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Article abstract

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Medical Aid in Dying and Dementia Directives

Thaddeus Mason Pope[a,b]

Résumé
Bien que le Canada ait récemment élargi l'accès à l'aide médicale à mourir, les Canadiens atteints de démence qui souffrent intolérablement doivent encore faire face à sept obstacles pour être admissibles à l'AMM. Les directives anticipées pour le AVMB constituent une alternative importante, mais sous-estimée.

Abstract
Although Canada recently expanded access to medical assistance in dying, intolerably suffering Canadians with dementia still face seven obstacles to qualify for MAID. Advance directives for VSED are an important, yet under-appreciated, alternative.

Mots-clés
AVMB, arrêt volontaire de manger et de boire, AMM, aide médicale à mourir, directive sur la démence, maladie d'Alzheimer, clause d'Ulysse

Keywords
VSED, voluntarily stopping eating and drinking, MAID, medical aid in dying, dementia directive, Alzheimer's disease, Ulysses clause

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INTRODUCTION

Since June 2016, Canadians suffering intolerably from a grievous and irremediable medical condition have been allowed to ask a doctor or (in most provinces) nurse practitioner to assist them in voluntarily ending their life (1). In March 2021, the Parliament of Canada relaxed the eligibility requirements for medical assistance in dying (MAID) (2). Bill C-7 widened access to MAID but many patients with dementia still face huge obstacles. What are those barriers? What alternatives do these patients have?

This paper addresses these questions in four steps. First, it explains why many patients with dementia want to hasten their death to avoid current or imminent intolerable suffering. Second, it shows how some of these patients have been able to access MAID even under the original, more restrictive law. Third, it demonstrates how many other patients with dementia have been unable to access MAID. This paper unpacks these obstacles, describing seven different impediments that thwart Canadians with dementia from accessing MAID. Fourth, it explains how advance directives for stopping eating and drinking offer another option for avoiding late-stage dementia (3).

WIDESPREAD FEAR OF LATE-STAGE DEMENTIA

Dementia causes significant morbidity and mortality. More than 750,000 Canadians have Alzheimer's disease or another type of dementia (4). More than 7000 die each year, making dementia a leading cause of death after cancer, heart disease, and stroke (5). Moreover, dying from dementia entails a long progressive decline lasting eight or more years.

Many individuals want to avoid living with late-stage dementia. They are afraid of being unable to recognize their family, afraid of being unable to toilet themselves, afraid of making abusive comments, and afraid of other consequences of major cognitive decline (3,6). This fear is illustrated in compellingly worded book titles such as *O, Let Me Not Get Alzheimer's, Sweet Heaven: Why Many People Prefer Death or Active Deliverance to Living with Dementia* (7).

Dementia fear is also illustrated by widely reported and discussed cases like Vancouverite Gillian Bennett, who took her own life in 2014 (8). She reported that dementia was "taking its toll," and "I have nearly lost myself. I have nearly lost me." (9) More recently, dementia fear has been articulated through the vigorous and extensive advocacy of Canadians like Ontarioan Ron Posno who has been pushing the federal government to make MAID more accessible for patients with dementia (10).

SOME DEMENTIA PATIENTS CAN ACCESS MAID

In June 2016, when Bill C-14 went into effect and MAID was first available in Canada, many doubted that patients with dementia would be eligible (1,11,35). These doubts were reasonable and grounded. After all, the law required, among other things, that the patient satisfy two eligibility requirements at the same time (1). First, the patient must have decision-making capacity. Second, the patient's death must be reasonably foreseeable. Given the long, multi-year course of dementia, many figured that early in the disease trajectory when the patient still had decision-making capacity, her death would not be reasonably foreseeable. Conversely, late in the disease trajectory when death was reasonably foreseeable, the patient would no longer have decision-making capacity.

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Over the next several years, some clinicians managed to escape this Catch-22, determining that decision-making capacity and a reasonably foreseeable natural death were not necessarily mutually exclusive (12). They identified a thin zone of overlap. At precisely the right moment, some patients with dementia could satisfy both requirements at the same time (13). On this understanding, one leading MAID clinician, Ellen Weibe, was able to help several patients with dementia (11). Another, Stefanie Green, was able to help Gayle Garlock whose case attracted significant media attention (14). Another high-profile case attracted not only media but also regulatory attention. After physician Konia Trouton helped Mary Wilson, Dr. Trouton found herself the subject of a disciplinary investigation by the College of Physicians and Surgeons of British Columbia (11), although she was ultimately exonerated (15). But the mere prospect of investigation may deter other MAID clinicians from helping patients with dementia (16). Moreover, not all clinicians agree that patients with dementia can satisfy current MAID eligibility criteria.

PATIENTS WITH DEMENTIA HAVE ONLY LIMITED ACCESS TO MAID

Despite the high-profile cases of Gayle Garlock and Mary Wilson, many other patients with dementia have been unable to access MAID. Leading commentators acknowledge these constraints. For example, the Canadian Civil Liberties Association writes that “those with dementia may be disqualified” (16); the British Columbia Civil Liberties Association writes that MAID for patients with dementia is “not flatly barred” (18); and Dying with Dignity Canada says that eligibility criteria “may limit access” for these patients (19).

Other commentators use even more qualified and conditional language. The Canadian Association of MAID Assessors and Providers (CAMAP) writes that that dementia “can be” a qualifying, standalone diagnosis (13). Stefanie Green, the president of CAMAP, states that “some” patients with dementia may be eligible in “certain circumstances.” (14) Jocelyn Downie, the leading Canadian legal scholar on MAID, writes that C7 will allow “some Canadians” with dementia” to get MAID (20). Green and Downie together acknowledge that “many people with dementia aren’t helped.” (21) In short, there is consensus that patients with dementia face significant impediments to accessing MAID.

ELIGIBILITY OBSTACLES

What exactly are these obstacles? There are seven. Four relate to the eligibility requirements while three relate to the rules for waiver of final consent. To be eligible for MAID, a patient must have a “grievous and irremediable medical condition.” That requirement has three subelements (1-2). First, the patient must have “a serious and incurable illness, disease, or disability.” Second, the patient must be in an “advanced state of irreversible decline.” Third, the patient must have “enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.”

1. Advanced State of Irreversible Decline. While patients with dementia are surely in a state of irreversible decline, it is less clear that the state is “advanced.” Look at the timeline. Patients must have decision-making capacity when they request MAID (1-2). Therefore, the patient must request MAID early in the course of their disease, probably by stage three of Alzheimer’s. At that point, the patient has not yet suffered severe or even moderate decline. They have not yet reached more than half the seven stages of Alzheimer’s disease (22). Some clinicians are comfortable finding the condition is satisfied (13). But others remain uncertain whether a patient still in an early stage of dementia is in an “advanced” state of decline.

2. Enduring and Intolerable Suffering. In addition to being in an advanced state of irreversible decline, patients seeking MAID must have “enduring physical or psychological suffering.” (1-2) Gayle Garlock satisfied this requirement because losing the ability to read was an intolerable loss for the retired university librarian and scholar (14). Mary Wilson satisfied this requirement because her inability to perform most activities of daily living was intolerable to her (11,15). But many other patients with dementia may be unable to satisfy this requirement (23). They are concerned with future suffering, not present suffering. The conditions that would make their lives intolerable have not yet obtained. Therefore, these patients do not yet have a grievous and irremediable medical condition. Some MAID assessors are more flexible than others (36). But many would conclude that these patients are not eligible for MAID. Worse, they may never be eligible for MAID because by the time their suffering becomes intolerable, they no longer have decision-making capacity.

3. Ten Minutes to Midnight Rule. Some clinicians have circumvented the first two obstacles by using the “ten minutes to midnight” rule (13,14). They advise patients to request MAID right before losing decision-making capacity. At that point, the clinician is comfortable affirming that the patient is both 1) in an advanced state of irreversible decline and 2) experiencing enduring and intolerable suffering. They reason that both conditions are satisfied because they are imminent even if not yet present. But not all clinicians are comfortable making these determinations. Many MAID requests are rejected on grounds that the patient is ineligible (12).

4. Closing Window of Opportunity. Even if more clinicians subscribed to the Ten Minutes to Midnight Rule, it is hardly an ironclad guarantee. Timing the MAID request so precisely is like playing a dangerous game of “chicken.” Under this rule, the patient must race right up to the cliff edge, waiting until just before losing capacity to request MAID. This is risky because prognostication is imprecise. The window of opportunity may close, and the patient may miss her chance (3,6). The patient may lose capacity before making her MAID request.

OBSTACLES REGARDING THE WAIVER OF FINAL CONSENT

From 2016 to 2021, Bill C-14 required that the patient provide final consent to MAID at the time of administration (1). But some patients, like Audrey Parker, had progressive illnesses that were likely to rob them of decision-making capacity before the time they wanted MAID (24). These patients were put into the impossible bind of either getting MAID earlier than desired or not getting MAID at all. Bill C-7 relieved patients of this Hobson's choice by waiving the requirement of final consent (2). Today, patients must have capacity at the time they request MAID (2). But patients need not also have capacity at the time MAID is administered. Instead, the patient and clinician can execute a "written arrangement" specifying a future date on which the patient will receive MAID (37). This is an important option for patients with dementia. But there are still obstacles.

5. Death Must Be Reasonably Foreseeable. Under Bill C-14, no patient was eligible for MAID unless their death was "reasonably foreseeable". While Bill C-7 removed that categorical requirement for all patients, it continues to require a reasonably foreseeable natural death (RFND) for written arrangements (2). But for patients with dementia, what C-7 gives with one hand, it takes away with the other. It is often difficult for patients with dementia to satisfy this RFND requirement. Remember, patients must request MAID when they still have capacity. For patients with dementia, this means that they are often requesting MAID five or more years before death. Admittedly, some clinicians judge these deaths reasonably foreseeable because death is predictable even if not imminent (11,13,14) – the patient is on a trajectory toward death even though that death is still years away. But not all clinicians are comfortable with this reasoning, judging that assessing RFND requires imposing some temporal limit.

6. Incapacitated Vetoes. Even if patients with dementia qualify for written arrangements, they are still concerned about inadvertently revoking that consent. Recall the case of Margot Bentley. A British Columbia court held that even if her advance directive had been valid, by opening her mouth to take food and swallow she revoked any prior consent (25). The court ruled that revocation was effective even though Bentley was in stage seven Alzheimer's and did not understand the consequences of her own actions. Consequently, many patients with dementia would like to write a Ulysses contract. They would like to instruct: "While my future incapacitated self may seem not to want MAID, listen to my now self and administer MAID." But Bill C-7 prohibits this, providing that "any words, sounds, or gestures" indicating resistance or refusal invalidates the patient's prior consent (2). Thus, the clinician would not be allowed to proceed. Contrast this situation with the Netherlands, where the clinician may rely upon the advance request even in the face of apparent resistance or refusal (26).

7. Unwilling Clinicians. Even if the patient is qualified and even if she does not inadvertently veto her own MAID request, new evidence from several recent studies shows that many Canadian clinicians are unwilling to provide MAID unless they both get the patient's contemporaneous consent and witness the patient's contemporaneous suffering (27-29). Similar data has been reported in Belgium and in the Netherlands (30). This reluctance is not surprising. After all, it is one thing to help a patient with advanced cancer who can confirm that she wants to proceed. It is quite another to help a patient who appears content and who cannot confirm that she wants to proceed. The clinician has only a written agreement that the patient signed some months (or perhaps even years) in the past. In short, even if Parliament removed the legal obstacles, significant practical ones would remain. So, what are alternatives for patients with dementia who want to hasten their death?

ADVANCE DIRECTIVES FOR STOPPING EATING AND DRINKING

Voluntarily Stopping Eating and Drinking (VSED) is an important alternative to MAID. This is perhaps best illustrated by the documented experience in the Netherlands (38), where nearly 2% of all deaths are from VSED, half the rate of deaths from MAID. These patients can take food and fluid by mouth, but they make a voluntary, deliberate decision to stop, causing their death from dehydration (3). That normally happens in eight to fourteen days. VSED deaths are reported to be peaceful and comfortable; VSED is supported by a wide range of professional societies (3); and VSED is legal in Canada (31). Nevertheless, while there is medical, ethical, and legal support, VSED is not an attractive option for many patients with dementia. The problem is that patients must VSED when they still have decision-making capacity. For many patients with dementia, this is too soon: their life is still worthwhile and enjoyable when they still have capacity.

To circumvent this dilemma, a rapidly growing number of patients with dementia are completing advance requests for VSED, sometimes called "dementia directives." (3) Patients complete an advance directive when they still have capacity, requesting VSED later when certain conditions are satisfied (like the inability to recognize family). In late-stage dementia, patients are dependent upon others for hand feeding. VSED directives instruct caregivers to stop providing that food and fluid by mouth. VSED directives offer a promising option to avoiding late-stage dementia. First, they are legal in almost every Canadian province and territory (32-33). Second, they face none of the seven obstacles confronting patients with dementia seeking MAID. The right to refuse lifesaving and life-sustaining interventions (including food and water) is settled and well-grounded.

REMAINING CHALLENGES FOR DEMENTIA DIRECTIVES

While VSED directives are an important alternative to MAID, work remains to make the option practically available. These obstacles are not legal ones as with MAID. Parliamentary action is not required to make VSED and VSED directives more available. But expanding access does require education and guidance.

First, Canadian clinicians lack protocols for counselling and managing patients who VSED. This is fixable. Over the past five years, professional medical societies and provincial colleges across Canada have developed substantial guidance for MAID. These same private and public regulators must develop guidance on how clinicians can best support patients with VSED.

Second, some are concerned that the *Bentley* case dooms VSED directives. After all, the court held that the mere opening and swallowing by a patient in late-stage dementia constituted a revocation of her prior directive (25). Indeed, many incapacitated patients may say or do things that contradict their prior instructions. But the standard for revoking an advance directive is higher than the "any words, sounds, or gestures" standard in C-7. While in the *Bentley* case, the court found that the higher standard was satisfied, that finding was based on the peculiar expert witness evidence offered by parties in that case. That ruling has little relevance for other Canadian patients with dementia. While patients with capacity can always revoke prior instructions, it is inconceivable, if not absurd, that a patient in stage-7 Alzheimer's has capacity to revoke her prior consent (3,39,40).

Third, some are concerned that surrogates or substitute decision makers will be unwilling to implement VSED directives. They may procrastinate, waiting for further evidence that the patient is ready. But this risk can be mitigated with better advance care planning documents (3). The patient can specify not only the conditions under which she would want VSED but also how she wants the satisfaction of those conditions to be measured. For example, the patient can specify that she want VSED when she can no longer recognize her family. She can further specify that this condition is satisfied only after being documented on at least ten separate occasions on ten different days. Fortunately, clinicians and advocacy organizations are already developing better VSED directive forms and planning guides (3).

CONCLUSION

Today, patients with dementia can sometimes access MAID. But not all clinicians interpret the eligibility conditions as broadly as necessary. The ongoing work of a Parliamentary Special Joint Committee may lead to broader permission for advance MAID requests (34). In the meantime, VSED and VSED directives are an important alternative option. But they need more clinical and policy attention.

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