



Canadian Association of MAiD  
Assessors and Providers



Association Canadienne des Évaluateurs  
Et Prestataires de l'AMM

# Assessment for Capacity to give Informed Consent for Medical Assistance in Dying (MAiD)

## Review and Recommendations

A Canadian Association of MAiD Assessors and Providers (CAMAP) white paper  
on complex capacity assessments

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## 1. Introduction

In this paper we discuss the assessment of capacity to give informed consent to Medical Assistance in Dying (MAiD). Canada's law on MAiD, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), known as Bill C14 [1], 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” and that clinicians “immediately before providing the medical assistance in dying [...] ensure that the person gives express consent to receive medical assistance in dying”. Assessment of capacity is required by both of the two independent clinical assessors as well as any additional clinician who is asked to do a capacity assessment.

In many MAiD assessments, the conversation the clinician has with the patient about how they came to the decision to request an assisted death provides ample evidence that the patient has a good knowledge of their medical condition, of the available treatments for the condition and any symptoms they have, of their choices at the end of life and the consequences of those choices and that their reasoning is sound. In this paper we discuss the more challenging situations in which a capacity assessment is complicated by cognitive impairment, communication difficulties or psychiatric illness.

All forms of medical intervention performed by clinicians require informed consent [2]. Informed consent is task, context, and time specific and requires voluntary choice in a patient who has been adequately informed and who has capacity to consent [2-5]. The assessment of capacity can be affected by contextual factors including the experience and values of the assessor. For example, Ganzini et al (2000) found that assessors with previous bias against assisted dying are more likely to find patients incapable than those who accept assisted dying as a potential end-of-life choice [6].

Ideally an assessor of capacity for MAiD has good understanding of the underlying condition precipitating the request for MAiD, is fully familiar with the processes required for MAiD, and also has a balanced, objective view of end-of-life choices.

The elements of informed consent are as follows [7]:

- i. Information given to the patient should include:
  - a. Nature of the medical condition(s)
  - b. Proposed treatment(s)
    - i. Risks

- ii. Benefits
    - c. Alternate treatments available
    - d. Likely outcome with no treatment
- ii. The patient should have the linguistic ability to comprehend the information, and the assessor should provide a “reasonable” amount of information on the above domains.

Capacity requires the following: [3, 5, 8]:

- Ability to **understand** the relevant information;
- Ability to **appreciate** the relevant information and the consequences of accepting or declining the proposed treatments or interventions
- Ability to **reason** about treatment options and their consequences.
- Ability to **communicate** a choice;(even with appropriate help)

There are up to three times when capacity assessments are required during the MAiD process. The first time capacity must be determined is when a clinician performs an eligibility assessment for MAiD. The second time is immediately prior to administration of medication, to ensure final consent prior to beginning the MAiD procedure. And the third possible time capacity must be determined is if a consultant capacity assessment has been requested.

A summary and case examples are at the end of the paper

## 2. Assessment of Capacity in Patients with Cognitive Impairment

*Elements of this section are excerpted from “Medical Assistance in Dying (MAiD) in Dementia”, a clinical guidance document produced by CAMAP in 2019*

### Prevalence of incapacity in mild cognitive impairment and dementia

The presumption of intact decisional capacity is a bioethical standard [3, 9]. While patients with dementia can lose their ability to provide informed consent to medical treatment due to loss of cognitive functioning [8, 10], this capacity can persist to varying degrees [11-14]. For example, in a study comparing capacity assessment tools in 79 patients with mild to moderate dementia, Gurrera et al.[12] found that overall capacity was impaired in 13.9% to 30.4% of patients, depending on the tool being used. Okonkwo et al. [13], in their study assessing capacity in patients with mild cognitive impairment (MCI) and mild Alzheimer’s Disease (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. While most patients with MCI and early dementia retain capacity, this capacity can be expected to deteriorate as the disease progresses, so should be reassessed periodically [13].

The timing of this deterioration can be difficult to predict. In cases of AD, one study found that the mean duration of early dementia was 5.6 years from the time of diagnosis to onset of moderate dementia [15]. 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 [16-18].

### **Communication challenges in dementia**

Patients with all forms of dementia have at least some word-finding difficulty. In vascular dementia, one may also see expressive aphasia and dysarthria that severely affect communication. Previously multilingual individuals may revert to their mother tongue and require a translator. With dementia, memory impairments can make it difficult for patients to follow a conversation or a train of thought.

For further information and practical tips see Section 3 and Table 1

### **Assessment tools for assessing capacity in cognitive impairment**

Assessment of capacity in patients with cognitive impairment remains a clinical challenge. Expert opinion may overestimate capacity [8, 19]. While formal capacity assessment tools may be useful in determining capacity there is no gold standard for assessing capacity to consent to treatment in patients with dementia [4, 10, 19]. Several tools have been widely studied including the Aid to Capacity Assessment (ACE) [20] and MacCAT-T.

The MacCAT-T is the most widely used [8, 10], and may be the most suitable across a variety of populations [21]. In a 15- to 20-minute semi-structured interview procedure, this tool assesses competency to make treatment decisions by examining capacity in four domains [22]:

- i. Understanding information relevant to a condition and recommended treatment;
- ii. Appreciating the nature of their situation and the consequences of their choices; and
- iii. Reasoning about the potential risks and benefits of their choices;
- iv. Expressing a choice.

The MacCAT-T has been used in a variety of populations including dementia and has been shown to have high inter-rater reliability [4].

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) [4, 20].

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 [13]. They may, however, be useful in informing decisions around capacity: an MMSE score of <19 was shown to predict incapacity, while scores of 23 to 26 were highly likely to have capacity [14, 23]. To our knowledge, the MoCA has not undergone similar investigation of its ability to predict capacity.

Assessment tools have limitations. For example, they may grant too great an importance to a person's measurable cognitive skills and not enough to their ability to make others aware of their wishes through verbal and non-verbal communication [5]. Many capacity tools may not give an overall rating or score, as they are designed to complement and not replace professional judgement [19]. In practice the formal use of capacity assessment tools is not generally necessary.

Ensuring optimal assessment conditions should be prioritized to increase rates of autonomous decision making [10]. The domain of understanding has been shown to be most frequently deficient, as it relies most heavily on short-term memory and is therefore vulnerable to the amnesic deficits in MCI and mild AD [8, 12]. 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 [18]. For example, one can write down the alternatives of continuing with palliative care and having MAiD and show this to the patient when asking which they prefer. It is important to note that deficits in short-term memory do not necessarily preclude capacity.

## Documenting capacity in dementia

Rigorous documentation of capacity, particularly in patients who have a diagnosis of dementia, is crucial. Using empirical tools, such as those described above, may strengthen the documentation, but it is more important to systematically document the findings as they relate to the four domains of capacity described above: understanding, appreciation, and reasoning and choice.

### 3. Assessment of Capacity in Patients with Communication challenges

When working with patients with communication barriers clinicians must remember that they are not assessing a patient's communication skills but their decision-making capacity. In order to do so effectively, they must facilitate and maximize a patient's communication abilities. Only then can it be certain that the patient's underlying competence is being assessed [24].

**Hearing loss:** In Canada, an estimated 54% of adults aged 40-79 (8.2 million) have at least mild hearing loss in the speech-frequency range [25-27]. This rises to 93% for individuals aged 70-79 years. Many individuals deny awareness of their hearing loss and therefore many patients may not be appropriately aided. Consider carrying a small personal amplifier (e.g. Pocket Talker) that can be used with older adults who do not have hearing aids but who might benefit from an improved signal (clinician's voice) to noise (anything else) ratio. We also recommend following the general suggestions listed in Table 1. Their use allows communication to be maximized without needing to wait for patients to self-declare as hard of hearing. It is important to note, however, that these suggestions are not appropriate for members of the Deaf community, who will require a Sign Language interpreter.

**Motor speech disorders:** Motor speech disorders affect an individual's ability to produce a voice and/or articulate speech sounds making it difficult, or even impossible, for a listener to understand. These disorders do not on their own affect an individual's cognition. There are two broad categories of motor speech disorders: dysarthria (weakness, incoordination, impaired muscle tone) and apraxia (motor planning and programming deficit) [28].

Some individuals with motor speech disorders may use Augmentative and Alternative Communication (AAC) systems to facilitate communication. These may be low tech and/or high-tech systems; may have a variety of access methods including direct touching of a keyboard/screen, switch access, head mouse, or eye-gaze; and be used in a variety of ways to support communication. AAC systems may include, but are not limited to, writing, alphabet board, E-tran (eye-transfer) boards, and speech generating devices (picture or word based).

When communicating with individuals with motor speech disorders, consider the following:

- A non-response should not be used to indicate "no" (e.g. better to suggest squeeze once for yes and twice for no, rather than do nothing for no). This is especially crucial in the context of MAiD where there is the need to clearly document how an individual communicated his/her intent [29].

- Ask the patient if they would like to complete their sentences or if they want you to guess (when appropriate) to save them energy.
- One consistent, intentional muscle movement, such as blinking, may be sufficient to communicate using partner assisted scanning. ([http://www.lburkhart.com/Isaac\\_instructional\\_06.pdf](http://www.lburkhart.com/Isaac_instructional_06.pdf)).
- The general communication tips noted in Table 1 may also improve communication with individuals with motor speech disorders.
- The MAiD Assessment Tool for Patients with Motor Speech Disorders (available on the CAMAP website) can be used to provide a framework for interviewing patients using a yes/no format.
- If a patient requesting MAiD appears to be limited to yes/no responses, clinicians may consult a speech and language pathologist (SLP) for additional communication supports

**Aphasia:** Aphasia involves varying degrees of impairment in four primary areas: spoken language expression (speaking), spoken language comprehension (listening), written expression and reading comprehension. Be aware that deficits in comprehension may not be obvious because the patient may compensate by using context and observation of non-verbal communication to interpret meaning. Aphasia can occur in the absence of significant cognitive impairments. Receptive aphasia (impaired comprehension of spoken and/or written language) is specific to linguistic comprehension and does not, on its own, preclude an individual from having preserved decision-making capacity [30-32].

Communication partner training is effective in improving a patient’s ability to demonstrate their underlying competence and can act almost as a translator to help the patient with aphasia to understand information and to communicate their response [33, 34]. Communication partner training involves learning to use a variety of communication supports to maximize the receptive and expressive abilities of the patient with aphasia. These supports can include spoken and written keywords, body language and gestures, drawings, photographs and other visual supports. Ideally, this person would be an SLP, however there are resources available to train other people to provide this support [24, 35].

**English as an Additional Language:** Current evidence holds professional interpreters as the “gold standard” for patients using English as an additional language, due to their impartiality, respect of patient confidentiality, and knowledge of the patient’s culture and customs [37]. Despite the fact that the use of ad hoc interpreters occurs frequently in health care, the use of family members as interpreters is more fraught, since their use can compromise family dynamics, patient confidentiality, and the accuracy of the information being communicated [37]. Professional interpreters are available by telephone without prior arrangement in many communities. It’s important to understand that being a functional English speaker does not necessarily

mean that one cannot benefit from a language interpreter in the context of assessing capacity for MAiD. This is particularly true given the complexity of the issues being discussed.

Of note, cognition and communication are inextricably linked. While the communication tips noted below may help support communication with individuals with impaired cognition, it is important to review Section 2 for a detailed discussion of cognitive impairment and its potential impacts on decision making capacity.

#### **4. Assessment of Capacity in Patients with Psychiatric Diagnoses**

While mental health disorders have the potential to affect capacity, it is crucial to remember that all patients, including those with psychiatric illness, are to be presumed capable unless evidence suggests otherwise [7]. When mental illness does impair capacity, it most often affects the “appreciation” branch, which reflects insight. Patients may lack insight where their psychiatric illness is concerned but still retain full insight where other medical illnesses are concerned; the reverse is also possible. It is therefore vital that the assessor recall that capacity is both context and task specific. It is also important to recognize that patients who are incapable with respect to MAiD due to an acute exacerbation of a mental illness, such as a manic or psychotic episode, can regain capacity with treatment and may therefore require serial assessments.

A full review of statistics on treatment decision-making capacity in specific mental illnesses is beyond the scope of this guideline. The available literature generally uses the McArthur Competence Assessment Tool for Treatment (McCAT-T) to assess medical decision-making capacity in psychiatric populations, but similar data specific to MAiD decisions is not yet available. In brief, the available literature indicates that even among individuals involuntarily hospitalized for mental illness, 70-80% may be capable with respect to treatment decisions [38]. Of note, capacity can vary by diagnosis and severity. For example, one study on capacity for treatment decisions, among inpatients, found that 31% of individuals with severe unipolar major depressive disorder (MDD) lacked capacity, whereas 80% of patients with acute psychosis due to schizophrenia lacked capacity [39]. Fewer studies have examined treatment decision-making capacity in outpatients with psychiatric illness, although it is likely that rates of capacity are higher in outpatients.

Numerous challenges may arise when assessing capacity in individuals with psychiatric illness. Cognitive impairment and fluctuating cognition are discussed in Sections 2 and 6. Here, we discuss some additional challenges:

i. Discerning conventional suicidality from a rational request for MAiD

The very existence of MAiD law implies that a desire to die, in the context of unbearable suffering due to irremediable illness, can be rational. Similarly, it is implied that hopelessness in this context can also be rational. In the absence of a diagnosable mental illness or psychiatric history, assessors are less likely to doubt that a MAiD request is rational; however, in the presence of psychiatric illness, greater doubt can arise. This is in part because hopelessness and suicidality are both listed as diagnostic criteria for major depressive disorder (MDD), and suicidality is also listed as a diagnostic criterion for borderline personality disorder (BPD) [40].

Several factors must be considered given the complications posed by these diagnostic criteria: firstly, the existence of hopelessness or suicidality does not automatically imply that the request for MAiD is merely based on a symptom of a mental disorder, or that every individual with MDD or BPD is irrational when requesting MAiD. Secondly, individuals without a diagnosed mental illness can also develop suicidality, and so the presence or absence of a disorder is less important than the individual capacity assessment. Thirdly, the examiner must consider general differences between suicide and MAiD. Broadly, suicidality in its conventional sense is a greater concern when the following characteristics or situations are present: impulsivity; ambivalence; an acute exacerbation of an underlying mental illness; or a situational crisis such as a major loss or separation or a newly acquired severe, permanent injury [41, 42]. Again, these generalizations cannot act as a replacement for a nuanced capacity assessment. Furthermore, safeguards exist within other eligibility criteria such as the requirement for an “enduring” request, non-ambivalence, and voluntariness. When doubt arises about suicidality during a capacity assessment, it may be necessary to request additional opinions.

ii. Cognitive distortions

Cognitive distortions are defined as “systematic errors in reasoning,” leading to biased and distorted processing of external events or internal stimuli [43].

These distortions can affect the way individuals see themselves, the world around them, and their future [44]. Examples of distortions include: filtering (focusing only on negative input rather than noticing the full picture); dichotomous thinking (seeing the world in black and white, all or nothing); overgeneralization (drawing a broad conclusion based on an isolated event); catastrophizing (imagining the worst case scenario); and arbitrary inference (drawing a conclusion in the absence of any evidence) [44, 45].

Concerns have been raised about the fact that individuals with mental illness are prone to cognitive distortions that could affect their capacity [46]; however, after an extensive literature review, the present authors were unable to find any empirical research examining how, and when, cognitive distortions affect capacity for medical and end of life decision-making, including decision-making about MAiD. Further research is clearly needed. Meanwhile, it is important to remember that cognitive distortions and dysfunctional beliefs also exist in patients without mental illness, and therefore assessors should be cognizant of distortions in every patient, with or without mental illness. It is also important to recall that a patient may have values or beliefs with which the assessor disagrees, or a challenging personality style. Assessors must avoid confusing these factors with incapacity.

iii. Countertransference and challenging personality styles

It is important for assessors and providers of MAiD to be aware of their reactions to patients who have particularly challenging personality styles; of course, this may occur whether mental illness is present or not. It is important to avoid confusing disagreeableness or intense anger with incapacity, for example. When a patient interaction leads to strong emotions in the assessor, we suggest the following options: step back from the situation and take the necessary time to reflect; consult with colleagues; end the assessment and return another day if possible; or ask for an additional assessment/opinion if necessary.

iv. Substance use disorders

Individuals with active substance use disorders can still be capable with respect to medical decision-making. It may be necessary to treat these individuals the same way one would treat individuals with other causes of fluctuating capacity; for example, someone who is acutely intoxicated or going through withdrawal would very likely have impaired capacity, whereas at another day or time, when not intoxicated or not in withdrawal, they may well possess capacity. Individuals with chronic, stable substance use, such as alcoholism, may be able to demonstrate capacity all or most of the time.

v. Personality disorders

Individuals with certain personality disorders such as BPD may have intense fluctuations in domains such as mood, affect, and impulsivity, and may be more likely to demonstrate ambivalence. At times, assessors may also need to treat these individuals in the same way as those with fluctuating capacity. Collateral

history from those who know the patient well may be particularly helpful, and when possible, a longer assessment period with multiple separate assessments over time may be necessary to ensure the consistency and stability of the request. Ideally, assessors should aim to assess these individuals when they are in a euthymic state rather than when emotions are more intense.

The “Aid to Capacity Evaluation” tool, produced by the Joint Centre for Bioethics in Toronto, is an excellent resource for capacity assessment in general and where mental illness is concerned [6, 47]. The document contains useful sample questions. For example, if a patient presents with MDD, sample questions include: “Do you think that you’re a bad person?” and “Do you deserve to be treated?” If a patient presents with psychosis sample questions include: “Do you think your condition is caused by someone trying to hurt/harm you?” and “Do you trust your doctor/nurse?” These kinds of questions can get at underlying cognitive distortions or delusions that may affect capacity. Similar questions, employed by members of this working group, where MDD is concerned, include: “Do you feel that you deserve to die?” and “Do you feel that other people would be better off without you?”

The above suggestions may help to guide capacity assessment where mental illness is present, but there are times in which a patient’s presentation is particularly challenging and complex. The authors of this guideline urge assessors and providers to consult frequently with each other and to call in additional assessors in those cases. CAMAP provides a list of mentors and consultants for members to contact when facing challenging assessment. We urge members to make use of those resources.

## **5. Assessment of Capacity in Patients with Intellectual/developmental disability**

Concerns about vulnerability of this group have been expressed strongly by patient advocates citing a history of abuse of this population including involuntary segregation and sterilization, eugenic extermination, and prenatal testing resulting in termination of fetuses carrying disability-related traits [48]. The potential broadening of MAiD eligibility criteria, particularly removing the requirement for a reasonably foreseeable natural death, is seen as particularly problematic, as it might then enable people with just intellectual/developmental disabilities to request and receive medically assisted deaths. However, there is also very strong support from other patient advocacy communities to increase autonomy and decision-making by people with intellectual disabilities using a range of techniques. These include supported decision-making (including care providers and family members to help the person make decisions), shared decision-making (having clinicians use collaborative decision-making processes in helping clarify the patient’s decision) and using a variety of other communication

supports as necessary to allow the person to understand their choices and make an informed decision [49]. Authors note that many adults with mild intellectual/developmental disability can make simple, familiar decisions about healthcare but might need support for more complex ones. Most adults with moderate intellectual disability will need more accommodation and support from others to enable them to make even simple health care decisions. More specific guidelines for obtaining informed consent, with greater focus on supportive decision-making compared to the general population, were published in 2011 by Surrey Place Centre in Toronto [50]. Based on this literature, it is clear that the predominant focus in health care decision making for adults with intellectual/developmental disabilities is to maximize autonomous choices, while providing as much as necessary support to enable this process. This is consistent with adults with intellectual/developmental disabilities also making choices about the end-of-life, as long as they fulfill basic criteria for decision-making capacity as described by Sullivan and Heng, 2018 (49).

## 6. Assessment of Capacity in Patients with Fluctuating Capacity

Given the high incidence of delirium in Palliative care units (up to 60%) and in frail elderly adults who are nearing the end of life, it becomes necessary to address the issue of assessing capacity to request MAiD in adults with fluctuating capacity. Many providers have faced the dilemma and sense of urgency of assessing for or providing MAiD before delirium sets in and patients lose eligibility. Patients may refuse symptom control or may undergo MAiD earlier than they would prefer out of fear of losing capacity.

In order to support decision making in patients who are in a mild delirium or may be at risk of delirium we would suggest the following strategies:

- i. Communication strategies should remain simple and explicit in all adults who are at risk of delirium. (See Table 1)
- ii. Timing of the assessment is crucial to optimize function and cognition. Nursing staff or family may be able to provide information about what time of day a patient is particularly alert so the clinician can schedule a visit at an optimal time. This is frequently shortly before comfort care medications such as opiates and benzodiazepines are due to be given. Patients are often more alert in the early part of the day and become less able to engage in conversation as the day progresses.

- iii. Engage substitute decision makers to support the patient in communication and understanding, and attempt to get an understanding of the patient's prior values
- iv. A second opinion from a colleague who has experience in areas of delirium and capacity may be useful. Request a consultation to assess reversible factors in the delirium e.g. anticholinergic medications, hydration etc.
- v. Engage the team to document the patient's expressed wishes at times when not in a formal interview to ensure consistency of the request
- vi. Delirious elderly may experience distress and hopelessness that resolve with symptom resolution. Also, patients may be highly distressed and agitated during a delirium and can voice death wishes or engage in self-harm actions, which may disappear after the delirium has resolved. Clinicians/care teams should only ask the patient about MAiD when the delirium has cleared, either temporarily or permanently.
- vii. Clinicians need to be aware that imminent death is often signaled by pre-death delirium and that it may not be feasible or in the patient's best interest to go through all the complexities of the process of MAiD (a witnessed, written request, two independent assessments, etc). Families are often reassured by a discussion of symptoms predictive of rapidly approaching death such as agonal breathing, cyanosis, and decreased alertness. Otherwise they may fear a lengthy, drawn-out death. If not already begun, it is often best to ensure good end-of-life palliative care is instituted and support is provided to families in this very difficult stage.

## 7. Documenting capacity

*Elements of this section are excerpted from "Medical Assistance in Dying (MAiD) in Dementia", a clinical guidance document produced by CAMAP in 2019*

Providing MAiD in the absence of capacity is a serious offence. Rigorous documentation of capacity, particularly in patients who have cognitive impairment, communication challenges or psychiatric diagnoses, is therefore crucial.

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

### **i. Understanding**

Understanding necessitates a working knowledge of one's health. Individuals must demonstrate 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 clinical assessment of their understanding [4, 5, 8]. The clinician must ensure that the patient has had 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, including palliative care, and the risks and benefits of these treatments; and
- The risks and benefits of MAiD, with an emphasis on irreversibility.

### **ii. Appreciation**

Appreciation requires that a patient be able to apply the above information to their personal circumstances [4] and attach personal meaning to the facts of a given situation [9]. For example, some people may be able to repeat information but may not see how these factors apply to their personal situation [9]. 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;
- 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).

### **iii. Reasoning and rational manipulation of information**

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” [9]. 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 [4].

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.

#### **iv. Choice**

To have capacity, patients must be able to make and express a choice [3, 5, 9]. Expression of a desire for MAiD is the choice that will have led to a MAiD assessment. The choice for MAiD should be consistent and predictable over time, although reasonable levels of ambivalence do not preclude capacity.

### **8. Additional Considerations:**

#### **i. Clinician Disagreement**

At times, assessors or providers of MAiD may disagree about a patient's capacity to consent to MAiD. Although the two assessors must be independent, a conversation between assessors may be beneficial or even necessary when there is disagreement. One assessor may have access to different information than the other. Documentation is especially important when a provider decides to proceed with MAiD after a previous colleague has concluded that the patient is ineligible, whether by virtue of incapacity or any other reason. It is crucial for the provider to document why they disagree with the assessor(s) who found the patient ineligible and to provide a clear rationale for proceeding. This should include, whenever possible, detailed documentation of collateral history from the patient's physicians, loved ones, or caregivers.

#### **ii. Role of Patient's Values**

Interestingly, the more widely used capacity assessment tools do not include a consideration of the patient's values and whether the request for MAiD is consistent with those values. Especially in situations where a capacity determination is more challenging, being able to ascertain, from the patient and/or collateral sources, whether the request is in line with the patient's longstanding values can add strength to the determination of capacity. At the same time, it is important to recognize that values can change over time, and that if the decision is inconsistent with the patient's longstanding values, this

does not necessarily negate capacity.

## 9. Summary

### Assessment for capacity to give informed consent for MAiD

Capacity is task-specific and includes the ability to:

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

For people with issues such as cognitive impairment, communication difficulties, or psychiatric illness one should document each of these four abilities. It is important to facilitate communication and to help those with communication or cognitive impairments understand and communicate their wishes. See Table 1.

**Table 1: General Communication Tips**

**Tips for setting up the communication environment**

- Limit the number of people involved in a conversation with the patient
- Sit face-to-face with the patient
- Ensure that there is good lighting with limited glare
- Limit the number of distractions to conversation (e.g. turn off the TV, close the door to a noisy hallway)
- If they wear them, ensure that the patient's glasses are clean and on
- If the patient wears hearing aids, make sure that these are turned on and, in their ear,(s)
- If the patient has a hearing impairment but no hearing aids, consider a voice amplifier (e.g. a pocket-talker)

**Strategies to Facilitate the Patient's Comprehension**

- Allow sufficient time for your conversation so that you do not rush
- Use a normal intonation pattern, do not artificially slow your speech, or speak in a sing-song pattern
- Take short pauses between sentences to allow the patient to process what they hear
- Avoid jargon
- Repeat information in different ways
- Identify the topic before you start the conversation **“Let’s talk about your family”** followed by a short pause and then, **“Do you have any children?”**
- Clearly identify any topic shifts **“Now I want to change topics”** followed by a short pause and then, **“Which other treatments have you tried?”**
- Keep sentences short and simple. Instead of, **“Tell me about your suffering including physical, mental, emotional and existential”** you could say, **“I want to ask about different types of suffering”** and then after a pause **“Can you tell me about any physical suffering?”**

- Ask the patient to summarize what they have understood to confirm comprehension

### Strategies to Facilitate the Patient's Expression

- Be aware that fatigue can negatively impact communication and schedule interviews when the patient is most alert
- Clearly identify the patient's ideal means of expressive communication prior to the conversation and use it consistently (this may require a SLP)
- Give the patient plenty of time to answer - they may be formulating their thoughts or trying to think of the right words
- Use closed-ended questions, such as “**yes or no**” or multiple-choice questions, when asking about specific information
- Always offer a “**something else**” option in multiple-choice questions
- Do not be afraid to ask follow up questions if you need additional information - patients may find communicating effortful and may not readily volunteer additional information without prompting
- If you do not understand, do not pretend that you do - tell the patient and ask them if they want you to guess or if they want to try to clarify
- Instead of asking the patient to repeat themselves, encourage them to “**say it another way**”

## APPENDIX 1: Case examples

### Mental Illness:

Case example 1: Ms. P. is a 66-year-old married woman with metastatic ovarian cancer, who has discontinued chemotherapy and radiation after several trials over a span of 6 years. Her reasons for discontinuation include intolerable side effects and increasing pain and disability from the effects of metastases that have not responded well to treatment. She is referred to psychiatry for a capacity assessment when she requests MAiD because she has a history of severe MDD with a very serious suicide attempt three years ago. At interview, she appears tired and mildly dysphoric but her affect is reactive and she smiles when talking about her pets. She recounts that she received one year of outpatient psychotherapy following the suicide attempt and that her depression has been in remission ever since. Her former psychiatrist and her husband corroborate this history and her recovery. She says she feels very different now than when she was severely depressed in the past. She states that she feels sad at times due to her illness and impending death and says, “I want to live but I cannot tolerate any further treatment and I know the cancer will end my life.” She denies suicidal ideation, plan, or intent. She denies anhedonia, or feelings of guilt or worthlessness. She does endorse fatigue, insomnia, poor appetite and weight loss (which she attributes to the cancer) and she feels “slowed down.” You, as the assessor, determine that although these latter five symptoms can be attributable to neurovegetative symptoms of MDD, they are, in Ms. P’s case, more likely to be due to her advanced cancer and side effects of her medications. Your rationale is based on the differences between how she experienced her depression in the past - as reported by both her and collateral sources - and how she feels now, as well as on the fact that her sadness is intermittent, her affect is reactive, and she denies anhedonia, guilt, or worthlessness.

### Mental Illness Plus Dementia:

Case example 2: Mr. J. is a 75-year-old married man with Lewy Body dementia (LBD) and COPD. He was diagnosed with LBD five years ago and the COPD has been slowly worsening. He requests MAiD now because his LBD is progressing and he is losing his independence; he knows that soon he will need to move into assisted living and for him this would be unbearable. He is referred to psychiatry for an additional capacity assessment because he has a history of severe MDD with three past serious suicide attempts (all prior to 10 years ago) and also has ongoing symptoms, such as poor self-esteem and guilt, related to severe childhood trauma, but he does not meet criteria for PTSD. He takes an antidepressant which he finds helpful. At interview, he states that his depression is less severe than it was before he met his partner 10 years ago but he does endorse chronic low mood and feelings of guilt in addition to fatigue and

insomnia. His appetite is good. His mood is “gloomy and dark” but he denies anhedonia, in that he can enjoy food, music, and time spent with friends. He experiences frequent visual hallucinations due to the LBD: sometimes “plants turn into cats” and “vases become peoples’ faces.” He does retain insight during the hallucinations. MOCA on assessment was 19/26 (modified due to tremor). He is consistent and clear in his request for MAiD, which according to him, his partner, and his family physician, is consistent with his longstanding values; and he demonstrates full understanding and appreciation on assessment. In terms of reasoning, he states: “My illness is progressive and I have already lost too much of the quality of my life,” and “I would have to move to a nursing home soon and I cannot bear that.” He denies suicidal ideation, stating that his desire to die faded, though did not completely disappear, after he married his partner. You, as the assessor, determine that although he suffers from persistent depressive disorder, he demonstrates capacity. Your rationale, based on his reasoning process, is that his depression is not what is currently driving his MAiD request.

### Non-Verbal Neurodegenerative Condition

Case example 3: Ms. A is a 53-year-old married woman with two daughters (aged 21 and 18 years) diagnosed with bulbar amyotrophic lateral sclerosis (ALS) three years ago. She is still living at home with the support of her husband, children, and extended family. She has requested MAiD because despite excellent palliative care she struggles to maintain her airway (does not want a tracheostomy), has lost her sense of self, and has painful spasms in her right shoulder. She cannot move her extremities and her head control is too poor to use her high-tech communication device. Instead, Ms. A now uses an e-tran board (clear plexi-glass board with an alphabet). Her conversation partner points to letters and Ms. A blinks once to indicate that they have the right letter. She continues this process to spell out words. You consult a SLP who facilitates your conversation with Ms. A; your interview is a combination of yes/no questions and open-ended questions. Ms. A explains, “Both are terrible - getting through the day and the night” “I don’t want to leave my kids but I don’t want to choke to death”. You determine that she demonstrates capacity. A month later, Ms. A’s husband calls you to ask for an assisted death. However, Ms. A’s palliative care team has documented concerns about Ms. A’s decision-making, charting that Ms. A “can’t make up her mind” and “doesn’t know if she wants help to die”. You visit Ms. A and you explore her ambivalence within the limits of her communication abilities and energy. You ask her to answer some yes/no questions: is she 100% sure she wants an assisted death? (Ms. A responds “no”). Is she at least 50% sure? (Ms. A responds “yes”). At least 80% sure? (“yes”). At least 90% sure? (“yes”) At least 95% sure? (“yes”). Is she 100% sure? (“no”). You explore this <5% uncertainty with her using more open-ended questions and find that it is related to being sad about leaving her children. She indicates that she still wants an assisted death. You find that she has

capacity for MAiD and agree to provide for her given what is a reasonable amount of ambivalence. Ms. A chooses a date for provision. On your arrival, Ms. A's family assures you that Ms. A would like to proceed with an assisted death, however Ms. A is no longer able to consistently blink a response. Despite multiple attempts the SLP, who is present for the provision, is unable to find any other consistent means of communicating with the patient. At times, Ms. A cannot be roused. Given that Ms. A is unable to provide informed consent, you do not provide an assisted death. You hear that Ms. A died without medical assistance the next morning.

## Traumatic brain injury

Case example 4: Ms. C is a 36-year-old single woman. She suffered a severe traumatic brain injury 15 years ago secondary to a snowboarding accident. Ms. C is a functional quadriplegic, ventilated and has a J-tube for feeding. She has infrequent but significant seizures that have gradually decreased her overall level of functioning. Ms. C lives on a long-term chronic care unit to support her high care needs. As per family report, Ms. C communicates almost exclusively with yes (slight nod) or no (tilting head to one side) response. Her impaired vision and nystagmus prevent use of eye-gaze. As per her chart, Ms. C has difficulty following complex conversation and struggles with memory and attention deficits. It appears that Ms. C's hearing is intact. Ms. C's immediate family is supportive and visits regularly. Her regular nurse referred her to you for MAiD. You use yes/no questions to explore Ms. C's request, making sure to avoid long sentences, double negatives and complex sentence structure. You ask similar questions in multiple ways to ensure consistent responses. Initially, you feel that she is responding consistently but midway through her responses become erratic. Her brother notes that Ms. C was likely distracted by a conversation outside her door. After closing the door, Ms. C's responses become consistent again. In response to yes/no questions, Ms. C indicates that she has requested an assisted death because she cannot do the things that give her life meaning (e.g. sports, play the piano, go out with friends), she is afraid of getting worse and being unable to communicate her choices and no longer wants to suffer. Ms. C is unable to give the correct date, the date of her injury or whether her mother visited yesterday or the day before. Still, when the environment is ideal, Ms. C demonstrates knowledge of her injury and limitations (she needs a ventilator to breath, cannot walk, eat or do any other activities of daily living (ADLs) without full assist), that they are permanent and that her functional status is unlikely to change. Ms. C has good family and spiritual support and, though there was concern she might be depressed this was assessed and shown not to be the case. You visit on multiple occasions and Ms. C's responses are consistent over time. You find that Ms. C currently has decision-making capacity for MAiD. You note that Ms. C must have capacity on the date of provision and that this will depend on

her medication schedule and fatigue level; she will need to be provided with communication supports on that day.

### Fluctuating Capacity

Case example 5: Ms S is a 57-year-old woman with metastatic breast cancer. She is brought to emergency by her sister because she has become confused. The sister also says to the doctor in emergency that Ms S wants MAiD. Her oncologist is contacted and agrees that she had had a conversation with Ms S about MAiD and that she (the oncologist) would complete the assessment for MAiD. The emergency doctor is concerned because Ms S is not oriented to person, place or time. He consults a psychiatrist to assess capacity. The psychiatrist sees Ms S in the ER and writes a consult saying that she is incapable of medical decisions, most particularly a decision to have MAiD. The MAiD program is contacted and arranges for witnesses for the written request. Ms S is admitted to a ward and her pain medications are adjusted and she is re-hydrated. When the second assessor arrives, Ms S is very weak and speaks only a few words at a time, very quietly. She knows she is dying of cancer and that she wants to die quickly rather than linger. She knows that her pain could be controlled but she says that she just wants to “go”. The two assessors talk and agree that she has capacity and that MAiD needs to be expedited because she is likely to become confused again soon. MAiD is provided that same evening. The psychiatrist writes a formal complaint because his opinion has been overridden by the two assessors (an oncologist and a GP). In the hospital investigation, it is agreed that the assessors had done their due diligence in assuring that Ms S had capacity.

### Intellectual Disability

Case example 6: Mr. C is a 75-year-old man with mild intellectual disability (ID) who has been living in a basement suite of an intellectual disabilities group home, receiving weekly supportive visits from an independent living support worker. He has been using the city bus to attend an ID seniors’ day program twice per week. His support worker comes with him to doctor’s appointments, making sure symptoms are reported and treatments recommended are adequately discussed and understood. He signs his own consent for treatments after he and his support worker have discussed this long enough for him to understand the benefits and risks adequately. Mr. C develops increasing abdominal pain and has imaging that confirms metastatic cancer. Surgery is not recommended due to the widespread lesions. The cancer clinic admits him and starts chemotherapy, which makes him very nauseated so he refuses to continue these as he feels better without it. He says that he is getting better and wants to go home.

Mr. C is discharged with comfort medication to the respite group home which has 24/7 care. His support worker spends much time with him explaining that he will not get better and explains what options he has, including palliative care and palliative sedation, which might keep him comfortable. He understands this eventually and his support worker makes sure all his best friends have a chance to visit him. His abdominal pain gets worse and he eventually says he wants to join his parents in heaven. His sister, who lives out of province, calls the support worker and asks if MAiD has been considered. The support worker goes online and finds out information about MAiD, then receives permission (after much discussion) from her organization to talk to Mr. C about this briefly, which then results in a referral to a MAiD assessor. The assessor is told that the usual consent process involves collaborative decision-making and that the support worker would be present during the interview, as would the sister via telehealth.

During the interview there is much four-way discussion about MAiD, and Mr. C says he knows he will not get better and that he wants to join his parents in heaven as soon as possible. He knows that his parents died, that he would die and that this would be permanent. He understands that the doctor would give him medicine to take his pain away forever, but does not recall the names of the medications discussed. He chooses to talk more privately with his support worker and sister, and the assessor is asked to come back in a few days. Both assessors meet with Mr. C separately without the support worker and he tells them each very clearly that he wants to join his parents in heaven. Later that evening he signs his own written request form, witnessed by two independent witnesses. The first assessor comes back in one week, meets with Mr. C again alone, and Mr. C again says he wants to get the medicine as soon as possible. MAiD is provided the following week.

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