

Why Advance Requests for MAID Raise Fundamental Ethical and Human Rights
Concerns
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We already witness how lack of housing, disability support, and quality elderly care, lead Canadians who are not dying to request MAID. In this context some promote Advance Requests [AR] for MAID as a ‘solution’ to what is they term a ‘loss of dignity’. Yet, we know that housing, disability support, and good quality care are possible, and allow the preservation of dignity that is inherent to all human beings, as recognized in international human rights and constitutional law.

For some, health care providers would even need to introduce MAID when informing a patient of a devastating diagnosis, say, of early Alzheimer’s, to let them prepare an AR. This ignores the dynamics of doctor-patient relations and the pressure potentially resulting from professionals suggesting to patients that medicalized death is a solution, particularly in a context where lack of social support and good elderly care are *already* undermining consent. Creating a duty to put ending-of-life on the table when informing a patient of a devastating diagnosis would undermine the important role of physicians in instilling hope and reassuring patients that they will be there to care for them and to act in their best interest.

ARs for MAID further raise insurmountable ethical and human rights concerns. This is reflected in this: Belgium only allows MAID based on AR when persons are permanently unconscious, to avoid euthanizing people who still enjoy life and may resist. The Netherlands originally had difficulty with MAID based on AR, since it was considered impossible to defend this practice on the basis that persons ‘suffer unbearably’, when they were no longer able to confirm this. It now has permitted it for persons even when they appear to resist.

Neither regime involves explicit, contemporary consent, which is arguably constitutionally required. The Supreme Court explicitly restricted in *Carter* its

ruling to the circumstances of the case, a case that involved a capable person able to express her wish, and approaching her natural death. If one combines the emphasis on the exceptional nature of active ending of life, the need for stringent safeguards, and the emphasis on 'clear consent', ARs for MAID appear to run counter to the Supreme Court's parameters in *Carter*.

Allowing ARs for MAID reflects the idea that prior wishes of patients, who cannot fully appreciate what future illness will bring, have priority over current interests; that this can be done through procedures that give third persons clarity about patients' experience of suffering and their real wishes; and that there are no serious implications for family members, health care providers, other disabled persons, and society at large. ARs for MAID are, in this view, a question of management.

The CCA Expert report shows that procedural solutions cannot fully address the legal and ethical concerns. Even the CCA report's discussion of communication tools to reduce uncertainty shows that these solutions are theoretical and speculative. The CCA report discusses how advance directive regimes in standard health care practice are also confronted with problems of interpretation. Importantly, while these indeed allow abstaining from health care interventions that may save people's lives, this can be more easily defended from the perspective of erring on the side of non-violation of a person's bodily integrity, in situations of uncertainty about current wishes.

When we are dealing with MAID, the situation is reversed: implementing an AR for MAID involves an active intervention that most definitely intrudes upon a person's physical integrity. In the absence of consent, such an invasion of bodily integrity is in law an assault. Abstaining from health care interventions without consent, even if it results in death, is never assault. This makes respect for ARs for MAID fundamentally different from respecting advance directives in standard medical care.

The International Convention on the Rights of Persons with Disabilities explicitly recognizes in article 12 the inherent legal capacity of persons with cognitive disabilities. This implies a duty to enable expressions of current interest.

Evidence from the Netherlands, the only jurisdiction that allows euthanasia of persons with advanced dementia who are still conscious, shows what implementing ARs for MAID requires. It inevitably involves third-party consent and evaluation of the person's suffering. It usually involves surreptitious medicating patients to suppress resistance; and then actively ending life. Contrary to withholding treatment, it involves an active invasion of a person's bodily integrity. Surreptitious medicating and suppressing resistance fundamentally violate ethical norms and run counter to the duty to enable an expression of current interests of cognitively disabled persons, which the International Convention requires. It moves us into involuntary ending of life.

It further confirms in law the view that life with cognitive disability involves loss of dignity. Once we agree in a legal regime that this is appropriate for persons with dementia, even if it is on the basis of prior consent, we make a collective statement about the value of the life of persons with cognitive disabilities who cannot--or no longer--consent. This violates a core foundation of human rights: the recognition of the universal and equal value of all human beings.

I urge the committee to obtain a translation of a recent article by Belgian and Dutch experts (many if not all in support of legalized euthanasia) who argue, with comprehensive arguments and up to date evidence, why "advanced directives for euthanasia... are not easy to implement in an optimized dementia care pathway."¹ Belgium legalized euthanasia in 2002. Twenty years later, and informed by the practice in the neighbouring country, it still has not expanded its AR regime for MAID.

Our current MAID regime already goes beyond Belgian law while our social and health care support is below the OECD average. The Dutch experience reveals that ARs for MAID create insurmountable ethical and legal concerns. We need instead to invest in health care and social support that promotes the human rights of all, including those with cognitive disability.

¹ J. Versijpt, P. Crass, L. Dewitte, JJM. van Delden & C. Gastmans, "Euthanasie bij dementia middels een voorafgaande wilsverklaring: een reflectie vanuit België en Nederland"