



Canadian Association of MAiD
Assessors and Providers



Association canadienne des évaluateurs
et prestataires de l'AMM

Medical Assistance in Dying (MAiD) Assessments for People with Dementia

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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 MAiD care in Canada. Founded in 2016, their mission is to support MAiD professionals in their work, educate the public and the health care community about MAiD, and to provide leadership on determining national standards and guidelines of practice in MAiD provision. CAMAP members strive to achieve the highest level of care for patients and to model this care for a national and international audience. CAMAP aims to work with governments in Canada at all levels, provincial medical and nursing licensing bodies, national medical and nursing colleges, national professional groups, medical and nursing colleagues, and national advocacy groups.

Process

Medical Assistance in Dying (MAiD) Assessments for People with Dementia was first drafted by the CAMAP Working Group on Dementia. The Working Group included MAiD providers with experience in primary care and dementia. After review and revision by the CAMAP Education Committee and Board, the next draft was circulated to national stakeholders for comment and further amendments were made by the Working Group. This was revised again in 2024 and the final draft has been approved by the CAMAP Board of Directors for publication on the CAMAP website. It is a working document and will be amended as experience is gained in the provision of MAiD to patients with dementia.

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Introduction

In this paper, only people with a diagnosis of dementia who would be eligible for Medical Assistance in Dying (MAiD) according to the Canadian law are considered. Among Canadians who seek MAiD, dementia may be the primary medical condition or cognitive impairment could complicate the assessment of a patient with a different primary medical condition. This paper will provide guidance to clinicians who assess and provide MAiD in Canada. Three important issues facing people with dementia will be covered, namely the assessment of:

1. Whether the patient is in an advanced state of decline in capability;
2. Whether the patient has capacity to make the decision to have MAiD; and
3. Whether the patient's natural death is reasonably foreseeable.
4. The issue of when and how to use waivers of final consent in Dementia patients will be covered in a separate document

Note: Not all of this paper will be applicable in Quebec. There is a summary and case examples at the end of this paper.

In Canada, 500,000 people are estimated to have dementia, making it the most common type of neurodegenerative disorder (1,2). Furthermore, 0.8% of Canadians over age 45 living in private households and 45% of all people living in long-term care facilities are diagnosed with dementia (3). The Canadian Study of Health and Aging reported that the prevalence of dementia in Canada was 2.4% for those age 65 to 74, 11.1% in those age 75 to 84, and 34.5% in those age 85 years and older (4). Similar data was reported by Statistics Canada, separating rates by private households and long-term care institutions (5). The prevalence of dementia increases with age so as the global population ages, there will be an increase in dementia diagnoses. It is estimated that the number of people living with dementia worldwide will double in the next 20 years (1).

The most common primary dementia syndromes are Alzheimer's disease (AD), vascular dementia (VD), dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD). There are other rarer causes for dementia such as Huntington's disease, Parkinson's disease (PD) and Creutzfeldt-Jakob disease. AD is most common and accounts for 60% to 70% of all dementia diagnoses (7). VD is the second most common cause of dementia, accounting for 17.6% of dementia diagnoses in European and North American populations (8). Each dementia syndrome has a recognizable disease profile (Table 1).

Table 1. Epidemiology and features of common causes of neurodegenerative dementia.

Disease	Age at diagnosis (years)	% of dementias	Onset	Life expectancy after diagnosis (years)	Clinical features	References
AD	>65 (late) or <65 (early)	60-70	Gradual	3-12	Impairment of memory and attention; visuospatial difficulties	(7,9,10)
VD	>60	17.6	Sudden, stepwise, or more gradual if small vessel disease	3-5	Executive dysfunction (deficits depend on location of stroke/lesion); behavioural problems	(8,9)
DLB	70s	5-15	Gradual, with fluctuations in cognition	2-20	Impairment of visuospatial skills and attention; visual hallucinations; parkinsonism	(9,11,12)
FTD	<65	3-25	Gradual	2-15	Difficulty with language and executive function; behavioural change (disinhibition)	(9,13,14)
Other	Various	Minimal	Mainly gradual	<1-20+	Various	(9)

Assessing and documenting the diagnosis of dementia

Diagnosing dementia

It is not the responsibility of the clinician who assesses eligibility for MAiD to formally diagnose dementia, but it may be necessary for that clinician to form an opinion as to the presence, duration, impact, and type of cognitive impairment or dementia. Specialist reports, neuropsychological testing, and conversations with the primary care provider or family members and friends may be sufficient. Sometimes the diagnosis of dementia is not well-documented or supported by much evidence. Dementia is a clinical diagnosis; biomarkers are not used to establish a diagnosis (15).

The DSM-5 has renamed dementia as “major neurocognitive disorder”. However, the principles of diagnosis remain similar. The core diagnostic criteria include:

1. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on:
 - Concern of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function; and
 - A substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.
2. The cognitive deficits interfere with independence in everyday activities (i.e. at a minimum, requiring assistance with complex instrumental activities of daily living, such as paying bills or managing medications).
3. The cognitive deficits do not occur exclusively in the context of a delirium.
4. The cognitive deficits are not better explained by another mental disorder (e.g. major depressive disorder, schizophrenia).

The DSM-5 has renamed mild cognitive impairment as “mild neurocognitive disorder”. The diagnostic criteria include:

1. Evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on:
 - Concern of the individual, a knowledgeable informant, or the clinician that there has been a mild decline in cognitive function; and
 - A modest impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.
2. The cognitive deficits do not interfere with capacity for independence in everyday activities (i.e. complex instrumental activities of daily living such as paying bills or managing medications are preserved but greater effort, compensatory strategies, or accommodation may be required).
3. The cognitive deficits do not occur exclusively in the context of a delirium.
4. The cognitive deficits are not better explained by another mental disorder (e.g. major depressive disorder, schizophrenia).

Reversible causes of cognitive decline

If a diagnosis remains to be established, the following reversible causes of cognitive decline should be excluded:

- Depression/cognitive impairment secondary to depression
- Adverse effects of medications
- Delirium
- Substance use disorders
- Sleep apnea and other sleep disorders
- Chronic hypoxia
- Recurrent hypoglycemia
- Thyroid disease
- B12 deficiency
- Environmental toxicities
- Mass lesions (neoplasms, intracranial hematomas, normal pressure hydrocephalus)
- Seizure disorders

The clinician assessing for MAiD eligibility is not responsible for testing and excluding these possible contributing factors but should be assured that reasonable efforts have been made to exclude and/or mitigate them.

With a similar context, the following tests should have been considered:

- Vital signs
- Complete blood count
- Glucose
- Blood urea nitrogen
- Creatinine
- Electrolytes, including calcium, magnesium, and phosphorus
- Liver enzymes
- Thyroid stimulating hormone
- Vitamin B12
- CT or MRI of brain
- EEG
- Neuropsychological testing

Depression

Careful attention should be paid to possible underlying depression and cognitive impairment secondary to depression; the clinician assessing eligibility for MAiD should ensure that this is also excluded, or not significantly interfering with judgment. Depression may co-exist in more than one-third of dementia patients. Table 2 may be helpful in determining the cause of cognitive decline.

Table 2. Differentiating features of dementia and depression.

	Dementia	Depression
Onset	Progressive, insidious	Either acute or insidious
Course of time	Unrelenting	Variable
Attention	Intact until end-stage	Decreased concentration and attention to detail
Memory	Prominent feature	Usually, normal
Speech	Aphasia, anomia	Slowed

Neuropsychological assessment should be considered in difficult cases. It is reasonable for the primary care clinician to attempt a six-week trial of an antidepressant to solidify the diagnosis of dementia. Those with cognitive impairment secondary to depression are at high risk of developing dementia over the following few years and should be monitored closely.

While not required to qualify for MAiD, establishing the subtype of dementia is helpful in establishing the natural history of the disease and for prognostication (Table 1).

Documenting the presence of dementia in MAiD assessment

Dementia can be a qualifying, stand-alone diagnosis for MAiD if capacity to make reasoned or considered decisions about one's health care has not yet been lost. It is important to document the evidence supporting the diagnosis and ensuring exclusion of other compounding factors.

This can include, but is not limited to:

- Specialist consults
- Clinical course
- Objective testing and work-up to exclude reversible causes
- Conversations with a primary care provider, friends, and family
- Relevant medication trials

It is advisable to specifically document the presence or absence of depression and cognitive symptoms related to depression, as this is a key diagnostic consideration. It is helpful to document the dementia subtype and the primary features at presentation, in order to establish natural history and prognosis.

Assessing and documenting capacity in dementia

Informed consent and capacity

Federal legislation governing MAiD requires that patients “give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care”. It also requires that clinicians “immediately before providing the medical assistance in dying (...) ensure that the person gives express consent to receive medical assistance in dying”. Providing informed consent necessitates an assessment of capacity to ensure that that consent is valid. An assessment of capacity in the context of MAiD may also elicit information that informs other aspects of the assessment, including the nature of their suffering, and the information about their underlying condition.

All forms of medical intervention performed by clinicians require informed consent (16). Informed consent is task and time specific and requires voluntary choice in a patient who has been adequately informed and who has capacity to consent (16-19).

Capacity should be considered to be lacking if any one of the following four domains is deficient (17,19,20):

1. Ability to communicate a choice;(even with appropriate help)
2. Ability to understand the relevant information;
3. Ability to appreciate the current situation and its consequences; and
4. Ability to reason about treatment options and their consequences.

This communication may require a speech and language pathologist and various aids, such as letter boards. Although there is provincial variation in interpretation, Canadian regulations emphasize (1) the ability to understand information that is relevant to making a decision about treatment, namely the nature and anticipated effect of proposed medical treatment and alternatives; and (2) the ability to appreciate the likely consequences of accepting or refusing treatment (16,21,22).

Prevalence of incapacity in mild cognitive impairment and dementia

The presumption of intact decisional capacity is a bioethical standard (17,22). While patients with dementia can lose their ability to provide informed consent to complex medical treatment due to loss of cognitive functioning (20,23), this capacity can persist to varying degrees in dementia (24-27). For example, in a study comparing capacity assessment tools in 79 patients with mild to moderate dementia, Gurrera et al. (24) found that overall capacity was impaired in 13.9% to 30.4% of patients, depending on the tool being used. Okonkwo et al. (25), in their study assessing capacity in patients with mild cognitive impairment (MCI) and mild AD, found that a reasonable number of patients with MCI still possessed medical decisional capacity; however, patients with AD showed lower levels of capacity, particularly in the domain of understanding. Finally, Moye et al. (26) found that, at baseline, 9% of their cohort of patients with dementia lacked capacity; this increased to 24% nine months later. It can be concluded, therefore, that while most patients with MCI and early dementia retain capacity, this capacity can deteriorate as the disease progresses, so should be reassessed periodically (26).

The timing of this deterioration can be difficult to predict. Li et al. (28) found that cognitive decline can appear at least 10 years before clinical diagnosis of dementia, and there appeared to be an accelerated decline 3 years before the diagnosis. Kua et al. (29), in their study of 77 cases of AD, found that the mean duration of early dementia was 5.6 years from the time of diagnosis to onset of moderate dementia. Higher levels of education can delay the onset of accelerated cognitive decline; however, in these patients, the decline is more rapid once deficits do appear (30-32).

Communication challenges in dementia

Patients with all forms of dementia have at least some word-finding difficulties. In vascular dementia, one may also see expressive aphasia and dysarthria that severely affects communication. Previously multilingual individuals may revert to their mother tongues and require translators. In order to have successful communication, information first needs to be understood before a response can be expressed. With dementia, memory impairments can make it difficult for patients to follow a conversation or a train of thought. This can interfere with how they respond to people and questions.

The issue of communication challenges is addressed in Bill C14 as follows (Para 241.2(3)i): “If the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision”.

In some situations, a speech and language pathologist could be consulted. The following steps may be helpful:

1. Consider the best environment for assessment; for example, a quiet space with no distractions, morning rather than afternoon, or having someone present who has experience communicating with the patient.
2. Establish the patient’s method of communication; for example, a letterboard, a tablet, yes and no answers, etc.
3. Facilitate communication with the patient; for example, ensure they have their glasses, hearing aids, a translator, etc.
4. Adapt the usual open-ended questions, such as “How does your illness impact your daily activities?”, to yes and no questions, such as “Are you able to wash yourself?”
5. Have one main thought per sentence and pause between sentences to give processing time.
6. Clarify the responses with follow-up questions.

Assessment of capacity

Assessment of capacity in patients with cognitive impairment remains a clinical challenge. Expert opinion may overestimate capacity (20,33) and have very poor interrater reliability (18). Formal capacity assessment tools may be useful in determining capacity; however, there is no gold standard for assessing capacity to consent to treatment in patients with dementia (18,23,33). Several tools have been widely studied including the Aid to Capacity Assessment (ACE) (34) and MacCAT-T. The latter is the most widely used (20,23), and may be the most suitable across a variety of populations (35). In a 15- to 20-minute semi-structured interview procedure, the MacCAT-T assesses competency to make treatment decisions by examining capacity in four domains (36):

1. Understanding information relevant to a condition and recommended treatment;
2. Reasoning about the potential risks and benefits of their choices;
3. Appreciating the nature of their situation and the consequences of their choices; and
4. Expressing a choice.

The MacCAT-T has been used in a variety of populations including dementia and has been shown to have high interrater reliability (18). The ACE is a semi-structured interview that focuses on understanding (i.e. medical problem, proposed treatment, alternatives to proposed treatment, and option of refusing treatment) and appreciation (i.e. reasonably foreseeable consequences of accepting and refusing proposed treatment) (18,34).

The Mini-Mental Status Examination (MMSE) and the Montreal Cognitive Assessment (MoCA) are two commonly used tools for the detection of cognitive impairment. In and of themselves, these tools are not suitable for measurement of capacity (26). They may, however, be useful in informing decisions around capacity. For example, in two small studies, an MMSE score of <19 was shown to predict incapacity, while scores of 23 to 26 were highly likely to have capacity (27,37) and indeterminate scores of 18 to 25 may be useful in identifying cases where more rigorous assessment is required (23). To our knowledge, the MoCA has not undergone a similar investigation of its ability to predict capacity.

Assessment tools have limitations. They may be overly “cognitivist and rationalistic in their conception, and thus may not take into account subjective, intuitive, and contextual factors” (19). In other words, they may grant too great an importance to higher scores in tests that value certain measurable cognitive skills over the patient’s ability to sense and feel distress at their situation and their ability to make others aware of this through verbal and non-verbal communication. Many capacity tools may not give an overall rating or score, as they are designed to complement, not replace, professional judgement (33). Indeed, as Pennington notes: *“no current instrument is sufficiently flexible or broad in scope to consider individual and contextual factors in the assessment of capacity and for this reason expert judgement and due attention to patient values and narratives are essential.”*

In practice, the formal use of capacity assessment tools is not generally necessary. However, in cases where capacity is not clearly present, they may be employed either by the clinician assessing eligibility for MAiD or by a specialist engaged for the purpose of a formal capacity assessment. If employed, familiarity in the use of tools such as ACE and MacCAT-T is recommended.

Ensuring optimal assessment conditions should be prioritized to increase rates of autonomous decision making (23). The domain of understanding has been shown to be most frequently underestimated (20, 25). Understanding is a highly factually intensive domain which relies most heavily on short-term memory and is therefore vulnerable to the amnesic deficits in MCI and mild AD (25). Memory aids such as Rubright et al.’s, that simplify factual information onto a single, easily-digestible page, increase rates of capacity (32). While short-term memory is compromised in patients with mild to early moderate AD, recognition memory is relatively well-preserved; as such, a memory and organization aid may enhance focus and understanding (32).

Other means of optimizing capacity assessment include accommodating preference for time of day (19,33), treating underlying conditions (23), using the patient’s native language, and simplified wording.

Documenting capacity in dementia

Providing MAiD in the absence of capacity is a serious offence in the absence of a valid waiver of final consent. Rigorous documentation of capacity, particularly in patients who have diagnoses of dementia, is therefore crucial. Documentation can be strengthened by the employment of empirical tools such as those described above, along with the clinical assessment that considers the individual situation of the patient.

Clinicians should systematically document their findings, specifically as they relate to the four domains of capacity described below: choice, understanding, appreciation, and reasoning.

a) Choice

To have capacity, patients must be able to make and express a choice (17-19,22). Expressing a desire for MAiD is the choice that will have led to a MAiD assessment. In the case of dementia, this is the domain that is least demanding (18) and retained the longest (25). The choice for MAiD should be consistent and predictable over time, although reasonable levels of ambivalence do not preclude capacity.

b) Understanding

Understanding necessitates a working knowledge of one's health. Individuals must retain sufficient cognitive and intellectual ability to process and paraphrase information about their health and treatment options. The clinician may disclose information to the patient, and having the patient explain their understanding of the information may improve assessment of understanding (18-20). The clinician must ensure that the patient has the opportunity to learn this information.

In the context of a MAiD request, this information may include:

- An understanding of their underlying illness, disease, or disability;
- The natural course of their condition (i.e. what to expect going forward);
- Treatments available for their underlying condition, if any, and the risks and benefits of these treatments; and
- The risks and benefits of MAiD, with an emphasis on irreversibility.

c) Appreciation

Appreciation requires that a patient be able to apply the above information to their personal circumstances (18) and attach personal meaning to the facts of a given situation (22). For example, some people may be able to repeat information but may not see how these factors apply to their personal situation (22). In the context of a MAiD assessment, appreciation may include:

- Appreciation of how their underlying illness, disease, or disability is affecting them and their quality of life (this may include the nature of their suffering);
- Explanation of how any proposed treatments for their underlying condition, if any, may affect them, and why they are/are not desirable;
- Insight into why they are requesting MAiD, how they feel MAiD would help them, and any drawback to MAiD;
- Appreciation of what would happen if they received MAiD;

- Appreciation of the risks and benefits of alternatives to MAiD (e.g. palliative care) in their particular situation, and why these alternatives are not desirable for them; and
- Appreciation of the impact of their decisions on others important to them (e.g. close family members).

d) Reasoning and rational manipulation of information

Reasoning requires an elucidation of the reasoning process, to ensure that the choice being made is based on reality. Clinicians should examine the chain of reasoning to ensure there is logical consistency and that the choice being made is not predicated on “false or irrelevant beliefs” (22). Of note, the clinician is not assessing the reasonableness of the MAiD request, but rather ensuring that the choice is well-reasoned. In discussing understanding and appreciation, the chain of reasoning may become clear, although patients who have adequate understanding and appreciation can still be considered incompetent if their thought process is illogical (18).

Chain of reasoning may be elicited by inquiring as to:

- When they first started to consider MAiD;
- How they arrived at the decision to request MAiD;
- Why they feel that MAiD is the best choice in their particular situation; and
- Why they have decided to reject alternatives, such as moving to a hospice or treatment for any underlying conditions.

The definition of “natural death in the foreseeable future” in dementia

According to a seminal article on Canada’s MAiD legislation by Jocelyn Downie and Jennifer Chandler (36), establishing that a person’s natural death is “reasonably foreseeable” implies that at least one of the following two criteria exist:

1. That the person’s death will likely occur in a time “not too remote”; or
2. That the cause of the person’s death is predictable.

The CAMAP Clinical Practice Guideline on the interpretation of “reasonably foreseeable” also suggests interpreting “reasonably foreseeable” as meaning “reasonably predictable” (39). This interpretation has been accepted as correct at the level of regulatory authorities (40). In the case of a person with dementia, both of the above conditions are fulfilled. The second criterion is the most straight-forward: all the primary dementia syndromes are progressive and ultimately fatal diseases. Therefore, the cause of death of a person diagnosed with dementia is predictable; they are on an irreversible trajectory toward death. Given this, it is not necessary to consider the predicted life expectancy of an individual with dementia. However, the first criterion is discussed here as it is also clear that a person diagnosed with dementia will die in a time “not too remote”.

According to the Legislative Background document on Bill C-14 (41), the law does “not impose any specific requirements in terms of prognosis or proximity to death”; in other words, there is no fixed time frame in which death must be predicted to occur. As an important illustration of this, the Canadian Minister of Justice stated in 2016 that Kathleen Carter of *Carter v. Canada* would have qualified for MAiD under the legislation, despite the fact that Ms. Carter, who was 87 and suffered from spinal stenosis, likely had some years to live (42). The life expectancy of the average 87-year-old Canadian woman is 5 to 6 years (43). There has only been one court decision on Bill C14. The decision supported the lack of a specific time frame in which death must occur. In *A.B. v. Canada*, the plaintiff was a 79-year-old female with severe osteoarthritis (44); like Kathleen Carter, she was someone who might have had years to live, albeit in excruciating pain. The average life expectancy of a Canadian female age 79 is 11 years (43). Justice Perell of the Ontario Superior Court ruled that the determination of the time window for anticipated death may be helpful but is not required to reach a determination that natural death has become reasonably foreseeable. He stated:

“Natural death need not be imminent and...what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan. (...) In formulating an opinion, the physician need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime.”

Justice Perell concluded that A.B.’s death was “reasonably foreseeable”.

The death of a person with dementia will occur at a time “not too remote”. A review of the natural history of dementia (29) shows that life expectancy is considerably reduced. According to a recent study in the United Kingdom, the median survival from diagnosis is about 7 years in AD and 4 years in LBD (45). In a study in the United States, James et al. found that the median time from AD diagnosis to death in individuals over age 75 was even shorter: 4.4 years (46). Life expectancy in most types of FTD is similar to AD (47); in VD, it is somewhat less. Predictors of

increased mortality are greater age at onset, male gender, medical and psychiatric co-morbidities, and possibly, increased education level. Assuming that most MAiD requests would occur partway through the mild phase of dementia, the life expectancy of most dementia patients requesting MAiD would likely be less than 5 years, particularly in older patients. This is well within the timeframe that has been considered, in the cases described above and in others, as “not too remote”.

It should be noted that these considerations may not apply to individuals diagnosed solely with MCI. Not all those diagnosed with MCI will progress to dementia and the rate of transition is somewhat uncertain. Therefore, the natural cause of death in people with MCI alone (i.e. without significant co-morbidities) is **not** reasonably foreseeable. If a person fulfills all the eligibility criteria for MAiD and their natural death is not reasonably foreseeable, then they would require additional safeguards, including:

1. a minimum of 90-day reflection period,
2. The MAiD Provider must ensure the patient is aware of and has seriously considered, where appropriate, counselling services, mental health and disability supports, community services and palliative care and has been offered consultation with relevant health professionals who provide those services or that care
3. If neither assessor has expertise in the condition causing suffering a consult must be sought to gain information on possible care options, which must be returned in writing to both assessors

Assessing and documenting “advanced state of irreversible decline in capability” in dementia

The degree of irreversible decline in capability may be quite apparent in the case of an intelligent and highly functional person with a diagnosis of mild dementia because of their previous abilities. By comparison, it might appear difficult to label a person who was previously functionally less able but who has now reached the same point in terms of cognitive ability as having suffered an “advanced” state of irreversible decline. However, the determination of “advanced state” relates not only to the amount of cognitive decline that has occurred from baseline but also to the absolute degree of the patient’s decline and the state in which the person now finds themselves (i.e. at imminent risk of loss of capacity through dementia). MAiD is prohibited to those who have lost capacity. Currently it is not permissible for a person to receive MAiD via advanced directive. One philosophical and ethical justification for this prohibition is that a person with capacity ought not to be permitted to make decisions for the person that they will become post-capacity loss, since their interests may not be the same; they may become, in effect, a different person.

Imminent loss of capacity through dementia is therefore *prima facie* (i.e. in and of itself) an advanced state of irreversible decline in capability. This is because the person is soon to be so affected by their disease that they would be (1) prohibited from making a decision about the course of the rest of their life (through the removal of MAiD as a permissible option); and (2) a person deemed to have potentially different interests to the person they currently are.

If a person with mild dementia requests MAiD and is assessed as eligible except for being in an advanced state of irreversible decline in capability, then they should be reviewed periodically by their primary care provider (if willing to do so and experienced in the assessment of capacity) or by the clinician who is willing to provide MAiD. When it is believed that they are close to losing capacity the clinician should explicitly inform the patient that this is the case. The provider may wish to have the decision confirmed by the other MAiD assessor or the primary care provider, but this is not necessary. The patient may then choose to have MAiD as all criteria are satisfied. The patient is not obliged to accept the provider’s advice and may request continued ongoing review but should be made aware that they might lose capacity and therefore their right to have an assisted death.

Many neurological diseases have both physical and cognitive decline and the “advanced state of irreversible decline in capability” may be either one or a combination of both physical and cognitive decline.

Summary and plan for assessing and providing MAiD for patients with dementia

As in all cases of MAiD, it must be documented that a patient with dementia fulfills each of the criteria required by law. The three criteria that may be more difficult to assess in dementia patients compared to others are:

a) “They are in an advanced state of irreversible decline in capability.”

The majority of patients with dementia have had decline in function for years before the diagnosis. Someone who has mild dementia according to the Clinical Dementia Rating scale will be in “an advanced state of irreversible decline” if loss of capacity is believed to be imminent. It is important to document the decline from their previous level of normal function.

b) “They give informed consent.”

Capacity is task-specific and includes the ability to:

- Communicate choice
- Understand the relevant information
- Appreciate the consequences of the decision
- Reason about the alternatives

In people who have a diagnosis of dementia, it is recommended that clinicians specifically document the findings in each of these four domains.

c) “Their natural death has become reasonably foreseeable.”

All of the primary dementias have shortened life expectancies; they are ultimately fatal. Thus, death is reasonably predictable and is therefore reasonably foreseeable. Many of the conditions in which dementia may develop secondarily, such as PD, also put patients on a trajectory towards death, making their deaths reasonably foreseeable.

10 minutes to midnight

There has never been a court decision or legislation that excludes people with dementia from accessing MAiD in Canada. The challenge lies in the requirement to simultaneously fulfill all eligibility criteria, which includes being both in an advanced state of irreversible decline in capability - in dementia patients what would typically be due to an advanced state of decline in cognition - while still retaining sufficient capacity to make health care decisions.

Borrowing from a model used by colleagues in the Netherlands, “midnight” represents a time when capacity is irreversibly lost. There is consensus amongst even the most reticent to MAiD that once a person's capacity to make health care decisions for themselves is lost, they are considered to be in “an advanced state of decline in capability”. MAiD practitioners have successfully determined that when such a loss of capacity is imminent, at “10 minutes to midnight”, a person is already in an advanced state of decline in capability, but that they have a small window of time where capacity may still be present. At such a time, a person could arguably become eligible for MAiD assuming all other criteria and safeguards are met.

This possibility will not be true of all patients with cognitive challenges, as many will lose insight into the advancement of their illness or the decline they are experiencing. For patients who lose this insight, a request to proceed with MAiD when finally eligible- at “10 minutes to midnight”- is unlikely. However, for cognitively challenged patients whose insight remains intact, with whom practitioners have met on multiple occasions and who have been closely followed, in whom the clinician could justifiably conclude that, in their best medical opinion, the person is at significant risk of losing capacity within ~3-4 months (that they are at “10 minutes to midnight”), the possibility of a MAiD death becomes viable.”

Many patients who have been diagnosed with dementia still have good quality of life but fear losing capacity, and so request MAiD. Patients can be reviewed periodically for capacity and informed when they have reached the point when it is believed that they still have capacity but will soon lose it. This is known to some as the “10 minutes to midnight” approach. It is difficult to predict with certainty when a patient will lose capacity. However, if the MAiD provider is of the opinion that loss of capacity is imminent, and the “advanced state of irreversible decline in capability” criterion is thus satisfied, the patient can be given this information and may act upon it by choosing MAiD while they are still permitted to make such a decision.

Those who have been assessed as Track 1 (their natural death is reasonably foreseeable) may have the option of entering a waiver of final consent. Providers using waivers of final consent with persons with dementia should be aware of the potential for difficult circumstances (ref CAMAP guideline on waivers).

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Appendix A: Case examples

MAiD request for worsening dementia; capacity retained

Kelly was a 61-year-old woman with FTD diagnosed 18 months ago. She was well-educated and had worked as a senior manager. She had been very active: kayaking, hiking, etc. Now she lived at home with a daily caregiver. She was still able to walk but was at significant risk of falling and getting lost, so she never left the apartment alone. She needed help with all instrumental activities of daily living (IADLs). She could speak but had marked difficulty with word-finding.

i. “They are in an advanced state of irreversible decline in capability.”

She had deteriorated a great deal in the 2 years since she had been fully functional at work and at play. She was assessed as being close to losing capacity and therefore was “advanced”, even though she could still talk and walk. This change was confirmed by reviewing some work documents from 2 years before as well as her recent neurological testing.

ii. “They give informed consent.”

In order to assess capacity and her understanding of her illness and of MAiD, sometimes “yes” and “no” questions were necessary. For example, she could not remember the name of her diagnosis, but could say “yes” when it was named. She could correctly answer the questions “Can your condition be cured?” and “Is it fatal?”. To assess depression causing cognitive distortions, she was asked, “If your condition could be cured, would you still want to die?” and “Do you think you deserve to have this illness?”. To assess her ability to understand her alternatives, she was asked whether she would prefer to die sooner or later, to stay at home or go to a care facility. She was consistent and clear in her answers and therefore had the capacity to choose MAiD.

iii. “Their natural death has become reasonably foreseeable.”

FTD has a life expectancy at diagnosis of 5 to 10 years. It is a fatal illness. She was on a trajectory towards death and her death was reasonably predictable and thus “reasonably foreseeable”.

Kelly was found eligible by two assessors and had MAiD approximately 2 months after her request.

MAiD request for worsening dementia; capacity lost

Jim was a 56-year-old man diagnosed with AD 4 years ago. His wife said that Jim had always been clear that he did not want to go into a care home and shared a document he had written two years earlier that described his wishes very clearly. He was still able to do all activities of daily living (ADLs) with direction but needed help with all IADLs. He had marked difficulty with word-finding.

i. “They are in an advanced state of irreversible decline in capability.”

Jim had deteriorated very significantly in the last 4 years and in the 2 years since he had written the document, and even more in the past 6 months. Loss of capacity was imminent, so his condition was advanced. This was confirmed by his repeated neurological testing, conversations with his family doctor, his neurologist, and his wife.

ii. “They give informed consent.”

He had capacity. When asked if the document still reflected his wishes, he agreed that it did. He was not able to name his diagnosis, but clearly could say “yes” when asked if he had dementia. He also gave congruent “yes” and “no” answers to questions about prognosis, his understanding of what a care home is and whether he wanted to live in one, and whether he wanted to die. He was able to talk about his parents who both died of dementia and he said that he didn’t want to die like them.

iii. “Their natural death has become reasonably foreseeable.”

At his age, he had about a 10-year life expectancy upon diagnosis 4 years previously. At the time of his MAiD request, he therefore might have a 6-year life expectancy. His disease was fatal, and he was on a trajectory towards death. As a result, his death was predictable and thus foreseeable.

He was not ready to set a date for MAiD and was told that he was weeks or a few months at most away from losing capacity. He agreed to visit every two weeks with either his family doctor, his neurologist, or the clinician willing to provide MAiD and said he was hoping for another summer (i.e. another 6 months). Six weeks after the first assessment, he could not answer correctly that he had AD and he said that he wanted to live longer, even if that meant going into a care facility. He had lost understanding of his disease, lost his desire for MAiD and lost his eligibility for MAiD.

MAiD request in a person with frailty and mild dementia

Tom was a 91-year-old gentleman who had become increasingly frail over the past year. He had osteoarthritis, atrial fibrillation, and urinary incontinence. He used a walker. He was very forgetful and needed to be reminded about ADLs. He was living at home with the help of daily caregivers. He had had no imaging, but his family doctor had diagnosed vascular dementia (VD). His symptoms of pain, “wooziness”, and incontinence were difficult to manage. He was no longer able to do the things he had enjoyed, such as walking his dog. He was very articulate about his desire for MAiD: “This is no life. I had a great life, a great career, wonderful family. Now I am finished. I know this (forgetfulness) will just get worse.” After a careful examination of his records and after talking with the family doctor, the clinicians assessing eligibility for MAiD recognized that reversible causes had been ruled out (his tests included a complete blood count, glucose, renal function (GFR), electrolytes, liver enzymes, thyroid function (TSH) and vitamin B12). He had not had any imaging of his brain, but because the history was clear, the assessors decided that no further diagnostic testing was necessary.

i. “They are in an advanced state of irreversible decline in capability.”

Tom had declined slowly over the years, with recent further deterioration, and now was “advanced” by virtue of his overall medical condition including frailty. He had a clinical frailty score of 6.

ii. “They give informed consent.”

Although he didn’t remember that the other clinician had assessed him for MAiD at his home the day before, at the second assessment he still understood his medical conditions and was clear that his suffering was intolerable. He said he was not depressed, that he was grateful for the

good life he had had, but that now he was finished. He did not want a higher level of caregiving. He was deemed to have capacity.

iii. “Their natural death has become reasonably foreseeable.”

A 91-year-old man has a life expectancy of about 4 years. Vascular dementia further shortens life expectancy. He had deteriorated over the past year and was on a trajectory towards death. His death was predictable and thus “reasonably foreseeable”.

Tom asked for and received MAiD as soon as the 10-day reflection period had passed.