2025

MAiD Death Review Committee (MDRC) Report: 2025 – 2

Navigating MAiD with Persons with Dementia

Ministry of the Solicitor General | Office of the Chief Coroner

BACKGROUND

Under the *Coroners Act*, physicians and nurse practitioners who provide Medical Assistance in Dying (MAiD) are required to notify the Office of the Chief Coroner (OCC) of the death and provide relevant information to support MAiD death review, oversight, and Health Canada mandatory reporting requirements. Ontario has an established team of highly skilled nurse coroner investigators (MAiD Review Team) who retrospectively review every reported MAiD death in Ontario. A structured feedback approach for practitioners is followed to respond to concerns with statutory requirements, regulatory policies, and/or professional practice when identified during the review process. Further investigation is undertaken as required in accordance with the *Coroners Act* and with the Chief Coroner. The majority of reported MAiD deaths in 2024 (N=4,356 or 88% of all MAiD deaths) reviewed by the MAiD Review Team were evaluated to have met all legislative requirements, with no additional complexities identified requiring further evaluation. Approximately 602 MAiD deaths in 2024 required further in-depth review (N=321) or went on to require an investigation (N=281).[1]

Reflecting the more mature state of MAiD practice, in January of 2023, the OCC modernized its approach to MAiD death review and oversight. Through the modernization process, the OCC review and oversight approach has continued to evolve to include, when indicated, enhanced expert review to respond to increasing social and systemic complexities within the contexts and circumstances surrounding MAiD legislation, practice, and care. Ontario is the first province in Canada to develop a multi-disciplinary expert death review committee to provide enhanced evaluation of MAiD deaths and to explore end-of-life complexities that have systemic and practice implications.

The MAiD Death Review Committee (MDRC) was established in January of 2024. The committee is comprised of 16 members from across multiple disciplines (law, ethics, medicine, social work, nursing, mental health and disability experts, and a member of the public) who bring a diverse background of expertise in providing advisory support to MAiD oversight in Ontario.

The MDRC seeks to provide recommendations and guidance that may inform the practice of MAiD through the evaluation and discussion of topics, themes, and trends identified by the MAiD Review Team (MRT).

Committee Aim

The MDRC provides multidisciplinary expert review of MAiD deaths in Ontario with legislative, practice, health, social, and/or intersectional complexities identified through

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[1] Preliminary overview of 2024 data. A small number of MRT reviews are pending final review outcomes.

the oversight and review process. MDRC members review and evaluate the contextual circumstances that impact MAiD and inform the ecology of care for persons, families, and communities. MDRC members review relevant MAiD trends, topics, or issues and offer insights, perspectives, or interpretations and assist in formulating recommendations to inform system improvements (e.g., education of MAiD practitioners, review of regulatory body policies) with a goal to support quality practice and the safety of patients and MAiD practitioners.

Acknowledging there is public discourse regarding MAiD, the MDRC is committed to increasing public transparency of the MAiD oversight and review process through the dissemination of reports.

Acknowledgement of Persons, Families, and Communities

The MDRC acknowledges the deaths of persons who have experienced profound suffering at end-of-life. We acknowledge the losses to partners, families, close relations, and communities.

During the death review process, the OCC protects the personal biographies of the persons who have accessed MAiD. In this report, while some personal information was included for a small number of MAiD deaths, efforts were taken to maintain privacy for persons and their families by sharing only the necessary details and circumstances of their death to support understanding of the issues explored. When we identified that a person's particular circumstance may be identifiable to a person's close relations, we have made efforts to inform their next of kin. We are respectful to the persons whose aspects of their lives are shared in the information presented.

In alignment with the OCC's motto to "speak for the dead to protect the living", the MDRC approaches this important work to learn from each MAiD death. By examining these deaths and presenting this information, we aim to support reflection to inform continued improvement for how MAiD is provided in the province of Ontario.

Acknowledgement of MAiD Practitioners

We extend recognition to clinicians who provide dignified care to persons who have requested MAiD. We respect the clinicians who commit to on-going learning and integrate evolving MAiD practice improvements into their approaches to care. We also acknowledge that clinicians are navigating care for persons accessing MAiD within the limitations of our health and social systems. We further recognize that the OCC MAiD oversight process is an additional step in the provision of MAiD; we are appreciative of the important role of clinicians in the Ontario MAiD oversight process.

Approach to MDRC Review

Through the OCC MAiD death review process, only a small number of MAiD deaths in Ontario have identified concerns. MAiD deaths illustrative of specific circumstances, identified during review by the MRT, are provided to the Committee. The Committee review approach is to gain understanding of the circumstances of the deaths and any issues arising, with the goal to inform improvements to MAiD care. While the circumstances of the deaths reviewed are not representative of most MAiD deaths, the themes identified during the review are not uncommon within the MAiD review process and likely have implications for emerging MAiD practice. The deaths selected are chosen for the ability to generate discussion, thought, and considerations for practice improvement. Reporting of the review discussions is largely focused on identifying areas where there may be opportunities to prompt such improvements.

The deaths reviewed by the Committee are intended to initiate discussions around areas of MAiD practice and encourage practitioners, policymakers, and other stakeholders to explore the issues presented that are relevant to their scope of decision-making. We have selected topics and deaths that depict circumstances that often represent divergence from typical practice and thereby allow new and possibly emerging practice concepts to be evaluated.

Practice considerations and recommendations may have varying levels of transferability to broader MAiD practice and policy. Some practice considerations raised by the Committee should be considered by care teams integral to the delivery of healthcare, more generally (e.g., primary care, mental health services, specialty care teams). Moreover, all persons experiencing profound suffering would likely benefit from improved access to comprehensive care which may require investments in health and social systems to meet the rising expectations of MAiD practices.

Approach to MDRC Report

The Committee reports include a diversity of thought and perspectives from committee members. Statements do not reflect the views of individual members. We did not aim to establish consensus – we recognize that MAiD practice in Ontario is evolving and may benefit from this varied discourse. Committee member opinion, in favor of or in opposition to, a particular recommendation or discussion point or idea, were not collated or counted and we have employed qualifiers such as “few, some, many, and most” to acknowledge the extent of support by committee members. We do not intend for these qualifiers to reflect the validity of some of these statements – some members of the Committee offer more unique expertise and may prompt the reader to consider differing perspectives. Moreover, a variety of statements included in this report may have varying significance for different stakeholders.

Recommendations provided in the report have been informed by and developed from the Committee’s written and verbal discussions. Recommendations are addressed to the organizations that are believed to be positioned to effect change and support MAiD practice and policy. The recommendations are specifically provided and disseminated by the OCC accompanied by a request for a response from the recipient.

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INTRODUCTION

As access to Medical Assistance in Dying (MAiD) continues to evolve, MAiD deaths involving persons with dementia present additional complexities. Between 2023 and 2024, 103 MAiD deaths were reported where dementia was identified as the primary condition contributing to suffering, representing a small proportion of MAiD deaths (1.1% of Track 1 MAiD deaths). MAiD requests involving dementia require additional considerations for interpreting eligibility criteria, assessing capacity, and ensuring informed consent. Evaluation of data from the MAiD Review Team (MRT) indicates that dementia-related MAiD deaths are associated with a higher frequency of next-of-kin concerns and practitioner feedback, underscoring the potential benefit for more structured guidance in this area.

In response, the MDRC has undertaken a focused review to explore practice considerations for persons accessing MAiD with dementia. This report presents MDRC perspectives on key areas including eligibility determination, safeguard assignment (Track 1 vs. Track 2), capacity assessment, and opportunities to enhance dementia care within MAiD practice.

Terminology

For the purposes this review, the following language has been employed:

Dementia: A syndrome characterized by impaired cognition (in one or more brain functions) impacting day-to-day function (basic or instrumental activities of daily living).

Dementia ‘diagnosis’*: A determination of the underlying cause of a person’s dementia (e.g., Alzheimer’s disease, vascular dementia, frontotemporal dementia).

*****DSM-V criteria for a major neurocognitive disorder with an etiological specifier is not always documented by MAiD practitioners.

Stage of dementia: Given the variable documentation provided by MAiD practitioners, the stage of dementia is generally abstracted from the reporting of the person’s functional capabilities.

> **Mild:** Instrumental activities of daily living are impaired (e.g., higher order tasks such as driving, finances, housekeeping)
>
> **Moderate:** Basic activities of daily living are impaired (e.g., personal care tasks such as eating, dressing, bathing)
>
> **Severe or Advanced:** Dependent for many activities of daily living (i.e., typically require 24-hour care [long-term care])

Global judgements of capacity*: Confirmatory evaluation and documentation of capacity (e.g., “they are capable (or incapable) for all decisions and show appropriate mentation”) with limited documentation of the various legal components of capacity (e.g., establishing whether a person can understand and appreciate a healthcare decision).

****Note:*** Following this approach to documentation typically does not demonstrate the legal test for capacity as defined under Section 4 of the Healthcare Consent Act (1996).

TOPIC OVERVIEW

MAiD Reporting Data

To determine the number of persons with dementia who accessed MAiD, a search of the free text field, “*Immediate Cause of Death*”*,* in the MAiD Death Report (MDR) was completed to identify all deaths in 2023 and 2024 in which dementia or Alzheimer’s disease was listed. The keyword search – using the terms ‘dement*’, ‘alz*’, or ‘major neurocognitive’, identified 103 deaths with a cause of death of dementia. Following the keyword search, all other *Immediate Cause of Death* fields were manually reviewed when the cause of death was categorized as ‘neurocognitive’. No additional dementia-related deaths were found following the manual review. The distribution of the 103 dementia cases by year and diagnosis is presented in Table 1. Between 2023 and 2024, 1.1% of all MAiD deaths were due to dementia. Of the 103 MAiD deaths of persons with dementia, 102 were classified as Track 1 MAiD provisions. As such, all further comparisons made in the analyses are based on Track 1 provisions.

Table 1. Distribution of MAiD Deaths in Ontario with a Cause of Death of Dementia by Diagnosis, January 2023 to December 2024

Dementia categories	2023	2024	TOTAL
No dementia specifier (i.e., etiology)	15	21	36
With dementia etiology			
Alzheimer's	13	28	41
Frontotemporal	3	2	5
Lewy body	4	8	12
Mixed	1	2	3
Vascular	3	3	6
Total number of dementia provisions	**39**	**64**	**103**
Total number of MAiD provisions (Track 1 and Track 2)	**4,644**	**4,958**	**9,602**
Percent of all provisions that were dementia	**0.8%**	**1.3%**	**1.1%**

The demographics of persons whose cause of death (COD) was dementia compared to all other CODs are presented in Table 2. The average age of persons with a COD of dementia was 80 years. 60.2% of the persons who accessed MAiD with dementia were males. Just over one-third of persons with dementia who accessed MAiD reported a disability. The length of time spent with a disability was lower for persons with dementia than for all other CODs, averaging 2 years and 8 months.

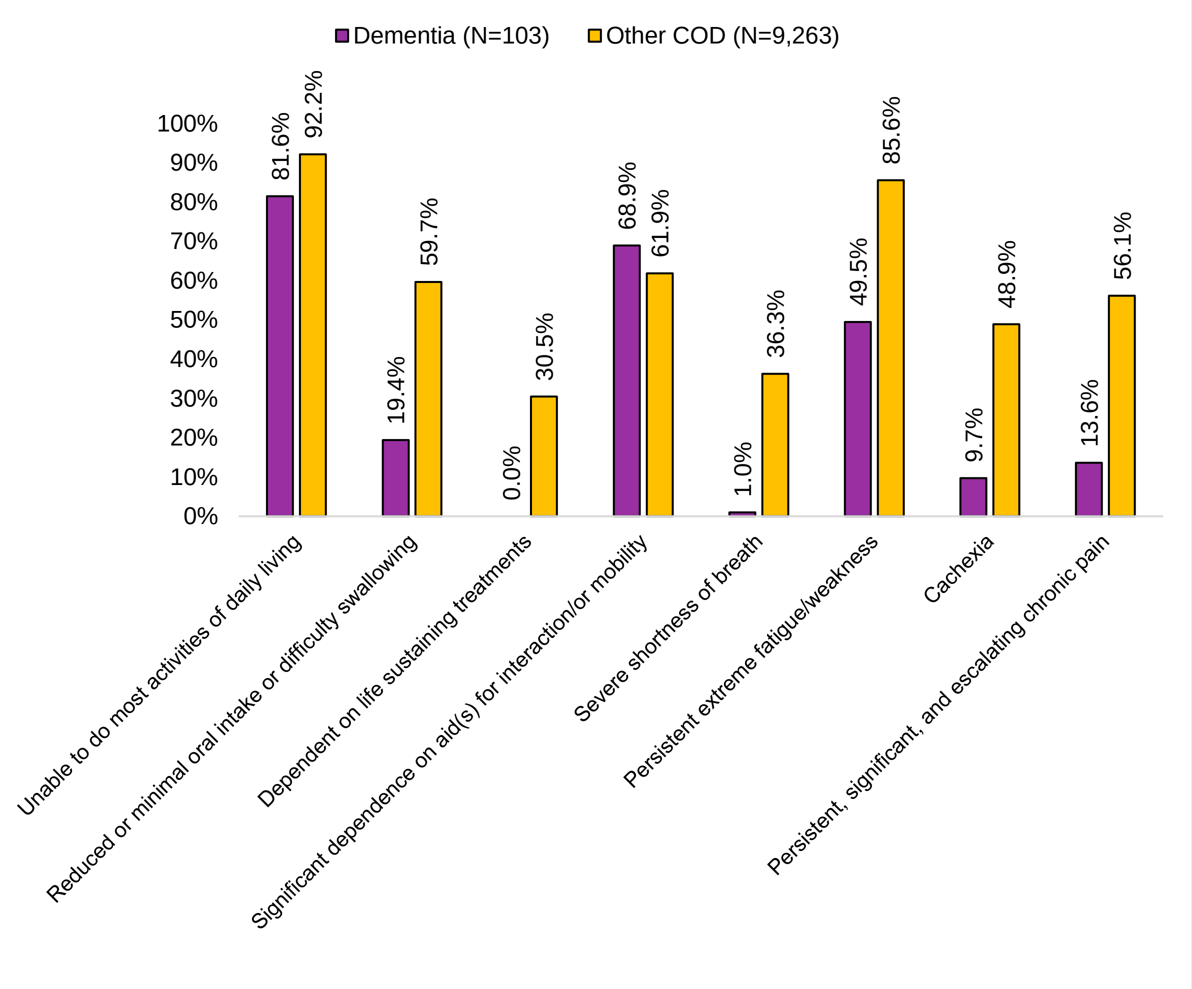
Table 2. Demographics of Track 1 MAiD Deaths in Ontario by Cause of Death, January 2023 to December 2024

Cause of death	Average age	Percent over 80	Percent males	Percent with self-reported disability	Average months with disability
Autoimmune (N=32)	76	59.4%	34.4%	50.0%	13 yrs 5 mos
Cancer-related (N=5,429)	75	36.1%	52.9%	14.7%	6 yrs 10 mos
Cardiovascular (N=1,022)	85	77.3%	48.3%	33.2%	4 yrs 5 mos
Complex chronic (N=281)	82	66.9%	44.5%	49.8%	6 yrs 0 mos
Gastrointestinal (N=177)	79	54.2%	45.2%	22.6%	7 yrs 5 mos
Musculoskeletal (N=140)	88	85.7%	31.4%	53.6%	7 yrs 3 mos
Neurological - Dementia (N=103)	80	55.3%	60.2%	35.9%	2 yrs 8 mos
Neurological - Other (N=721)	73	30.0%	53.8%	53.5%	6 yrs 7 mos
Respiratory (N=894)	79	51.6%	50.8%	28.0%	5 yrs 11 mos
Other (e.g., renal failure, frailty, sepsis) (N=567)	85	72.8%	42.5%	34.6%	6 yrs 2 mos

Comparisons of the nature of decline and nature of suffering of MAiD recipients whose COD was dementia compared to Track 1 recipients with other CODs are presented in Figures 1 and 2, respectively. Further data can be found in Appendix Table A1.

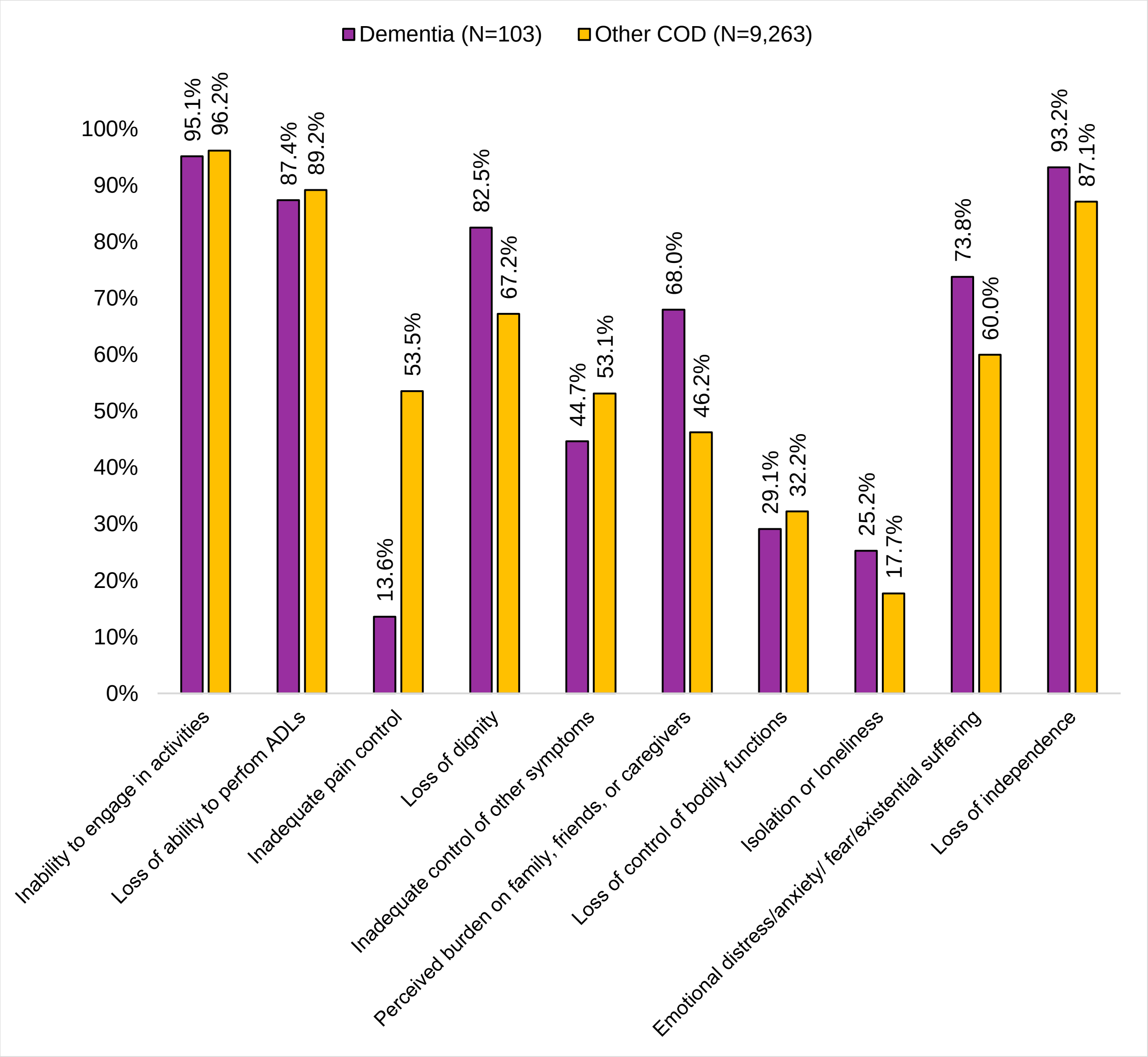
Persons with dementia reported lower levels of decline in all but one of the reported characteristics of decline. The exception was for ‘significant dependence on aid(s) for interaction or mobility’, which was reported by 68.9% of those with COD of dementia compared to 61.9% of persons with other CODs. None of the persons whose COD was dementia reported being dependent on life sustaining treatments, and very few (1.0%) reported severe shortness of breath.

Figure 1. Nature of Decline Among MAiD Recipients in Ontario with Dementia and Track 1 Recipients with Other Causes of Death (COD), January 2023 to December 2024



The reported suffering of persons with dementia was higher for experiences such as ‘loss of dignity’, ‘being a perceived burden on family, friends, or caregivers’, ‘emotional distress/anxiety/fear/existential suffering’, and ‘loss of independence’ compared to persons with other CODs. Persons with dementia less frequently reported suffering from ‘inadequate pain control’.

Figure 2. Nature of Suffering Among MAiD Recipients in Ontario with Dementia and Track 1 Recipients with Other Causes of Death (COD), January 2023 to December 2024



Factors related to the MAiD process for those with a COD of dementia can be found in Table 3. Persons with dementia had greater use of the MAiD coordination service to facilitate their request for MAiD (59.2% vs 45.9%). Persons with dementia had a longer wait time between the MAiD request and the provision. 88.3% of persons with dementia had a wait time of at least 15 days, compared to 51.5% of persons with other CODs with wait times longer than 2 weeks.

In addition, the types of professionals involved to assess for eligibility of a person with dementia differed from persons with other CODs, with more frequent consults with primary care providers, psychiatrists, geriatricians, and neurologists.

Table 3. Factors Related to the MAiD Process Among MAiD Recipients in Ontario with Dementia and Track 1 Recipients with Other Causes of Death (COD), January 2023 to December 2024

		Dementia (N=103)		Other COD (N=9,263)	
		Number	Percent	Number	Percent
MAID request	Direct request to MAiD provider	26	25.2%	2,277	24.6%
	Care coordination service	61	59.2%	4,254	45.9%
	Other	16	15.5%	2,732	29.5%
Time between request and provision	0-1 day	1	1.0%	437	4.7%
	2-7 days	6	5.8%	2,554	27.6%
	8-14 days	5	4.9%	1,503	16.2%
	15-30 days	19	18.4%	1,364	14.7%
	31+ days	72	69.9%	3,405	36.8%
Types of consults to determine eligibility	Nurse	2	1.9%	298	3.2%
	Primary care provider	8	7.8%	396	4.3%
	Palliative care specialist	0	0.0%	565	6.1%
	Social worker	0	0.0%	255	2.8%
	Oncologist	0	0.0%	226	2.4%
	Psychiatrist	7	6.8%	79	0.9%
	Geriatricians	6	5.8%	12	0.1%
	Neurologist	8	7.8%	50	0.5%
	Physiatrist/rehab professionals	0	0.0%	4	0.0%

Characteristics of palliative and disability care of MAiD recipients are presented in Table 4. 13.6% of persons with dementia received palliative care services, compared to 82.3% of persons with other causes of death. A higher proportion of persons with dementia (56.3%) received disability services compared to 45.5% of those with other causes of death.

Table 4. Palliative Care and Disability Services Among MAiD Recipients in Ontario with Dementia and Track 1 Recipients with Other Causes of Death, January 2023 to December 2024

		Dementia (N=103)		Other COD (N=9,263)	
		Number	Percent	Number	Percent
Palliative care	Palliative care required	15	14.6%	7,759	83.8%

	Palliative care received	14	13.6%	7,627	82.3%
Length of palliative care	Less than 2 weeks	3	21.4%	1,260	16.5%
	2 weeks to less than 1 month	0	0.0%	1,338	17.5%
	1-6 months	8	57.1%	3,082	40.4%
	More than 6 months	2	14.3%	1,481	19.4%
	Unknown	1	7.1%	466	6.1%
Type of palliative care	Pain/symptom management	11	78.6%	7,433	97.5%
	Palliative chemotherapy	0	0.0%	1,353	17.7%
	Palliative radiation	0	0.0%	1,173	15.4%
	Personal Support services	9	64.3%	3,958	51.9%
	Volunteer supports	1	7.1%	320	4.2%
	Physiotherapy	3	21.4%	705	9.2%
	Occupational therapy	2	14.3%	865	11.3%
	Psychosocial care/ counselling	2	14.3%	1,617	21.2%
	Spiritual care/ counselling	0	0.0%	820	10.8%
Disability services	Disability care required	59	57.3%	4,449	48.0%
	Disability care received	58	56.3%	4,218	45.5%
Length of disability services	Less than 6 months	11	19.0%	1,669	39.6%
	6 months to less than 1 year	11	19.0%	549	13.0%
	1 year to less than 2 years	15	25.9%	390	9.2%
	2 years or more	10	17.2%	864	20.5%
	Unknown	11	19.0%	746	17.7%
Type of disability services	Aids to support mobility	42	72.4%	3,558	84.4%
	Aids to support communication	9	15.5%	503	11.9%
	Aids to support ADLs/transfers	21	36.2%	2,458	58.3%
	Disability income support	1	1.7%	281	6.7%

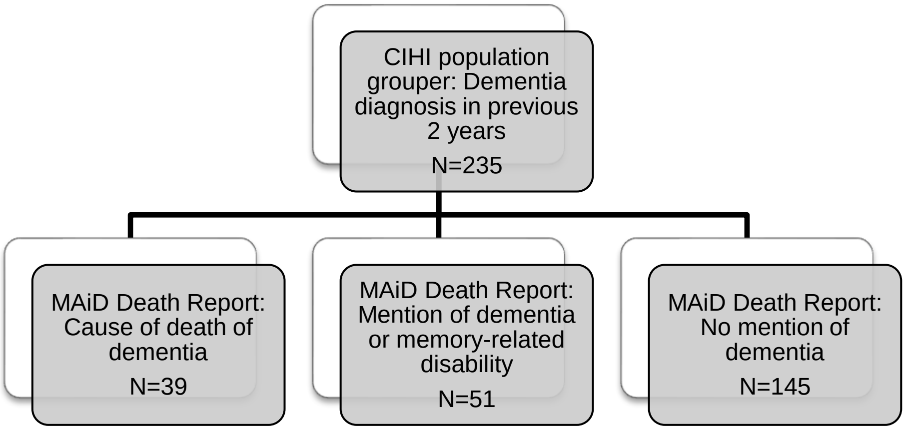
	Mental health/social support	6	10.3%	382	9.1%
	Physical support	41	70.7%	3,141	74.5%
	Physiotherapy	10	17.2%	563	13.3%

Health Services Data

Through linkage of the 2023 subset of MAiD deaths and administrative datasets held at the Ontario Ministry of Health (MOH), all MAiD recipients with a diagnosis of dementia two years prior to death were identified. This involved the use of the Canadian Institute for Health Information (CIHI) Population Grouper (Grouper). The Grouper is a population grouping methodology that produces a clinical summary for all Ontarians with a valid health card number. The clinical summary includes all health conditions identified from two consecutive years of inpatient, day surgery, emergency department, hospital clinic, continuing care, home care, physician claims, and primary care data.

Based on the Grouper, 235 of the 2023 MAiD deaths had a clinical diagnosis of dementia (Figure 3) prior to their death. This included 39 individuals whose cause of death was dementia; another 51 individuals whose MAiD Death Report identified dementia as one of the person’s incurable illnesses or who identified a memory-related disability; and 145 individuals where there was no reference to dementia or memory-related issues in the MAiD Death Report. All 235 MAiD recipients with a dementia diagnosis were over the age of 50.

Figure 3. Persons who Accessed MAiD in 2023 with a Diagnosis of Dementia in the CIHI Population Grouper



For the purposes of comparison, the Grouper was also used to identify two other cohorts:

1. Persons aged 50+ with a dementia diagnosis who died in 2023 but did not access MAiD.
2. Persons aged 50+ with a dementia diagnosis who were alive at the end of 2023.

These three cohorts, outlined in Table 5, were used to compare health system utilization between persons with dementia who accessed MAiD, persons with dementia who died without accessing MAiD, and persons with dementia who were living at the end of 2023. For persons who died, all analyses are based on the date of death, and for persons alive at the end of 2023, the analyses are based on the full calendar year.

Table 5. Cohorts Used for Comparison of Health System Utilization Between Ontarians with Dementia Who Accessed MAiD, Who Died Without MAiD, and Who were Living, 2023.

Dementia status	Cohort A: Received MAiD in 2023 (aged 50+)	Cohort B: Died in 2023, not from MAiD (aged 50+)	Cohort C: Living at the end of 2023 (aged 50+)
Dementia diagnosis in previous 2 years	**235 (5.2%)**	**15,662 (14.5%)**	**182,573 (2.9%)**
No dementia	4,284 (94.8%)	92,641 (85.5%)	6,151,081 (97.1%)
TOTAL	4,519	108,303	6,333,654

Primary care utilization was examined across the cohorts for a five-year period (Table 6; Appendix Table A2). Of the three cohorts, persons with a dementia diagnosis who died of MAiD had the highest proportion of persons who were rostered to a primary care provider in the previous year (88.5%). This was nearly 10% higher than the proportion of persons with dementia who did not access MAiD (Cohort B). There is less of a difference across cohorts with access to primary care in years 2 to 5 before death.

Table 6. Comparison of Access to Primary Care Among Ontarians with Dementia who Died of MAiD, Who Died Without MAiD, and Who Are Living, 2023

	Cohort A: Received MAiD in 2023, with dementia (N=235)	Cohort B: Died in 2023, not from MAiD, with dementia (N=15,662)	Cohort C: Living at the end of 2023, with dementia (N=182,573)
Rostered to a primary care group in year prior to death	88.5%	80.5%	83.7%
Visit with a family doctor			
1 year prior	99.6%	99.1%	96.4%
2 years prior	96.6%	95.5%	94.8%
3 years prior*	92.3%	93.1%	92.2%
4 years prior*	94.0%	93.5%	90.6%
5 years prior	94.9%	94.0%	92.8%

*During COVID pandemic

Specialist access was examined focusing on three specialties – geriatrics, neurology, and psychiatry (Table 7; Appendix Table A.3). Findings varied by specialty.

Cohort A, persons with dementia who accessed MAiD, had a higher proportion of persons who had a healthcare visit with a neurologist, and this pattern was consistent over the five years prior to death. This cohort also had a higher proportion of persons who had a healthcare visit with a psychiatrist, although there was less difference between cohorts as the years before death increase. Healthcare visits with geriatricians showed similar proportions in all three cohorts for the first year prior to death, however the proportion of persons in Cohort A who had accessed in the years prior to death was smaller. Overall, for all three specialties examined, similar to primary care, persons who accessed MAiD had the same level of access to specialist care, as persons with dementia who died without accessing MAiD.

Table 7. Comparison of Access to Specialists Among Ontarians with Dementia Who Died of MAiD, Who Died Without MAiD, and Who Are Living, 2023

	Cohort A: Accessed MAiD in 2023, with dementia (N=235)	Cohort B: Died in 2023, not from MAiD, with dementia (N=15,662)	Cohort C: Living at the end of 2023, with dementia (N=182,573)
Visit with a geriatrician			
1 year prior	23.0%	20.9%	23.0%
2 years prior	16.6%	15.6%	19.6%
3 years prior	9.4%	13.5%	14.0%

4 years prior	5.5%	12.3%	10.6%
5 years prior	5.5%	11.7%	9.9%
Visit with a neurologist			
1 year prior	34.5%	12.6%	15.8%
2 years prior	28.1%	9.9%	14.7%
3 years prior	24.7%	9.6%	12.7%
4 years prior	21.3%	9.9%	11.3%
5 years prior	23.0%	10.1%	11.6%
Visit with a psychiatrist			
1 year prior	22.1%	12.4%	13.1%
2 years prior	14.5%	9.3%	11.4%
3 years prior	10.6%	8.0%	9.9%
4 years prior	11.1%	7.3%	8.6%
5 years prior	8.9%	7.0%	8.5%

Other types of health care access examined were emergency department (ED) visits and hospitalizations (see Table 8, Appendix Table A4). In the year prior to death, persons who died (Cohorts A and B) had much higher proportions of both ED visits and hospitalizations than persons who were living. The proportion of Cohorts A and B with an ED visit or hospitalization was less after the first year prior to death, but remained at, or above, the proportion of Cohort C for the remaining years.

Table 8. Comparison of Emergency Department Visits and Hospitalizations Among Ontarians with Dementia Who Died of MAiD, Who Died Without MAiD, and Who Are Living, 2023

	Cohort A: Accessed MAiD in 2023, with dementia (N=235)	Cohort B: Died in 2023, not from MAiD, with dementia (N=15,662)	Cohort C: Living at the end of 2023, with dementia (N=182,573)
Emergency department visits			
1 year prior	71.5%	68.1%	49.5%
2 years prior	57.9%	48.3%	45.7%
3 years prior	43.0%	42.3%	40.1%
4 years prior	37.9%	43.8%	35.4%
5 years prior	42.1%	44.8%	38.4%
Hospitalizations			
1 year prior	51.9%	52.3%	28.6%
2 years prior	35.7%	29.0%	24.2%
3 years prior	21.7%	23.0%	18.4%
4 years prior	16.6%	21.8%	15.2%

5 years prior	17.5%	20.8%	14.9%

Overall, the healthcare service patterns are similar for persons who accessed MAiD with dementia, regardless of whether the dementia was related to their reasons for accessing MAiD, and persons who died without accessing MAiD.

COMMITTEE REVIEW

CASE 6A

CASE OVERVIEW

Mrs. 6A, a female in her late 80s, had a multi-year history of cognitive decline. She had transitioned to a retirement residence due to moderate functional support needs.

Several months prior to requesting MAiD, she was referred to a geriatric psychiatrist for evaluation of cognitive changes, low mood, and suicidal ideation. Her Montreal Cognitive Assessment (MoCA) score was 17/30, a decline from 19/30 the previous year. She was diagnosed with moderate-stage Alzheimer's disease and assessed to have partial insight and judgment.

The psychiatrist further diagnosed her with an adjustment disorder with low mood, attributed primarily to her transition from independent living to a retirement residence. At the time, she was not found to be experiencing active suicidal ideation. Medication adjustments were recommended to optimize her cognitive and psychological symptoms.

Approximately three months later, Mrs. 6A presented to her family physician with significant physical and functional decline, including frequent falls, an uncontrolled resting tremor, and reduced ability to care for herself. She also reported severe anxiety. During this visit, she requested MAiD, citing her cognitive decline and anticipatory fear of further deterioration.

Approach to Diagnosis, MAiD Assessment, and Care

Mrs. 6A's family physician conducted the primary MAiD assessment during this appointment, with an adult child present. Based on her clinical presentation, the physician diagnosed her with Lewy Body Dementia, noting Parkinsonian features and a marked decline in function over the previous year. Her suffering was described as intolerable, and she was assessed to have "remarkable insight" sufficient to provide informed consent for MAiD.

The family medicine physician assumed the role of MAiD provider and coordinated ongoing care with the family. Given the risk of progressive cognitive decline, a waiver of final consent was completed. A provision date was scheduled approximately three months in advance.

On the same day, a second MAiD assessment was completed by another family physician, who also confirmed Mrs. 6A's eligibility for accessing MAiD with Alzheimer's disease.

As part of the assessment process, the MAiD provider contacted another family member to discuss Mrs. 6A's decision. This family member expressed no concerns with their mother's decision to access MAiD.

On the day of the MAiD provision, one family member raised concerns regarding the MAiD assessment process and the request for MAiD. These included:

- Questions about the accuracy of the diagnosis, and implications for prognosis and care, particularly the diagnostic etiological change from Alzheimer's disease to Lewy Body Dementia.
- Concerns about acute changes, possibly reversible
- Concerns about the presence of depressive symptoms and whether they had been adequately addressed.
- The perception that MAiD was accessed before all recommended care optimizations, such as medication adjustments, had been fully implemented.

Given family concerns, on the day of the provision, the MAiD provider discussed with Mrs. 6A whether she would prefer to delay her MAiD provision. Mrs. 6A was clear in her decision-making for MAiD, provided final consent, and the provision of MAiD occurred.

DISCUSSION

Diagnosis and Prognosis

MDRC members examined the role of diagnostic specificity in dementia, such as distinguishing between Alzheimer's disease and Lewy Body dementia, and its relevance to MAiD assessments and end-of-life planning. While different dementia types have distinct prognoses[i], many MDRC members with clinical expertise noted that, in practice, diagnostic specificity has limited influence on MAiD eligibility decisions, particularly when determining a serious and incurable condition - all forms of dementia are progressive and incurable. Moreover, persons with dementia frequently seek MAiD when functional decline and symptom burden typically outweigh diagnostic nuances. In particular, MDRC members with dementia care expertise offered clinical perspective that prognostication is more impactful earlier in the dementia trajectory, where it can guide care planning, support services, and patient-family discussions. In later stages, functional status, frailty, and co-morbidities[ii], rather than the specific dementia subtype, are believed to be more critical in shaping end-of-life decisions.

Several MDRC members emphasized that diagnostic clarity may be essential to ensuring informed consent when persons with dementia consider accessing MAiD. In circumstances where there are differing or uncertain clinical dementia diagnoses, MAiD assessors should engage in a transparent discussion with the person about whether further diagnostic clarity could meaningfully influence their decision to access MAiD. Where necessary, MAiD practitioners should facilitate access to additional diagnostic investigations or specialist referrals to support informed, values-based decision-making.

Most MDRC members acknowledged that diagnostic ambiguity may lead to confusion and distress among family members, as seen in the circumstances in which Mrs. 6A's MAiD care was navigated. The lack of clarity surrounding her diagnosis contributed to uncertainty for a family member about her decision to pursue MAiD. As a result, MDRC members strongly advocated for clear, comprehensive communication about what is known, or not known, about the person's diagnosis, prognosis, and illness trajectory as part of the MAiD assessment process. Such discussions are essential to support informed consent, align care with patient values, and reduce misunderstandings among family and caregivers.

Evaluating Functional Changes

MDRC members reviewed the available documentation regarding concerns raised by a family member about potential acute functional changes experienced by Mrs. 6A. Many MDRC members noted that it was unclear whether these changes reflected a typical progression of dementia, or an acute decline potentially linked to a reversible cause such as infection or dehydration.

These circumstances highlighted for many MDRC members the importance of longitudinal engagement with persons with dementia requesting MAiD and their caregivers. Understanding a person's baseline cognitive and functional status is critical for contextualizing changes, offering care alternatives, and informing discussions around the timing of MAiD.

Many MDRC members suggested that when an acute functional change is observed, MAiD practitioners should assess and document whether the decline is potentially reversible, and under what context such reversibility would be acceptable to the person requesting MAiD. The person must be fully informed of all available alternatives, including rehabilitation, supportive housing, community services, enhanced home care, and pain or symptom management. These options may be particularly relevant when functional decline or falls appear to be accelerating the request for MAiD.

Many MDRC members emphasized that such assessments should be part of a comprehensive and person-centered approach, ensuring that decisions are made with full awareness of the clinical context and available supports.

Psychological and Existential Support

Several MDRC members emphasized the importance of assessing for mood-related conditions, such as adjustment disorder or depression, particularly when persons with dementia, such as noted with Mrs. 6A, express distress related to functional decline or disease progression. While such conditions may not preclude eligibility for MAiD, they should be carefully explored to assess the potential for reversibility and to determine whether additional psychosocial or mental health supports may be beneficial.

In addition, a few members reflected on the potential role of existential distress in Mrs. 6A's decision to pursue MAiD. Existential distress, characterized by fear, loss of meaning, and anxiety about future decline, is a well-documented experience in serious illness, including dementia[iii]. These members noted that while existential suffering is not uncommon, this experience may be under-recognized and insufficiently addressed in MAiD assessments and related documentation. Evidence-based interventions such as meaning-centered therapy, dignity therapy, and existentially focused palliative care may help alleviate this form of suffering.

These MDRC members stressed that addressing existential distress should be considered a core component of comprehensive MAiD assessments. This approach serves as a safeguard to ensure that persons are making informed, values-based decisions with full awareness of available supports and alternatives to alleviate their suffering.

PRACTICE CONSIDERATIONS

Communicate Diagnosis and Prognosis

- MAiD practitioners should clearly communicate what is known and any uncertainty about a person's dementia diagnosis and prognosis, and where permitted, with their caregivers.
- MAiD practitioners should facilitate diagnostic clarification when there is uncertainty that may influence the person's decision-making for accessing MAiD. In such circumstances, MAiD practitioners should facilitate referrals to dementia specialists when appropriate.

Assess Functional Changes

- MAiD practitioners are encouraged to establish and document baseline cognitive and functional status to help contextualize any observed changes over the course of several interactions.
- When acute functional decline is observed, MAiD practitioners should evaluate potentially reversible causes (e.g., infection, dehydration, medication effects)

  and document whether reversibility is possible and acceptable to the person requesting MAiD[2].
- MAiD practitioners should ensure the person is informed of all care alternatives, with specific considerations for persons with dementia of rehabilitation, supportive housing, enhanced home care, and symptom management options. This approach is important to evaluating informed consent when functional decline appears to be accelerating the MAiD request.

Consider Psychosocial and Existential Distress

- Emerging care practices are incorporating therapies that may help address existential and psychological suffering that persons with dementia may experience. MAiD practitioners are encouraged to consider referrals to dementia care specialists who may offer these supportive interventions as part of a holistic care approach.
- The progression of functional decline in persons with dementia is often accompanied by profound loss. MAiD practitioners are encouraged to consider referrals for grief and bereavement supports for the person with dementia and their caregivers throughout the MAiD process.

Adopt a Longitudinal Approach to MAiD Assessments

- MAiD assessments and care for persons with dementia should be facilitated, when possible, over multiple interactions. Understanding and discussing a person’s cognitive and functional trajectory, and considering options to alleviate suffering, is more likely to require more complex assessments and monitoring.

CASE 6B

Note: *Cases B and C were presented to the Committee for review to support comparison of the application of Track 1 and Track 2 safeguards. A discussion will follow the presentation of Case C.*

Mr. 6B, a male in his late 70s, was diagnosed with a major neurocognitive disorder of unspecified etiology. At the time of his probable diagnosis, over one year prior to accessing MAiD, his MoCA score was 28/30. He reported subjective cognitive decline. Mr. 6B was a highly intelligent individual with a professional background.

Over the course of a year, he underwent multiple cognitive assessments and neuroimaging studies, which supported the clinical diagnosis. He was started on pharmacological treatment for dementia.

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[2] Also see discussion in MDRC Report 2024 – 1, p. 21.

Three months prior to accessing MAiD, Mr. 6B was reassessed at a memory clinic, where his MoCA score had declined to 26/30, with notable deficits in delayed recall. He was also exhibiting impairments in instrumental activities of daily living (e.g., could no longer drive and could not engage in hobbies). In the following months, he developed behavioral and psychiatric symptoms of dementia, particularly nighttime agitation.

Mr. 6B chose to pursue MAiD due to psychological suffering related to his loss of independence, inability to engage in meaningful activities, and anticipatory fear of further cognitive and functional decline.

Track 1 MAiD Assessment

Mr. 6B was assessed by a family medicine practitioner who was also as the MAiD provider. Over multiple follow-up visits, he was determined to be eligible for MAiD. His clinical diagnosis of dementia had been confirmed via a geriatric specialist. He exhibited functional impairments in instrumental activities of daily living. His suffering was primarily psychological in nature. Mr. 6B was in the mild stage of dementia and retained clear decisional capacity.

A secondary assessment was conducted by a palliative medicine practitioner, who also confirmed Mr. 6B’s eligibility.

Both the MAiD provider and the secondary assessor concluded that Mr. 6B’s natural death was reasonably foreseeable due to the terminal and progressive nature of his condition.

CASE 6C

Mrs. 6C, a female in her 70s, presented over a four-year period with subjective cognitive decline, dizziness, unsteadiness, and visual disturbances. She was diagnosed by a geriatrician with a Major Neurocognitive Disorder, likely Alzheimer’s disease in the mild stage. Her MoCA score was 20/30. Functionally, she was unable to engage in hobbies and she required assistance with instrumental activities of daily living.

Throughout her diagnostic journey, Mrs. 6C was evaluated by multiple specialists, including geriatricians and neurologists, to explore differential diagnoses such as Alzheimer’s and vascular dementia subtypes, and a potential motor neuron disease.

While under the care of a specialized geriatric team, Mrs. 6C requested MAiD, citing her dementia diagnosis. She expressed a desire to access MAiD once she required assistance with personal care. Her suffering was described as intolerable, stemming from both physical symptoms (e.g., dizziness, vision changes) and the psychological burden of increasing dependency and loss of autonomy. At the time of her initial request, she was no longer able to participate in meaningful activities (e.g., hobbies).

Over the following six months, Mrs. 6C experienced significant physical decline, particularly in mobility, and became dependent on assistance for basic activities of daily living. She chose to proceed with MAiD based on this decline.

Track 2 MAiD Assessment

Mrs. 6C was followed by a MAiD provider over a six-month period. Initially, she was deemed “conditionally eligible” for MAiD: she met the legislative eligibility criteria, but her functional status had not yet reached the threshold she had personally set for accessing MAiD. The MAiD practitioner did not consider her natural death to be reasonably foreseeable, and therefore, Track 2 safeguards were applied. Expert consultation was obtained from her geriatrician.

The MAiD provider maintained regular follow-up via telephone to monitor her clinical progression. Prior to the provision of MAiD, a comprehensive reassessment confirmed that all eligibility criteria and safeguards were met. The provider documented a consistent and informed request, Mrs. 6C’s clear articulation of suffering, an understanding of her condition and its progression, and available care options.

A secondary assessment was conducted by Mrs. 6C’s family physician, who confirmed her eligibility and agreed that her natural death was not reasonably foreseeable.

DISCUSSION

Track 1 vs Track 2 Safeguards

A comparison of Cases 6B and 6C was provided to illustrate how safeguards are applied for persons in the mild stage of dementia. The MDRC discussions revealed a range of perspectives, particularly with both the clinical and procedural approaches to assigning Track 1 versus Track 2 safeguards.

Some MDRC members advocated for a prognostic approach to determining whether natural death is reasonably foreseeable. In their view, persons in the early stages of dementia, who retain significant cognitive and functional capabilities, may have a prolonged trajectory of decline, potentially spanning years. For these circumstances, Track 2 safeguards were seen as more appropriate, and in greater alignment with the needs of this group, offering a more structured and longitudinal assessment period. Within the prognostic approach to safeguard assignment, several members acknowledged that comorbid conditions and overall frailty should be considered when determining whether Track 1 safeguards are appropriate, as these factors may shorten the expected trajectory toward natural death.

An additional MDRC perspective emphasized that the issue may be less about safeguard assignment and more about normative clinical practice. Several members noted that dementia is a terminal condition, and as such, persons with dementia were considered eligible for MAiD since the enactment of Bill C-14, with supporting guidance from CAMAP[iv]. For these members, the focus should be on ensuring ongoing, longitudinal care, including multiple assessments over time, regardless of the assignment of safeguards. In both Cases 6B and 6C, such a prolonged assessment period was evident, even when Track 1 safeguards were applied in Case 6B. These members emphasized the importance of continued follow-up to:

- Establish a cognitive and functional baseline at the time of the request,
- Confirm consistency in the person's MAiD request and capacity to provide informed consent,
- Explore alternative supports such as palliative care; and
- Facilitate end-of-life planning, including discussions about functional decline and potential timing of the MAiD provision.

A few MDRC members also noted that Track 1 allows for the use of a waiver of final consent, which may be beneficial for persons with dementia who are at risk for a loss of capacity. However, these members acknowledged the complexities and ethical challenges associated with using waivers in this population (see MDRC Report 2024.1).

Some MDRC members with clinical expertise shared that, in their experiences, most individuals with dementia tend to access MAiD during the moderate stage of decline, when assistance with basic activities of daily living becomes necessary. In such circumstances, natural death is often clearly foreseeable. These members suggested that persons requesting MAiD in the early stages of dementia may benefit from being referred back to their primary care provider for continued dementia care and end-of-life planning, with MAiD revisited farther in their disease trajectory.

Advanced State of Irreversible Decline

Given the mild stage of functional decline observed in both Cases 6B and 6C, a few MDRC members presented questions about whether the grievous and irremediable criterion was satisfied, in particular because of the absence of an advanced state of irreversible decline. These members expressed concern that a decline limited to higher order executive functions, such as a loss of ability to engage in hobbies, may not reflect a sufficiently robust or ethically sound interpretation of this criterion. In particular, these members offered perspective that the "advanced" qualifier within the legislation serves to balance the autonomy of persons wishing to access MAiD with the protection of persons who may be vulnerable to accessing MAiD prior to receiving applicable healthcare. Additionally, a few members offered perspective that an "advanced state" implies a significant and progressive deterioration in function, not merely the signs or symptoms of mild cognitive or functional loss[v]. These members suggested that interpreting "advanced" to encompass early stages of decline, including early stages of loss of cognitive function, weakens the protective intent of legislation. If mild cognitive and functional impairments are deemed sufficient to meet this threshold, the term "advanced" loses its substantive meaning, and the eligibility criteria may become overly permissive.

Other members emphasized the importance of a person-centered approach to interpreting this legislative requirement – suffering is a subjective experience. In the case of Mr. 6B, a highly intelligent person with an advanced professional background, the loss of his ability to read and participate in intellectually stimulating activities was viewed as a profound and deeply personal decline representative of a significant departure from his previous quality of life and identity. Other MDRC members explored that differentiating suffering associated with dementia based on perceived intellectual capabilities prior to the onset of dementia may reflect ableist stereotyping.

Additionally, a few MDRC members offered perspective that the risk of imminent loss of capacity itself could satisfy the criterion of an advanced state of decline. They noted that a dementia diagnosis introduces an unpredictable timeline for cognitive decline, during which individuals may lose the ability to make informed healthcare decisions. In this view, the ongoing risk of losing capacity places persons in a continuous state of functional loss, which may warrant appropriate application under the current legislative framework. Other MDRC members disagreed, explaining that "advanced" should indicate a present state of decline, not a projected or anticipated future state of loss. These members opined that legislative criterion of advanced decline would not be met in such circumstances.

PRACTICE CONSIDERATIONS

- MAiD practitioners should consider that persons with dementia would benefit from longitudinal MAiD assessments to determine eligibility and navigate potential alternate care options (e.g., Alzheimer's Society, community support groups, rehabilitation).
- MAiD practitioners should consider when functional losses appear mild, that the eligibility assessment and documentation reflect a nuanced understanding of the personal meaning the requestor attaches to these changes.
- In such circumstances where mild functional decline may be accompanied by profound existential distress, including perceived loss of identity, autonomy, or dignity, MAiD practitioners are encouraged to explore and document these experiences in depth and to consider offering supportive interventions, such

as dignity therapy or existential counseling, as part of informed consent for MAiD.

CASE 6D

CASE OVERVIEW

Mr. 6D was a male in his 80s with a diagnosis of Major Neurocognitive Disorder, specifically Alzheimer’s disease, made approximately ten years prior to his MAiD request. Over time, he experienced progressive cognitive and functional decline.

Approximately one year before requesting MAiD, Mr. 6D was hospitalized with normal pressure hydrocephalus. Following treatment, he was transferred to inpatient rehabilitation, where his cognitive function was evaluated using the MoCA, scoring 9/30. At his functional baseline following rehabilitation, Mr. 6D ambulated with a walker, required supervision for transfers, and needed frequent cues for orientation. Due to his high level of care needs, a transition to long-term care was planned. Mr. 6D was unable to return home because his caregiver was experiencing health challenges.

One week prior to this transition, Mr. 6D developed symptoms of an intra-abdominal infection accompanied by delirium. He expressed a desire to be discharged home to initiate the MAiD assessment process and received in-home palliative care.

Mr. 6D cited his acute illness, cognitive decline, and the impending admission to long-term care as reasons for requesting MAiD. He experienced both physical and psychological suffering related to these conditions and transitions.

Approach to MAiD Assessment for a Person with Advanced Dementia

Mr. 6D required a transfer from in-patient rehabilitation to initiate the MAiD assessment process as MAiD assessments were not permitted while he was an inpatient due to organizational policy. For this reason, MAiD assessments were completed at his private residence on the same day, at different times, by two different palliative medicine physicians. Given his risk for loss of capacity, a waiver of final consent was also completed.

The MAiD provider assessed Mr. 6D separately from family to ascertain his voluntariness and decisional capabilities to provide informed consent. The MAiD provider documented Mr. 6D’s responses, including documenting direct quotes. Following the conversation with Mr. 6D, the MAiD provider invited family to offer their perspectives – the MAiD provider established that Mr. 6D’s request was aligned with long-standing values and end-of-life goals. The MAiD provider subsequently determined all legislative eligibility criteria were met.

The secondary MAiD assessor confirmed eligibility criteria were met; however, this MAiD practitioner provided confirmatory documentation, without directly illustrating Mr. 6D's perspectives and responses.

The MAiD provision occurred within two weeks of eligibility confirmation.

DISCUSSION

Approach to Evaluating Capacity

Several members of the MDRC acknowledged the complexity of evaluating cognitive capacity to provide informed consent in circumstances when persons with advanced dementia request MAiD. Members with clinical expertise emphasized that specific cognitive domains, particularly insight and judgment, may be uniquely impaired in dementia, complicating the evaluation of decision-making capabilities.

Concerns were raised by some members regarding the limited documentation available to support whether Mr. 6D was capable of providing informed consent. In particular, a few members noted that the documentation suggested the presence of delirium, which could significantly impact capacity, without a formal clinical evaluation of the delirium recorded. Several members expressed perspectives that MAiD assessments should occur during times when a person is best able to express themselves – their suffering, reason for seeking MAiD, and understanding. These members suggested that the MAiD assessments should have been paused until his delirium was appropriately treated and resolved. This absence of comprehensive documentation outlining the approach taken to navigate Mr. 6D's delirium led some MDRC members to express concerns about proceeding with MAiD in this circumstance.

A few MDRC members highlighted the challenges with obtaining informed consent during periods of acute health changes, such as episodes of delirium, and during transitions in care, including admission to long-term care facilities. These members noted that Mr. 6D's decision-making may have been influenced by potentially reversible functional impairments associated with his delirium. They also emphasized that transitions in care are often highly stressful and life-altering experiences, which can significantly impact a person's psychological state and capacity for informed decision-making. A few members suggest that serial capacity evaluations should be conducted to understand whether a person's decisional capabilities are impacted by acute changes.

The Committee discussed the need for a more robust and standardized approach to documenting capacity evaluations, especially in complex circumstances involving cognitive impairment. Members recommended that such documentation practices be reflected in clinical protocols, regulatory frameworks, and oversight mechanisms.

While a few members advocated for maintaining consistency with standard healthcare practices, suggesting that the rigor of capacity evaluations for MAiD should not exceed that of other clinical contexts, other MDRC members disagreed. These members emphasized the unique and irreversible nature of MAiD decisions and referenced the legislative requirement to ensure informed consent, offering their perspectives that this necessitates a higher standard of evaluation and documentation.

Voluntariness of Request

A few MDRC members raised concerns about the voluntariness of Mr. 6D’s request for MAiD, particularly given the timing of the decision during a period of acute illness and planned transition into long-term care. These members discussed that these circumstances could possibly compromise the authenticity of the person’s request during transient circumstances. Additionally, some MDRC members noted that the timing of the request appeared to be aligned with Mr. 6D’s main caregiver being unable to continue providing care for him at home, potentially shaping the context of his decision.

Some members noted that while the MAiD provider did explore whether Mr. 6D’s request was aligned with his long-standing values, these members opined that there was not detailed documentation of exploration of these influencing circumstances. These members emphasized that MAiD requests should be deferred during periods of medical instability or significant life transitions, and that eligibility assessments should reflect a consistent and sustained pattern of decision-making, rather than one shaped by temporary or situational factors.

PRACTICE CONSIDERATIONS

- MAiD practitioners should consider that evaluating informed consent for MAiD during periods of acute health changes (e.g., delirium) and transitions in care (e.g., admission to long-term care) may require additional evaluation.
    - Consideration should be given to defer capacity assessments until the requestor is medically and cognitively stable, and any reversible conditions, such as delirium, have been appropriately clinically evaluated and managed.
    - Consider implementing serial capacity assessments to evaluate the consistency of a person’s decision to pursue MAiD and to monitor the stability of their decisional capacity over time.
    - Additional safeguards should be implemented during care transitions, including repeated MAiD assessments over time and input from

interprofessional team members familiar with the person's baseline functioning.

- Documentation should clearly reflect the timing and context of consent discussions, including any recent health changes or transitions that may affect capacity.
- MAiD practitioners should take additional steps to ensure the voluntariness and consistency of the request for MAiD, particularly in circumstances involving persons with cognitive impairment, who may be dependent on others for their care.
- Assess for contextual influences such as caregiver burnout, loss of home supports, or psychosocial stressors that may shape the urgency or nature of the request.
- Document a consistent pattern of decision-making that aligns with the requestor's long-standing values and preferences.

CASE 6E

CASE OVERVIEW

Mr. 6E was a male in his 80s who accessed a memory clinic after experiencing mild cognitive and functional changes. He was diagnosed with probable Alzheimer's disease, in the mild stage. The memory clinic team arranged for a neurology consultation, initiated an acetyl-cholinesterase inhibitor, and facilitated supports through the Alzheimer's Society. Following diagnosis, Mr. 6E experienced profound anticipatory fear of his cognitive and functional decline. During his initial assessment, Mr. 6E expressed a request to access MAiD. The memory clinic team attempted to provide reassurances regarding his functional trajectory and quality of life.

Six months later, Mr. 6E was seen in follow-up with the memory clinic team. A neurologist consult had been completed in the interim and a clinical diagnosis of Alzheimer's disease had been confirmed. During this follow-up, due to social supports and other interventions, Mr. 6E had experienced cognitive and functional improvements. His MoCA was 24 out of 30.

Mr. 6E continued to express anticipatory fear of his cognitive and functional decline. He elected to initiate the MAiD process. He declined further follow-up with the memory clinic.

Approach to MAiD Assessments

Approximately two months prior to receiving MAiD, Mr. 6E was assessed on separate occasions by two MAiD practitioners. These assessments occurred roughly a year and a half after his last documented follow-up with the memory clinic. Both practitioners provided detailed documentation supporting Mr. 6E’s eligibility, incorporating direct quotes and demonstrating a clear understanding of his request and the nature of his suffering. Mr. 6E described significant distress related to his cognitive and functional decline, maintaining insight into his memory and language impairments, as well as increasing difficulty with daily activities. He consistently expressed a desire to access MAiD once he could no longer independently complete basic activities of daily living or if long-term care became necessary.

Both practitioners engaged in follow-up. The MAiD provider completed a waiver of final consent three months in advance. The secondary assessor sought additional context from Mr. 6E’s memory clinic physician to better understand his diagnostic history and illness trajectory. The secondary assessor advised Mr. 6E of their concern that he might lose the capacity to consent within six months. However, the MAiD practitioner did not clearly outline in their documentation the clinical findings or rationale to support this prognostication.

Approach to End-of-Life Planning

Mr. 6E’s caregiver expressed concern about the challenges of navigating end-of-life planning in the context of dementia. They reported difficulty accessing clear and timely information, particularly regarding MAiD, which made it more difficult to support informed and confident decision-making. The caregiver also highlighted uncertainty in understanding Mr. 6E’s cognitive and functional trajectory, which complicated efforts to assess his readiness for MAiD. In retrospect, the caregiver expressed concern about whether Mr. 6E may have accessed MAiD earlier than in alignment with his values, at a time when he might still have experienced a meaningful quality of life.

DISCUSSION

Several MDRC members emphasized the importance of ensuring that persons with dementia and their caregivers have access to timely education and support to navigate the complexities of dementia care and end-of-life decision-making. Members highlighted the critical role of specialized geriatric services in facilitating early and ongoing conversations about diagnosis, prognosis, and care planning. These services may help persons with dementia and families better understand the trajectory of dementia and explore end-of-life options, including MAiD, within a broader context of quality-of-life considerations and personal values.

In addition, some MDRC members discussed the need for MAiD practitioners who assess individuals with dementia to have additional training in both cognitive and functional assessment and values-based care planning. This includes the ability to recognize when a person’s expressed end-of-life preferences may not align with their current cognitive and functional state. For example, in Mr. 6E’s case, a few members questioned whether there was a missed opportunity to further explore supportive care options and revisit his end-of-life goals before proceeding with MAiD. They noted that he appeared to access MAiD during a relatively early stage of dementia, which may not have fully reflected his previously stated values. In such circumstances, MAiD practitioners would likely benefit from enhanced expertise in assessing cognitive and functional capabilities, interpreting quality-of-life indicators, and engaging in longitudinal care planning that supports persons with dementia and their caregivers in navigating MAiD decisions over time.

PRACTICE CONSIDERATIONS

- MAiD practitioners should consider employing a structured exploration of a requestor’s values, goals, and quality-of-life expectations when navigating dementia assessments. MAiD practitioners should have the knowledge and expertise to identify when a person’s current cognitive and functional state may not align with their expressed end-of-life intentions, and to facilitate end-of-life discussions.
- In circumstances where dementia is not yet advanced, MAiD practitioners should consider a longitudinal approach to MAiD care planning. This may include revisiting goals of care over time, exploring community and supportive care options, and ensuring that end-of-life decisions are made at a point in their dementia trajectory that reflects the person’s values and their experience of decline.
- Functional staging tools (i.e., FAST tool) may assist practitioners in determining a person’s end-of-life trajectory.
- As a component of MAiD care, MAiD practitioners should consider the needs of caregivers, such as providing accessible, accurate information about MAiD and dementia care. This may help caregivers understand the implications of cognitive and functional decline and support them in navigating complex decisions alongside the person with dementia.

CASE 6F

CASE OVERVIEW

Mrs. 6F was a female in her late 80s with cognitive impairment who resided in a retirement home due to her need for daily functional support. Approximately nine months prior to accessing MAiD, she was admitted to hospital following multiple falls and increasing care needs, both attributed to her cognitive decline. During her hospital intake assessment, she demonstrated significant cognitive impairment and was diagnosed with “moderately advanced dementia” [no etiology was documented].

During her hospital stay, Mrs. 6F was found to have substantial functional support needs. She was dependent on assistance for most basic activities of daily living, primarily due to severe short-term memory loss and executive dysfunction. Specifically, she required stepwise instructions to complete a task. She required supervision for eating due to over-filling her spoon and choking. Due to advanced care needs, she was transferred to complex continuing care while awaiting placement in long-term care.

At one point during her admission, Mrs. 6F reportedly expressed a “wish to die” to a family member. This was communicated to her care team, who initiated a referral for MAiD. A MAiD navigator accepted the referral and arranged for a MAiD assessment. After discussion with a MAiD practitioner, Mrs. 6F chose to transition to long-term care and decided not to pursue MAiD at that time.

Following her admission to long-term care, Mrs. 6F reportedly renewed her request for MAiD. The MAiD process was navigated by a family member. At this point in time, Mrs. 6F was largely bedbound and experienced additional physical symptoms, including dyspnea and pain. She also suffered from psychological and existential distress related to her increasing dependency and cognitive decline.

Initial Request and Referral Process

Mrs. 6F’s expression of a wish to die was interpreted by a family member as a potential request for MAiD. A family member discussed Mrs. 6F’s wish to die with her care team who facilitated a referral. The most responsible physician advised the family of anticipated challenges in proceeding with the MAiD eligibility assessments, primarily due to Mrs. 6F’s significant cognitive impairment and aphasia.

To support potential MAiD planning, a MAiD navigator met with Mrs. 6F. Given her cognitive limitations, the navigator determined it was not appropriate for them to proceed with facilitating the signing and witnessing of Mrs. 6F’s written request for MAiD (Clinician Aid A). As such, the navigator referred her to a MAiD practitioner with clinical expertise in complex MAiD requests and assessments.

The MAiD practitioner (serving as the secondary assessor) met with Mrs. 6F. During this encounter, Mrs. 6F reportedly sought information about MAiD; however, a formal assessment was not conducted. Following this discussion, Mrs. 6F opted to transition to long-term care as her primary goal-of-care.

Re-referral and Approach to MAiD Assessments

Approximately four months after her transition to long-term care, a family member initiated a re-referral for MAiD. This referral was navigated through the provincial care coordination service. The MAiD provider accepted the referral.

The MAiD provider conducted an eligibility assessment during a single interaction, with a family member present. The provider documented that Mrs. 6F met the criteria for an incurable condition, citing advanced dementia, chronic comorbidities, and terminal frailty. Mrs. 6F had profound functional and physical decline associated with these conditions (e.g., inability to self-care, dyspnea, and arthritic pain). The provider also noted that Mrs. 6F experienced “marked existential suffering” and was “clear she did not want to continue to live as she [was].”

The provider acknowledged communication challenges during the MAiD eligibility assessment. A general statement was documented indicating that the process was “managed in a way that worked for her”.

The MAiD practitioner documentation demonstrated limited evaluation of Mrs. 6F’s cognitive impairments – her condition was documented as “moderately advanced dementia”. A limited cognitive and functional history was reported, with few details regarding diagnosis. An evaluation of Mrs. 6F’s cognitive impairments, such as short-term memory loss, insight, judgement, or aphasia were not documented.

Global statements regarding informed consent and capacity were included in the documentation. The provider reported that Mrs. 6F was able to repeat questions verbatim and respond appropriately, and that she understood she could continue to receive care, including palliative care, in her current long-term care setting. However, no direct quotations from Mrs. 6F were included in the documentation to substantiate the eligibility determination.

This MAiD practitioner facilitated the completion of the written request. Although Mrs. 6F attempted to sign the form, her signature was illegible. A third-party signer, a member of the MAiD provider’s clinical staff, was engaged.

The secondary assessor employed a similar approach to documenting their MAiD eligibility determination. This MAiD assessor did not provide additional insights about their previous interaction with Mrs. 6F in their documentation.

Final Consent and Provision

The MAiD provision was scheduled one week after determination of eligibility. On the day of the provision, Mrs. 6F was reportedly overwhelmed by the presence of additional visitors. These individuals were asked to leave to ensure a calm environment. Final express consent was determined based on Mrs. 6F’s ability to repeat the consent question and via squeezing the provider’s hand.

DISCUSSION

Approach to Evaluating Cognition

Most MDRC members emphasized the importance of documenting a clear and comprehensive understanding of a person’s cognitive capabilities as part of the MAiD eligibility assessment. While there was broad agreement on the need to assess current cognitive functioning, perspectives varied regarding the appropriate methods and depth of evaluation.

There was no agreement amongst MDRC members on the necessity of formal cognitive testing, such as the Mini-Mental State Examination (MMSE) or Montreal Cognitive Assessment (MoCA), to inform eligibility. MDRC Members with clinical expertise in dementia care noted that while cognitive test scores alone cannot determine decisional capabilities, such tools may help identify cognitive impairments that should be considered during a capacity evaluation. Most members agreed that some form of cognitive assessment is essential to identify affected cognitive domains to inform their MAiD assessments, such as short-term memory loss, word-finding difficulties, or executive dysfunction. For some members, understanding the cognitive and functional trajectory over time was also considered important.

Many MDRC members emphasized that cognitive assessments may help MAiD practitioners identify impairments to support the development of tailored strategies, such as specific cues or communication adaptations, to accommodate cognitive limitations during MAiD eligibility assessments. Some members also expressed concern that the absence of a structured cognitive assessment in Mrs. 6F’s circumstance limited their ability to understand how her eligibility, namely capacity to provide informed consent, was determined.

Approach to Evaluating Capacity

Many MDRC members with clinical expertise acknowledged that persons with dementia may retain decision-specific cognitive capabilities sufficient to provide informed consent for MAiD. However, they emphasized that MAiD practitioners should adopt a rigorous approach to capacity evaluation, given the complexity of assessing decision-making in this population.

Some MDRC members discussed that due to the gravity of MAiD as a life-ending decision, the threshold for determining capacity should be high. Other MDRC members opined that the approach to evaluation and expectations for decisional capacity to access MAiD should not exceed the thresholds applied in normative clinical practice. Many members contended to the requirement of adhering to legislative and regulatory standards, regardless of variability in broader healthcare settings.

Most MDRC members agreed that best practice would involve comprehensive, structured documentation of a person's understanding and appreciation of their decision to access MAiD. They expressed concern that the use of generalized statements of capacity, such as those documented in Mrs. 6F's case, do not provide sufficient insight into the individual's decisional capabilities, or support a comprehensive determination of legislative eligibility. Several members referenced established frameworks[vi] for assessing capacity, which include evaluating a person's capability to understand relevant information, appreciate the consequences of their decision, reason through care options, and communicate a choice.

When reviewing documentation provided for Mrs. 6F's eligibility, some MDRC members presented concerns that Mrs. 6F appeared to have limited cognitive capabilities for navigating everyday basic care and routines. While some members acknowledged this does not preclude Mrs. 6F from having decisional capabilities to access MAiD, these members acknowledged that capabilities for executive function, such as maintaining insight and judgement required for complex decision-making, are more difficult to ascertain in such circumstances. While most MDRC members opined that Mrs. 6F appeared to be able to communicate a choice (i.e., by agreeing or squeezing a hand), some MDRC members noted that the MAiD practitioners did not adequately document their assessment of other components of capacity, such as her understanding, appreciation, or reasoning. Some MDRC members discussed that Mrs. 6F's communication via repeating a question is not an indication of understanding or appreciating a healthcare decision. A few members were reassured that Mrs. 6F had previously declined to access MAiD and elected to transition to long-term care, as such her rational decision-making was evident.

Some MDRC members noted possible reliance on a family member to facilitate the MAiD process, illustrating potential opportunity for undue influence. Some MDRC members speculated that compassion for Mrs. 6F's 'wish-to-die' may have had undue influence within the MAiD eligibility assessments.

Some MDRC members discussed that Mrs. 6F's perspectives were minimally represented in the MAiD documentation, with some MDRC members opining that there appeared to be reliance on a family member to navigate and interpret her decision to access MAiD. MDRC members encouraged MAiD practitioners to prioritize direct engagement with the person requesting MAiD, using adapted communication strategies where necessary, and to document the requestor's own words and reasoning wherever possible.

Lastly, a few MDRC members presented concerns about Mrs. 6F's overwhelmed response to having multiple people in her room at the time of the MAiD provision, potentially signaling her lack of understanding of the circumstances of the MAiD provision.

Additional Considerations

A few MDRC members were concerned that Mrs. 6F was unable to sign a written request (Clinician Aid A) for MAiD. A few MDRC members questioned whether her inability to sign was indicative of a lack of understanding of the written request, or an additional sign of advanced functional impairment. These MDRC members suggested that the use of a third-party signer should be clearly justified, particularly when questions of capacity are present.

PRACTICE CONSIDERATIONS

- Cognitive assessments should be used to inform MAiD eligibility assessments. MAiD practitioners should consider:
    - Evaluate and document the requestor's cognitive presentation, including domains such as short-term memory, executive function, language abilities, and insight/judgement.
    - While formal cognitive testing (e.g., MoCA, MMSE) is not required, it may help identify impairments that should be evaluated in a capacity evaluation.
    - Consider the person's cognitive and functional trajectory over time to contextualize current decision-making abilities from baseline.
- MAiD practitioners must employ a structured framework for capacity evaluations that meets the legal test for capacity, as outlined in Section 4 of the Healthcare Consent Act (1996). MAiD practitioners should document the person's understanding and appreciation of the decision to access MAiD, their reasoning for evaluating alternate care options, and their communication of a choice. MAiD practitioners should document the requestor's own words and reasonings to support the determination of capacity and informed consent.
- MAiD practitioners should avoid relying on global statements[2] (e.g., "the person was capable") or physical cues (e.g., hand squeeze) without supporting documentation of cognitive capabilities and decision-making.
- While MDRC members acknowledged that family members may have an increased role in assisting persons with dementia in navigating the MAiD process, MAiD practitioners should prioritize separate and direct engagement with the person requesting MAiD to the greatest extent possible.
- MAiD practitioners should evaluate possible sources of external pressure.

SUMMARY

Eligibility and Safeguard Determinations

Advanced State of Irreversible Decline

A few MDRC members expressed concern about the interpretation of the legislative criterion of an “advanced state of irreversible decline in capability” as it applies to persons in the mild stage of dementia. Specifically, these members questioned whether persons who have lost the ability to perform instrumental activities of daily living (IADLs), such as driving, managing finances, or engaging in complex hobbies, yet still retain the ability to participate meaningfully in daily life, should be considered to meet this legislative criterion.

These MDRC members emphasized that the criterion of an “advanced state of irreversible decline” is intended to safeguard against premature or inappropriate access to MAiD. In their view, this safeguard ensures that MAiD is reserved for persons whose loss of function is profound and enduring, and significantly compromises their quality of life. They offered perspectives that interpreting the loss of some higher-order functions as evidence of an advanced decline risks undermining the intent of the legislation.

Furthermore, these members raised ethical concerns about the potential for ableist biases to influence MAiD assessments. They cautioned that equating the inability to perform complex tasks with a life no longer worth living may inadvertently devalue the lives of persons with disabilities or chronic illnesses. Such interpretations, they offered, could lead to systemic inequities, and erode public trust in the safeguards designed to protect vulnerable persons.

Several MDRC members offered an alternate perspective, emphasizing that for many persons with dementia, the cognitive and functional losses experienced, even in the mild stages, can have a profound and deeply personal impact on their sense of identity, autonomy, and quality of life. In particular, the early loss of cognitive abilities may impair a person’s capacity to engage in complex decision-making, such as planning for future health care, managing finances, or maintaining meaningful social roles. For some, this erosion of autonomy represents a significant and distressing loss that fundamentally alters their experience of living.

Some members proposed that the legislative criterion of an “advanced state of irreversible decline” should not be interpreted solely through a clinical lens (i.e., level of functional impairment). Rather, it should be understood within a broader, person-centered and psychosocial framework - one that recognizes the subjective meaning persons assign to their cognitive and functional decline. From this perspective, the loss of higher-order cognitive functions may, for some persons with dementia, constitute an advanced state of decline, even if basic daily activities remain intact.

In light of these considerations, most MDRC members advocated for a more rigorous and nuanced application of the “advanced decline” criterion - one that takes into account not only observable impairments but also the individual’s values, goals, and lived experience. This approach would require MAiD practitioners to engage in comprehensive, person-centered assessments that explore how the person requesting MAiD interprets and is affected by their functional decline. This comprehensive approach to assessment should be carefully documented.

To support this approach to assessment, several members recommended that MAiD assessments for persons with dementia be guided by interdisciplinary expertise, including professionals in geriatrics, neurology, psychiatry, and palliative care. Such collaboration would help support eligibility determinations to be ethically sound, clinically informed, and sensitive to the diverse ways in which dementia affects persons and their families.

Informed Consent and Capacity Determinations

Several MDRC members expressed concerns regarding the current approach to evaluating and documenting key components of capacity in MAiD assessments. These members questioned whether the threshold for determining capacity in the context of MAiD should be higher than in other clinical decisions, given the irreversible nature of the outcome. They advocated for a shift in normative practice toward more rigorous and comprehensive capacity evaluations, particularly in circumstances involving cognitive decline or psychosocial vulnerability. These members recommended involving independent capacity experts, such as geriatricians, psychiatrists, or designated capacity assessors, in complex circumstances.

Other MDRC members emphasized the importance of upholding individual autonomy in end-of-life decisions. They shared their perspective that there is no need to impose a higher standard for capacity evaluations in MAiD cases, as the existing legislative framework already requires capable decision-making and informed consent, consistent with other healthcare decisions. From this perspective, maintaining a consistent approach to capacity evaluations, aligned with other healthcare decision-making, supports the deeply personal and values-driven nature of MAiD requests.

Some MDRC members also questioned whether the integrity of the informed consent process is being adequately upheld. Many MDRC members noted that MAiD death reviews often lacked clear evidence that comprehensive discussions about alternate options to alleviate suffering were meaningfully explored and understood by the requestor. Some members discussed that informed consent for MAiD should include a comprehensive discussion of alternate options and consequences of their decision. Key areas of quality care, not frequently documented, include: review of options such as community support services (e.g., support and advocacy groups, community groups, supportive care services), existential and dignity therapies for suffering, and exploration of possible impact of decision to access MAiD on family members and caregivers.

Safeguard Determination

The MDRC engaged in substantive discussion regarding the appropriate application of MAiD safeguards for persons with dementia, particularly those in the mild stages of illness. Several members emphasized that dementia, by its progressive and terminal nature, renders natural death reasonably foreseeable at any stage of functional decline. This perspective aligns with earlier MDRC findings (see MDRC Report 2025.1), which noted that individuals with dementia have historically been deemed eligible for MAiD under Bill C-14, thereby supporting the normative use of Track 1 safeguards.

Some members cautioned against a diagnosis-dependent approach to safeguard assignment. They highlighted that current practice guidance recommends confirming MAiD eligibility prior to determining the appropriate safeguard track. This approach ensures that safeguard assignment is informed by the person’s clinical presentation and prognosis, rather than solely by their diagnostic category.

MDRC members expanded these perspectives sharing that persons in the early stages of dementia may still have many years of meaningful life ahead. For these members, Track 2 safeguards, requiring structured, expertise-led assessments, could better support informed consent and ensure that MAiD care planning includes psychological support, existential therapies, and a focus on optimizing quality of life and function. These members expressed concern that Track 1 assessments may overly emphasize end-of-life considerations, potentially limiting the scope of care discussions. They offered perspective that approaching these dementia cases under Track 2 safeguards could help shift the clinical lens toward a quality of life (e.g., rehabilitation focused) and community support services (e.g., Alzheimer’s Society, community groups).

Other MDRC members maintained that this same structured, longitudinal approach could be achieved within Track 1, especially when integrated with specialized geriatric care. They emphasized the importance of the waiver of final consent, which Track 1 uniquely allows, to ensure equitable access to MAiD for persons at risk of losing capacity.

Practice Standards

Through their MAiD case reviews, MDRC members have consistently identified areas where the interpretation and application of legislative criteria generate significant debate. An emerging discussion is the need for the development of robust MAiD practice standards to ensure that the law's protective intent is upheld and that eligibility criteria are not applied in an overly permissive or inconsistent manner. While clinical frameworks, such as dementia staging, do not always align with legal terminology, this misalignment should not justify reinterpreting legal definitions to fit clinical norms. Instead, clinical assessments must be adapted to meet the legal thresholds as written.

To address this, some MDRC members suggest that regulatory bodies should lead the development of practice standards that guide MAiD practitioners in applying legal criteria consistently and ethically. These standards should define how key legal terms are to be interpreted in clinical contexts, establish expectations for documentation and interdisciplinary consultation, and outline when independent expert input (e.g., geriatric specialists) is warranted. By anchoring clinical practice in a shared, principled framework, regulatory guidance can reduce variability, support practitioner accountability, and reinforce public trust in the integrity of MAiD assessments.

Establishing Dementia Expertise within MAiD Practice

Given the unique complexities associated with evaluating capacity and voluntariness in persons with dementia requesting MAiD, some MDRC members suggested there is a growing need to recognize dementia assessments as a distinct expertise within MAiD practice – akin to a sub-speciality. Generalist MAiD practitioners may not possess the nuanced clinical expertise required to evaluate cognitive decline, fluctuating capacity, and the contextual factors, such as caregiver burnout, that influence decision-making in this population. Furthermore, providing MAiD in the context of dementia requires a tailored approach to monitoring functional decline and integrating these evaluations into person and caregiver end-of-life planning discussions.

To address this gap, the Canadian Association of MAiD Assessors and Providers (CAMAP) could consider establishing a specialized cohort of MAiD practitioners with additional training in dementia care. Moreover, CAMAP, along with provincial communities of practice, could have a central role in convening case conferences and fostering peer consultations among practitioners with dementia expertise. Formalizing recognition of this distinct expertise would enhance the quality, consistency, and ethical integrity of MAiD assessments involving persons with dementia who are requesting MAiD.

Role for Specialized Geriatric Services and Palliative Care

Specialized Geriatric Services

Many MDRC members observed that in most of the reviewed MAiD deaths persons who had accessed MAiD had received a dementia diagnosis through specialized geriatric services. Many members emphasized that early diagnosis and access to comprehensive dementia care are critical components of effective end-of-life planning, particularly when MAiD is being considered. In several of the MAiD circumstances, members highlighted the essential role of geriatric specialists in supporting this planning, addressing key issues such as the projected trajectory of functional decline, the person's cognitive capabilities to make informed healthcare decisions, psychosocial challenges such as caregiver burnout, and navigating care to enhance quality of life.

Many MDRC members described an ideal model in which MAiD practitioners are integrated into the broader continuum of geriatric care, becoming involved later in their dementia care when the person expresses readiness to pursue MAiD. This approach, contrasted with MAiD practitioners independently navigating the complexities of dementia care, was seen as more likely to ensure quality care and reduce the risk of unmet complex care needs.

Palliative Care

Some MDRC members observed that many persons with dementia who accessed MAiD did not appear to have received palliative care, raising concerns about whether the full spectrum of end-of-life care options was made available for informed consent. This gap may reflect broader systemic issues, including the under-recognition of dementia as a terminal condition and the absence of clear clinical indicators to guide access to palliative care. A few members with clinical expertise discussed that the unpredictable progression of dementia often complicates the identification of when palliative care should be introduced, and fragmented care pathways can result in MAiD being pursued without adequate exploration of alternative supports. Some MDRC members emphasized that palliative care should be a foundational component of end-of-life planning for persons with dementia, particularly when MAiD is being considered. Several MDRC members emphasized that persons accessing MAiD with a diagnosis of dementia, regardless of disease stage or clinical indicators, should have access to palliative care. The decision to navigate a request for MAiD is an indicator that the person is on an end-of-life trajectory, warranting the availability of supportive care options.

A few MDRC members noted that persons accessing MAiD in the mild stages of dementia often do not meet the clinical thresholds for palliative care services, which are typically aligned with more advanced disease stages. In these circumstances, some members suggested that Track 2 safeguards, designed for persons whose natural death is not reasonably foreseeable, may be appropriate. These safeguards allow for a more deliberate and supported decision-making process, including time to explore care options within complex care pathways.

RECOMMENDATIONS

In collaboration with the MAiD Review Team to inform MAiD oversight in Ontario, the MDRC aims to inform enhancements to MAiD practice and safety through system recommendations. The Office of the Chief Coroner (OCC) will disseminate this review to Ontario MAiD practitioners, government and regulatory bodies, and professional organizations identified in the recommendations to inform potential improvements to MAiD practice.

The OCC has identified recipients and recommendations to inform potential improvements to the MAiD system in Ontario. These recommendations were informed by MDRC submissions and discussions specific to this topic and this review; however, some recommendations would benefit from consideration and implementation across all MAiD practices, and for all persons needing and/or seeking end-of-life care. Moreover, these recommendations should be situated within broad health and social system improvements, considered with a summative understanding of this report, and understanding the limitations of this report.

1. **To Health Canada:**

1.1 To strengthen consistency, quality, and oversight of the provision of MAiD for persons with dementia, Health Canada to facilitate interjurisdictional knowledge exchange and policy alignment through their Federal-Provincial-Territorial Assistant Deputy Minister Committee on MAiD:

- Facilitate interjurisdictional knowledge exchange with regulatory bodies, and other stakeholders, to strengthen MAiD practice standards and guidelines for determining MAiD eligibility and navigating safeguards for persons with dementia. A priority area for dialogue may be considering standards for capacity evaluations (e.g., assessing cognitive capabilities, decision-making framework, involvement of capacity experts) and informed consent (e.g., consideration of community supports, existential therapies to alleviate suffering).

- Facilitate interjurisdictional knowledge exchange on oversight mechanisms employed by provinces and territories when reviewing MAiD deaths involving persons with dementia.

2. **To Ontario Ministry of Health:**

2.2 The Ontario Ministry of Health (MOH) should consider in their development of the Provincial Framework on Dementia Care, as mandated by Bill 121, the palliative and end-of-life care needs of persons living with dementia, including considerations related to accessing MAiD. An emerging area of consideration presented in this report is the recognition that a request for MAiD may serve as an indicator of end-of-life care needs.

3. To Ontario Health:

3.1 To the Ontario Palliative Care Network (OPCN), via Ontario Health, to consider evaluating existing palliative care pathways to better understand how persons requesting MAiD access palliative services, with a focus on enhancing accessibility to palliative care for persons with distinct end-of-life trajectories, such as persons with dementia.

4. To Ontario Ministry of Health and Ontario Health:

4.1 In alignment with previous MDRC recommendations, the Ontario Ministry of Health (MOH) and Ontario Health (OH) to consider developing and funding a coordinated MAiD system of care that supports longitudinal assessment and care delivery, with integrated palliative care, mental health, and dementia care specialists.

4.2 Ontario Ministry of Health (MOH) and Ontario Health (OH) to consider the integration of grief and bereavement supports into a coordinated MAiD system of care.

5. To the Provincial Geriatrics Leadership Ontario:

5.1 Provincial Geriatrics Leadership Ontario (PGLO) should consider addressing this emerging area of end-of-life care for older persons living with dementia, particularly considerations related to MAiD, within its policy development, clinical practice guidance, and provincial leadership initiatives.

6. To the Canadian Association of MAiD Assessors and Providers:

6.1 The Canadian Association of MAiD Assessors and Providers (CAMAP) to consider establishing a collective of MAiD practitioners with specialized expertise in navigating MAiD for persons with dementia and facilitating knowledge exchanges and professional development for MAiD practitioners engaged in this area of practice.

6.2 CAMAP, in collaboration with geriatric experts, should consider the emerging areas for practice improvement presented in this MDRC report to review and accordingly update their practice guidance, “Assessing MAiD in Dementia”.

7. To the College of Physicians and Surgeons of Ontario (CPSO) and College of Nurses of Ontario (CNO):

7.1 The College of Physicians and Surgeons of Ontario (CPSO) and the College of Nurses of Ontario (CNO) should consider advancing their MAiD practice guidance for their respective members through the integration of MAiD legislative interpretations and applications, such as Health Canada's "Model Practice Standard for MAiD", to inform consistent high quality MAiD practice for its members.

7.2 CPSO to consider engaging the Federation of Medical Regulatory Authorities of Canada to inform interjurisdictional knowledge exchange of MAiD practice standards to inform a provincial approach to MAiD standard development.

STAKEHOLDER DISSEMINATION

This MDRC report will be shared with the following stakeholders who have continued to commit to on-going MAiD practice improvements through informing their members of necessary practice guidance updates.

8. **To College of Physicians and Surgeons of Ontario, College of Nurses of Ontario, Canadian Medical Protection Association, Canadian Nurses Protective Society, and Ontario Medical Association:**

8.1 The College of Physicians and Surgeons of Ontario (CPSO), College of Nurses of Ontario (CNO), Canadian Medical Protective Association (CMPA), Canadian Nurses Protective Society (CNPS), and Ontario Medical Association should consider the findings of this report when updating their practice guidance or informing their members.

RESOURCES

Consider the following resources to inform MAiD practice:

CAMAP: Assessment for Capacity

CAMAP: Assessing MAiD in Dementia

Health Canada: Implementing the Framework

MAiD Reports: Please contact occ.deathreviewcommittees@ontario.ca to request previous MDRC reports.

APPENDIX

Table A1. Nature of Decline and Suffering Among MAiD Recipients in Ontario with Dand Other Causes of Death (COD), January 2023 to December 2024

		Dementia (N=103)		Other COD (N=9,263)	
		Number	Percent	Number	Percent
Decline	Unable to do most activities of daily living	84	81.6%	8,539	92.2%
	Reduced or minimal oral intake or difficulty swallowing	20	19.4%	5,530	59.7%
	Dependent on life sustaining treatments	0	0.0%	2,826	30.5%
	Significant dependence on aid(s) for interaction/or mobility	71	68.9%	5,733	61.9%
	Severe shortness of breath	1	1.0%	3,362	36.3%
	Persistent extreme fatigue/weakness	51	49.5%	7,927	85.6%
	Cachexia	10	9.7%	4,533	48.9%
	Persistent, significant, and escalating chronic pain	14	13.6%	5,201	56.1%
Suffering	Inability to engage in activities	98	95.1%	8,907	96.2%
	Loss of ability to perform ADLs	90	87.4%	8,260	89.2%
	Inadequate pain control	14	13.6%	4,960	53.5%
	Loss of dignity	85	82.5%	6,228	67.2%
	Inadequate control of other symptoms	46	44.7%	4,922	53.1%
	Perceived burden on family, friends, or caregivers	70	68.0%	4,284	46.2%
	Loss of control of bodily functions	30	29.1%	2,984	32.2%
	Isolation or loneliness	26	25.2%	1,641	17.7%
	Emotional distress/anxiety/ fear/existential suffering	76	73.8%	5,555	60.0%
	Loss of independence	96	93.2%	8,070	87.1%

Table A2. Comparison of Access to Primary Care Among Ontarians with Dementia Who Died of MAiD, Who Died Without MAiD, and Who are Living, 2023

	Cohort A: Received MAiD in 2023, with dementia (N=235)	Cohort B: Died in 2023, not from MAiD, with dementia (N=15,662)	Cohort C: Living at the end of 2023, with dementia (N=182,573)
Rostered to a primary care group in year prior to death	208	12,614	152,736
Visit with a family doctor…			
1 year prior	234	15,524	175,963
2 years prior	227	14,955	173,069
3 years prior*	217	14,588	168,366
4 years prior*	221	14,648	165,384
5 years prior	223	14,723	169,369

Table A3. Comparison of Access to Specialists Among Ontarians with Dementia Who Died of MAiD, Who Died without MAiD, and Who are Living, 2023

	Cohort A: Received MAiD in 2023, with dementia (N=235)	Cohort B: Died in 2023, not from MAiD, with dementia (N=15,662)	Cohort C: Living at the end of 2023, with dementia (N=182,573)
Visit with a geriatrician			
1 year prior	54	3,272	42,040
2 years prior	39	2,441	35,728
3 years prior	22	2,111	25,550
4 years prior	13	1,930	19,335
5 years prior	13	1,835	18,001
Visit with a neurologist			
1 year prior	81	1,965	28,886
2 years prior	66	1,557	26,841
3 years prior	58	1,503	23,257
4 years prior	50	1,551	20,541
5 years prior	54	1,576	21,169
Visit with a psychiatrist			
1 year prior	52	1,937	23,972
2 years prior	34	1,454	20,880
3 years prior	25	1,258	18,004

4 years prior	26	1,149	15,667
5 years prior	21	1,089	15,436

Table A4. Comparison of Emergency Department Visits and Hospitalizations Among Ontarians with Dementia who Died of MAiD, Who Died Without MAiD, and Who are Living, 2023

	Cohort A: Accessed MAiD in 2023, with dementia (N=235)	Cohort B: Died in 2023, not from MAiD, with dementia (N=15,662)	Cohort C: Living at the end of 2023, with dementia (N=182,573)
Emergency department visits			
1 year prior	168	10,667	90,274
2 years prior	136	7,561	83,336
3 years prior	101	6,622	73,145
4 years prior	89	6,866	64,654
5 years prior	99	7,010	70,061
Hospitalizations			
1 year prior	122	8,186	52,148
2 years prior	84	4,546	44,100
3 years prior	51	3,599	33,623
4 years prior	39	3,415	27,759
5 years prior	41	3,258	27,196

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