

# Medical Assistance in Dying and End-of-Life Care

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### Introduction

On June 17, 2016, Royal Assent was given to Bill C-14 on Medical Assistance in Dying (MAiD). The legislation amended sections of the *Criminal Code of Canada* that previously prohibited euthanasia and assisted suicide provided certain conditions are met. According to the 2nd Interim Report on Medical Assistance in Dying in Canada (Health Canada, 2017), there were 803 fulfilled requests for MAiD in the period between June 17 and December 31, 2016 and 1,179 in the first six months of 2017. Due to privacy concerns, these numbers do not include figures from the Yukon, the Northwest Territories, and Nunavut. The average age of individuals who requested MAiD during this period was 73 years. The majority of individuals had a primary diagnosis of cancer (57% of cases in the first six months and 63% of cases in the most recent six months), while the second most prevalent diagnosis was neuro-degenerative disorders (23% and 13% respectively; Health Canada, 2017).

MAiD can be provided legally by a physician or nurse practitioner<sup>1</sup> by one of two means; either by directly administering a substance that causes death (commonly referred to as voluntary euthanasia), or by providing a prescription that will cause death that is to be self- administered (commonly referred to as assisted suicide).<sup>2</sup>

The federal law governing MAiD requires that once an individual has signed a request for MAiD, a period of 10 days must pass prior to proceeding with the procedure. An exception to the 10-day waiting period can be made if the individual's death is fast approaching or if there is a high likelihood that the individual will lose capacity to provide informed consent within the 10-day period.

To be eligible for MAiD an individual must: (1) be at least 18 years of age; (2) be deemed mentally competent to make informed health care decisions; (3) have a grievous and irremediable medical condition; (4) be experiencing unbearable suffering; (5) be in an advanced state of decline in which death is reasonably foreseeable; (6) make the request free of pressure or external influence; and (7) be eligible to receive health services in Canada. The latter stipulation is intended to prevent non-residents from coming to Canada specifically to access MAiD. The government of Canada fashioned the existing law such that individuals having a mental disorder in the absence of a physical disorder cannot undergo MAiD, nor can MAiD be accessed by mature minors. Finally, requests for MAiD cannot be made through advance directives, including by individuals with dementia or other degenerative conditions (Government of Canada, 2017).

Passage of the federal law governing MAiD was highly controversial. Canadian psychologists have been involved in this issue in various capacities for many years, including participating in public debate and discussion regarding conducting research on end-of-life care and end-of-life decision-making, and serving as expert witnesses in legal cases that considered the question of assistance in dying, including "the Carter Case," which led to the ultimate passage of Bill C-14. The practice of MAiD is not without

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<sup>&</sup>lt;sup>1</sup> Physician administers in 96.7% of cases, nurse administered in 4.3% of cases.

<sup>&</sup>lt;sup>2</sup>There were five cases of self-administered MAiD in the past year.

controversy, directly impacting issues regarding personal dignity, healthcare ethics, individual freedoms, and societal protections, among others.

Once the law governing the practice of MAiD was introduced, it was expected that court challenges would likely follow, calling for it to be expanded based on the Canadian Charter of Rights and Freedoms (Constitution Act, 1982). Indeed, the British Columbia Civil Liberties Association has filed such a challenge, contending that the law excludes individuals who are disabled, those who may be experiencing unbearable suffering but whose death is not imminent, and younger persons (Julia Lamb and the British Columbia Civil Liberties Association v. Attorney General of Canada, 2016). Others have argued that an individual should have the right to request MAiD through an advance directive in much the same way as existing law allows one to prohibit the use of extraordinary measures in the event of a life-threatening health crisis (Menzel & Steinbock, 2013; The Canadian Press, 2016). On the other side of the debate, the Council of Canadians with Disabilities and the Canadian Association for Community Living argue that MAiD legislation does not recognize the social vulnerability of persons with disabilities (CCD/CACL, 2016). Similarly, Chochinov (2016) noted: "Mental illness is one of the best predictors, more so than poverty, of inequitable access to healthcare in Canada. People with severe mental illness die about 25 years earlier than adults in the general population. Making a fairness argument for the availability of physician-hastened death for a group of people treated so unfairly seems a cruel irony."

In recognition of these complexities, the Board of Directors of the Canadian Psychological Association (CPA) commissioned a Task Force on MAiD and End-of-Life Issues. The Task Force was asked to consider these issues and put forth recommendations that could inform the CPA's policy on calls to revise the existing law governing the practice of MAiD.

The Task Force addressed three questions:

- 1) Can a mental disorder be considered grievous and irremediable, and if so, should individuals diagnosed with a mental disorder in the absence of a concurrent physical illness or disability have access to MAiD?
- 2) What factors should be considered when assessing capacity for consent, and what is the potential role of psychologists in that process?
- 3) Should a mature minor with a grievous and irremediable condition have access to MAiD?

The CPA distributed a call to the membership of the association inviting participation on the Task Force. Several individuals expressed interest based on experience, knowledge, and/or their professional role. Three additional members were invited based on their particular areas of expertise. Members of the Task Force self-selected to serve on one of three sub-groups, each tasked with focusing on one of the questions. In practice however, all sub-groups dealt with all three questions and various issues related to the Supreme Court decision and the law regulating the practice of MAiD. The sub-groups met over a

period of several months via telephone conferencing, and through extensive deliberations, put forth the recommendations that follow.

### **Cautionary Note**

Canadians vary in their support of MAiD. Likewise, members of the psychology community hold widely differing perspectives on the issue. In recognition of this reality, Sub-group 3 of the Task Force surveyed Canadian psychologists using a questionnaire adapted from that used by the External Panel on Options for a Legislative Response to Carter v. Canada (the Panel; see Department of Justice, 2016). The Panel employed a methodology called the "Issue Book," part of which asked participants to consider how they would feel and what choices they would make if faced with various scenarios including significant life-threatening illness, life-altering but not life-threatening illness, a progressive condition, and a mental illness. It should be noted that the degree of knowledge and experience with issues related to MAiD varied considerably among survey respondents, as this was a general survey of psychologists in Canada. A copy of the questionnaire used by Sub-group 3 can be found in Appendix A with the complete results summarized in a report entitled, "Medical Assistance in Dying (MAiD) Survey: Final Report." The report includes several results relevant to the questions addressed by the Task Force.

The material that follows reflects the collective work of the Task Force; however, we would emphasize that there was not unanimous agreement on all points.<sup>3</sup> As desirable as full agreement would have been, it is unrealistic given the complexity of the questions considered by Task Force members and the diversity in their practice backgrounds and experience, their theoretical perspectives, and their ethical perspectives as related to MAiD. To the extent possible, recommendations were guided by available evidence.

### I. Mental Disorders and MAiD

### Can Mental Illness be Considered Grievous and Irremediable?

A survey of Canadian psychologists conducted by Sub-group 3 provided respondents with definitions of "grievous" and "irremediable" and asked whether these could apply to mental illness. Nearly all respondents believed that mental illness can be grievous (95.3%). In contrast, just over half believed that mental disorders are irremediable (53.8%) and one-third (32.7%) expressed uncertainty about this. This pattern of high belief that mental disorders can be grievous and high uncertainty over whether they can be irremediable held regardless of practitioners' experience with different client types.

The survey additionally revealed that 33.6% of respondents agreed that MAiD legislation should be extended to allow access to individuals diagnosed with chronic mental disorders, 28.1% disagreed, and 38.4% were uncertain (see Appendix B for more details). In a similar survey of Canadian psychiatrists,

<sup>&</sup>lt;sup>3</sup> Dr. Marnin Heisel requested specific mention that he was not in support of an extension to existing MAiD provisions.

29.4% of respondents supported MAiD on the basis of mental disorders alone, 61.2 % did not, and 9.5% said they did not know (Rousseau, Turner, Chochinov, Enns, & Sareen, 2017).

A survey of the Canadian public that employed a representative sample of the population found that 29% agreed or strongly agreed that individuals diagnosed with a chronic mental disorder should have access to MAiD, 48% disagreed or strongly disagreed, and 20% were neutral (Department of Justice, 2016). In summary, the majority of Canadian psychologists and psychiatrists surveyed either disagreed or were uncertain that MAiD should be extended to individuals with mental disorders who do not have a concurrent physical illness; a position that appears consistent with views expressed in surveys of the Canadian general public.

In addition to reviewing findings of the CPA members' survey, the Task Force discussed a number of issues, questions, and points of consideration relevant to the question of whether mental disorders can be considered irremediable. These discussions included the following ideas:

- 1) Treatments and interventions are constantly being developed, adapted, and improved, such that even conditions that at one point in time may have no known remedy may in fact be treatable or remediable in the future.
- 2) There is a lack of consensus among mental health practitioners about whether mental disorders are irremediable. Our survey revealed that while almost all respondents believed mental disorders could be "grievous," only slightly more than half believed they could be "irremediable."
- 3) Regardless of whether a mental disorder can ultimately be "cured" or not, and whether interventions exist that can completely alleviate a condition's symptoms or not, psychological and other interventions can help with the management of those conditions and enhance psychological well-being (e.g., Barth et al., 2013; Cuijpers, Cristea, Karyotaki, Reijnders, & Huibers, 2016; Mayo-Wilson et al., 2014).
- 4) There is concern that clinicians who communicate a professional opinion to a client that one's disorder is irremediable, or that the client is beyond help, may be contributing to iatrogenic harm, may be incorrect, and may dangerously impede that individual's sense of hope. Hope plays a critical role in psychological treatment (e.g., Moore, 2005; Snyder, Wrobelski, Parenteau, & Berg, 2004), and hopelessness (which research suggests is more like pessimism than absence of hope) is strongly and significantly associated with psychological despair, the wish to hasten death, suicide ideation, self-injury, and risk for death by suicide (Brown, Beck, Steer, & Grisham, 2000; Heisel & Flett, 2005).
- 5) Suicide ideation and the wish to hasten death can be remedied. Research supports the effectiveness of psychotherapy (alone or in combination with medication) in reducing or resolving suicide ideation among individuals with an active mental disorder (e.g., Bruce et al., 2004; Heisel, Talbot, King, Tu, & Duberstein, 2015; Szanto, Mulsant, Houck, Dew, & Reynolds, 2003). The desire

to hasten death among individuals with terminal illness can also be transient and ambivalent (Chochinov, Wilson, Enns, Mowchun, Lander, Levitt, & Clinch, 1995) and is sometimes treatable (Breitbart et al., 2015). Although the desire to undergo MAiD can certainly be stable over time (Wilson et al, 2007), requests are sometimes rescinded (Li et al, 2017).

- 6) Risk factors associated with suicidal ideation, such as lack of interpersonal relationships, social isolation, and stigma are more prevalent among persons with a mental disorder compared to the general population (e.g., Rüsch, Zlati, Black, & Thornicroft, 2014; van Orden et al., 2010). Thus, the role of external factors should be considered to determine their influence on decision-making capacity and whether associated suffering can be treated or managed.
- 7) In many instances failure to reduce suffering associated with mental disorders stems from social conditions limiting access to evidence-based treatments. Some of these factors include availability of qualified practitioners in certain communities, a level of demand that exceeds available publicly funded treatment, or an inability to cover the cost of required treatment and aftercare services. Other social determinants of health may also affect access to effective treatment.

Some mental disorders can result in a foreseeable death, including those that contribute to other health conditions, such as anorexia nervosa, and those that are both a progressive disease and a mental disorder, such as dementia. Other mental disorders, such as depression and obsessive compulsive disorder, do not result in a foreseeable death; however, in some cases, they can have a chronic, unremitting course with limited response to pharmacotherapy or evidence-based psychological treatment and with significant functional impairment and poor quality of life (e.g., Mrazek, Hornberger, Altar, & Degtiar, 2014). Individuals with these disorders may experience their condition as both grievous, or full of suffering, and irremediable, or without a cure or possibility of significant improvement in their quality of life (e.g., Lynch, Moore, Moss-Morris, & Kendrick, 2011). Mental disorders also significantly increase risk of death by suicide (e.g., WHO, 2014).

### **Recommendation 1**

Bearing these various considerations in mind, the Task Force elected not to comment definitively on the question of whether a mental disorder is irremediable or not,<sup>4</sup> and not to offer a specific recommendation related to this question. However, the Task Force is calling for additional research and evaluation of this question and the continued development and testing of psychological interventions to help alleviate suffering. It also recommends that practitioners consider the above-mentioned and other points when discussing the anticipated prognosis and course of treatment for an individual with a mental disorder.

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<sup>&</sup>lt;sup>4</sup> Sub-group 1 proposed a set of conditions to be considered in future efforts to define or deem a mental disorder as irremediable (see Appendix C). The Task Force recognizes that any such definition must be support by empirical evidence and additional input from mental health experts and stakeholder groups.

### **Mental Disorders and Capacity**

The law governing MAiD does not prevent individuals with mental disorders from accessing MAiD, provided they meet all current eligibility criteria. These criteria include that death must be reasonably foreseeable and that the mental disorder does not compromise decision-making capacity.

Under existing Canadian law, individuals who do not qualify for MAiD include:

- individuals diagnosed with a mental disorder in the absence of a concurrent physical illness;
- individuals whose death is not reasonably foreseeable;
- individuals whose mental disorder compromises their ability to provide consent; and
- individuals younger than 18 years of age.

The literature on decision-making bias of both clinicians and patients is extensive and a comprehensive review of it is beyond the scope of this document. Consideration of the research on clinical decision-making bias and its implications for the assessment of capacity in response to requests for MAiD is important. The existing law stipulates that two independent clinicians are required to assess the capacity of an individual requesting MAiD, one of which is usually the treating physician. The Task Force affirms the importance of ensuring that an independent assessment is carried out as part of determining eligibility for MAiD. Given the finality and gravity of a decision to proceed with MAiD, accurate determination of capacity is critical, and safeguards are essential to minimize the impact of either negative or positive biases.

### **Recommendation 2**

Galbraith and Dobson (2000) noted that mood and anxiety disorders, personality disorders, chronic suicidality, and other relevant factors can affect decision making. It is also recognized that psychotic symptoms and cognitive decline can compromise decision-making capacity (Okai et al., 2007). Thus, when an individual with a mental illness requests MAiD, special care needs to be taken to assess the potential impact of such factors.

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<sup>&</sup>lt;sup>5</sup> For example, Okai, Owen, McGuire, Singh, Churchill, and Hotopf (2007) examined the concept of mental capacity of psychiatric patients to make treatment decisions by addressing three questions: (1) Can mental capacity of psychiatric patients be assessed reliably? (2) With what frequency are psychiatric patients judged to lack the capacity to make treatment decisions? (3) Are there sociodemographic factors associated with capacity? Results revealed that interrater reliability was high when standardized assessment instruments were used to assess mental capacity of individuals having a psychiatric disorder. However, rates of agreement were much lower when comparing decisions arrived at by interviewers using standardized assessment tools and those made by treating clinicians. Specifically, treating clinicians were much less likely to rate their patients as lacking capacity.

<sup>&</sup>lt;sup>6</sup> The specific requirements vary across Canadian jurisdictions. For details see <a href="https://www.canada.ca/en/health-canada/services/provincial-territorial-contact-information-links-end-life-care.html">https://www.canada.ca/en/health-canada/services/provincial-territorial-contact-information-links-end-life-care.html</a>

In light of this, the Task Force recommends that the CPA petition the government to amend the existing law such that in situations where MAiD is being requested by an individual diagnosed with a mental disorder concurrent with a physical illness, assessments for determining eligibility for MAiD should be conducted in person by at least two independent duly qualified health professionals. In such instances, if the patient's physical state permits, at least one of the professionals should employ standardized objective measures of cognitive and/or emotional functioning as appropriate in accordance with best practices in assessment.

The Task Force recognizes that the government intends to further study whether individuals diagnosed with mental disorders that do not have a concurrent physical illness/disability should have access to MAiD. The Task Force emphasizes that a mental disorder does not *ipso facto* indicate that an individual is not competent to make a MAiD decision. If the existing law is amended to allow MAiD for this group of individuals, an individual's capacity to make a reasoned and informed decision needs to be assessed and established using best practices in the determination of consent and capacity. As noted above, in such instances it is imperative that assessment confirm that the individual's decision-making capacity is not limited by the presence of symptoms that may impair judgment and the ability to provide informed and reasoned consent for MAiD.

#### **Recommendation 3**

Additional investment should be made to support research aimed at developing a better understanding of the impact of symptoms of mental disorders, personality traits, and lifelong coping practices on decision making capacity; promoting an understanding of factors inherent to the therapeutic relationship that may impact determination of capacity (e.g., Audet & Everall, 2010; Sheehan & Burns, 2011); and developing standardized measures to assess capacity in a structured and systematic manner that is relatively free of bias (Shanker, 2016; Sturman, 2005). Support is also needed for research investigating the impact requests for MAiD have on members of an individual's support network, including their health and wellbeing, psychological factors associated with requests for MAiD, psychological interventions aimed at supporting individuals requesting MAiD and their families, and interventions supporting members of the healthcare team involved in MAiD cases.

### II. Advance Directives

Canadian law allows the use of advance directives to prohibit the use of extraordinary measures to sustain life and/or to permit the removal of life support. Within the Canadian landscape these laws vary by jurisdiction.<sup>7</sup>

Advance directives are expressions of wishes made by competent individuals about future care in the event they are unable to communicate, or lose competence; for example, due to a prolonged vegetative

<sup>&</sup>lt;sup>7</sup> See Health Law Institute, Dalhousie University for a listing of jurisdiction specific regulations: http://eol.law.dal.ca/?page\_id=231

state or brain death. Advance directives take two forms (Health Law Institute, n.d.): instructional directives, in which an individual communicates in advance the health care decisions that should be made when they are unable to do so (also known as "Living Wills"); and proxy directives, in which an individual specifies who should have the power to make health care decisions when they cannot do so (also known as "durable powers of attorney for healthcare"). An advance directive can be made in writing or verbally. Advance directives are not treatment decisions; rather, they are a means of guiding a substitute decision maker as to an individual's autonomous wishes for future care. In this sense, an advance directive communicates to a substitute decision maker and not to a health practitioner. An advance directive is not consent, nor is it an inviolable command.

An advance directive may specify the types of medical treatments the person wants or does not want under specific circumstances, but it is the role of the substitute decision maker to interpret and apply the directive in a given context. A substitute decision maker is required to give or refuse consent to treatment in accordance with the expressed wishes of an individual (i.e., their advance directive) and to act in the incompetent person's best interest. It is worth noting that a substitute decision maker may interpret that a previously given advance directive does not apply to the context within which a treatment decision is required, and thus decline to follow a known advance directive. Under current legislation, a substitute decision maker cannot give consent for MAiD, regardless of the presence of an advance directive requesting it.

The current MAiD legislation is restricted to individuals who have a grievous and irremediable illness who are likely to die of a natural cause in the "reasonably foreseeable" future. Moreover, the individual is required to be mentally competent to make the MAiD decision at the point at which the procedure is implemented. There is considerable ambiguity around the definition of the term "reasonably foreseeable," which could be interpreted as days, weeks, months, or years, depending on individual circumstances. This leads to a consideration of such questions as, "How far in advance of a natural death can a person make an acceptable MAiD request?" Related questions are: "Is there a role for advance directives in MAiD?" "Is it acceptable for a competent person with a dementing illness to pre-specify a MAiD death to be implemented at a future point when he/she has become incompetent to make the decision?" "How often would such a request need to be renewed?" "What if an individual who had expressed a wish for MAiD in the context of future cognitive impairment appears contented at such a time?" "What is the role of assent in such circumstances?"

These and other questions are pertinent to the MAiD legislation as it currently stands, as well as to discussions of possible extensions to patient groups that are not yet eligible.

When considering whether allowing MAiD by advance directive can ever be justified, it is instructive to consider different scenarios involving advance directives:

1) Unexpected diminution of competence in a patient already approved for MAiD. The current legislation requires a 10-day waiting period between assessment for and documentation of the MAiD request prior to carrying out the intervention. This ensures a period of reflection during

which an individual can change his/her mind. However, in some cases there can be deterioration in the individual's health during the waiting period that results in the individual no longer being deemed competent. In this scenario, the patient's wishes were documented and criteria for MAiD were met. Would it ever be possible under these circumstances for individuals to receive MAiD even though their competence can no longer be established?

- 2) Likely death but not clearly foreseeable. Some individuals develop conditions that have a high likelihood of a fatal outcome, but the expected time to death may be uncertain and quite variable from person to person. In these cases, it may be comforting to know that MAiD will be available if suffering becomes unbearable. At what point does a MAiD request by such an individual become valid, given potential uncertainty and limits to foreseeability? These individuals may not necessarily be asking for MAiD in the short-term, but rather wishing to ensure that the legal requirements are in place so that they can turn their attention to other priorities.
- 3) **Expectation of future incompetence.** An extension of the scenario noted above is that in which there is a high likelihood of a fatal outcome in the long term, and as a result of the health condition, decision-making capacity is likely to be compromised once death becomes reasonably foreseeable. This might, for instance, occur in the case of dementia.

Of note, in the survey of the CPA's members conducted by Sub-group 3, 75% of respondents agreed or strongly agreed that MAiD should be available to incompetent patients with severe dementia who had previously written an advance directive. The result is somewhat perplexing, given that it represents far more support than existed for other extensions. Dementia is now more widely acknowledged as a life-limiting illness, although whether it is a 'terminal' condition (i.e., causes death) continues to be disputed (Sachs et al., 2004). As such, the survey result might be explained by concerns for justice; for instance, a belief that it is unfair for people with other life-limiting health conditions to be able to request MAID. Nevertheless, each possible extension scenario in the survey reflected, to some degree, a potential justice concern. A further possibility is that the result is influenced by the widespread prevalence of stigma, both in Canada, where more than one third of people admit to being uncomfortable socializing with someone who has dementia (Ubelacker, 2018), and globally (e.g., Milne, 2010; Swaffer, 2014). Research confirms that health professionals are not immune from negative stereotypes about dementia (e.g., Gove, Downs, Vernooij-Dassen, & Small, 2016). Inadequacies in supportive care for dementia, including symptom management and end-of-life care, have been documented in Canada and globally (see Hunter et al., 2015, for review), and may contribute to beliefs that dementia implies suffering (Swaffer, 2014). Research also supports the idea that those who have greater familiarity with specific conditions, such as dementia, also have more positive attitudes (e.g., Angermeyer & Deitrich, 2006). Thus, at least some of the variability in the survey results may be explained by socially-derived negative expectations about dementia, and by varying levels of personal experience with the disease.

4) Non-specific advance directive. When members of the public are asked to speculate about their reactions in hypothetical situations of terminal illness, it is common for many to report that they would want to receive MAiD. Their responses in this regard are similar to those in other situations involving Living Wills and advance directives prepared by people who are currently healthy, but who want their preferences known in the event that they develop a life-threatening condition. If advance directives of any type are to be considered in the context of MAiD, then consideration should be given to the validity of non-specific advance directives for MAiD prepared by individuals who have not yet developed a qualifying illness, and as such, cannot make an informed treatment decision.

#### **Recommendation 4**

The assessment of capacity to provide consent is of particular importance in the initial stages of documenting an advance directive. For some conditions, such as dementia or other pathologies of the brain, a diagnosis is often made after manifestations of compromised cognitive functioning have been observed, at which point mental capacity may have been impacted (Sampson & Burns, 2013). For example, it has been noted that a present-oriented perspective, including difficulty imagining the future self, has been observed in dementia (Dening, Jones, & Sampson, 2013; Hsiao, Kaiser, Fong, & Mendez, 2013) and that preferences for care can and do shift as people with dementia adapt to their illness (de Boer, Hertogh, Dröes, Riphagen, & Jonker, 2007; Kirschner, 2005). In light of this, it is critical to ensure ongoing verification of the individual's wishes during the phase of the disorder in which competence is reasonably assured. However, it is also the case that changes in cognitive functioning do not always results in compromise mental capacity with respect to health care decision making.

The Task Force recommends that an individual should have the option to choose MAiD through the use of an advance directive. The individual must have a terminal illness and have the ability to make an informed and reasonable health care decision at the time of fashioning the advance directive. If these conditions are met, the requirements of imminent death and the presence of intolerable suffering should be waived. However, in such cases where death is not reasonably foreseeable the request for MAiD must be reaffirmed at least annually and under conditions of continued capacity. Advance directives for MAiD should only be considered valid when made after a certain amount of time has passed following diagnosis of the illness in order to allow for improvement in the underlying condition and for the individual to adjust to the circumstances.

#### **Recommendation 5**

The Task Force does not perceive that any new and unresolvable problems would be created by an extension of MAiD by advance directive in the scenario that an individual's capacity is diminished during the (minimum) 10-day waiting period.

<sup>&</sup>lt;sup>8</sup> Of course, some exceptions exist such as instances in which an individual chooses to undergo genetic testing to identify vulnerability markers for a particular disorder.

Further discussion and study is needed on the following issues:

- 1) Whether a wish to revoke a request for MAiD by a substitute decision maker should take priority over wishes stated in an advance directive expressed while an individual was competent and, if so, whether an advance directive needs to make this option clear.
- 2) Defining reasonable safeguards that ensure a substitute decision maker is acting objectively and in the best interest of the individual, particularly in cases where the perception exists that substitute decision make may benefit from the death.
- 3) Additional procedures are needed to define intolerable physical or psychological suffering.

The Task Force underscores the importance of supporting basic and applied research relevant to these and related questions.

### III. Mature Minors and MAiD

The existing legislation stipulates that requests for MAiD can only be made by individuals who are at least 18 years of age and mentally competent to make health care decisions. Requests by mature minors are not permitted at this time, and consideration of this issue is highly controversial. In most Canadian jurisdictions, the determination of competence of a minor to provide consent for health care or to refuse treatment is not determined by age but rather by the minor's ability to demonstrate the capacity to understand the nature and consequences of a health care decision. Some jurisdictions have formalized mature minor legislation that provides legal status for minors to make health care and other decisions. Some preliminary investigations suggest that children with life-threatening illnesses have a mature understanding of death when compared to age-matched healthy children (McPoland, Friebert, & Allmendinger-Goertz, 2017). However, Siegel, Sisti, and Caplan (2014) point out that in the case of requests for MAiD, a critical distinction between adults and minors is that of prior experience. The authors point out that the decisions of individuals that request MAiD are often driven by "fear of a loss of control, not wanting to burden others, or not wanting to spend their final days fully sedated" (p. 1964), particularly if they have witnessed the loss of dignity of a loved one, whereas children may not have had such experiences. Specifically, Siegel et al. (2014) note that children may not have the life experience needed to appreciate some MAiD-relevant considerations, such as what it means to have dignity at the end of life, or what palliative sedation would be like. For this reason, they argue that capacity is unlikely to be adequately demonstrated under Belgian legislation (which permits euthanasia for 'children' rather than 'mature minors').2

<sup>&</sup>lt;sup>2</sup> See Canadian Paediatric Society (2004) for a more thorough discussion of end-of-life and other treatment decisions regarding minors.

Results of the Sub-group 3 survey of Canadian psychologists found respondents were split on whether requests for MAiD should be extended to mature minors: 33.9% supported extending the provision of MAiD to mature minors who would otherwise qualify for the procedure, 33.9% opposed such an extension, and 32.2% were uncertain (see Appendix B). This finding is at odds with results of the survey conducted by the External Panel on Options for a Legislative Response to Carter v. Canada. The Panel's survey found 16% of a representative sample of Canadians agreed or strongly agreed with extending the provision of MAiD to a mature minor, 67% disagreed or strongly disagreed and 15% were neutral (Department of Justice, 2016), suggesting that the majority of Canadians do not support extending access to MAiD to mature minors.

In contrast, 46% of respondents to the Canadian Paediatric Society Attitudes survey were in favour of extending the MAiD option to mature minors who are experiencing progressive or terminal illness or intractable pain (Davies, 2017; 29% survey response rate).

#### **Recommendation 6**

The above results suggest that much more needs to be understood and considered with respect to this issue. As such, the Task Force determined that it was premature to put forward a policy recommendation on whether MAiD should be permitted or prohibited when the individual is a mature minor. However, the Task Force recommends that in the event that MAiD is extended to mature minors, requests by minors must include a formal determination that the minor has the capacity to make such decisions. This determination should include:

- ensuring the minor possesses a measured and stable emotional state (i.e., is not making a
  decision in a heightened state of distress);
- ensuring the minor demonstrates an understanding and appreciation of the magnitude of the decision;
- ensuring the minor is able to appreciate alternatives and the irreversibility of a decision to proceed with MAiD; and
- ensuring the minor is free of coercion and is able to exercise volition.

## IV. Role of Psychologists

## Psychologists' Role in Assessment

To the extent that psychologists are involved in assessing individuals requesting MAiD, they are likely to be called on to inform, in some manner, the determination of capacity to provide consent according to health care consent legislation. The final decision regarding capacity and eligibility lies with the physicians and/or qualified nurse practitioners involved in the case; however, assessments by

psychologists might provide useful information to physicians and/or nurse practitioners who are assessing MAiD eligibility.

According to Grisso, Appelbaum, and Hill-Fotouhi (1997; see also Hall, Prochazka, & Fink, 2012) the assessment of capacity to provide consent involves four related questions:<sup>9</sup>

- 1) The ability to express a choice about treatment.
- 2) The ability to understand the information relevant to the decision being made and the procedure being requested.
- 3) The ability to appreciate the consequences of the decision or lack of a decision for one's own situation.
- 4) The ability to reason through the relevant information in order to weigh the relevant options.

Understanding requires an intact capacity for comprehension, reasoning, and memory regarding details of the procedure and its consequences. Understanding should include an awareness of all available treatment options including palliative care interventions, and where there is the presence of a concurrent mental disorder, the availability of psychological, medical, social, and where relevant, spiritual care.

The individual's ability to appreciate the consequences of the decision involves a determination of the extent to which he/she is able to consider the request for MAiD within the context of his/her overall life circumstances.

The consent process must ensure that the individual has had the opportunity to obtain answers to all of his/her questions regarding MAiD and alternatives to MAiD, potentially including available psychological interventions to ease suffering and enhance coping, and any other considerations that are of importance to the individual.

Kolva, Rosenfeld, Brescia, and Comfort (2014) underscore the importance of ensuring that assessment of decisional capacity in patients with terminal illness is comprehensive and extends beyond the use of global measures of mental status or a diagnosis of a mental disorder.

<sup>&</sup>lt;sup>9</sup> See also Canada's Traditional and Current Legal Capacity Laws (https://www.lco-cdo.org/en/our-current-projects/the-law-and-persons-with-disabilities/disabilities-call-for-papers-january-2010/commissioned-papers-the-law-and-persons-with-disabilities/a-new-paradigm-for-protecting-autonomy-and-the-right-to-legal-capacity/v-canadas-traditional-and-current-legal-capacity-laws/)

### Other Roles of Psychologists

In addition to determining whether a requesting patient has capacity to provide consent, other roles assumed by psychologists can include:

- providing consultation and/or support to patients, family members, and members of the medical team;
- counselling patients considering MAiD and/or family members that express a desire for support;
- participating in government and institutional consultation related to end-of-life policy and legislation;
- assisting and supporting patients in end-of-life decisions if needed, and with the patient's consent;
- being involved in quality of care issues of persons with a terminal or general medical condition;
- providing psychotherapy to patients who are nearing the end-of-life;
- conducting research on end-of-life issues; and
- developing and delivering continuing education programs on end-of-life issues and MAiD for practicing psychologists.

### **Recommendation 7**

Drawing on their expertise in psychometrics and test construction, psychologists involved in work related to MAiD and end-of-life care are encouraged to take an active role in developing and/or evaluating the reliability and validity of objective measures and subjective reports of suffering and in advancing research in this critical area of assessment, specifically within the context of end-of-life care. The Task Force underscores the importance of ongoing support for research focused on these and related areas of study.

#### **Recommendation 8**

The Board of Directors of the CPA is encouraged to establish a task force charged with developing practice guidelines for psychologists involved in the various aspects of end-of-life care, including the assessment and/or counselling of individuals requesting MAiD. Given that health care is regulated at the provincial/territorial level, and given the number of ethical issues involved, a task force on practice guidelines should consult with representatives of the various provincial and territorial associations as well as the Committee on Ethics of the CPA.

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# Appendix A

# Online Medical Assistance in Dying (MAiD) Survey

There are 61 questions in this survey.

### AREAS OF PROFESSIONAL PRACTICE AND MEDICAL ASSISTANCE IN DYING (MAID)/END-OF-LIFE CARE

Have you ever provided services to a client with:		
Please choose the appropriate response for each item:		
	Yes	No
a terminal illness (expected to live just a few months)?	0	0
a terminal illness who perceived that their suffering was intolerable?	0	0
Have you provided services to a client with:		
Please choose the appropriate response for each item:		
	Yes	No
a permanent physical disability?	0	0
a permanent physical disability who perceived that their suffering was intolerable?	0	0
Have you provided services to a client with:		
Please choose the appropriate response for each item:		
	Yes	No
dementia?	0	0
dementia who perceived that their suffering was intolerable?	0	0
Have you provided services to a client with:		
Please choose the appropriate response for each item:		
	Yes	No
a mental disorder?	0	0
a mental disorder who perceived that their suffering was intolerable?	0	0

The legislation regulating MAiD stipulates that MAiD is applicable to individuals who have a medical condition that is "grievous and irremediable." According to the Oxford Dictionary, "grievous" means "very severe or serious" and "irremediable" means "impossible to cure or put right."

Do you believe that psychological disorders can be:			
Please choose the appropriate response for each item:			
	Yes	Uncertain	No
"grievous"	0	0	0
"irremediable"	0	0	0
usually helped, even if they cannot be entirely "cured or put right"	0	0	0
Have you ever worked with a patient that you would deem to have (i.e. cannot be entirely "cured or put right") mental disorder, even the physical illness or medical condition?			
Please choose <b>only one</b> of the following:  O Yes O No			
Please describe your current level of awareness of the law around r including Physician or Nurse Practitioner assisted suicide) in Canada		ssistance in dyin	ng (MAiD;
Please choose <b>only one</b> of the following:			
O Until now, I was not aware that MAiD is legal.			
I am aware that there are developments, but have not follo			
<ul><li>I am aware that there are developments, and have followed</li><li>I have reviewed the legislation.</li></ul>	d with int	erest.	
Since the Medical Assistance in Dying Legislation passed in June 201 you the option of hastening death?	L6, has ar	ny client discusse	ed with
Please choose <b>only one</b> of the following:  O Yes O No			

### How many clients have done so since June 2016?

### Only answer this question if the following conditions are met:

Answer was 'Yes' at question '8 [A23]' (Since the Medical Assistance in Dying Legislation passed in June 2016, has any client discussed with you the option of hastening death?)

Only numbers may be entered in this field.

Please write your answer here:

### Of these, how many do YOU consider to have been eligible to request MAiD?

### Only answer this question if the following conditions are met:

Answer was 'Yes' at question '8 [A23]' (Since the Medical Assistance in Dying Legislation passed in June 2016, has any client discussed with you the option of hastening death?)

Only numbers may be entered in this field.

Please write your answer here:

### To the best of your knowledge, how many have made a formal request for MAiD?

### Only answer this question if the following conditions are met:

Answer was 'Yes' at question '8 [A23]' (Since the Medical Assistance in Dying Legislation passed in June 2016, has any client discussed with you the option of hastening death?)
Only numbers may be entered in this field.

Please write your answer here:

### For how many was a request for MAiD approved; if unknown, please leave blank?

### Only answer this question if the following conditions are met:

Answer was 'Yes' at question '8 [A23]' (Since the Medical Assistance in Dying Legislation passed in June 2016, has any client discussed with you the option of hastening death?)
Only numbers may be entered in this field.

Please write your answer here:

request MAiD?

O Yes O No

Please choose **only one** of the following:

Comments:
Only answer this question if the following conditions are met:
Answer was 'Yes' at question '8 [A23]' (Since the Medical Assistance in Dying Legislation passed in June
2016, has any client discussed with you the option of hastening death?)
Please write your answer here:
Have you ever provided consultation on or directly assessed or assisted with a MAID assessment?
Please choose <b>only one</b> of the following:
<ul> <li>Yes, I was consulted (either individually or as part of a treatment team)</li> </ul>
<ul> <li>Yes, I conducted the MAiD assessment</li> </ul>
Yes, I assisted with a MAiD assessment
O No, the opportunity never presented itself
O No, although I was asked to do so, I declined
Have you ever had a care-giving role for a family member or friend who had a terminal illness?
Please choose <b>only one</b> of the following:
O Yes
O No
Have you ever had experience with a family member or friend who experienced significant pain and/or suffering while dying?
Please choose <b>only one</b> of the following:
O Yes
O No
Do/will organizational policies within your practice setting define how you interact with clients who

Please explain how:
Only answer this question if the following conditions are met:  Answer was 'Yes' at question '16 [A28]' (Do/Will organizational policies within your practice setting define how you interact with clients who request MAiD?)
Please write your answer here:
Do/will organizational policies within your practice setting require that you be a conscientious objector?
Please choose <b>only one</b> of the following:  Yes  No
Please explain how:
Only answer this question if the following conditions are met:  Answer was 'Yes' at question '18 [A29]' (Do/Will organizational policies within your practice setting require that you be a conscientious objector?)
Please write your answer here:
Do/will organizational policies within your practice setting restrict clients' access to MAiD?
Please choose <b>only one</b> of the following:  Yes  No
Please explain how:
Only answer this question if the following conditions are met:  Answer was 'Yes' at question '20 [A30]' (Do/Will organizational policies within your practice setting restrict clients' access to MAiD?)
Please write your answer here:

#### **SCENARIOS**

In this section you will be presented with a series of questions that ask you to consider four scenarios that were part of a national survey developed by the House of Commons External Panel on Options for Medical Assistance in Dying. Your responses will allow us to gain a better understanding of psychologists' views and how they compare to the views of the general population.

SCENARIO #1: "Imagine that you have a serious life-threatening illness. Your doctor has told you that the disease has advanced, and that you likely only have months to live. Despite not having any significant discomfort, you are not interested in going through a long and lingering death. You are considering your end-of-life options."

considering your end-of-life options."					
On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, Please choose the appropriate response for each item:	to wha	at exter	nt do y	ou	
	1	2	3	4	5
agree or disagree that you (and others in this same scenario) should be able to receive MAiD?	0	0	0	0	0
On a scale of 1 to 5, where 1= strongly disagree and 5 = strongly agree, to disagree that you (and others in this same scenario) should be able to replease choose the appropriate response for each item:			-	ou agre	e or
	1	2	3	4	5
You could live for a few months, although there will be a challenging balance between pain control and side effects.	0	0	0	0	0
Your condition may extend up to a year or two, although there will be a challenging balance between pain control and side effects.	0	0	0	0	0
Regardless of how much time you may have, you are concerned about being a burden to others, either emotionally or financially.	0	0	0	0	0
You are 16 years of age and have a full and complete understanding of your condition and wish to die.	0	0	0	0	0

SCENARIO #2: "Imagine that you have lost both of your legs in a serious accident. While your life expectancy has not changed, your life certainly has. You can no longer do many of the activities you enjoyed before your accident. Life feels bleak, as many of the plans you made now seem impossible. You are now considering your options."

On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, Please choose the appropriate response for each item:	to wha	at exte	nt do y	ou	
riease choose the appropriate response for each item.	1	2	3	4	5
agree or disagree that you (and others in this same scenario) should be able to receive MAID?	0	0	0	0	0
On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, or disagree that you (and others in this same scenario) should be able to Please choose the appropriate response for each item:			-	ou agre	ee
	1	2	3	4	5
Your accident occurred five weeks ago, and you have just begun a long process of rehabilitation – at this stage you are not fully aware of the supports that might enable you to live a very good quality of life.	0	0	0	0	0
Before your accident, you were a high-performance athlete and you now feel that your life has lost meaning.	0	0	0	0	0
Your accident occurred five years ago and despite receiving excellent supports (for example, a vehicle with hand controls) you are dissatisfied with your quality of life.	0	0	0	0	0
Your accident occurred five years ago and only minimal supports have been available, leaving you dissatisfied with your quality of life.	0	0	0	0	0

SCENARIO #3: "Imagine that you have just been diagnosed with Alzheimer's. The disease will have a serious impact on your life and will worsen over time. You have discussed your prognosis extensively with your physician, and you have a clear understanding of what lies ahead for you. You are considering options available to you."

On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, Please choose the appropriate response for each item:	to wha	it exte	nt do y	ou	
	1	2	3	4	5
agree or disagree that you (and others in this same scenario) should be able to receive MAID?	0	0	0	0	0
On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, or disagree that you (and others in this same scenario) should be able to Please choose the appropriate response for each item:			-	ou agre	ee
	1	2	3	4	5
You have minor memory loss and you cannot bear to think of your future and loss of independence.	0	0	0	0	0
You now frequently have trouble remembering your family members' names, sometimes forget to shut the stove off, and are occasionally found wandering down the street.	0	0	0	0	0
You now have advanced dementia and cannot make decisions on your own. However, just after your diagnosis you wrote an advance directive indicating that you would want to have MAiD at this stage of illness.	0	0	0	0	0

Make a comment on your choice here:

SCENARIO #4: "Imagine that you have suffered from a mental health condition for much of your life. Your condition has interfered with your ability to hold down steady work and has put a strain on your relationships. You have tried many treatments, most of which did not help or caused side effects that made you want to quit. You feel frustrated and hopeless about your future. Despite excellent care, you are considering ending your life, but you're afraid to try by yourself in case you don't die and end up making things worse."

On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, Please choose the appropriate response for each item:	to wha	it exter	nt do y	ou	
	1	2	3	4	5
agree or disagree that you (and others in this same scenario) should be able to receive MAiD?	0	0	0	0	0
On a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree, or disagree that you (and others in this same scenario) should be able to Please choose the appropriate response for each item:			-	ou agre	ee
	1	2	3	4	5
Your condition has worsened recently, but your physician feels that this can be helped with a change in medications.	0	0	0	0	0
You've been in this frame of mind before, and improved. Your condition can vary from month to month, in worse periods leaving you with suicidal thoughts.	0	0	0	0	0
You are 17 years old, have a full and complete understanding of your condition and wish to die.	0	0	0	0	0
ADDITIONAL THOUGHTS					
I think psychologists should receive training in the field end-of-life issue decision making, psychological interventions, and MAiD.	s, sucl	n as ass	sessme	nt,	
Please choose <b>only one</b> of the following:  Agree Undecided Disagree					

Please choose <b>only one</b> of the following:  Yes Uncertain No
Make a comment on your choice here:
What training have you received in providing services to terminally ill clients?
Please choose all that apply:  University course Internet-based course Supervised clinical experience during degree program Supervised clinical experience after registration Palliative care conference 1-3 day workshop Educational seminar (<1 day) Other
I am confident in my ability to assess the competence of terminally ill adults who are pursuing MAiL
Please choose <b>only one</b> of the following:  O Yes O Uncertain O No
Make a comment on your choice here:
Do you support the new MAiD legislation?
Please choose <b>only one</b> of the following:  Yes Undecided No  Make a comment on your choice here:

I possess the training necessary to assess the competence of terminally ill adults who are pursuing

MAID.

Please choose <b>only one</b> of the following:  Yes Undecided No
Make a comment on your choice here:
Do you support extending the provision of MAiD for someone with dementia?  Please choose only one of the following:  Yes  Undecided  No
Make a comment on your choice here:
Do you support extending the provision of MAiD for someone with a chronic mental disorder?
Please choose <b>only one</b> of the following:  Yes Undecided No
Make a comment on your choice here:
Do you support extending the provision of MAiD to mature minors who would otherwise qualify for the procedure except for age?
Please choose <b>only one</b> of the following:  Yes Undecided No  Make a comment on your choice here:

Do you support extending the provision of MAiD for someone because of permanent physical

disability?

What do you think the official public position of the Canadian Psychological Association should be with regard to any future extension of MAiD? Please choose all that apply: ☐ no public position advocate against the extension of MAiD legislation advocate for the extension of MAiD legislation What action(s) do you think the Canadian Psychological Association should be taking with respect to MAiD? Please choose all that apply: no action provide guidance regarding training and required competencies for Psychologists support creating clinical practice guidelines for Psychologists support and advocate for increased research funding for research in Palliative and End-of-life care support and advocate for independent monitoring of the use and application of MAiD provide information to practitioners regarding MAiD review the Code of Ethics in light of MAiD make training opportunities in palliative/end-of-life care available to psychologists Other: You are almost done the survey. Your responses to the remaining few questions will help us understand our respondent group. Although not as substantive in content, they are vital to the analysis of the survey data. TRAINING AND DEMOGRAPHICS What is your age, as of today? Only numbers may be entered in this field. Please write your answer here: Select the gender with which you most identify: Please choose **only one** of the following: O Male O Female

TransgenderNon-Binary

# Please choose **only one** of the following: O Undergraduate degree O Master's Doctorate What is your primary province/territory of residence (current year only)? Please choose **only one** of the following: O British Columbia O Alberta O Saskatchewan O Manitoba Ontario O Quebec O Nova Scotia O New Brunswick O Prince Edward Island O Newfoundland and Labrador O Yukon Northwest Territories O Nunavut Other - United States Other – International Are you a member or affiliate of the Canadian Psychological Association (CPA)? Please choose **only one** of the following: O Yes O No

What is the highest level of degree you have obtained?

Please specify:
Only answer this question if the following conditions are met:  Answer was 'Yes' at question '26 [A7]' (Are you a member or affiliate of the Canadian Psychological Association (CPA)?)
Please choose <b>only one</b> of the following:  Full Member  Retired Member  Honorary Life Fellow / Honorary Life Member  Student Affiliate  Special Affiliate  International Affiliate  International Student Affiliate
Are you a member of a Provincial/Territorial Psychological Association?
Please choose <b>only one</b> of the following:  Yes  No
Please specify:
Only answer this question if the following conditions are met:  Answer was 'Yes' at question '28 [A8]' (Are you a member of a Provincial/Territorial Psychological Association?)
Please choose <b>only one</b> of the following:  Full Member  Student  International Affiliate  Non-Psychology Affiliate
Do you live in a geographic area that is typically classified as:

Yes

No

Please choose the appropriate response for each item:

remote (>500 km from a well-serviced urban centre)

northern

your pro	fessional time?
0	Small urban (1,000-29,999)
Which b	est describes your primary professional activity at present?
000000	Clinical Practice – Professional Leadership Consultation Administration Retired/On leave
Make a d	comment on your choice here:
Are you	currently registered to practice psychology in a Canadian jurisdiction?
Please ch	noose <b>only one</b> of the following: Yes No
Only ans Answer v	ur scope of practice allow you to make and communicate a diagnosis?  swer this question if the following conditions are met:  was 'Yes' at question '33 [A10]' (Are you currently registered to practice psychology in a jurisdiction?)
Please ch	noose <b>only one</b> of the following: Yes No

Which of the following best describes the population size of the place(s) in which you spend most of

# With what specialty do you professionally identify?

Please cl	noose <b>all</b> that apply:
	Clinical Psychology
	Counselling Psychology
	Forensic Psychology
	Child and Adolescent Psychology
	Geropsychology
	School Psychology
	Health Psychology
	Industrial/Organizational Psychology
	Couple and Family Psychology
	Research
	Professor/Teaching
	Supervision
	Group Therapy
	Rehabilitation Psychology
	Neuropsychology
	Administration
	Other:
-	e involved in clinical practice, which of the following describes the main practice setting in ou provide clinical services:
Please cl	noose <b>only one</b> of the following:
0	Private practice
0	Provincial/Territorial health system
0	School system
0	College/University
0	Corrections/Forensic
0	Industry
0	Other

If you are engaged in clinical practice in the provincial health system, which best describe(s) the primary setting in which you provide services:

Please cl	noose <b>only one</b> of the following:
0	General Hospital
0	Children's Hospital
0	Tertiary Care Mental Health Centre (Psychiatric Hospital or Unit
0	Forensic Facility
0	Publicly Funded Rehabilitation Facility
0	Primary Care Group
0	Community Mental Health Service
0	Extended Care Facility
0	Hospice/Palliative/End-of-life Care
0	University/School Health Clinic
0	Other
Which b	est describes the age grouping within which most of your clients fall?
Please cl	hoose all that apply:
	Seniors/Older Adults
_	Non-senior Adults
	Children/Adolescents
	Not applicable
	Other:
14/ha# ia :	
wnat is	your religious denomination?
Please cl	noose <b>only one</b> of the following:
0	Roman Catholic
Ö	Protestant
0	Jewish
0	Muslim
Ö	Hindu
Ö	Buddhist
Ö	None
Ö	Other - please specify
_	

Make a comment on your choice here:

How reli	gious would you say you are?
0	noose <b>only one</b> of the following:  Not religious at all  Not too religious  Fairly religious  Very religious
How oft	en do you attend services at your church, synagogue, temple, place of worship?
0000	Never Once a year A few times a month At least once a week Nearly every day
Apart fro	om when you go to church, synagogue, temple, place of worship, how often do you pray?
Please cl	Never A few times a year A few times a month At least once a week Nearly every day

Thank you for taking the time to complete this survey. Results of the survey will help to inform the Board of Directors of the Canadian Psychological Association about the training and professional development needs of psychologists working in end-of-life care and how best to respond to the needs of Canadians facing these issues.

Should you have any questions/comments regarding the CPA's involvement in this area, please contact us by email at <a href="mailto:executiveoffice@cpa.ca">executiveoffice@cpa.ca</a>.

# **Appendix B**

## A Sampling of Results from the Task Force Survey of Canadian Psychologists

(Complete results can be found in Medical Assistance in Dying (MAiD) Survey: Final Report)

**TABLE 1.1**Participant Demographics.

Age	Sex	Highest	Religious	М	Primary	Age of	Primary
	% [N]	Degree	Identity	Religiosity	Work	Clients	Work
		% [N]		[SD]	Activity	% [N]	Setting
					% [N]		% [N]
M: 49.2	Female:	Doctorate:	Catholic:	Catholic:	Clinical	Non-senior	P/T Health
	75.6%	71.9% [217]	17.1% [50]	8.66 [3.23]	Service	Adults:	System:
	[223]				Delivery:	71.7% [220]	44.2% [122]
					70.9% [214]		
Median: 49	Male:	Master's:	Protestant:	Protestant:	Other:	Seniors/	Private
	23.4% [69]	26.2% [79]	19.1% [56]	8.68 [3.18]	29.1% [88]	Older	Practice:
						Adults:	39.1% [108]
						24.4% [75]	
SD: 13.1	Non-binary:	Bachelor:	Other:	Other:		Children/	Other:
	1.0% [3]	2.0% [6]	18.8% [55]	7.16 [3.81]		Adolescents:	16.7% [46]
						30.3% [93]	
Range:			None:	None:			
21-79			45.1% [132]	3.53 [1.17]			
_				Overall:			
				6.09 [3.42]			

Note: Percentages calculated using total number of respondents to a given question.

**TABLE 2.1**Registered Practitioners' Experience Working with Clients with Varying Physical and Mental Health Issues.

Have you ever provided services to a client with:	Yes	No	%Total <sup>1</sup>	% Intolerable <sup>2</sup>
A terminal illness (expected to live just a few months)?	130	133	49.4%	
A terminal illness who perceived their suffering was	77	183	29.6%	59.2%
intolerable?				
A permanent physical disability?	244	20	92.4%	
A permanent physical disability who perceived that their	115	147	43.9%	47.1%
suffering was intolerable?				
Dementia?	123	141	46.6%	
Dementia who perceived that their suffering was	31	227	12.0%	25.2%
intolerable?				
A mental disorder?	264	0	100.0%	
A mental disorder who perceived that their suffering was	203	59	77.5%	76.9%
intolerable?				

<sup>&</sup>lt;sup>1</sup> Based on the total number of respondents for that question.

A 4x2 Chi-square test was conducted to explore whether the proportion of registered practitioners who perceived a client's suffering as intolerable differed depending on the condition. Overall, the observed vales were significantly different from expected,  $\Box^2 = 30.76$ , p < .001.

Fisher's exact tests were then conducted to directly compare proportion of perceived intolerability by condition, using a Bonferroni-adjusted alpha level of p=.008 (i.e., .05/6). Proportion of perceived intolerability was significantly lower for dementia than terminal illness (p<.001), physical disability (p=.007), and mental illness (p<.001). In addition, proportion of perceived intolerability was significantly higher for mental illness than physical disability (p=.001). Proportion of perceived intolerability did not differ significantly between terminal illness and either physical disability or mental illness.

<sup>&</sup>lt;sup>2</sup> Calculated by dividing the number of "intolerable" responses by the number of non-"intolerable" responses for a given condition. E.g., "Dementia-intolerable" / "Dementia" \* 100 = % Intolerable Dementia.

**TABLE 2.2**Registered Practitioners' Views on Whether Psychological Disorders Meet the Criteria for MAiD in Canada.

Do you believe that psychological disorders	% Yes [N]	% No [N]	% Uncertain [N]
can be:			
Grievous?	95.3% [253]	0.8% [2]	3.4% [9]
Irremediable?	53.8% [140]	13.5% [35]	32.7% [85]
Usually helped, even if they cannot be	93.5% [244]	0.4% [1]	6.1% [16]
entirely "cured or put right?"			
Have you ever worked with a patient that you	56.5% [148]	43.5% [114]	
would deem to have a grievous and			
irremediable mental disorder?			

**TABLE 2.8**Registered Practitioners' Familiarity with MAiD Legislation in Canada.

Level of Familiarity	N	% Total
Until now, I was not aware that MAiD is legal.	5	1.9%
I am aware that there are developments, but have not followed these.	89	33.8%
I am aware that there are developments and have followed with interest.	128	48.7%
I have reviewed the legislation.	41	15.6%
Since the MAiD legislation passed, a client has discussed with me the option of	35	13.3%
hastening death.		
I have provided consultation on a MAiD assessment (either individually or as	6	2.3%
part of a treatment team).		
I have assisted with a MAiD assessment.	1	0.4%
I was asked to provide consultation on or directly assist with a MAiD	1	0.4%
assessment but declined.		

**TABLE 3.1**Levels of Agreement with MAiD for Different Physical and Mental Health Conditions.

Scenario	N	М	Median	SD
1 (Terminal Illness)	303	3.73*	4	1.39
2 (Physical Disability)	303	2.16	2	1.35
3 (Alzheimer's)	304	3.67*	4	1.47
4 (Severe Mental Illness)	304	2.90**	3	1.40

<sup>\*</sup>Significantly higher than Scenarios 2 and 4 at p < .001.

Scales Ranged from 1 (Strongly Disagree) to 5 (Strongly Agree).

<sup>\*\*</sup>Significantly higher than Scenario 2 at p < .001.

**TABLE 4.1**Support for Extending the MAiD Legislation under Different Circumstances, with Overall Support for the Current Legislation.

Do you support extending the provision of MAiD for:	% Yes [N]	% No [N]	% Uncertain [N]
	0.000/[4.07]	0.0.40/ [==]	27.50/5443
Someone because of permanent physical	36.3% [107]	26.1% [77]	37.6% [11]
disability?			
Someone with dementia?	68.3% [198]	13.1% [38]	18.6% [54]
Someone with a chronic mental disorder?	33.6% [98]	28.1% [82]	38.4% [112]
Mature minors who would otherwise qualify	33.9% [100]	33.9% [100]	32.2% [95]
for the procedure except for age?			
Do you support the new MAiD legislation?	72.3% [214]	10.5% [31]	17.2% [51]

A 5x3 Chi-square analysis was conducted to test whether level of agreement (yes, no, uncertain) with the existing MAiD legislation or extensions to MAiD was significantly different from expected values. Overall, the observed values were significantly different from expected,  $\Box^2 = 188.9$ , p < .001.

Fisher's exact tests were conducted to directly compare conditions on the number of respondents who agreed vs. disagreed with supporting the provision of MAiD to that condition (i.e., excluding the 'uncertain' option for a series of 2x2 designs). Using a Bonferroni corrected alpha level of .005 (i.e., .05/10), support for extending the provision of MAiD for dementia was significantly higher than all other conditions (all ps < .001). Differences between all other conditions were not significant.

Support for the existing MAiD legislation was significantly higher than for extending the provision of MAiD for mental illness, disability, or to mature minors who would otherwise qualify (all ps < .001). Support for the existing MAiD legislation did not differ significantly from support for extending the provision of MAiD for individuals with dementia.

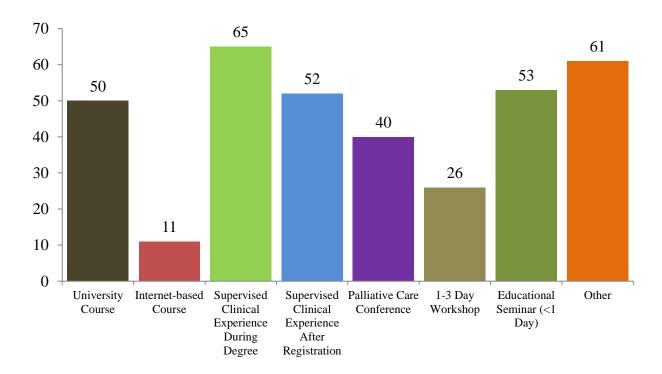
**TABLE 4.6**MAID Survey Respondents' Views on What the Official Public Position of the CPA Should Be with Regard to any Future Extension of MAID.

Official Public Position of the CPA	% in Support [N]
No public position	26.0% [75]
Advocate against the extension of MAiD legislation	17.0% [49]
Advocate for the extension of MAiD legislation	57.1% [165]

**TABLE 4.10**MAID Survey Respondents' Views on the Action(s) the CPA Should Take with Regard to MAID, Ranked in Order of Overall Support. Note that Multiple Selections Were Possible.

CPA Action Pertaining to MAiD	% [N]
Support creating clinical practice guidelines for psychologists	86.8% [264]
Provide guidance regarding training and required competencies for psychologists	85.5% [260]
Make training opportunities in palliative/end-of-life care available to psychologists	85.5% [260]
Review the Code of Ethics in light of MAiD	82.6% [251]
Provide information to practitioners regarding MAiD	82.6% [251]
Support and advocate for increased research funding for research in palliative and end-of-life care	70.4% [214]
Support and advocate for independent monitoring of the use and application of MAiD	56.9% [173]
Other	9.2% [28]
No action	1.6% [5]

**FIGURE 4.1**Sources of Registered Practitioners' Training in the Field of End-of-Life Issues among MAiD Survey Respondents. Note that Multiple Selections Were Possible.



Of those with training, 57.8% (n = 111) selected only one of the sources depicted in Figure 4.1, with the remaining 42.2% (n = 81) having received training in the field of end-of-life issues from two or more sources (M = 1.3; median = 1; range = 1 to 7).

### **Appendix C**

The Task Force offers the following definition of "irremediable" for psychologists and clients to consider together:

- 1) The individual has had a poor or unsatisfactory response to at least two distinct modes of adequate (optimal dosage and duration) medically oriented treatments that:
  - a. have been provided by regulated health care practitioners with relevant experience in the diagnosis and treatment of the disorder(s) in question,
  - b. are evidence-based or widely accepted and sanctioned methods, which may include but are not limited to pharmacological treatment, neurostimulation, or electroconvulsive therapy, and
  - c. are relevant to the amelioration of the disorder experienced by the individual.
- 2) The individual has had a poor or unsatisfactory response to at least two adequate (i.e., optimal duration) trials of non-medical, psychologically-oriented treatments that have been provided by a regulated health care practitioner with relevant experience in the diagnosis and treatment of the disorder(s) in question.
- 3) The practitioner uses evidence based or widely accepted and sanctioned modalities shown to be effective for treatment of that condition.
- 4) A poor or unsatisfactory response to treatment has been deemed to not be a function of misdiagnosis, poor treatment adherence or attendance, poor therapeutic alliance or insufficient access to treatment.

In essence, the proposed definition would require an individual to undergo four failed treatments. We recognize that for some mental disorders, four or more evidence-based treatments may not have been established as of yet, or may not be readily available to the individual. In such instances, the appropriate adjustment would need to be made in accordance with the existing state of science. We also recognize that the requirement of undergoing four failed evidence-based treatments is a high standard to deem a condition irremediable; however, given that the field is at an early stage in establishing which treatment or combination of treatments are likely to be most effective for a given individual, and given the finality of a decision to undergo MAiD, the Task Force feels that this standard was reasonable starting point for discussion and research inquiry.

The Task Force additionally recognizes legislation supporting the autonomous right of an individual diagnosed with a mental disorder to decline treatment.