

## Medical aid in dying by advance directive

Brief submitted to the *Committee on Health and Social Services (Commission de la santé et des services sociaux)* studying Bill 38, *An Act to amend the Act respecting end-of-life care and other legislative provisions*

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As physicians in Geriatric Medicine, a large part of our practice involves the care of patients with dementia (major neurocognitive disorder). We have expertise in decision-making capacity assessment, and often see victims of elder abuse. We teach on these topics and testify frequently in court for patients. Among us, we have cared for and accompanied many thousands of people with dementia and their families.

We would first like to express our astonishment at the speed at which the study of Bill 38 is being conducted. Extending medical aid in dying to people incapable of consenting to it is a huge leap and cannot be taken lightly.

We are of course aware that *the Select Committee on the Evolution of the Act respecting end-of-life care (Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie)*<sup>1</sup> studied the question of MAiD by advance request in 2021. In the two short pages of their report that were allocated for the discussion of the risk of abuse with this practice, most of the concerns raised by people such as ourselves are dismissed with the statement that such abuses have not been observed under the current Quebec end of life law. However, no mechanism exists to collect such observations. The information on MAiD collected by the *Commission des soins de fin de vie* is limited to self-reported data by the physician having authorized and performed the procedure. It is impossible for that data to capture conflict of interest, external pressure, fear of being a burden or other devaluing of certain populations. Elder abuse is nevertheless very real. The statement that *"We are convinced that the care teams, together with the loved ones, will be able to give careful consideration to advance requests, as they are already doing for requests since the Act respecting end-of-life care came into force"*<sup>2</sup> can only be explained by extreme naiveté or by wilful blindness driven by ideology.

We are also astonished that the only individuals and groups who testified on this question in the two-day consultation period for the Bill are known proponents of MAiD by advance request. This discredits the whole parliamentary process.

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<sup>1</sup> <http://www.assnat.qc.ca/en/travaux-parlementaires/commissions/cssfv-42-1/index.html>

<sup>2</sup> Report of the *Select Committee on the Evolution of the Act respecting end-of-life care*, page 35

## The weakness of advance consent

We have noticed in this debate the assumption that written advance directives are a proven tool that enables autonomy and provides adequate free and informed consent to medical interventions. This is false.

For consent to be valid it must be voluntary, the patient must have the capacity to consent and must be informed. Consent is *informed* when the patient has received and understands detailed information on the diagnosis, including any uncertainty about it; the proposed investigations or treatments, their chances of success, available alternatives and their risks, and the potential consequences of leaving the condition untreated.<sup>3</sup>

Advance consent can never be fully informed. The 2018 **Council of Canadian Academies (CCA) Expert Panel on MAiD by advance request**<sup>4</sup> cited knowledge gaps and a lack of evidence regarding its safety.

Neither the **Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie** nor the **Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir** appears to have reviewed the extensive medical literature on advance care planning (ACP). The **CCA Expert Panel** did review it.

Advance care planning has developed over several decades to improve medical decision-making toward the end of life. It is not limited to advance directives: in fact, its scope is becoming broader over time, as the limitations of such directives, also called “living wills”, become evident. Articles published by experts include Joanne Lynn’s **Why I don’t have a living will**<sup>5</sup> in 1991, and Fagerlin and Schneider’s **Enough: the failure of the living will**<sup>6</sup> in 2004.

Definitions of ACP refer to a reflection and communication process to ensure goal-concordant care near the end of life for people lacking decisional capacity. Components include discussion of broad life and health care goals, and naming a substitute decision-maker.

Of the research reviewed by the **CCA Panel**, very little studies written directives alone. The panel found no evidence that written directives affected any meaningful outcomes, and in one Canadian study, the documented preferences did not match the expressed wishes of the patient 70% of the time.<sup>7</sup>

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<sup>3</sup> [https://www.cmpa-acpm.ca/serve/docs/ela/goodpracticesguide/pages/communication/Informed\\_Consent/three\\_key\\_elements-e.html](https://www.cmpa-acpm.ca/serve/docs/ela/goodpracticesguide/pages/communication/Informed_Consent/three_key_elements-e.html)

<sup>4</sup> Council of Canadian Academies, 2018. The State of Knowledge on Advance Requests for Medical Assistance in Dying: <https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf>

<sup>5</sup> Lynn J. Why I Don't Have a Living Will. *Law, Medicine and Health Care* 1991; Volume: 19 issue: 1-2, 101-104.

<sup>6</sup> Fagerlin A, Schneider CE. Enough: the failure of the living will. *Hastings Cent Rep*. Mar-Apr 2004; 34(2):30-42. DOI: [10.2307/3527683](https://doi.org/10.2307/3527683)

<sup>7</sup> Heyland, D. K., Barwich, D., Pichora, D., Dodek, P., Lamontagne, F., You, J. J., ... Simon, J. (2013). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Internal Medicine*, 173(9), 778-787

A 2020 review of 69 studies<sup>8</sup> found no effect of advance care planning on goal-concordant care or quality of life.

These results make sense, given the evidence that people predict poorly their quality of life in hypothetical situations.<sup>9</sup> This has been attributed to known cognitive biases, such as:

- projection bias (projecting current preferences onto future situations),
- focalism (focusing on what gets worse, not what remains positive); and
- immune neglect (underestimating one's adaptive capacity).

We often see a change in preferences for care as a person adapts to advancing illness. This is true even in dementia, and is why we respect the current wishes of incapable patients, as long as they are not harmful to the patient. For example, Quebec law does not allow medical interventions on incapable persons who refuse them, or their relocation to a residential setting against their will, unless a judge is satisfied that it is absolutely necessary for the person's well-being.

More and more end of life experts express serious doubts about the utility of written advance directives. Recent articles include Morrison's *Advance directives/care planning: clear, simple and wrong*<sup>10</sup> in 2020, Morrison, Meier & Arnold's *What's Wrong With Advance Care Planning?*<sup>11</sup> in 2021, and Smith's *Should we still believe in advance care planning?*<sup>12</sup> in 2022.

Morrison et al state: "Treatment choices near the end of life are not simple, consistent, logical, linear, or predictable but are complex, uncertain, emotionally laden, and fluid. Patients' preferences are rarely static and are influenced by age, physical and cognitive function, culture, family preferences, clinician advice, financial resources, and perceived caregiver burden [...]"<sup>13</sup>

For these reasons, there has been a shift in practice from promoting written documents to a dynamic process of dialogue. Programs include **Advance Care Planning Canada**<sup>14</sup> and **The Conversation Project**<sup>15</sup> in the US.

This is the standard of care for end of life decision-making.

With all the limitations of written advance requests for treatment refusal or withdrawal, they are ethically distinct from what is being considered under this Bill. They are a request to be left

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<sup>8</sup> McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? A scoping review. *J Am Geriatr Soc* 2020; 69: 234-244. DOI: [10.1111/jgs.16801](https://doi.org/10.1111/jgs.16801)

<sup>9</sup> van den Bosch GJ, Roos RA, Otten R, Bockting C, Smulders YM. Are patients accurate forecasters of their emotional response to medical conditions? A scoping review on affective forecasting. *BMJ Open* 2021;11:e053370. DOI: [10.1136/bmjopen-2021-053370](https://doi.org/10.1136/bmjopen-2021-053370)

<sup>10</sup> Morrison RS. Advance directives/care planning: clear, simple and wrong. *J Palliat Med* 2020 Jul;23(7):878-879. DOI: [10.1089/jpm.2020.0272](https://doi.org/10.1089/jpm.2020.0272).

<sup>11</sup> Morrison RS, Meier DE, Arnold RM. What's Wrong With Advance Care Planning? *JAMA*. 2021;326(16):1575-1576. DOI:[10.1001/jama.2021.16430](https://doi.org/10.1001/jama.2021.16430)

<sup>12</sup> Smith AK. Should we still believe in advance care planning? *J Am Geriatr Soc*.2022;1-3. DOI: [10.1111/jgs.17727](https://doi.org/10.1111/jgs.17727)

<sup>13</sup> Morrison RS, Meier DE, Arnold RM. Op. cit.

<sup>14</sup> <https://www.advancecareplanning.ca/>

<sup>15</sup> <https://theconversationproject.org/>

alone, to not be touched. If one dies after treatment is refused or withdrawn, it is through the natural progression of the illness. An advance request for MAiD, on the other hand, is asking for an active intervention to end life. This distinction is often blurred in the current debate.

Since advance consent for MAiD cannot be equated with that for treatment refusal or withdrawal, already of uncertain validity, nor with contemporaneous consent, because it lacks the quality of being informed, the only logical conclusion is that such consent cannot be obtained. ***MAiD cannot be performed on people incapable of decision-making.***

We are very alarmed by the popularity of the notion of MAiD by advance request in Quebec. We believe it is driven by fear, ageism, ableism, and negative stereotypes of life with dementia. In any case, laws should be driven by facts, not by popularity: in this case, evidence that real consent is possible and that the law will not cause harm to already marginalized Quebecers unable to defend themselves. That evidence does not exist.

### **The process for MAiD by advance request proposed in Bill 38**

The bill requires health professionals who diagnose dementia to facilitate advance requests for MAiD by helping patients describe what sort of future suffering they consider intolerable. They must ensure that this patient in crisis is making a free decision that they want their life ended upon reaching a certain stage in their disease.

They must then remind them “at reasonably spaced intervals” that they may change or withdraw their request.

In Geriatric Clinics, in the past we saw many patients for straightforward diagnosis of common dementias such as Alzheimer’s. However more and more family physicians are now able to make these diagnoses, and they often do not refer to us unless there is a problem. In fact, the ***Centre de répartition des demandes de service (CRDS)*** referral form for Geriatrics discourages referral for typical neurocognitive disorders, prioritizing atypical dementias or typical ones that lead to some unusual problem.

Will family doctors be expected to support the formulation of advance requests for MAiD? Most have neither the time nor the expertise to do this. It is one thing to diagnose typical dementia, and quite another to educate the patient on the expected future course of the disease, and what suffering might lead them to prefer death. Will there be referrals to Geriatrics for the sole purpose of facilitating advance requests for MAiD? We already lack resources for what we do now.

In the past, after having diagnosed a neurocognitive disorder and possibly started a pharmacological treatment, our practice was to follow the patient every 6 to 12 months in order to address new problems related to the dementia as they arose. The policy of many hospitals now is that we are a specialty clinic and should not follow patients over the long term; we are urged to return the patients to their primary care physician (if they have one) after the

initial one or two visits. Even if we agreed with MAiD by advance request, we could not ethically introduce such a discussion into the visit at which we inform the patient of the diagnosis. But if they tolerate the medication and are stable, we might not see them again for several months, if at all. And follow-up visits are very short. Who will carry out this delicate and complex communication? Who will remind the patient “at reasonably spaced intervals” that they may change their mind as long as they remain capable of decision-making?

Our prediction, if this Bill is adopted, is that geriatric care will be disrupted by the demand for MAiD, just as palliative care is now. The extensive counselling and reflection required by the Bill will only detract from the already limited resources available. They will be stretched past their limit to include MAiD consultations. Assessments will be rushed. Decisions will be made based on fear and stigma. Patients will suffer and will die prematurely.

When the patient becomes incapable of decision-making, MAiD will be performed, not upon the autonomous request of the patient, but because a third party assesses their suffering as intolerable.

Is that what you want?

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The Netherlands, the only country in the world that allows euthanasia of conscious patients by advance request, is mired in controversy over the practice.

To cause the death of a person with dementia, who is not asking for it, in the absence of adequate consent, is contrary to autonomy and beneficence, and should not be permitted in a civilized country.

Respectfully submitted,

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