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**MEDICAL ASSISTANCE IN DYING**

**MAiD Research Forum 2026:  
Research to Inform Practice and Policy:  
Abstracts**

**Navigating End-of-Life Choices:  
Perspectives of Individuals Living with  
Multiple Sclerosis on Medical Assistance in  
Dying in Various Hypothetical Situations**  
Janine Brown, PhD; Katherine B. Knox; Lilian  
Thorpe; Lorelee Herter; Mir Nabila Ashraf;  
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**Dementia and MAiD**

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**Disrupting Death and Medical  
Assistance in Dying (MAiD):  
Podcasting as Public Scholarship  
and Knowledge Mobilization**  
Kathy Kortés-Miller, MSW, PhD  
Keri-Lyn Durant, PhD

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The Canadian Journal of MAiD holds that ethically sound clinical practice can only be built on a foundation of robust scholarship and critical reflection. The underlying objective of the journal is to create a space where the bravery to critique current practice is met with a commitment to rigorous engagement with constructive debate that actively considers multiple points of view.

The mission of the Canadian Journal of MAiD is to foster critical and constructive scholarly debate; develop new knowledge to inform practice; and engage multiple viewpoints with the goal of supporting a high-quality and ethically sound approach to MAiD in Canada.

**Disclaimer:** The planning committee was not involved in editorial review, oversight of the peer-review process, or final approval of submitted articles.

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# MAiD Research Forum 2026: Research to Inform Practice and Policy

Conducting research to inform practice and policy is essential to high-quality MAiD care in Canada. Twice yearly, CAMAP hosts a forum in which researchers from across Canada meet to share emerging and summative findings from their programs of research. When possible, the research forum is held in conjunction with the national CAMAP Conference. The following are the successful abstracts from researchers who were selected to present at the April 30, 2026 research forum in Montreal.

## Abstracts

### **MAiDHouse: A Qualitative Study on Structured Community-based Support for Grief and Bereavement**

#### **Background**

MAiDHouse is a national non-profit organization and registered charity that provides those eligible to receive medical assistance in dying (MAiD) with a supportive and comfortable setting. Although MAiDHouse does not provide MAiD assessments or MAiD itself, its supports may affect grief and bereavement for family and friends. The goal of this qualitative study was to understand how MAiDHouse's services shape experiences of grief and bereavement.

#### **Methods**

Primary contacts of individuals who received MAiD at MAiDHouse within a 12-month period were invited to participate in this qualitative study. Thirteen participants completed semi-structured interviews virtually or by phone. An interdisciplinary research group participated in the analysis. Transcripts were coded in duplicate and analyzed using a content-analysis approach through MaxQDA. Themes were developed deductively based on a previously published conceptual framework and inductively from the data.

#### **Results**

Participants' perceptions of MAiDHouse's grief and bereavement support ranged from net neutral to positive. During the MAiD process, participants described multiple sources of confusion with regard to MAiD access, provider responsibilities, and organizational roles, all of which they suggested can affect future bereavement. Participants expressed

appreciation for the responsiveness of MAiDHouse staff, personalized communication, and facilitation of logistics in shaping their grief experience.

#### **Discussion & Implications**

Findings suggest structured, community-based supports may meaningfully shape bereavement experiences surrounding MAiD. MAiDHouse was perceived as extending beyond a physical setting to function as an accessible resource addressing emotional, informational, and practical needs. Integrating similar community-based support models alongside MAiD delivery may improve continuity of care and support healthier bereavement outcomes for families and loved ones.

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### **Coordinating MAiD Services in Ontario: A Patchwork of Practices, Roles and Structures**

#### **Background**

In Ontario, coordination of medical assistance in dying (MAiD) services varies across healthcare settings. This study examined how MAiD services are coordinated in large and rural hospitals and

among solo practitioners, and how leadership, management of tensions, and legitimacy of MAiD coordination roles vary across sites.

## Methods

25 interviews were conducted with Ontario participants who held a role in coordinating or providing MAiD services in a variety of care settings. Interviews were audio-recorded, transcribed, and coded inductively using NVivo. Thematic analysis was informed by literature on program implementation, leadership, and role legitimacy.

## Results

MAiD program coordination varied across settings, reflecting differences in resources and leadership structure. Organizations with dedicated funding were more likely to establish formal MAiD coordination teams with distributed leadership, yet still struggled with role definition and caseload management. Organizations without dedicated funding often relied on individual practitioners to integrate MAiD responsibilities into existing roles, creating tensions for these practitioners and low MAiD organizational awareness. Leadership and coordination roles were inconsistently defined and left practitioners in these positions questioning the legitimacy and scope of their responsibilities. Rural settings faced compounded challenges due to limited resources.

## Discussion

Organizational and coordination dimensions of MAiD remain understudied compared with clinical perspectives, although they are equally important. The variability observed in Ontario highlights gaps shaping program implementation, role legitimacy, and MAiD program sustainability.

## Implications for MAiD Practice

A provincial policy framework defining coordination roles and expectations could reduce ambiguity and tensions, strengthen program legitimacy, and enhance consistent MAiD service delivery.

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## Thinking Together About MAiD and Mental Disorders: A Co-Developed Reflection and Discussion Guide

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### Background

Canada plans to expand medical assistance in dying to people whose sole underlying condition is a mental disorder (MAiD-MD). In this sensitive and highly polarized context, ethically informed preparation attentive to those directly affected is essential. The purpose of this project was to co-develop a resource grounded in the experiences of people living with mental disorders, family, and healthcare professionals.

### Methods

A participatory action research approach was undertaken. A reflection and discussion guide was co-developed through five steps: forming a working group, literature reviews, a focus-group series, community consultation, and preliminary evaluation.

### Results

The working group, involving key stakeholders, supported the project through 15 work sessions. Two literature reviews mapped: 1) moral concerns regarding MAiD-MD, and 2) existing and missing resources to address them. Nine focus-groups with people living with mental disorders, relatives, and healthcare professionals highlighted concerns, ideas for ethical support, and potential formats and content for a support tool fostering nuanced reflection and respectful dialogue. Ten informant groups refined the resulting guide, which was assessed as clear and relevant by 92% of preliminary evaluation participants (n=47).

### Discussion

An emerging need to create inclusive, supportive, and respectful spaces for discussing MAiD-MD oriented the project. Such spaces enable people to feel genuinely heard, acknowledged, and cared for. High stakeholder engagement throughout this project underscores the research's social relevance.

## Implications

Triangulating perspectives of people living with mental disorders, relatives, and healthcare professionals enriches the understanding of complex situations related to MAiD-MD. The guide developed from this project is a nuanced, content-rich tool, inclusive of multiple perspectives, that can inform practice and inspire adaptations according to needs and contexts.

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## Developing an Understanding of Decisional Vulnerability in the Context of MAiD Track 2

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### Background

One of the most significant controversies around the implementation of Track 2 MAiD in Canada relates to how internal (e.g., rigid thinking or past trauma) and external factors (e.g., poverty or precarious housing) might influence applicants' decisional vulnerability. Decisional vulnerability refers to a circumstance in which an individual's decision making might not truly be genuine or autonomous. The purpose of this knowledge exchange was to develop understanding related to vulnerability, voluntariness, and suffering in the context of applicant eligibility for Track 2 MAiD.

### Methods

Sixty-eight persons with expertise in Track 2 MAiD from across Canada participated in a 7-hour knowledge exchange conducted virtually. After an introduction to the legal context, seven expert panelists responded to a research-based case exemplar of a complex Track 2 applicant. Participants then engaged in small group discussions about the impact of the factors and applications to practice and policy. Findings were analyzed thematically.

### Results

Participants highlighted the clinical acumen required to conduct these assessments well and the potential therapeutic effect of a good assessment. There was strong consensus that understanding the lived experience of the applicant was an essential part of assessing decisional vulnerability and that there needed to

be standardized documentation of that process. Important oversight and system support were recommended for applicants who are at risk for decisional vulnerability.

## Conclusion

Findings provide important insights into understanding and mitigating decisional vulnerability in the context of Track 2 MAiD.

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## From Decision to Bereavement: Lived-Experience Peer Support and Medical Assistance in Dying

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### Background

Since legalization, over 76,000 Canadians have received Medical Assistance in Dying (MAiD). Family members navigate both the MAiD process and subsequent bereavement, often with inconsistent access to MAiD-specific psychosocial supports. Limited research has examined the experiences of individuals who seek one-to-one lived-experience peer support because of a loved one's decision for MAiD.

### Methods

This mixed-methods study employed Interpretive Description to generate clinically applicable insights into why family members seek peer support and how they experience it. Phase I involved an anonymous electronic survey (n=47) analyzed using descriptive statistics. Phase II comprised open-ended virtual interviews (n=21), which were analyzed interpretively.

### Results

Participants described a structural paradox: while playing a central role in facilitating access to MAiD through coordinating logistics, navigating institutional barriers, and advocating for their loved ones, they frequently felt peripheral, or even invisible. Left to interpret and process meaning alone. Four themes were identified: (1) Administratively Structured and Relationally Silent;

(2) Compression, Suppression, and Deferred Integration; (3) Moral CoCollaboration; and (4) Connection, Fit and a Moderating Effect.

## Discussion

MAiD is frequently experienced as a family-embedded moral event. System gaps transfer responsibility for support onto family members during periods of heightened vulnerability. Facilitating proactive family engagement, anticipatory guidance, and structured referrals to formal and peer support could improve family members' grief and bereavement.

## Implications for MAiD Practice

Proactive family engagement, anticipatory preparation, and moral validation should be incorporated into MAiD care. This approach would transition optional or passive grief support for family members to embedded assistance both before and after the MAiD event.

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## The Work of Track 2 MAiD

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### Background

Health professionals are challenged to respond to Track 2 MAiD requests and some program leaders, including in our region of Ontario, have had to make the difficult decision to cease or curtail intake to Track 2 MAiD programs. This study, a collaboration with the Greater Hamilton Health Network MAiD Steering Committee, is intended to support a sustainable regional model of care for Track 2 MAiD.

### Methods

This was a qualitative study using focus groups for data collection. The objectives of the focus groups were to: (1) Describe the work involved in responding to Track 2 MAiD inquiries. (2) Explore the question: what it is about the work that makes Track 2 MAiD care so demanding? (3) Consider the types of support that could make a difference for health professionals involved in MAiD. Focus groups were audio-

recorded, transcribed, and analyzed drawing on constructivist grounded theory methods.

## Results

Eight experienced MAiD assessors and providers participated in two focus groups. In describing the demands of Track 2 MAiD work, assessors identified the following factors: perceived negative judgements related to this work; factors that make some cases especially difficult; and situations in which provision can be justified in legal terms, but the assessor feels conflicted/is reluctant or unwilling to provide. In describing what makes it possible for them to continue with the work they identified: the value of slowing things down; the importance of company in trying to make sense of complex patient situations, navigate difficult patient interactions, and make morally weighty decisions; the necessity of triage; and the potential benefit of foregrounding the assessor's willingness to provide (rather than focusing exclusively/centrally on patient eligibility).

## Implications for MAiD Practice

This study provides insight into the particular challenges and dilemmas of Track 2 MAiD care, and suggests opportunities for program and practice change that have the potential to foster sustainable programs over the long run.

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### Lilian Thorpe

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# Navigating End-of-Life Choices: Perspectives of Individuals Living with Multiple Sclerosis on Medical Assistance in Dying in Various Hypothetical Situations

Janine Brown, PhD; Katherine B. Knox; Lilian Thorpe; Lorelee Herter; Mir Nabila Ashraf; Michael C. Levin; Ilia Poliakov

## Abstract

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### Background

Saskatchewan's multiple sclerosis (MS) prevalence rate is among the highest in the world. Although quantitative research has demonstrated a high hypothetical interest in assisted dying among individuals living with MS (ILMS), the underlying reasons potentially influencing their consideration of medical assistance in dying (MAiD) have not been explored qualitatively.

### Methods

An Interpretive Description methodology was used for this project. The dataset included 27 interviews (22 ILMS, five key informants), demographic data, interviewer field notes, and reflective content. Participants discussed their perspectives on MAiD across a range of hypothetical situations. Inductive reflexive thematic analysis and content analysis were completed.

### Results

When presented with hypothetical disease trajectory scenarios, participants indicated they *would* or *may* consider MAiD if experiencing unbearable pain (n=21), the need for continuous care (n=16), or perceptions of being a burden to others (n=14). Fewer participants reported that loss of pleasurable activities (n=6) or changes in living arrangements alone (n=8) *would* or *may* prompt consideration of MAiD. Four interconnected themes characterized participants' reasoning: 1) a shifting identity, 2) navigating

resource disparities, 3) the weight of guilt, and 4) care concerns for family.

### Discussion

ILMS may consider MAiD for various reasons. Decision-making at the end-of-life exists within a complex matrix of individual guilt and concern for family members while reappraising quality of life and accessing support through disease progression.

### Introduction

---

Multiple Sclerosis (MS) is a chronic and progressive neurological condition that often leads to physical, cognitive, and psychological challenges.<sup>1</sup> Globally, the prevalence of MS is 23.9 cases per 100,000 population,<sup>2</sup> while Saskatchewan, Canada, has one of the highest MS prevalence rates at 313.6 cases per 100,000 population.<sup>3</sup> Within the MS disease trajectory, individuals may experience increasing stigma from invisible symptoms,<sup>4</sup> cognitive dysfunction,<sup>5</sup> and chronic pain,<sup>6</sup> impacting their quality of life. Individuals may also experience emotional distress<sup>7</sup> and face complex decisions about planning for an uncertain future.<sup>8</sup> Considering the increasing life expectancy of individuals living with MS (ILMS),<sup>9</sup> and that MS remains a progressive and incurable illness, many ILMS express concerns about future loss of autonomy and the financial, emotional, relational, and professional impacts of their illness.<sup>10</sup> These realities make end-of-life (EOL) care planning a vital yet often under-discussed aspect of MS management, as it reflects individuals' values,

preferences, and wishes for future care. However, care providers may face challenges in discussing EOL care due to uncertainty about prognosis and the individual's emotional and ethical context.<sup>11</sup> As a result, this risks underrepresentation of ILMS and their families' perspectives in EOL decision-making.

With the passage of Bill C-14 in 2016 and the subsequent enactment of Bill C-7, those with and without temporal proximity to natural death may now be found eligible for medical assistance in dying (MAiD).<sup>12</sup> In 2024, the provision of MAiD accounted for 6.9% of reported deaths, an increase from 2023, with cancer as the most noted underlying medical condition, followed by neurological conditions.<sup>13</sup> The removal of the requirement for temporal proximity to death has prompted ethical discussions regarding autonomy, vulnerability, and adequate support available to individuals living with disabilities.<sup>14,15</sup> For ILMS, the changes require a deeper understanding of EOL care options to support informed decision-making.

Two quantitative studies have explored ILMS perspectives regarding assisted dying<sup>16,17</sup>; however, to our knowledge, no qualitative studies have focused on understanding how individuals living with MS personally interpret and negotiate EOL choices, including assisted dying when legally available. This paper will explore ILMS' perspectives on EOL care, involving MAiD, across various hypothetical situations.

## **Methodology & Methods**

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### **Study Design**

This qualitative exploratory study was grounded in the interpretive description methodology. This methodology contributes to a detailed description of the phenomenon and an understanding of disease-related consequences in a clinical context through an iterative, inductive process.<sup>18</sup> Ethical approval was obtained from the University of Regina (REB #029). The analysis reported here, focused on examining ILMS' perspectives on EOL care and MAiD within hypothetical scenarios, constitutes one component of a larger qualitative study with multiple distinct objectives funded by the Saskatchewan Health Research Foundation.

### **Study Setting and Participants**

Our team included a Saskatchewan-based patient-partner who has been living with MS

since 2005. This patient-partner and their spouse actively contributed to all stages of the project, including grant writing, data analysis, and knowledge mobilization. The research team also comprised a physiatrist, a nurse researcher, a master's student in aging studies, a MAiD provider, and two neurologists specializing in MS. Participants were recruited from the MS clinical research database using the following goal parameters: 1) 75% female representation, 2) 30% with an expanded disability status scale score of 8 or higher, 3) 30% diagnosed within the last 5 years, and 4) one-third residing outside the two urban areas. Additional recruitment occurred through posters in MS clinic areas, the MS Society, social media outreach, and snowball sampling.

### **Data Collection**

After participants reviewed the information and consent document, a mutually acceptable interview time and modality were agreed upon. At the start of the interview, the interviewer reviewed the consent form with the participant, obtained and documented informed consent on the recording, and provided a link to a Qualtrics demographic and contextual self-report survey that included validated self-report measures for the Multiple Sclerosis Impact Scale-29 (MSIS-29)<sup>19</sup> and the Patient-Determined Disease Steps (PDDS)<sup>20</sup> to ascertain disability level. The semi-structured interviews invited participants to respond to hypothetical disease scenarios similar to those presented in previous quantitative studies on ILMS and assisted dying,<sup>16,17</sup> and allowed space for conversation, clarification, and exploration. Interviewer field notes and reflective content were also collected at the conclusion of each interview.

### **Data Analysis**

The demographic and contextual data were summarized using frequencies and percentages. We conducted both content and thematic analyses. For the thematic analysis, we followed Clarke and Braun's Six-Step Data Analysis Process.<sup>21</sup> Two research team members repeatedly reviewed the transcripts to familiarize themselves with the data, then identified and inductively coded them with NVivo 12, to produce initial themes. These initial themes were then reviewed and refined by other research team members. These themes, accompanied by narrative definitions and supporting quotations, were collated, and the structure of the results was formulated.

We conducted a content analysis to explore ILMS' perspectives on MAiD across different hypothetical scenarios using an inductive coding approach. One researcher reviewed each transcript and categorized each hypothetical situation in an Excel template, after which a second researcher reviewed the transcription and cross-checked each case. The descriptive counts were reported in percentages and were presented in a bar chart.

## Results

We conducted interviews with 22 ILMS and five key informants. One ILMS did not complete the demographic data collection survey.

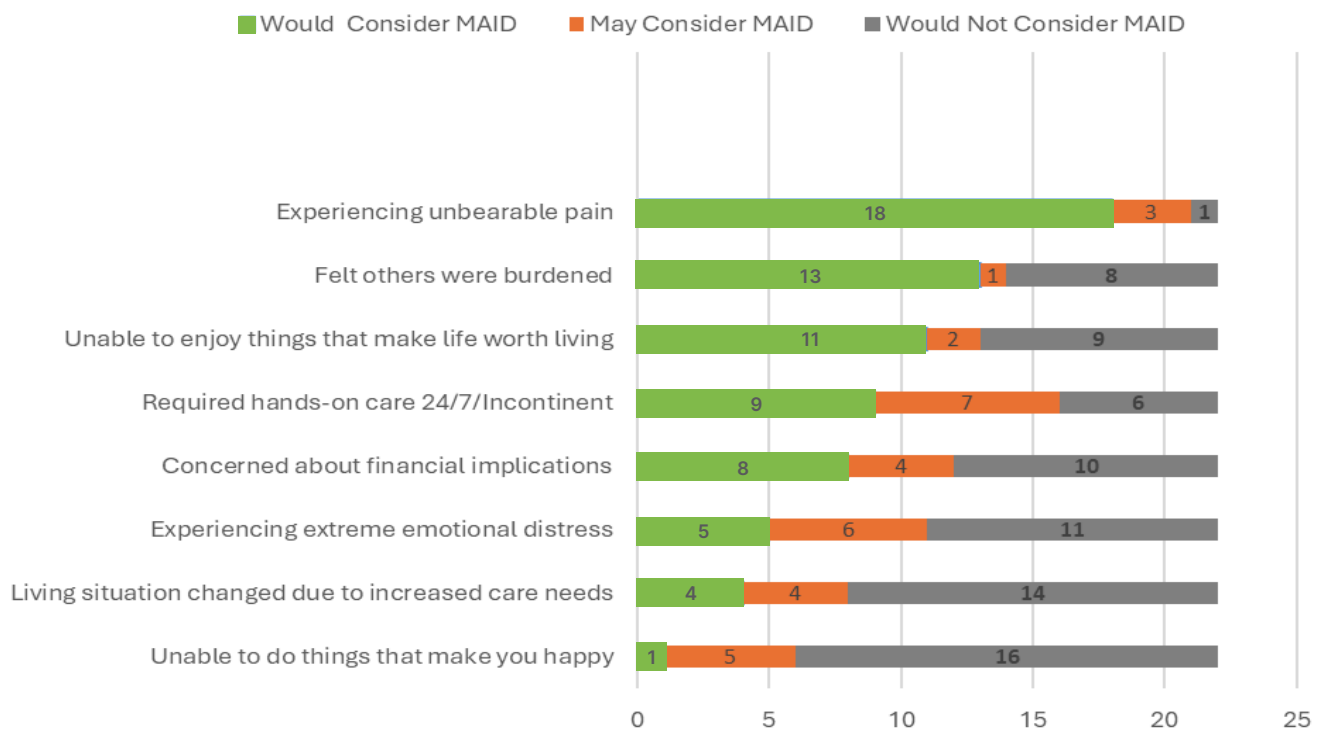
### Demographic and Contextual Data

Among the 21 ILMS, the majority were women (66.67%), with approximately half aged 18–44 years (57.14%). Approximately two-thirds were married, and about 45% were employed. Most participants had some level of post-secondary education. The majority (15 of 21) had been living with MS for 4–14 years, reflecting a mid-

range disease duration, while only a few had been recently diagnosed or had lived with the condition for more than 20 years. The MSIS-29 scores reflected a moderate level of symptom burden, with average physical and psychological impact scores of 36.2% and 35.2%, respectively, on a scale where 100% indicates the most severe symptom burden. The PDDS scores showed that nearly one-third of ILMS reported no functional limitations, while others experienced varying degrees of disability, ranging from mild impairments to reliance on mobility aids such as canes, bilateral supports, or wheelchairs. Additional contextual details are provided in **Table 1**.

### Content Analysis

When conducting the content analysis (n=22 individuals living with MS) on the hypothetical situations presented, we organized responses into three categories: participants would consider MAiD, participants may consider MAiD, or participants would not consider MAiD. The corresponding results are presented in **Figure 1**.



**Figure 1.** Individuals living with multiple sclerosis; perspectives on medical assistance in dying (MAiD) as an end-of-life option in various hypothetical situations; *courtesy of Janine Brown, PhD, et al.*

Variable	Category	n (21)
Mean (%) Patient-Determined Disease Steps	Normal (No limitations)	7 (33.33%)
	Mild Disability	4 (19.05%)
	Moderate Disability	1 (4.76%)
	Early Cane Use	2 (9.52%)
	Late Cane Use	2 (9.52%)
	Bilateral Support	3 (14.29%)
	Wheelchair Use	2 (9.52%)
Mean (SD) MSIS-29 Impact Scale	Physical (raw)	48.95 ± 21.08
	Physical (%)	36.2 (26.3)
	Psychological (raw)	21.67 ± 9.71
	Psychological (%)	35.2 (26.9)
Mean (%) Living Situation	Live alone independently	1 (4.76%)
	Live alone with support	1 (4.76%)
	Live with others independently	10 (47.62%)
	Live with others with support	8 (38.10%)
Mean (%) Household Size	2 persons	9 (42.86%)
	3 persons	7 (33.33%)
	4 or more persons	5 (23.80%)
Mean (%) Spirituality/Faith Importance	Not at all important	6 (28.57%)
	Slightly important	4 (19.05%)
	Moderately important	6 (28.57%)
	Very important	4 (19.05%)
	Extremely important	1 (4.76%)
Mean (%) Travel Distance to Primary Care	<10 km	15 (71.43%)
	11–100 km	5 (23.81%)
	100–300 km	1 (4.76%)
Mean (%) Use of Homecare Services	Yes	1 (4.76%)
	No	20 (95.24%)
Mean (%) Homecare Frequency	Daily	1 (4.76%)
	2–3 times/month	1 (4.76%)
	Unknown / Not applicable	19 (90.48%)
Mean (%) Types of Assistance	Rehabilitation/Physiotherapy	6 (22.22%)
	Emotional support	4 (14.81%)
	Housekeeping	4 (14.81%)
	Errands (e.g., shopping)	4 (14.81%)
	Companionship	3 (11.11%)
	Prefer not to disclose	3 (11.11%)

**Table 1.** Contextual Information of Participants Living with Multiple Sclerosis; *courtesy of Janine Brown, PhD, et al.*

\*note only variables with a response are noted

\*\* only 21 ILMS completed the contextual survey

**Abbreviations: MSIS-29 Impact Scale:** Multiple sclerosis impact scale 29; **SD:** standard deviation

## Themes

When discussing EOL care in various hypothetical situations, the participants' perspectives were clustered into four themes: 1) a shifting identity, 2) navigating healthcare resources, 3) the weight of guilt, and 4) care concerns for family. The exemplary quotations

illustrating the themes are incorporated into **Table 2**.

### A Shifting Identity

Participants emphasized the importance of shifting their self-identity and adapting their life focus along their illness trajectory, which helped them reappraise their quality of life as

Theme: A Shifting Identity
<p>"If there's nothing that you experience that makes you happy, or you're unable to do those things, it means finding something else that might or does." (ILMS 11)</p> <p>"I still feel like you have life to live. Yeah, maybe going to the bathroom, or having a bath or a shower looks different, but at the end of the day, you accomplish the same thing." (ILMS 18)</p> <p>"A big part of my identity has shifted. I've relied more on trying to enjoy what I can still do, which is being with my family and eating food. If I get even more disabled, it'll still be the same in that there will be a whole new set of things I can't do anymore that I can adjust to." (ILMS 20)</p>
Theme: Navigating Healthcare Resources
<p>"There just isn't enough support. I think healthcare as a whole, for anyone with a chronic illness, there's not enough physio. There's not enough OT. There's not enough long-term care or home care. It just becomes they're just doing the best with what they have...There's just not enough to go around." (KI 5)</p> <p>"I mean, there's definitely a lack of emotional support in that. I have a trained psychologist, but I know many MS patients don't, and they don't have that luxury, because they can't afford it through private benefits." (ILMS 16)</p> <p>"It's great to say, 'Oh, we have this wonder drug or device that you can use,' but if it's not affordable and accessible, then that's not helpful." (ILMS 19)</p>
Theme: The Weight of Guilt
<p>"I do know that if, and when, I make that decision, it is going to be what's best for me. Which is very hard for me to do, because I never put myself first, because I'm a mom, right... it doesn't matter how sick I am, he [my son] is going to want me around." (ILMS 15)</p> <p>"I was on six or seven different medications...The health insurance paid for 90% of it. But, if I hadn't had that, and my family, or my husband, had to bear that, those medical costs, that's where I say, I don't want to be a burden, financially or physically. That would be one of the reasons why I would choose MAiD, personally, that would be huge." (ILMS 14)</p> <p>"That is-is very uncomfortable for me and I feel like I will feel very guilty. I feel like I have let her down or like I'm giving up. I feel like that will be the hardest part." (ILMS 5)</p>
Theme: Care Concerns for Family
<p>"I guess I'm only concerned about my kids. I don't really care so much what happens to me, I don't really know how else to describe it." (ILMS 18)</p> <p>"But I just don't know if I'd be able to go through with it, because yeah, it affects the people around you so much more than it affects you." (ILMS 9)</p> <p>"I think it's highly desirable that they [family] be involved, and I will say this in part to the patients sometimes. You know, after this has happened, it's not going to bother you. You'll be dead. What is the effect of this going to be on the people who are still here?" (KI 2)</p>

**Table 2.** Resultant Themes Exemplar Quotations; *courtesy of Janine Brown, PhD, et al.*

**Abbreviations:** ILMS: individuals living with multiple sclerosis; KI: key informant; MAiD: medical assistance in dying; MS: multiple sclerosis; OT: occupational therapy; PT: physical therapy

their disease affected their daily functioning. They further identified that this shift helped them focus on quality of life in new ways. Although they acknowledged that this process was not easy, they emphasized that this adaptive mindset enhanced their quality of life.

### **Navigating Healthcare Resources**

Participants described a persistent gap between the resources they needed and those they could access. These resource shortages affected their quality of life and shaped their EOL considerations. Financial barriers, such as the costs of medications, mobility aids, emotional support, and home-based care were often prohibitive. Although participants wanted opportunities to discuss EOL options and goals of care, they felt limited time during healthcare appointments made this difficult. This lack of support frequently left them feeling vulnerable and forced to navigate a complex care system on their own.

### **The Weight of Guilt**

Participants expressed feeling guilty when considering EOL decisions and the possibility of MAiD. The guilt manifested in multiple ways, including the guilt of becoming a financial and physical burden to close ones, the guilt of giving up, the guilt that their care was impacting their family's future, the guilt of prioritizing their own wishes, and the guilt of leaving family members to make difficult decisions. At times, the weight of this guilt led them to avoid conversations about goals of care.

### **Care Concerns for Family**

Participants discussed how their disease and future care choices would affect their families. They were further concerned that their EOL care decisions, especially if choosing a MAiD death, could impact their families to a greater degree than themselves. The emotional weight of decision-making was described not only as a personal burden but also as a worry for those who would be left behind.

## **Discussion**

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Our qualitative research findings suggest that concerns about pain, functional decline, loss of independence, and the emotional burden placed on family members may contribute to choosing a medically assisted death. These insights align

with previous research on why individuals may choose an assisted death.<sup>13,21</sup> For example, in the Berkman (1999) study,<sup>16</sup> unbearable pain and fear of not enjoying life to the fullest (49% and 42% respectively) were factors that definitely or probably would result in considering an assisted death. Similarly, the study by Marrie et al.<sup>17</sup> reported that unbearable pain, causing a financial burden for family or caregivers, and being unable to do things that made one happy were factors identified by 65%, 41% and 34% of participants, respectively, as reasons they would definitely or probably consider an assisted death.

Our study highlighted the emotional complexity of EOL choices and identified that emotional or financial concerns for loved ones may influence decisions when reflecting on hypothetical scenarios. Psycho-emotional factors such as suffering, fear of loss of decision-making control, and concerns about dignity often influence decisions about EOL care options.<sup>22</sup> Collectively, these findings suggest that both personal and relational concerns shape EOL decision-making, as individuals weigh their own suffering alongside worries about becoming an emotional burden to loved ones.

Participants acknowledge that their EOL decisions may have profound, lasting effects on their families. This recognition suggests a need for holistic care planning that includes family members as an integral part of the EOL decision-making process. Prior evidence shows that family members can experience judgment, guilt, trauma about their role in the process, and distress during and after the MAiD death.<sup>23,24</sup> Integrating family early in EOL care discussions may help with emotional preparation, support communication, and improve understanding of choices.

Our study found that although certain services such as mobility aids, medications, and home care are theoretically part of healthcare systems, their costs, access processes, and eligibility requirements often make them difficult to access. This aligns with previous research showing that socio-economic status,<sup>25</sup> structural and societal issues, and knowledge of EOL options<sup>26</sup> can influence the EOL experience.

### **Strengths, Limitations and Future Research**

Strengths of our study include the use of both content and thematic analysis, which enabled a comprehensive understanding of the phenomenon and enhanced the depth of

interpretation by systematically identifying patterns and relationships within the data. However, several limitations should be noted, such as potential response bias, as individuals who did not wish to discuss EOL and/or MAiD would not have self-identified as potential participants. Additionally, we acknowledge that participants' responses were based on hypothetical situations, which may or may not reflect their actual contexts or EOL decisions. We also did not specifically seek to capture the perspectives of immigrant, minority, or Indigenous communities, whose distinct cultural and spiritual values may significantly influence EOL care preferences. As the study was conducted within a single Canadian province, the findings may not be generalizable to other regions or healthcare systems. Future research should include the perspectives of family members, caregivers, and policymakers, while accounting for cultural and geographical variation.

## Conclusion

This study contributes to the growing understanding of the complex contextual factors that may influence EOL decision-making when MAiD is a legal option. The results emphasize that EOL decisions are inherently relational and situated within social, emotional, and systemic contexts. Healthcare professionals and policymakers should recognize that EOL decisions may extend beyond individual preference and are deeply intertwined with family dynamics and access to supportive services. As MAiD legislation and EOL care practices continue to evolve in Canada, ongoing dialogue that includes patients, families, and policymakers is essential.

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## Financial Disclosures

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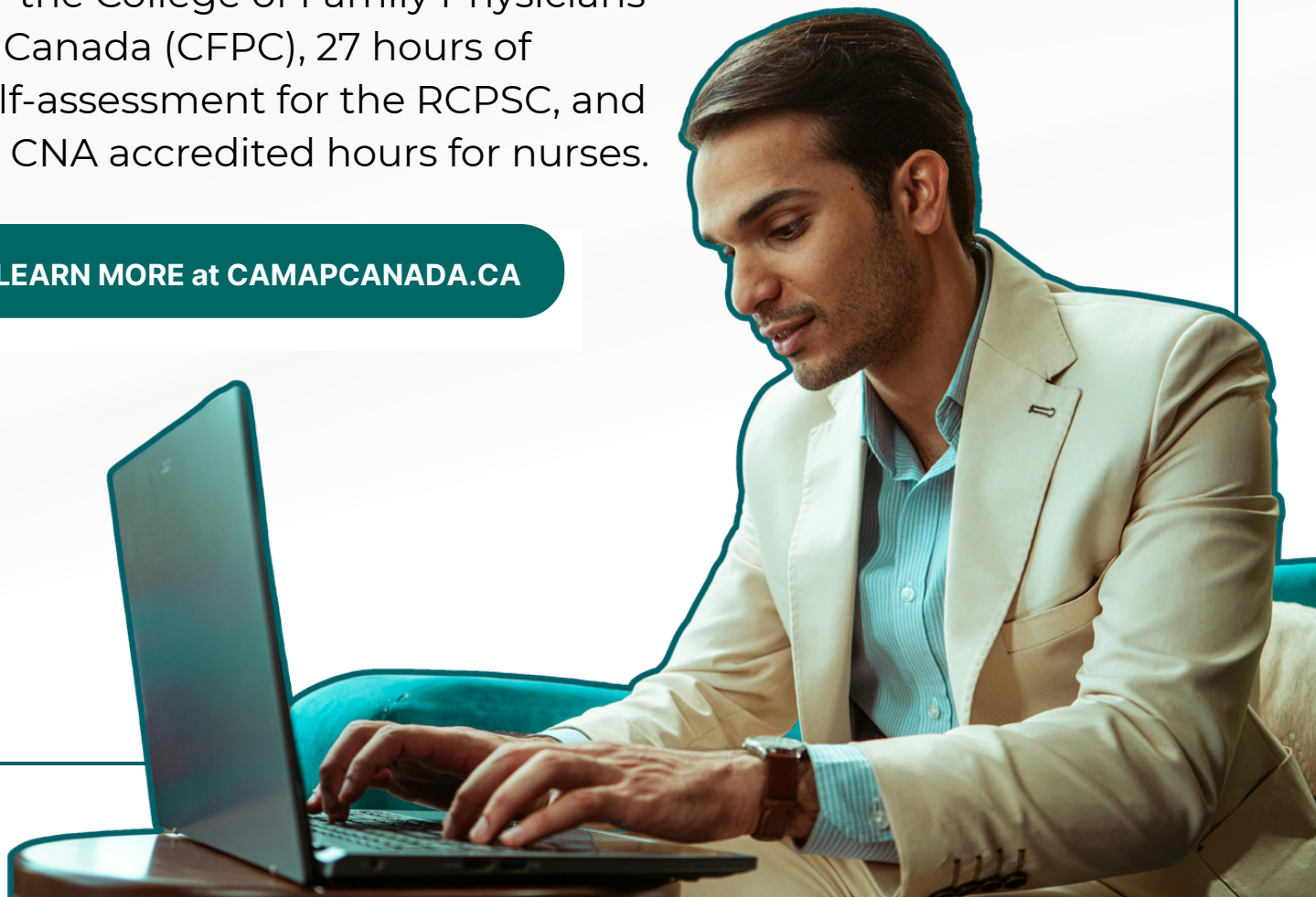
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# Dementia and MAiD

**Mark Lachmann, MD, MHSc, MA, FCFP, FRCPC**

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MAiD assessors and providers will encounter patients with some form of dementia in two ways. In the first instance, they may be asked to assess a patient who has a dementia but the primary diagnosis underlying the MAiD request is based on a different underlying illness, such as cancer or heart failure. In the second instance, the MAiD request may stem directly from the dementia itself. An understanding of the context in which MAiD is provided when dementia is present may be helpful for MAiD assessors and providers. Here, we will also explore the diagnosis of dementia itself to support MAiD assessors and providers as they engage with patients and families around this complex diagnosis.

## Context

It remains uncommon for a Canadian dementia patient to receive provision of MAiD. The MAiD Death Review Committee of the Office of the Chief Coroner in Ontario has specifically considered dementia with their 2025 report, “Navigating MAiD with Persons with Dementia.”<sup>1</sup> Between January 1, 2023 and December 31, 2024, there were 103 MAiD provisions in Ontario with cause of death indicated as dementia.<sup>1</sup> Of these, 102 were Track 1 MAiD provisions, occurring when patients have a naturally foreseeable death. MAiD provisions for dementia represented 1.1% of all MAiD provisions in Ontario over that time period. In addition, further analysis of the data from 2023, which included not only those who received MAiD for dementia but also those with a dementia diagnosis within two years prior to MAiD provision, identified 235 individuals who received MAiD in 2023. Of these, 39 MAiD provisions were attributable to the dementia itself. In contrast, the majority of cases (196/235, 83%) involved individuals for whom dementia was a significant aspect of their presentation but not the primary reason for requesting MAiD.<sup>1</sup> These findings suggest that it is more common to access MAiD with dementia, rather than for dementia. For context, in Ontario in 2023, an estimated

182,573 individuals were living with a dementia diagnosis and there were 15,662 deaths among individuals with dementia.<sup>1</sup> The vast majority of deaths in dementia patients are therefore not MAiD deaths.

## Major Neurocognitive Disorder

Clear and consistent language is important for MAiD clinicians when assessing patients with a dementia. The category word “dementia” has been replaced in the DSM-5 by the term “major neurocognitive disorder” to describe a range of illnesses, with specific illnesses retaining the dementia label i.e., Alzheimer’s dementia, Lewy Body dementia. While this change has been adopted by many practitioners in the field, the term “dementia” has remained pervasive in the collective consciousness of the medical community and the general public. See **Table 1** for a brief overview of dementia.

A major neurocognitive disorder is defined by a significant decline in at least one of the following cognitive domains: complex attention, language, executive functioning, learning and memory, perceptual motor function, or social cognition. A major neurocognitive disorder must be accompanied by a decline in function and may be categorized as “mild”, with impairments in instrumental activities of daily living (managing finances, grocery shopping), “moderate”, with impairments in basic activities of daily living (dressing, bathing, toileting), or “severe” with total dependence.<sup>2</sup> Each type of neurocognitive disorder, such as Alzheimer’s disease, has specific additional criteria beyond the general criteria described above.

An understanding of cognitive domains is crucial to recognizing the profiles of the major neurocognitive disorders. Complex attention describes the ability to focus and attend to a specific task. Language refers to both expressive speech/writing and receptive language comprehension. Learning and memory refers to both the registration and retrieval of new

information, as well as short-term and long-term memory function. Executive functioning includes skills such as planning, organizing, sequencing, and abstraction (an example of abstraction would be the ability to categorize two items). An example of a task that involves significant executive functioning is arranging for an appointment at a doctor's office. Perceptual motor function includes complex movements, such as dressing and bathing, as well as more basic domains of cognition such as visual and auditory processing. Social cognition refers to capacities such as empathy and the ability to follow social norms of behaviour.

Cognitive impairment, even when profound, does not always indicate the presence of a neurocognitive disorder. It is crucial to have a thorough assessment and diagnosis of a suspected major neurocognitive disorder to avoid overlooking reversible causes of cognitive impairment, such as untreated sleep apnea, B12 deficiency, delirium, untreated major depressive disorder, other mental disorder, and active or recent substance use including alcohol. An assessment to diagnose a major neurocognitive disorder should include a full history and physical, appropriate laboratory investigations, neuroimaging, and formal cognitive assessments.

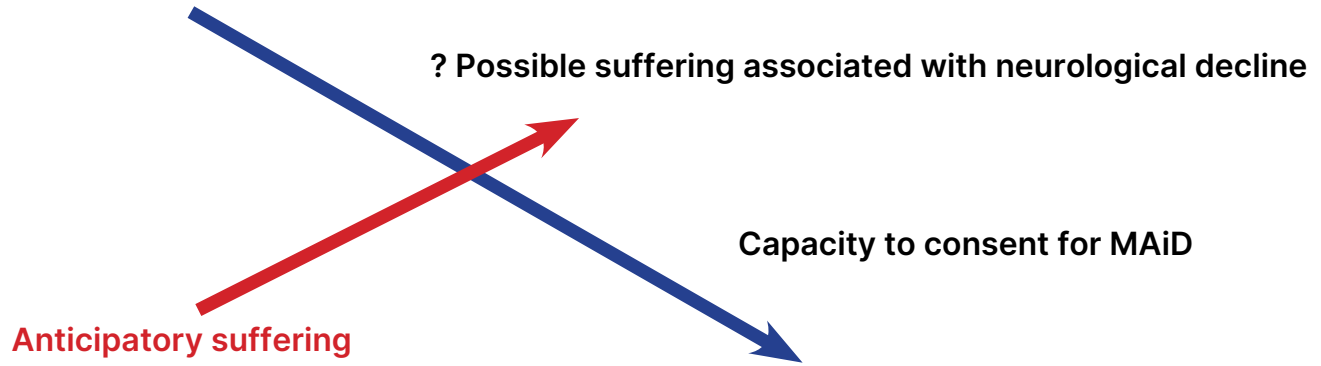
In addition, the diagnosis of a major neurocognitive disorder should be as specific as possible with respect to the type of disorder, such as Alzheimer's disease, vascular dementia, Lewy Body dementia, frontotemporal dementia, or mixed dementia.

An accurate diagnosis is particularly important in the context of MAiD, as it informs the prognosis and, specifically, the irremediability of the condition and the foreseeability of the person's death. Neurodegenerative etiologies such as Alzheimer's disease and Lewy body disease involve progressive deterioration in function leading to death. As patients live longer and present with increasing medical complexity, co-pathology (i.e., major neurocognitive disorder due to multiple etiologies) is common. However, there is often a predominant etiology that drives the patient's cognitive or behavioural symptoms.

The MAiD assessor is not expected to make the diagnosis of a major neurocognitive disorder, but is expected to exercise due diligence in ensuring such a diagnosis is made. If concerns about cognition arise during the course of a MAiD assessment, the assessor should refer the patient to an appropriate clinical service for formal evaluation. In accordance with national guidelines on assessing capacity to consent in the context

Clinical History on Initial Presentation	Cognitive Impairment Profile	Cognitive Test Affected	Common Disorder
Rapidly forgetting, repetitive	Amnesic	Delayed recall	Alzheimer's disease
Slow thinking, slow movement, executive dysfunction, and vascular comorbidities	Executive dysfunction Slow processing speed	Trails Clock draw	Vascular dementia
Behavioural changes Apathy or disinhibition	Normal Or mild executive dysfunction	Normal Or clock draw	Frontotemporal dementia behavioural variant
Fluctuations Visuospatial	Executive dysfunction	Figure copy Clock draw Trails	Lewy body dementia Parkinsons disease dementia
Language impairment	Language-predominant impairment	Globally impaired Boston naming	Primary progressive aphasia (several subtypes)

**Table 1.** Brief Dementia Overview; *adapted from Tang-Wai, DF et al., 2018*



**Figure 1.** Anticipatory suffering in early stages of dementia; *courtesy of Mark Lachmann, MD, MHSc, MA, FCFP, FRCPC, Gina D. Eom, MD, PhD, FRCPC, Eric E. Brown, MD, MSc, FRCPC*

of cognitive impairment and MAiD, structured instruments such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) may be utilized. Cognitive screening tests are also suggested as a component of the assessment of cognition in support of a thorough capacity evaluation.

Anticipatory suffering refers to the present psychological distress experienced by individuals with dementia, arising from the awareness that they may—or will—progress to a future state of significant cognitive and functional decline. This fear of a more advanced disease state can manifest as intolerable psychological suffering in the present. According to the Alzheimer Society of Canada, many individuals living with dementia experience anticipatory suffering, and for a small subset, it may constitute a meaningful factor in seeking eligibility for MAiD. Anticipatory suffering should not be confused with “anticipating suffering” in the future, but rather a current state of significant psychological distress.

Among individuals who received MAiD for dementia (where dementia was identified as the primary condition contributing to suffering) in Ontario between January 2023 and December 2024, the top five aspects of suffering, in descending order, were inability to engage in activities, loss of independence, loss of ability to perform activities of daily living, loss of dignity, and emotional distress, including anxiety, fear and existential suffering.<sup>1</sup> A key eligibility criterion to access MAiD is the patient’s experience of “enduring physical or psychological suffering that is intolerable to the person and cannot be relieved under acceptable conditions.”<sup>3</sup>

The evaluation of suffering by the MAiD clinician is an essential part of the MAiD assessment. Many common major neurocognitive disorders, including Alzheimer’s disease and Lewy body disease, are neurodegenerative, progressive, and terminal illnesses, with a somewhat variable course depending on the nature of the dementia. Evaluation of suffering, however, means that the MAiD clinician must engage deeply with the patient and place the illness experience in the context of their particular life history and circumstances. When evaluating suffering in a person with a major neurocognitive disorder, the clinician must evaluate the dementia experience in the context of the patient’s personhood through a detailed personal and social history.<sup>4,5</sup> As part of this assessment of suffering in a major neurocognitive disorder, other modes of relieving distress should also be explored, such as access to palliative care, increased home and community supports, or other supports as available.<sup>6,7</sup>

### Available Treatments

While disease-modifying therapy is changing rapidly in the field of dementia care, there are currently still no treatments that can meaningfully reverse or halt neurodegenerative major neurocognitive disorders. Some treatments including newer biologics can help delay or slow the progression of cognitive symptoms, or alleviate some of the behavioural and psychiatric symptoms associated with dementia that can contribute to suffering, such as depression and anxiety. Ongoing physical and social engagement are key to the care of the dementia patient. Palliative care is most often engaged in subsequent dementia

care stages, and plays a pivotal role to alleviate various symptoms and forms of suffering.

## Voluntariness

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All major neurocognitive disorders affect thinking and memory, and thus there are concerns that patients may be vulnerable to coercion across multiple domains. Careful inquiry into the motivation, degree of resolution, duration, and consistency of the patient's request for MAiD is essential and should be documented. As a MAiD assessor and provider, it is essential both to interview the patient with family and supports present, and to interview and assess the patient individually in a safe and confidential environment, with these conversations clearly documented.<sup>8,9</sup>

## Capacity

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Careful inquiry into decision-making capacity is essential in all MAiD assessments and even more so in the presence of a major neurocognitive disorder. MAiD assessments in dementia are, in practice, usually considered complex assessments de facto, due to the progressive decline in cognitive capacity to consent. Assessing capacity involves determining whether the patient understands their underlying medical condition, treatments available to them, or palliative measures available and applicable to their circumstances, and the nature of the MAiD procedure, as well as whether they appreciate how the decision to access or decline MAiD applies to their particular circumstance.<sup>10</sup> In exploring how a patient appreciates their own condition and the option of MAiD, the MAiD clinician also explores the patient's personhood and considers how the MAiD request aligns with the patient's pattern of decision making over their life course.<sup>11,12</sup> Clear documentation of the determination of the patient's capacity or incapacity, along with the facts that informed this conclusion, is essential.

## Advance Requests

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Advance requests for MAiD are currently permitted only in Quebec and are governed by a specific set of requirements intended to assist clinicians in determining when, along a major neurocognitive illness course, MAiD may be provided.<sup>13</sup> The use of advance requests for MAiD in Quebec has been described as having broad public support within the province.<sup>14</sup> A challenge

for the use of advance requests specifically in dementia care is that the individual's current self does not actually know how their future self will, or will not, experience suffering in the face of specific loss of function, such as losing the ability to recognize family members or feed oneself.<sup>15</sup> While these anticipated losses may cause the present self to experience intolerable suffering, it remains unclear whether the person will subjectively experience suffering in the moment as dementia progresses. Furthermore, Quebec's legislative language around advance requests for MAiD involves the subjective opinion of the provider that the patient appears to be suffering.<sup>16</sup> The Canadian conversation around advance requests for MAiD is ongoing.

## Waiver of Final Consent

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The waiver of final consent option was established for patients seeking MAiD whose death is reasonably foreseeable and for whom, while eligible and capable, have selected a date for the MAiD procedure. The waiver permits MAiD to proceed if the patient loses capacity for final consent just prior to the MAiD procedure. However, it also instructs the MAiD provider NOT to provide MAiD if the patient "demonstrates refusal or resistance to the administration of MAiD by words, sounds, or gestures." Under Federal legislation, there is no time limit on the validity of a waiver of final consent once someone is approved for MAiD. In contrast, Quebec legislation imposes a 90-day limit, and the intent is clear that the waiver of final consent is NOT a form of advanced request.<sup>17</sup> A good faith interpretation of the waiver of final consent is that it is intended for individuals seeking MAiD who are at risk of losing capacity due to the underlying illness state and who have scheduled a MAiD procedure while still capable, usually some weeks, or possibly several months in the future. The most common medical cause of loss of capacity to give final consent is delirium. According to Canadian Association of MAiD Assessors and Providers (CAMAP) guidelines, the waiver of final consent must be signed and documented by the intended provider of MAiD, that is, the final MAiD provider must personally obtain the prior waiver of final consent.

## Conclusion

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MAiD clinicians will assess patients with a major neurocognitive disorder who are requesting

MAiD either due to the major neurocognitive disorder itself or, more commonly, because of another serious illness in the context of co-existing major neurocognitive disorder. Most patients with a major neurocognitive disorder do not request MAiD. It is therefore essential to clearly identify and document that a diagnosis of a major neurocognitive disorder has been made. Establishing the type of neurocognitive disorder can inform the expected course of the illness as it relates to MAiD alternatives, as well as the MAiD process and eligibility criteria. MAiD assessors and providers should also ensure that patients with dementia, along with their care teams, have been offered local dementia and palliative care supports.<sup>18,19</sup> Understanding the pattern of cognitive impairment associated with a particular dementia subtype can be helpful in assessing the suffering experienced, and the decisional capacity of a particular patient. Careful exploration and documentation of the patient's lived illness experience, within the context of their life course, is essential when assessing a patient living with dementia for MAiD.

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**G.D.E.:** None declared.  
**E.E.B.:** None declared.

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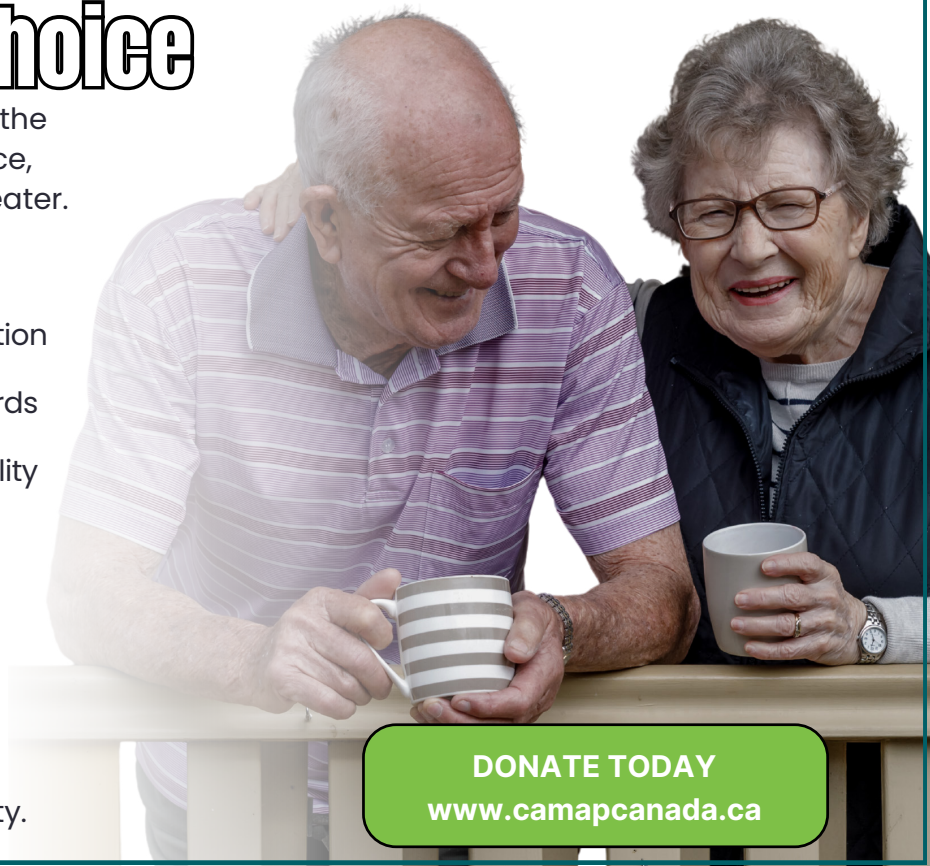
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## About the Authors



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Kathy Kortes-Miller, MSW, PhD is an Associate professor in the School of Social Work, the Director of the Centre for Education and Research on Aging and Health and the research chair in aging and end-of-life at Lakehead University, Thunder Bay, Ontario, Canada. Kathy has a passion for contributing to improving end-of-life care for all. Kathy's research is interdisciplinary and collaborative, and she is a founding member of the Canadian Grief Alliance. She is the author of the book *"Talking About Death Won't Kill You"* with ECW Press and her most recent projects include a podcast called *"Disrupting Death"* available wherever you get your podcasts and at <https://www.disruptingdeath.ca/episodes>.

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Keri-Lyn Durant, PhD Education (Lakehead University), is Knowledge Mobilization Lead on the Social Sciences and Humanities Research Council (of Canada) Insight Research Grant *"Disrupting Death"* which funds this podcast. She is currently also a full-time elementary school teacher. Keri-Lyn's background in applied theatre sparked a desire to learn more about digital storytelling and podcasting; she gratefully studied both through The Story Center (Berkeley, CA). In her spare time, she prefers to be outside, especially in the months that bring snow and anytime on the Bruce Trail.

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# Disrupting Death and Medical Assistance in Dying (MAiD): Podcasting as Public Scholarship and Knowledge Mobilization

Kathy Kortés-Miller, MSW, PhD  
Keri-Lyn Durant, PhD

## Introduction

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Since its legalization in 2016, medical assistance in dying (MAiD) has fundamentally reshaped end-of-life care in Canada. Nearly a decade later, public discourse around MAiD has become increasingly polarized, with sensationalized media coverage often obscuring the nuanced realities of how Canadians experience decision making at end-of-life. While exceptional cases dominate headlines, there is a pressing need for knowledge translation strategies that provide accurate, contextualized, and accessible information about MAiD policies, procedures, and lived experiences.

Podcasts have emerged as an increasingly valuable methodological and knowledge mobilization tool within qualitative and community-engaged research.<sup>1-3</sup> In response to this knowledge gap, the *Disrupting Death* podcast was launched to create space for thoughtful, critical, and compassionate conversations about dying, death, grief, and MAiD. Building upon a Social Sciences and Humanities Research Council (SSHRC) Insight Grant, the podcast serves as both a vehicle for research dissemination and as a platform for public scholarship that centres lived experiences alongside professional, ethical, and policy perspectives.

This paper examines the *Disrupting Death* podcast as a case study, exploring how podcasting can mobilize research findings, challenge dominant narratives, and foster more informed and empathetic public engagement with end-of-life issues.

## Podcasting as Public Scholarship and Knowledge Mobilization

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Researchers increasingly use podcasts to enable accessible knowledge translation beyond traditional academic audiences.<sup>2,3</sup> Podcasts provide opportunities to foreground participant voices and lived experiences through audio storytelling, fostering emotional and affective engagement that enhances empathy and understanding of complex issues. Moreover, podcasts can be structured as participatory or collaborative research methods that redistribute power between researchers and communities.<sup>1,4,5</sup>

Cox et al.<sup>6</sup> highlight how academic podcasting challenges traditional knowledge production by offering a more informal and accessible method of engagement. The authors emphasize that podcasts facilitate broader outreach, fostering social connections and strengthening academic networks. Similarly, DeMarco<sup>3</sup> presents a case study on the University of Toronto Mississauga's research podcast, demonstrating how this medium enhances knowledge translation and researcher visibility while reaching audiences who may lack access to traditional scholarly publications.<sup>7</sup>

## Podcasting in Palliative and End-of-Life Care

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Public awareness campaigns for palliative care have increasingly incorporated podcasts as vehicles to broaden public understanding and reduce stigma about end-of-life care.<sup>8</sup> Research examining the reception of palliative care campaigns by the public identifies audio media as particularly effective for reaching diverse audiences and fostering emotional engagement

with sensitive topics.<sup>8</sup> The accessibility and intimacy of audio formats which can be consumed while commuting, exercising, or performing household tasks make podcasts well-suited for public health communication about death and dying.<sup>1</sup>

Narrative approaches to knowledge translation, including podcasting, have been shown to enhance understanding, retention, and emotional engagement, particularly in applied health and social research contexts where influencing practice and public discourse is a core objective.<sup>9,10</sup> Listener feedback on scholarly podcasts suggests that integrating participant audio data helps connect listeners with research findings, enhancing uptake and impact in ways that traditional academic publications may not achieve.<sup>10,4</sup>

In the specific contexts of MAiD and end-of-life care, podcasts can facilitate public conversations that challenge stigma, offer accessible education, and mobilize research findings to inform policy and practice. Additionally, podcasts may challenge dominant narratives about “good deaths” or stigmatized forms of loss by creating counter-narratives that centre marginalized experiences and perspectives.<sup>5</sup>

## The Disrupting Death Podcast: Overview and Approach

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*Disrupting Death* is a Canadian podcast that creates space for thoughtful, critical, and compassionate conversations about dying, death, grief, and MAiD. The podcast builds upon an SSHRC Insight Grant and aims to offer accessible conversations that reduce stigma and challenge overly simplistic narratives about end-of-life experiences by centring lived experiences alongside professional, ethical, and policy perspectives.

## Production and Format

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Since its launch, *Disrupting Death* has published 39 episodes on a monthly schedule, featuring dozens of guests across health, social care, policy, research, and community sectors. Guests have included physicians, social workers, nurses, ethicists, coroners, policymakers, advocates, researchers, people with lived experience, and family members. Additionally, the podcast has interviewed artists, including

playwrights, authors, photographers, and musicians, whose work interfaces with MAiD.

Episodes are typically interview-based and conversational in tone, allowing guests to share their expertise and situated knowledge through reflective responses to questions that may be absent from formal academic or clinical spaces. Unlike conventional medical podcasts in which a case is introduced, discussed, and summarized for learning objectives,<sup>11</sup> *Disrupting Death* employs a semi-structured approach that allows for organic and rich discussions in conjunction with questions prepared in advance. This methodology enables conversations to follow wherever guests lead, creating space for unexpected insights and authentic dialogue.

## Reach and Impact

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The podcast has achieved substantial reach and engagement, with thousands of downloads and listeners in over 25 countries, reflecting global interest in end-of-life issues and MAiD. The most downloaded episode to date is Episode 4, entitled “A Death Positive Approach to Children and MAiD: Disrupting Death with Cynthia Clark.”<sup>12</sup>

Episodes are used as teaching tools in social work, healthcare, and education, serving as knowledge mobilization resources for practitioners, policymakers, and community organizations. Healthcare educators have reported using the podcast as “required listening” in their courses, while volunteer groups such as hospices have incorporated it into their training programs. This integration into professional and educational contexts demonstrates the podcast’s value as both a pedagogical resource and a knowledge translation tool.

## Core Themes in Disrupting Death

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Three overarching themes consistently emerge across episodes of *Disrupting Death*, reflecting the podcast’s commitment to public scholarship and social justice-oriented knowledge mobilization.

### Theme 1: Centring Lived Experience to Challenge Policy and Practice

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*Disrupting Death* is committed to centring lived experiences. Episodes foreground the voices of people who are dying, navigating MAiD, providing formal and informal care,

working as clinicians, and experiencing grief and bereavement. Rather than simply illustrating policy debates, these narratives strive to centre individual experiences of how macro systems and professional practices are experienced by Canadians.

A notable example of this commitment is the podcast's integration of digital storytelling as both a research method and a knowledge mobilization strategy. As part of the broader SSHRC research project, caregivers of people who used MAiD at the end of their lives created digital stories about their experiences. Digital stories are typically 3–5 minutes in length, feature first-person narratives, and may use still or moving images, music, or sound effects to tell a story about a person, event, or issue.<sup>13</sup>

The project produced 13 digital stories created with participants from across Canada who have intimate experiences with MAiD. The digital story creators were subsequently invited to participate as podcast guests to discuss their experiences with creating the stories. A coordinated “trifecta” of episodes released in August 2024 ensured that all participants' voices were heard. These digital stories have been shared in university classes, public talks, academic conferences, and are available on the project website for viewing. The digital story creators retain ownership of their stories and have been sharing them widely within their own networks.

To support the ethical and thoughtful use of these stories, the project team recently developed a digital story viewing toolkit, available [here](#)

The digital stories themselves can be accessed via the project website: [here](#)

This integration of digital storytelling into the podcast demonstrates how multiple forms of narrative knowledge can be mobilized in complementary ways, amplifying the voices of those with lived experience while providing accessible entry points for diverse audiences. The podcast consistently demonstrates that ethical and policy decisions about dying must be informed by how people live, suffer, hope, and grieve.

## Theme 2: Interrogating Power, Inequity, and Social Justice at the End of Life

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*Disrupting Death* applies a social justice lens to end-of-life care and MAiD. Conversations with invited guests consistently include questions of power: Who gets access to quality palliative and end-of-life care? Whose suffering is recognized

as legitimate? How do poverty, disability, racism, geography, and colonial legacies shape end-of-life options?

Rather than treating MAiD or palliative end-of-life care as neutral clinical interventions, the podcast situates them within broader structural conditions, emphasizing that inequity at the end-of-life mirrors inequity across the life course. This critical approach challenges listeners to consider how systemic barriers, including inadequate healthcare access, housing insecurity, disability discrimination, and the ongoing impacts of colonialism, shape who has meaningful choices at the end-of-life and whose deaths are deemed “good” or “dignified.” Through these structural analyses, *Disrupting Death* strives to contribute to a more complex and equity-informed public discourse about MAiD.

## Theme 3: Normalizing Difficult Conversations About Death, Dying, and Grief

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A third unifying theme is the deliberate effort to make conversations about death less hidden, less fearful, and more normalized within everyday discourse. Through accessible dialogue, reflective storytelling, and the use of gentle humour, the hosts model how to talk about dying, loss, and grief without shutting down or oversimplifying individual experiences.

The podcast hosts value curiosity, listening, and emotional honesty. A goal of the podcast is to contribute to broader death literacy and grief literacy, encouraging both professionals and the public to engage more openly with dying, death, loss, and grief as part of everyday life. This is particularly important in a cultural context in which death is often medicalized, isolated, and removed from public conversation.

## Listener Evaluation

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In the spring of 2025, the podcast team conducted a qualitative survey to learn more about the listenership and identify areas for improvement. The survey results showed that *Disrupting Death* is received as a trusted and meaningful resource for audiences engaging with MAiD in both personal and professional capacities.

## Audience Demographics and Engagement

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As expected, respondents are predominantly based in Canada, and most listeners from other countries also live in jurisdictions where assisted dying is legal. This suggests the podcast is reaching an audience directly navigating or working within this policy and practice context. Listeners most commonly reported tuning in to learn more about the MAiD process, or because they had supported someone through MAiD, underscoring the podcast's role as both an educational and experiential resource.

Engagement levels were high, with most respondents reporting they had listened to multiple episodes, with over 40% indicating that they had listened to over half of the available episodes. This engagement indicates genuine interest rather than one-off listening, suggesting that the podcast often maintains listener attention across episodes.

## Qualitative Feedback

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Qualitative feedback from listeners consistently described the podcast as accessible, informative, and well-balanced in tone, elaborating that it is serious without being overly sombre. Many highlighted the warm and welcoming approach of the hosts, as well as the diversity of voices and perspectives featured, including lived experience, professional expertise, and policy insight.

What survey respondents report valuing is the podcast's ability to create a dedicated space for nuanced, Canadian-specific conversations about MAiD, grounded in real-world experiences. The majority of respondents overwhelmingly indicated they plan to continue listening and would recommend the podcast to colleagues, patients, friends, and others navigating MAiD. This feedback confirms that *Disrupting Death* is fulfilling its knowledge mobilization mandate, reaching audiences and providing a resource that bridges research, practice, and lived experience.

## Discussion: Podcasting as Knowledge Mobilization

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Across its episodes, *Disrupting Death* operates at the intersection of story, system, and social change. The podcast mobilizes research and lived experience to inform public understanding,

professional practice, and policy discourse related to end-of-life care and MAiD. By integrating experiential knowledge, equity-focused analysis, and accessible communication, the podcast contributes to meaningful, evidence-informed engagement with complex social and ethical issues at the end-of-life.

The podcast demonstrates how audio storytelling can serve as a powerful knowledge translation tool, making academic research accessible to non-academic audiences while maintaining rigour. By featuring researchers, practitioners, and people with lived experience in conversation, *Disrupting Death* models interdisciplinary and community-engaged approaches to knowledge production and dissemination.

The integration of digital storytelling further amplifies this bridging function, providing multiple entry points for engagement and ensuring that participant voices remain central to how research is communicated and understood. This multi-modal approach to knowledge mobilization recognizes that different audiences engage with information in diverse ways and that narrative forms of knowledge can be particularly powerful for fostering empathy and understanding.

The podcast strives to provide accurate, contextualized information grounded in research and lived experience offering an alternative to uncritical advocacy and fear-mongering opposition. This is particularly important in the current polarized climate around MAiD, where misinformation and disinformation increasingly dominate public discourse.

Perhaps most importantly, *Disrupting Death* contributes to broader cultural shifts toward increased death literacy and more open public dialogue about dying, death, and grief. By normalizing difficult conversations and modelling how to engage with uncertainty and complexity, the podcast supports listeners in developing the knowledge, skills, and emotional capacities needed to navigate end-of-life issues in their own lives.

## Looking Forward: The Future of Disrupting Death

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As *Disrupting Death* approaches its third year of production, the podcast team remains reflective about where MAiD legislation might lead and how the podcast might contribute to emerging conversations. The team is cognizant of a shift in focus in media coverage of MAiD, noting

an increasingly polarized landscape in which anti-MAiD proponents often characterized by spreading misinformation and disinformation, have garnered much of the attention.

*Disrupting Death* remains committed to providing a platform for accurate information to be disseminated so that Canadians can access reliable resources to make informed decisions about end-of-life choices. The podcast's continued emphasis on lived experience and accessible communication positions it as a counterweight to sensationalized or ideologically driven coverage.

Moving forward, the podcast aims to continue serving as a comprehensive resource that humanizes the conversation around MAiD, offering diverse perspectives and fostering deeper understanding of this complex and sensitive topic. *Disrupting Death* maintains its commitment to public scholarship, knowledge mobilization, and social justice, and will continue to strive to contribute to a more informed, empathetic, and equity-oriented public discourse about end-of-life care in Canada.

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## Financial Disclosures

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**K.L.D.:** None declared.

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