

## MAiD by advance directive

Brief submitted to the **Special Joint Committee on Medical Assistance in Dying**

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I am a physician in the **Division of Geriatric Medicine** at the **McGill University Health Centre** since 1984; my practice is focused on patients with dementia. I am an expert in decision-making capacity assessment. I see victims of elder abuse. I teach on these topics and testify frequently in court for my patients.

I have cared for and accompanied thousands of people with dementia and their families. My perspective is very different from those who view my patients from an academic or political point of view.

I have learned how well people adapt to the changes in their life wrought by cognitive decline. There are many challenges, not least of which are the ageism, ableism and neglect they face in the health care system. Despite this, most people do well when measures are put into place to support them and their families. In 38 years, none of my patients or their relatives have ever requested MAiD because of a dementia diagnosis.

I 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>1</sup>

Advance consent can never be fully informed.

The 2018 **CCA Expert Panel on MAiD by advance request**<sup>2</sup> cited knowledge gaps and a lack of evidence regarding its safety.

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<sup>1</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>2</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>

They reviewed the literature on advance care planning (ACP), a field that has developed to improve medical decision-making toward the end of life. ACP 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>3</sup> in 1991, and Fagerlin and Schneider’s *Enough: the failure of the living will*<sup>4</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 report mentions no evidence that written directives affected any meaningful outcomes, and in one Canadian study<sup>5</sup> the documented preferences did not match the expressed wishes of the patient 70% of the time.

A 2020 review of 69 studies<sup>6</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>7</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.

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>8</sup> in 2020, Morrison, Meier & Arnold’s *What’s Wrong With Advance Care Planning?*<sup>9</sup> in 2021, and Smith’s *Should we still believe in advance care planning?*<sup>10</sup> in 2022.

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<sup>3</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>4</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>5</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

<sup>6</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>7</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>8</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>9</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>10</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)

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>11</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>12</sup> and **The Conversation Project**<sup>13</sup> in the US.

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

It is absurd and alarming that written directives, having failed for ordinary treatment decisions, are now being contemplated for MAiD.

To cause the death of a person with dementia, who is not asking for it, on the basis of advance consent that is necessarily uninformed, is contrary to autonomy and beneficence, and has nothing in common with treatment withdrawal decisions. There is a broad consensus in ethics and medicine that to directly cause death is distinct from allowing death to occur through the natural progression of an illness.

Advance directives for MAiD would lead to elder abuse through manipulation and forgery of directives. I have seen it with powers of attorney, where the consequences are not nearly as grave.

If MAiD by advance request became legal and binding, Canada would be the only place in the world where a state agency is obliged by law to kill an innocent and defenseless person.

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<sup>11</sup> Morrison RS, Meier DE, Arnold RM. Op. cit.

<sup>12</sup> <https://www.advancecareplanning.ca/>

<sup>13</sup> <https://theconversationproject.org/>