or insertion of a needle) **do not** constitute a demonstration of refusal or resistance.

According to Health Canada guidance, a demonstration of resistance permanently invalidates the waiver. However, if the person regains capacity at a later date, they could consent to MAiD being provided at that time or could complete a new waiver of final consent with their provider.[6] CAMAP sees some practical difficulties arising from this interpretation (e.g., a person being in a delirium and saying "I don't want that medication" coming out of the delirium in 24 hours and verbally saying they want the original waiver to still stand) and notes the idea of permanent invalidity has not been tested in the courts. Until such time, however, CAMAP recommends following Health Canada's guidance on this matter.

Reassessing consent

After a waiver of final consent is in place, the family/friends and/or healthcare team supporting the person may alert the provider to (a) the possibility that capacity has been lost; or (b) that any other agreed-upon stipulations have been met. It remains the responsibility of the MAiD practitioner to establish and document if and when these conditions have been met.

When invoking a waiver, consent to proceed is not sought unless the clinician believes capacity might have returned. If there is doubt, it may be best to take an indirect approach, through conversation, to first address level of consciousness, awareness, and orientation. If capacity has returned, the waiver cannot be invoked, and the person should be asked for express consent.

If capacity has been lost, neither family/friends nor the incapable person should be asked for consent to the provision: the family/friends have no authority to grant consent, and the person has already provided (advance) consent in the waiver agreement. What can be helpful are explanations of what is happening (e.g., reintroduce yourself to the person and their supporters, explain you are there to help, that the person no longer has capacity, and that you plan to proceed on the basis of the previously given consent).

Duration of validity

There is no limit in federal law as to how remote a specified date of provision can be from signing the waiver. Nonetheless, some provincial regulatory bodies have stipulated guidelines regarding such duration, and Quebec's *Act Respecting End-of-Life Care* requires the waiver of final consent agreement be entered into within 90 days of the date that MAiD will be administered.[2] Practitioners should take regional guidelines or standards into account in establishing their own comfort levels with respect to the duration of waivers, but this should be decided on a case-by-case basis.

Non-MAiD medication use

Regular medications, including routine or increasing doses of analgesics, should be used as medically indicated. If the result is loss of capacity, that may be acceptable (and perhaps one reason a waiver was sought and signed). With a waiver of final consent in place, people should not feel the need to withhold taking prescribed medication in order to preserve capacity.

Challenging Circumstances

For the majority of cases, the preceding section "Waivers of Final Consent: Clinical Implementation and Best Practices" will have provided sufficient information for the reader to appropriately incorporate waivers of final consent into their MAiD practice. The following section provides a deeper analysis of some of the circumstances where the use of a waiver may be especially challenging.

Same day provision

Some confusion exists regarding whether or not a person may receive MAiD on the same day that they sign a waiver of final consent (i.e., signed a waiver on June 1st for the specified date of June 1st.)

Federal legislation states:

3.2 (a)(iv) in the written arrangement, they consented to the administration by the medical practitioner or nurse practitioner of a substance to cause their death on or before the day specified in the arrangement *if they lost their capacity to consent to receiving medical assistance in dying* **prior to that day**; (emphasis ours)

The wording of the legislation entails a requirement that the person lose capacity *prior to the date specified for the provision of MAiD*. In most cases, this is not an issue because waivers are not usually intended for same day use. But because of this wording, in the exceptional case when a provider suspects a waiver may need to be invoked later in the same day on which it is completed (e.g., a person at high risk of incapacity who is waiting for the imminent arrival of a loved one before proceeding, or a person who is at risk of losing capacity the same day they are being assessed for eligibility and who wishes provision as soon as possible), the waiver should specify a date of expected provision one or more days from the completion of the agreement (i.e., signing a waiver on June 1st for the specified date of June 2nd may allow provision on June 1st).

This approach may be especially helpful in a person requiring sedation/analgesia during a forced transfer to a new facility for provision. If there is risk of loss of capacity due to appropriate symptom management prior to and during a forced transfer out of an objecting/abstaining healthcare institution, clinicians should consider using a waiver of final consent- dated the following day- prior to the transfer.

Requests for sedation prior to the arrival of the MAiD provider

As part of the discussion about a waiver of final consent, some people may ask that they be given sedating/anti-anxiety medications prior to the arrival of the MAiD practitioner.

If their purpose is, for example, to reduce a fear of the experience itself, to avoid family/friends misinterpreting an involuntary gesture as a refusal, or to manage the pain of a forced transfer from a faith-based institution to another site for the provision of MAiD, the provision of some

sedation/anti-anxiety medications may be clinically appropriate and a valid reason to enter a waiver agreement. Provision of MAiD under a waiver of final consent can proceed if capacity is lost secondary to the sedation/anti-anxiety medications.

If a person requests sedation to reduce anxiety, clinicians should explore the source of the anxiety to exclude the possibility of ambivalence about proceeding. In the case of suspected or apparent ambivalence, CAMAP advises against the purposeful use of sedating medication followed by MAiD under a waiver.

Requests to receive MAiD only after capacity is lost

Some people may choose a date for provision and sign a waiver of final consent with the express hope/plan of proceeding with MAiD only after their illness renders them unconscious or otherwise incapable of decision-making (i.e., in the hope of living every minute of their life while still cognitively capable and only receiving MAiD once capacity is lost).

As an example, a person might decline to accept amputation for an untreatable septic ulcer and expect to become systemically septic in short days/weeks. Only once this happens do they wish to proceed with MAiD, so they enter a waiver of final consent with a specified date perhaps 4 weeks into the future. Once they are overcome by their illness, have met all of the eligibility criteria for MAiD, and then lose capacity, their waiver can be invoked and MAiD provided.

This type of request might more commonly arise in people with dementia (specific complexities in the use of waivers in people with dementia are discussed below), or in people with cancer and metastases to the brain who hope to live every minute while still capable/cognitively intact and only receive MAiD once capacity is lost.

There is no legal obstacle to accepting such requests, but some clinical and logistical complexities might arise. Clinicians are reminded that all eligibility criteria must be met prior to the person losing capacity (i.e., it cannot be the loss of capacity itself that fulfills becoming eligible). They are also reminded of the importance of discussing reasonable expectations of how long it may take to respond to the onset of apparent incapacity (and meeting any other stipulations within the waiver agreement) and to reinforce the importance of a palliative care plan to keep the person comfortable until the provider has the opportunity to assess capacity, organize the resources required, and provide MAiD if appropriate.

Issues with family/friends

Circumstances may arise in which decisions about how to best move forward with invoking a waiver may be challenging.

a) Family opposition:
A person's family/friends may not be supportive of proceeding with MAiD and attempt to prevent a practitioner from providing MAiD to a person under the terms of a waiver despite the person’s having lost capacity.

Practitioners may wish to encourage people to share their intentions and involve their family/ friends in discussions about receiving MAiD. In this way, family/ friends will be aware of the person's wishes and more likely to respect them. In the same way, whenever possible, family/friends should be well briefed about the proper use of a waiver in the circumstances that such an agreement is entered into.

Clinicians are under no legal obligation to respect requests or demands by the person's family/ friends to interfere with the provision of MAiD under a waiver of final consent (rather they would be under a moral obligation to proceed given the agreement they entered into with the person). The family/friends are free to seek legal advice to determine if any legal actions can be taken to prevent an assisted death. Those seeking such action bear the burden of convincing the court there is sufficient grounds to intervene. Some precedent has been set by *Sorenson* [10,11] and *WV*[12] related to family members seeking to intervene; although these cases did not involve waivers of final consent, if the court's reasoning in these cases is followed, families wishing to intervene are not likely to succeed.

As always, a practitioner may choose not to proceed with MAiD provision based on their assessment of a situation or in consideration of their own comfort levels (e.g., despite previous knowledge of and agreement with a properly completed waiver, a person's spouse becomes acutely bereaved and vocally opposed/threatening toward the provider once their loved one's capacity is lost). Clinicians are reminded that while declining to provide care due to personal/moral discomfort normally engenders a duty of referral or an effective transfer of care, declining to act on a waiver once a person has lost capacity will mean the person will not be able to receive MAiD unless an alternate provider was appropriately and originally named in the written agreement, or had their own separate written agreement with the person. Determining the best possible course of action while respecting the expressed wishes of the ill person balanced against those of the surviving family and friends may be difficult and is best approached with open dialogue and compassion for all involved (including the provider).

b) Request for urgent provision:
Often when capacity is lost, natural death may be imminent and may not allow adequate time to activate the required resources for a MAiD provision. Family/friends may nevertheless insist a practitioner proceed with MAiD as per a waiver of final consent.

Loss of capacity is typically reported by family/friends, another healthcare provider, or a care coordination service. It is helpful to designate a person to inform the MAiD practitioner about a suspected loss of capacity, but be aware that family/friends may not know what constitutes loss of capacity, and in some cases they may not be aware that their loved one is already actively dying. Once again, the family/friends should, whenever possible, be well briefed about the proper use of a waiver of final consent, and explicit consideration and discussion should be had of the (im)practicalities of an urgent provision. They should be reminded of the tools and skills palliative care has to offer to manage symptoms and promote comfort until a provision can be organized or until the person's death without MAiD occurs.

Entering into a waiver agreement prior to all eligibility criteria being satisfied

Federal legislation does not set out criteria that must be met in order to enter into a waiver of final consent (i.e., entering into a waiver is never a criminal offence). Legislation lays out the criteria that must be met in order to proceed with MAiD on the basis of a waiver. In order to satisfy those criteria, a person must have a reasonably foreseeable natural death and have been informed of their risk of losing capacity to consent to MAiD prior to entering into a waiver. In order to proceed with MAiD using a waiver, a person must have a valid waiver in place and must have met all eligibility criteria and satisfied all procedural safeguards (except giving express consent immediately prior to administration of MAiD), **prior to losing capacity.**

Familiarity with Audrey Parker's story has led to common usage of the phrase "assessed and approved"- a phrase she used to describe herself as having already been assessed for MAiD and approved as eligible. In order to proceed with MAiD, legislation does require a person to be "assessed and approved" prior to loss of capacity, but, surprising to some, it does not require that a person be "assessed and approved" prior to entering into a waiver of final consent. This is in line with updated Health Canada guidance.[6]

Despite this nuance, the majority of MAiD providers practice in a way that ensures that a person *has* met all eligibility criteria and satisfies all safeguards prior to entering into a waiver. This practice streamlines the waiver process and is simpler to explain to patients and their family/friends. More importantly, it helps reduce the potential misunderstanding that entering into a valid waiver somehow renders someone eligible for MAiD, which it does not. A practice that requires all eligibility criteria and safeguards be met prior to entering into a waiver agreement will continue to make the most sense for most providers, and CAMAP endorses and supports this practice.

Willing providers who encounter the unusual circumstance when it appears beneficial to the patient to enter into a waiver of final consent before all eligibility criteria and safeguards have been met are not excluded from doing so (e.g., after an assessment of eligibility but prior to the second assessment being completed). Providers are reminded of the extra steps that must then be undertaken prior to invoking the waiver. These include that the provider must reassess the person and determine that all eligibility criteria have eventually been met, that all safeguards have been satisfied (except giving express consent immediately prior to administration of MAiD), and that they document all of this to have occurred prior to the person having lost capacity**.** If this is true and documented, you may proceed with MAiD under the terms of a waiver.

Clinicians are reminded that if the loss of capacity itself is what creates a person's advanced state of decline or their intolerable suffering, they have not fulfilled the requirement of meeting all eligibility criteria prior to the loss of capacity, and they may not proceed with MAiD under the terms of a waiver. This may be especially relevant when considering the use of a waiver in people with dementia (see below).

- What is the distinction between “anticipating suffering” and “anticipatory suffering”?

A person who suggests they are *anticipating suffering* from an expected future debilitation (e.g., "when I can no longer get out of bed on my own, it will be intolerable to me") is not yet suffering intolerably. The circumstance expected to cause their suffering has not yet arisen, so by their own admission they are not yet suffering from it. A person *anticipating suffering* is not yet eligible to receive MAiD. They are, however, able to enter into a waiver of final consent.

A person who is *currently* suffering from anxiety and/or fear of what they believe or know is to come may be experiencing intolerable *anticipatory suffering* (e.g., a person with ALS who is expected to require but does not wish for or intend to allow mechanical ventilation and is *currently* experiencing suffering from the fear and anxiety regarding the prospect of their future need for mechanical ventilation and/or the results of declining to accept it). Anticipatory suffering is a form of psychological suffering that is clearly expressed by the person and appreciated by the clinician that relates to a potential future loss or risk caused by a salient aspect of a person’s current medical condition, disease, or disability that otherwise qualifies them for MAiD. A person experiencing *anticipatory suffering* may meet the eligibility criterion of intolerable suffering right then.

In sum, a person anticipating suffering is not yet eligible for MAiD, but a person with anticipatory suffering may already be eligible. People either anticipating suffering or with anticipatory suffering can complete a waiver of final consent, but the provider for a person anticipating suffering cannot act on that waiver unless the person’s suffering comes to be realized before the person loses capacity.

Dementia and the use of waivers

Some people with dementia may meet the eligibility criteria and safeguards for MAiD and choose to proceed with an assisted death while they still have capacity. A previous CAMAP guidance document addresses the assessment and provision of MAiD for people suffering with dementia including a description of the “10 minutes to midnight” approach.[13]

Some people with dementia may wish the comfort of knowing they will be able to have MAiD after they lose capacity, but advance requests for MAiD are not yet permissible. CAMAP has previously presented guidance documents outlining the clinical reasoning as to why those with dementia are frequently determined to have a natural death that is reasonably foreseeable.[5,13] This reasoning appears to be supported by the *AB* case.[14] Therefore people with dementia are potentially eligible to complete a waiver of final consent. In fact, their natural death may have become reasonably foreseeable well in advance of meeting all of the other eligibility criteria, so entering into an early waiver may be a consideration. Clinicians are reminded that to proceed under a waiver, the person must have been assessed as having met all of the eligibility criteria and safeguards *prior to losing capacity*. Accordingly, they should explain that a waiver of final consent does not guarantee access to MAiD; a person will still need to satisfy all the eligibility criteria and safeguards and consent to MAiD before losing capacity.

Practically, this means that although a waiver can be signed after natural death has become reasonably foreseeable, the person will need to be followed carefully to ensure that consent to receive MAiD is distinctly given after the other eligibility criteria have been met and before capacity has been lost. This means, for example, that if a person enters into a waiver of final consent and then they lose capacity before their suffering has been documented as having become enduring and intolerable, they will not be able to access MAiD under the waiver agreement.

With dementia, a number of unique considerations can limit or complicate the use of a final consent waiver. Specifically, neurocognitive decline may be gradual or unpredictable, and the disease process itself may blur the transition from capacity to incapacity. Moreover, it may directly affect the person suffering from dementia by eroding key aspects of the self (such as memory, values, thoughts, beliefs and emotional responses) such that the person ceases to appreciate their condition, or their decline, and may no longer suffer in a way that is seemingly intolerable to them.

These circumstances may lead to situations in which a person has completed a waiver of final consent for MAiD, but their subsequent loss of capacity may not be immediately appreciated by those in their circle of care. A process for tracking this expected loss of capacity should be discussed and implemented with the person and their family/friends so that the provider can become aware/ be notified when capacity appears to have been lost (e.g., the clinician follows the person regularly and/or informs family/friends what to look for).

On approaching the specified date for MAiD, the person may no longer want an assisted death. If they still retain capacity and wish to defer MAiD to a later date, then consideration can be given to completing a new waiver with a new provision date (see below). If they have lost capacity to consent and demonstrate, by words, sounds, or gestures, refusal to have the substance administered or resistance to its administration, then MAiD must not proceed.

In some cases a person's decision not to proceed may be due to their loss of insight into their state of decline. As in all circumstances, a person retains the legal ability to refuse MAiD even though they may have lost the capacity to consent to it.

Another possible complexity can arise when a person retains their capacity to consent to MAiD and expresses their wish to postpone their MAiD provision beyond the date specified in the waiver. This decision must be honoured. However, the person might not retain the task-specific, higher level of capacity required to fully comprehend and complete another waiver of final consent.

Yet another possible scenario is that the person has lost capacity, their waiver is invoked, they do not resist or refuse the administration, but, although they were experiencing intolerable suffering before the loss of capacity, there is no contemporaneous sign of suffering due to their reduced cognitive state ("happily demented"). It is legal to provide MAiD in such cases, as stipulated in the waiver. However, this situation could be emotionally challenging for the person's family/friends and/or the MAiD provider when no obvious signs of suffering are present. Previous discussion with patients and their family/friends regarding the possibility of reduced signs of suffering following the loss of capacity, along with the potential for significant personality change, is important. No clinician is ever compelled to provide MAiD and so no clinician is

compelled to proceed in such a circumstance. However, it is important to discuss this possibility with the person during the process of coming to the written arrangement so that they (and their family/friends) understand that clinician discomfort may prevent them from receiving MAiD.

It is important for the provider to explain all of these possibilities to the person and their family/friends in advance, to describe the circumstances that might arise and the possible outcomes, to consider/ask whether people understand this information, and to document this discussion and their answers.

Providers using waivers of final consent with persons with dementia should be aware of the potential for difficult circumstances. In each case, providers should anticipate the possibility of problems specific to the use of waivers in dementia and consider in advance how they might manage them.

If unsure about how best to manage a particular case, providers should consider consulting experienced colleagues for advice and/or the CMPA/CNPS.

About the Authors

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Appendix A- Legal Foundation

From Criminal Code, RSC 1985, c C-46

Final consent — waiver

241.2(3.2) For the purposes of subsection (3), the medical practitioner or nurse practitioner may administer a substance to a person to cause their death without meeting the requirement set out in paragraph (3)(h) if

(a) before the person loses the capacity to consent to receiving medical assistance in dying,

(i) they met all of the criteria set out in subsection (1) and all other safeguards set out in subsection (3) were met,

(ii) they entered into an arrangement in writing with the medical practitioner or nurse practitioner that the medical practitioner or nurse practitioner would administer a substance to cause their death on a specified day,

(iii) they were informed by the medical practitioner or nurse practitioner of the risk of losing the capacity to consent to receiving medical assistance in dying prior to the day specified in the arrangement, and

(iv) in the written arrangement, they consented to the administration by the medical practitioner or nurse practitioner of a substance to cause their death on or before the day specified in the arrangement if they lost their capacity to consent to receiving medical assistance in dying prior to that day;

(b) the person has lost the capacity to consent to receiving medical assistance in dying;

(c) the person does not demonstrate, by words, sounds or gestures, refusal to have the substance administered or resistance to its administration; and

(d) the substance is administered to the person in accordance with the terms of the arrangement.

For greater certainty

241.2(3.3) For greater certainty, involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance for the purposes of paragraph (3.2)(c).

Advance consent invalidated

241.2(3.4) Once a person demonstrates, by words, sounds or gestures, in accordance with subsection (3.2), refusal to have the substance administered or resistance to its administration, medical assistance in dying can no longer be provided to them on the basis of the consent given by them under subparagraph (3.2)(a)(iv).

Advance consent — self-administration

(3.5) In the case of a person who loses the capacity to consent to receiving medical assistance in dying after self-administering a substance, provided to them under this section, so as to cause their own death, a medical practitioner or nurse practitioner may administer a substance to cause the death of that person if

(a) before the person loses the capacity to consent to receiving medical assistance in dying, they and the medical practitioner or nurse practitioner entered into an arrangement in writing providing that the medical practitioner or nurse practitioner would

(i) be present at the time the person self-administered the first substance, and

(ii) administer a second substance to cause the person's death if, after self-administering the first substance, the person lost the capacity to consent to receiving medical assistance in dying and did not die within a specified period;

(b) the person self-administers the first substance, does not die within the period specified in the arrangement and loses the capacity to consent to receiving medical assistance in dying; and

(c) the second substance is administered to the person in accordance with the terms of the arrangement.