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## The Waxing & Waning of Informed Consent: Medical Assistance in Dying and the Question of Advance Requests

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## Abstract

This paper traces the impact of the principle of informed consent on Canadian legal developments in the area of advance directives, medical assistance in dying (MAID), and (where the two converge) advance requests in the context of MAID. I show how recognition of the principle of informed consent has not only served to justify developments in the law facilitating advance directives; it has also played an important role in justifying the legalization, under specific circumstances, of MAID. The paradigmatic case of informed consent is where a clearly competent, fully informed adult effectively communicates with their physician, contemporaneously to the administration of treatment. Deviation from these conditions raises questions about how to apply the principle. I examine the claim that the ascendance of the informed consent principle has eclipsed other principles while obscuring the role that the professional judgment of physicians plays in the provision of medical treatment. I analyse this claim in relation to conflicts over prolongation of so-called futile treatment and access to MAID. I then argue why the capacity requirement, barring advance requests for MAID, is justified.

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# The Waxing & Waning of Informed Consent: Medical Assistance in Dying and the Question of Advance Requests

THOMAS B. MCMORROW\*

This paper traces the impact of the principle of informed consent on Canadian legal developments in the area of advance directives, medical assistance in dying (MAID), and (where the two converge) advance requests in the context of MAID. I show how recognition of the principle of informed consent has not only served to justify developments in the law facilitating advance directives; it has also played an important role in justifying the legalization, under specific circumstances, of MAID. The paradigmatic case of informed consent is where a clearly competent, fully informed adult effectively communicates with their physician, contemporaneously to the administration of treatment. Deviation from these conditions raises questions about how to apply the principle. I examine the claim that the ascendancy of the informed consent principle has eclipsed other principles while obscuring the role that the professional judgment of physicians plays in the provision of medical treatment. I analyse this claim in relation to conflicts over prolongation of so-called futile treatment and access to MAID. I then argue why the capacity requirement, barring advance requests for MAID, is justified.

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\* Associate Professor of Legal Studies, Ontario Tech University. I presented an early version of this article at the Third International Conference on End-of-Life Law, Ethics, Policy, and Practice in Ghent, Belgium in March 2019. I thank Benjamin Berger, Steffen T. de Kok, Cinzia Piciocchi, Richard Scott, L.W. Sumner, Sabrina Tremblay-Huet, and Ellen Wiebe, as well as the external reviewer and editors of the Osgoode Hall Law Journal, for their insights. Any faults are mine, of course. This article reflects the state of the law in Canada on March 11 2021. Bill C-7 was enacted and received royal assent on March 17 2021.

I.	THE PRINCIPLE OF INFORMED CONSENT .....	291
II.	ADVANCE DIRECTIVES .....	298
III.	IMPORTANCE OF INFORMED CONSENT IN JUSTIFYING ACCESS TO MAID .....	309
IV.	ADVANCE REQUESTS FOR MAID .....	318
V.	CONCLUSION .....	327

**IT IS A BASIC REQUIREMENT OF CANADIAN LAW** that patients must consent to receive medical treatment.<sup>1</sup> This principle reflects the public value placed on the protection of personal autonomy and bodily integrity.<sup>2</sup> How well application of the principle of informed consent approximates these values depends on the circumstances.<sup>3</sup> An unconscious person (or an individual who has otherwise lost their decision-making capacity) will not be able to contemporaneously consent to treatment. For this reason, the law permits individuals to prospectively issue instructions, appoint a trusted individual to give or refuse medical treatment on their behalf, or both.<sup>4</sup> Where a person lacks capacity, but has not issued treatment directives or named a surrogate in advance, the law may assign a substitute

1. A health care professional who performs a medical intervention without the patient's consent may be found, in criminal law, guilty of assault, or held civilly liable for battery. See *Criminal Code*, RSC 1985, c C-46, s 265 [*Criminal Code*]; *Malette v Shulman et al.*, (1990) 67 DLR (4th) 321 (Ont CA) [*Malette*].
2. See Joan Gilmour, "Legal Capacity and Decision-Making" in Joanna Erdman, Vanessa Gruben & Erin Nelson, eds, *Canadian Health Law and Policy*, 5th ed (LexisNexis Canada, 2017) cited in Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying: Expert Panel Working Group on Advance Requests for MAID" (2018), online (pdf): <cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf> at 30 [CCA, "Advance Requests"].
3. See *Fleming v Reid*, (1991) 82 DLR (4th) 298 (Ont CA) [*Fleming*].
4. This article focuses on the legislation in Ontario, which establishes the Health Care Consent and Capacity Board (CCB), an independent administrative tribunal that adjudicates conflicts over patient consent and capacity. The Ontario legislation shares many general features with other Canadian provincial and territorial laws, such as default rules for determining a proxy or substitute decision-maker where the patient has not designated one already. See *Health Care Consent Act*, 1996 SO 1996, c 2 Sched A [*HCCA*]; *Healthcare Directives Act*, CCSM 1993, c H27 [*Manitoba*]; *The Healthcare Directives and Substitute Healthcare Decision Makers Act, 2015*, SS 2015, c H-0.002 [*Saskatchewan*]; *Personal Directives Act*, RSA 2000, c P-6 [*Alberta*]; *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181 [*British Columbia*]; *Civil Code of Quebec*, SQ 1991, c 64 [*Québec*]; *Consent to Treatment and Healthcare Directives Act*, RSPEI 1988, c C-17.2 [*PEI*]; *Advance Health Care Directives Act*, SNB 2016, c 46 [*New Brunswick*]; *Advance Healthcare Directive Act*, SNL 1995, c A-4.1

decision-maker (SDM).<sup>5</sup> However, when medical assistance in dying (MAID) was legalized in Canada, patients were not permitted to provide their consent in advance. Neither could anybody else consent to MAID on the patient's behalf.

The 2016 MAID law, which modified the blanket prohibition in the *Criminal Code* on voluntary euthanasia and assisted suicide, states that “the medical practitioner or nurse practitioner must immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying.”<sup>6</sup> While part of the rationale behind the requirement is to prevent the possibility of patients receiving MAID against their wishes,<sup>7</sup> an inevitable consequence is that those who want MAID will not be able to get it once they lose capacity.<sup>8</sup> The loss of capacity may owe to the progression of an

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[*Newfoundland*]; *Personal Directives Act*, SNS 2008, c 8 [*Nova Scotia*]; *Personal Directives Act*, SNWT 2005, c 16 [*Northwest Territories*].

5. *HCCA*, *supra* note 4, ss 9, 20(1); *Manitoba*, *supra* note 4, ss 12-15; *Saskatchewan*, *supra* note 4, ss 11-16; *Alberta*, *supra* note 4, s 1(a); *British Columbia*, *supra* note 4, s 11(b); *Québec*, *supra* note 4, s 11; *PEI*, *supra* note 4, ss 11, 24(2); *New Brunswick*, *supra* note 4, s 20; *Newfoundland*, *supra* note 4, ss 10-11; *Nova Scotia*, *supra* note 4, s 14; *Northwest Territories*, *supra* note 4.
6. *Criminal Code*, *supra* note 1, s 241.2(3)(h). See also Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (medical assistance in dying)*, 1st Sess, 42nd Parl, 2016 (assented to 17 June 2016), SC 2016, c 3 [Bill C-14].
7. CCA, “Advance Requests”, *supra* note 2 at 176.
8. See Dena S Davis, “Alzheimer Disease and Pre-emptive Suicide” (2014) 40 *J Med Ethics* 543 [Davis, “Alzheimer”]. See also Stephen R Latham, “Living Wills and Alzheimer’s Disease” (2010) 23 *Quinnipiac Prob LJ* 425; Dennis R Cooley, “A Kantian Moral Duty for the Soon-to-Be Demented to Commit Suicide” (2007) 7 *Am J Bioethics* 37; Michael Wolff, “A Life Worth Ending” *New York Magazine* (28 May 2012). Cf Rebecca Dresser, “Precommitment: A Misguided Strategy for Securing Death with Dignity” (2003) 81 *Texas L Rev* 1823 [Dresser, “Precommitment”]; John A Robertson, “Second Thoughts on Living Wills” (1991) 21 *Hastings Center Rep* 6; Sanford H Kadish, “Letting Patients Die: Legal and Moral Reflections” (1992) 80 *Cal L Rev* 857; Gilbert Meilaender, “I Want to Burden my Loved Ones” *First Things* (October 1991) at 25. See also Jocelyn Downie & Georgia Lloyd-Smith, “Assisted Dying for Individuals with Dementia: Challenges for Translating Ethical Positions into Law” in Michael Cholbi & Jukka Varelius, eds, *New Directions in the Ethics of Assisted Suicide and Euthanasia* (Springer, 2015) 97.

incurable somatic illness (or the medication prescribed to control the resulting pain), a neurodegenerative condition, or an irreversible, catastrophic injury.<sup>9</sup>

To shed light on the question of Canadian law restricting access to MAID through advance request, this article identifies how the principle of informed consent has served to justify developments in the law's facilitation of advance directives as well as access to MAID. Part I situates the principle of informed consent, then examines the claim that its ascendance has eclipsed the role that the professional judgment of physicians plays in the provision of medical treatment. Part II considers this claim in relation to conflicts over the prolonging of so-called futile treatment.<sup>10</sup> The review exposes the potential for conflict intrinsic to end-of-life decision making for incompetent patients, as well as key features of one statutory regime intended to help prevent and resolve such conflicts, Ontario's *Health Care Consent Act (HCCA)*.<sup>11</sup> This framework, including the decision-making body it creates, the Health Care Consent and Capacity Board (CCB), has its strengths and limitations. Importantly, though, it illustrates the value of trying to establish a transparent and legitimate process for making decisions about when to withhold or withdraw life-sustaining treatment for incompetent patients.

Part III considers the claim in relation to the controversy surrounding access to MAID. The primacy of informed consent—and the values of protection of personal autonomy and bodily integrity that it reflects—is thoroughly woven through justifications for complying with advance directives, as well as fulfilling eligible requests for MAID. But the transition from following clear, competent treatment requests or refusals (made in the past) to providing MAID

9. See Québec, Ministère de la Santé et des Services sociaux, *L'aide médicale à mourir pour les personnes en situation d'incapacité : le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence*, (Report) (Gouvernement du Québec, 29 November 2019) at 37, online (pdf): <publications.msss.gouv.qc.ca/msss/fichiers/2019/19-828-04W.pdf> [*Québec Report*] (noting two other groups of people who may lack capacity to request MAID: those who already lack capacity due to an intellectual disability and those whose mental health condition renders them either permanently or temporarily incapable of providing valid consent).
10. See Paulina Kyriakopoulos, Mark Fedyk & Michel Shamy, "Translating Futility" (2017) 189 CMAJ E805 (distinguishing instances where treatment has zero chance of working, such as "using orange juice as an anticoagulant" and instances where one is making a judgment based on probabilistic, and at the same time, necessarily ethical, reasoning) at E805. See also Cheryl Misak, Douglas White & Robert Truog, "Medically Inappropriate or Futile Treatment: Deliberation and Justification" (2016) 41 J of Med & Phil 90 (discussing how views on medically inappropriate or futile treatment can and should relate to medical and societal standards, norms and values).
11. *HCCA*, *supra* note 4.

to patients lacking legal capacity (in the present) is not seamless. Advance and contemporaneous consent are not identical; neither is actively terminating a patient's life versus letting them die. But they are certainly similar. Indeed, Canadian jurisprudence makes it clear that in neither case is an absolute distinction tenable. My point is that it is impossible to detect when and how relevant distinctions arise (either between the two ways to consent or the two ways to die), if one is convinced that they are either always the same or always different, no matter what.

Part IV explains why the capacity requirement, barring advance requests for MAID, is justified. Entitling this article “the waxing and waning of informed consent” is meant to signal that—as illuminating as the principle is when grappling with the question of regulating access to MAID through advance consent—there is only so much light it can shed. Likewise, there is only so much decisional autonomy a person may reasonably expect to project into the future on the strength of instructions written in the past. Respecting a person's personal autonomy and bodily integrity requires more ethical imagination and decisional flexibility than is reducible to the imposition of a legal duty on a MAID provider to follow their patient's written instructions to terminate their life on an appointed date. The loss of legal capacity does not mean a person's interest in living, and indeed their right to life, diminishes. There is a pressing public interest in ensuring the law keeps it that way. The contemporary consent requirement constitutes a principled approach to regulating access to medical assistance in dying.

Lastly, Part V underscores the flaws in current proposals to change the law. If the law is to allow MAID through advance requests, the precise manner in which it does so matters enormously. Who has the authority to make life-ending decisions for patients when they lose capacity, as well as what rules, duties, and principles ought to guide such decisions, are crucial and complex questions. If the law is to permit advance requests for MAID without paying careful attention to these questions in deliberating over regulatory design, then the frequency, intensity, and complexity of the resulting conflicts will increase and intensify accordingly. Bill C-7, currently before Parliament, is not satisfactory in this regard.<sup>12</sup>

## I. THE PRINCIPLE OF INFORMED CONSENT

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12. *An Act to amend the Criminal Code (medical assistance in dying)*, 2nd Sess, 43rd Parl, 2021 (third reading 11 March 2021) [Bill C-7].

The principle of informed consent is central to the Canadian law governing end-of-life decision-making, since it provides “the primary paradigm for protecting the legal rights of patients and guid[es] the ethical practice of medicine.”<sup>13</sup> In effect, consent is “the vehicle that gives legal authority to individual healthcare decisions.”<sup>14</sup> To be valid, it must be given voluntarily by a person with capacity. Having capacity is not a zero sum equation, since the law recognises that those “incapable to make decisions regarding certain matters might still have sufficient mental capacity to give valid consent to medical treatment.”<sup>15</sup> Crucial is “whether the patient is able to appreciate adequately the nature of the proposed treatment, its anticipated effect and the alternatives.”<sup>16</sup> One cannot really consent if one does not possess the information necessary to know what it is to which one is consenting; thus, physicians have a duty to ensure that the patient’s consent is informed.<sup>17</sup> The principle of informed consent requires the patient’s physician to disclose the risks involved in the treatment, not just the physician’s assessment that the probable benefits outweigh the risks. After all, the patient might reach

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13. Daniel E Hall, Allan V Prochazka & Aaron S Fink, “Informed consent for clinical treatment” (2012) 184 CMAJ 533 at 533.

14. CCA, “Advance Requests”, *supra* note 2 at 50.

15. Kenneth Evans, “Consent: A Guide for Canadian Physicians” (2016), online: *Canadian Medical Protective Association* <[www.cmpa-acpm.ca/en/advice-publications/handbooks/consent-a-guide-for-canadian-physicians#capacity%20to%20consent](http://www.cmpa-acpm.ca/en/advice-publications/handbooks/consent-a-guide-for-canadian-physicians#capacity%20to%20consent)>; HCCA, *supra* note 4, s 4(1). Section 4(1) states that:

[a] person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

See also *Mental Health Act*, RSO 1990, c M7; *Substitute Decisions Act*, 1992, SO 1992, c 30. These statutes govern, respectively, “examinations of capacity to manage property upon admission to or discharge from a psychiatric facility...” and “Capacity Assessments regarding the ability to make decisions regarding property or personal care.” Law Commission of Ontario, “Assessing Legal Capacity: Improving Quality and Consistency” (2017), online: <[www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/final-report/5-assessing-legal-capacity-improving-quality-and-consistency](http://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/final-report/5-assessing-legal-capacity-improving-quality-and-consistency)>.

16. Evans, *supra* note 15.

17. See *Starson v Swayze*, 2003 SCC 32.

a different conclusion about whether the proposed treatment is worth it.<sup>18</sup> The choice to give or refuse consent belongs to the patient alone; so long as the patient has decision-making capacity and is acting voluntarily, the decision is theirs.

Thus, respecting the principle of informed consent means recognizing patient autonomy and resisting the presumption that “physician knows best.” The requirement stems, however, from deeper, more grave concerns than the mere risk of patients feeling patronized by their doctors. Robert Burt traces the roots of the concept in U.S. jurisprudence to the *Nuremberg Code*,<sup>19</sup> which declares that “the voluntary consent of the human subject is absolutely essential” when conducting medical research.<sup>20</sup> The U.S. war tribunal that drafted the code heard evidence that Nazi doctors conducted experiments to determine at which level of altitude prisoners’ lungs would explode, at what temperature they would freeze to death, and how long, left untreated, their burns would take to kill them.<sup>21</sup> It may seem extraordinary that in the face of such depraved and horrific crimes, the tribunal should respond: “The basic problem with these experiments is that the subjects did not agree to participate.”<sup>22</sup> And yet, as Burt explains, the tribunal came to the conclusion that absent “the individual subject-patient armed with the principle of self-determination”<sup>23</sup> no other criteria would offer an equal defence against doctors committing—and legal authorities condoning—such heinous acts in the name of science and medicine.

In this way, the principle of informed consent is a concept born of necessity: the need for some normative bulwark against members of the medical profession putting their power to destructive use against individual human beings. Consequently, Burt argues, the ideal of personal choice, autonomy, and self-determination has come to bear the normative weight that the professional

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18. See *Reibl v Hughes*, [1980] 2 SCR 880 at 895. It is noted that

[t]o allow expert medical evidence to determine what risks are material and, hence, should be disclosed and, correlatively, what risks are not material is to hand over to the medical profession the entire question of the scope of the duty of disclosure, including the question whether there has been a breach of that duty.

19. Robert Burt, *Death is that Man Taking Names: Intersections of American Medicine, Law, and Culture* (University of California Press, 2002) at 81. See also “Permissible Medical Experiments” in *Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10*, vol 2 (US Government, 1949) 181 [“Permissible Experiments”].

20. “Permissible Experiments”, *supra* note 19 at 181.

21. Burt, *supra* note 19 at 84.

22. *Ibid.*

23. *Ibid* at 85.

authority of physicians once did.<sup>24</sup> The informed consent requirement therefore functions as a shield. Like any defence mechanism, however, its utility is limited and contingent. Too much stress on the question of consent provides the rather curious framing of the patient's experience as primarily one of choice. People may choose to see a doctor, but seldom would they choose to get sick. Indeed, when it comes to one's health, the power to choose is intrinsically limited. For example, individual decisions intended to hasten death or to prolong life do nothing to change the fact that, in the end, death takes everyone.

Not all patients are equally self-reliant; some patients may require more ongoing support and communication from their healthcare providers to ensure they are exercising their decision-making autonomy in a meaningful way. Just because a patient has said "yes" (or signed a declaration to that effect) upon hearing the risks the proposed treatment involves, it does not mean they fully understand to what they have agreed.<sup>25</sup> If physicians adopt an overly rigid, mechanistic approach to respecting an abstract principle, individual patients may end up feeling abandoned to their own devices. This is one reason why James Downar et al stress that "[c]onsent is a process, not an event";<sup>26</sup> moreover, Cathy Charles et al go so far as to advocate for a "shared treatment decision-making model," which calls for physicians to take a flexible, dynamic, and interactive approach when responding to "individual differences in patient preferences."<sup>27</sup>

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24. *Ibid* at 83.

25. See Joseph C Lee, Sara H Thorn & Jia Wen Chong, "Patient Consent and Genuine Understanding" (2017) 47 *Internal Med J* 714 at 714 (observing "that resident medical officers tasked with obtaining patient consents often have a minimal understanding about the procedure the patient will be undergoing – and signing consent forms for"); Jürgen JW Muslow, T Martin Feeley & Sean Tierney, "Beyond Consent: Improving Understanding in Surgical Patients" (2012) 203 *Am J Surgery* 112 at 113 (noting that clinicians routinely presume patient understanding rather than formally assess it); Dena S Davis, "Opportunistic Testing: The Death of Informed Consent?" (2013) 23 *Health Matrix* 35 at 54 (noting that the more routinized the procedure, then the more rushed and pro forma the process for obtaining consent, and the less "opportunity for thoughtful informed consent").

26. James Downar et al, "Withholding and withdrawing treatment in Canada: Implications of the Supreme Court of Canada's decision in the Rasouli case" (2014) 186 *CMAJ* E622 at E625 [Downar et al, "Rasouli"].

27. Cathy Charles, Amiram Gafni & Tim Whelan "Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model" (1999) 49 *Soc Sci & Med* 651 at 651. Indeed, Carl Schneider writes: "Bioethics has routinely fobbed patients off with assurances that they are autonomous and will be guided by their own 'values.' Patients who want help thinking through their ethical obligations may generally look elsewhere." Carl Schneider "After Autonomy" (2006) 41 *Wake Forest L Rev* 411 at 442.

The ascendance of the “informed consent” principle risks eclipsing the larger context that informs medical decision-making. According to the principle of unqualified primacy, the active and creative role that physicians play in interpreting and applying it in practice.<sup>28</sup> Consent conditions the manner in which a physician provides care; it also reflects care for the human being receiving treatment. Healthcare professionals exercise their clinical and ethical judgment in circumstances subject to material and temporal constraints. The practice of medicine is not reducible to the satisfaction of patient preferences.<sup>29</sup> Patients do not have a right to any treatment they want. Indeed, the ethical duties of physicians extend beyond non-interference with patient autonomy. Doctors must offer treatment they consider to be clinically indicated or, in other words, medically beneficial.<sup>30</sup> This does not mean, however, that doctors have the legal authority to act unilaterally or that the law reduces all treatment decisions to clinical appraisals of medical benefit. On the contrary, conflicts over

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28. See Hilary Young, “A Proposal for Access to Treatment Contrary to Clinical Judgment” (2017) 11 McGill JL & Health 1 at 39-40, 57 [Young, “Contrary to Clinical Judgment”] (arguing in favour of a “role for paternalism in a demand context, notwithstanding the fact that in law there is virtually none in the refusal context,” while contending that “the law of informed consent should not dictate the outcome of disputes between physicians and patients or SDMs about whether certain treatment should be provided”); James Downar, Michael Warner & Robert Sibbald, “Mandate to obtain consent for withholding nonbeneficial cardiopulmonary resuscitation is misguided” (2016) 188 CMAJ 245. See also Edmund D Pellegrino, “Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship” (1994) 10 J Contemp Health L & Pol’y 47.
29. Such a state of affairs would reflect a client-based, service industry model of medicine—one that displaces the ethos of healing with a culture of “the customer is always right,” which, as Young notes, would result in giving capable patients whatever they want, “including antibiotics for a viral infection and opiates when they are not in pain.” Young, “Contrary to Clinical Judgment”, *supra* note 28 at 40. See also Edmund D Pellegrino, “The Internal Morality of Clinical Medicine: A Paradigm for the Ethics of the Helping and Healing Professions” (2001) 26 J Medicine & Philosophy 559 (discussing the nature of the clinical encounter and the kind of relationship that arises between physician and patient, thus grounding ethical obligations in a manner that is distinct from, say, a commercial transaction).
30. *Cuthbertson v Rasouli* 2013 SCC 53 at para 173 [*Rasouli*] (noting that, “[i]n my view, there is no general common law right or entitlement to treatment that a doctor considers medically ineffective or contrary to the professional standard of care”).

the withdrawal of treatment from patients who have lost capacity show how controversial such matters can be.<sup>31</sup>

Indeed, the legal principle of informed consent has made in-roads into certain domains of decision-making over which many physicians would have hitherto considered themselves sovereign.<sup>32</sup> The Supreme Court of Canada (SCC)'s 2013 decision in *Rasouli*,<sup>33</sup> that physicians do not possess the authority to *unilaterally* withdraw life support from a patient when they believe such a decision is medically indicated, established the authority of Ontario's CCB to settle disagreements over health care interventions between SDMs and physicians, which the latter deem

31. See Hilary Young, "Why Withdrawing Life-Sustaining Treatment Should Not Require 'Rasouli Consent'" (2012) 6 McGill JL & Health 54; Joan Gilmour, "Death, Dying and Decision-Making About End of Life Care" in Jocelyn Downie, Timothy Caulfield & Colleen M Flood, eds, *Canadian Health Law and Policy*, 4th ed (LexisNexis, 2011) 385; Glen Rutland, "Futile or Fruitful: The Charter and the Decision to Withhold or Withdraw Life-Sustaining Treatment" (2009) 17 Health LJ 81; Jocelyn Downie, "Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment: A Violation of Dignity Under the Law in Canada" (2004) 20 J Palliative Care 143.
32. See Downar et al, "Rasouli", *supra* note 26. See also David Cape et al, "The Impact of the Rasouli Decision: a Survey of Canadian intensivists" (2016) 42 J Medical Ethics 180. For example, in 2016, the College of Physicians and Surgeons of Ontario revised their end-of-life decision-making policy to require physicians to obtain consent to withhold cardiopulmonary resuscitation. Downar, Warner, and Sibbald criticize the College's policy revision because it effectively mandates doctors to provide CPR in cases where they judge it to be medically inappropriate. Downar, Warner & Sibbald, *supra* note 28. The College's introduction of the policy followed a recommendation of the Health Professions Appeal and Review Board, which found that the College's disciplinary committee had not adequately addressed an allegation of physicians implementing a Do Not Resuscitate Order contrary to a substitute decision-maker's "Full Code" instructions. The CCB found that the *HCCA* governs the decision to withhold life-sustaining treatment, just as the SCC held that it governs the decision to withdraw such treatment. *EGJW v MGC*, 2014 CanLII 49888 (Ont HPARB) at para 51 (stating "[i]n the Board's view, the Court's remarks apply equally to the withholding of treatment and a withdrawal of treatment"). However, the Superior Court of Ontario has held, in relation to the medical malpractice suit involving the same parties in the disciplinary board decision, that a physician's decision to no longer offer a treatment they viewed as medically inappropriate is distinguishable from withholding a treatment within a patient's plan of treatment. Were it not, the patient would be "able to pick and choose their own treatment." *Wawrzyniak v Livingstone*, 2019 ONSC 4900 at paras 223-24. Cf. Jocelyn Downie, Lindy Willmott & Ben P White, "Next Up: A Proposal for Values Based Law Reform on Unilateral Withholding and Withdrawal of Potentially Life Sustaining Treatment" (2017) 54 Alta L Rev 803 at 811-12; Chris Kaposy et al, "The Distinction Between Withholding and Withdrawing Treatment in Rasouli: Providing a Solution to an Ethical Problem" (2014) 21 Health LJ 29.
33. Downar et al, "Rasouli", *supra* note 26.

to have no medical benefit.<sup>34</sup> *Rasouli* involved an SDM (the wife of Mr. Rasouli, who had been in a persistent vegetative state for three years) refusing to consent to the withdrawal of life support.<sup>35</sup> The patient's physicians argued *inter alia* that consent was not required because, for an intervention to constitute medical treatment it had to be medically indicated, and for it to be so indicated, there had to be some medical benefit.<sup>36</sup> In this case, the doctors maintained there was no medical benefit to maintaining life support, so the decision to take Mr. Rasouli off life support did not constitute treatment and therefore ought not to require his SDM's consent.<sup>37</sup> The SCC held, however, that evidence of medical benefit was not necessary to trigger the principle of informed consent; on the Court's interpretation of the applicable provincial legislation, consent was required for any intervention undertaken for a "health-related purpose."<sup>38</sup> Where consent could not be obtained, resort had to be made to the CCB, the body created and empowered by statute to settle these kinds of disputes.<sup>39</sup>

With consent as the vehicle delivering authority to individual health decisions, if the patient no longer has the capacity to personally direct the process, then their SDM takes control. The SDM's decisions are meant to embody the patient's autonomy.<sup>40</sup> The patient's previously expressed wishes exercise considerable force. Notably, there are limits to the decisional power SDMs have. The relationship between informed consent, proxy decision-makers, and the patient's prior expression of treatment wishes will be addressed next in the discussion of advance directives.

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34. Prior to *Rasouli*, the Royal Society of Canada Expert Panel noted the law was unsettled, citing cases supporting the authority of physicians to act unilaterally and others casting doubt on it. See Udo Schüklenk et al, "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) 25 *Bioethics* 1 at 24-25. Providing an update on the RSC's 2011 report, see L Wayne Sumner et al, *End-of-Life Decision Making: Policy and Statutory Progress (2011-2020)* (Royal Society of Canada, 2020) at 19 (noting that "much remains legally unsettled with respect to the authority of a physician to make a unilateral decision to withhold or withdraw treatment").

35. *Rasouli*, *supra* note 30.

36. *Ibid.*

37. *Ibid.*

38. See *HCCA*, *supra* note 4, s 21(1).

39. See Jocelyn Downie & Michael Hadskis, "In Defence of Consent and Capacity Boards for End-of-Life Care" (2014) 61 *Can J Anesthesia* 899. Cf Robert Sibbald, Paula Chidwick & Laura Hawryluck, "Standard of Care and Resource Implications of the *Cuthbertson v. Rasouli* Ruling" (2014) 186 *CMAJ* 327.

40. CCA, "Advance Requests", *supra* note 2.

## II. ADVANCE DIRECTIVES

Although the paradigmatic case of informed consent is that of a competent patient expressing their wishes immediately prior to treatment, cases of patient incapacity or unconsciousness make such contemporaneous communication of informed consent impossible. To address this problem, advance directives may be created which express treatment preferences, designate an SDM in the event a person loses decision-making capacity, or both.<sup>41</sup> Given the distinct heads of power assigned to federal and provincial law-makers, healthcare is primarily in the jurisdiction of provinces, but criminal law lies in federal hands.<sup>42</sup> Accordingly, what constitutes a crime, in the context of end-of-life decision-making, applies across the country, but the protocols, processes, and procedures for determining consent and capacity in each provincial health care system may vary. In a given province, there may be (as one court has described it) “a veritable thicket” of interlocking statutes and regulations with implications for advance directives.<sup>43</sup> Notwithstanding these variations, the general principle “that the prior-expressed wishes of previously competent adults should be respected when it comes to end-of-life decision-making” is reflected across all provinces and territories.<sup>44</sup>

Across Canada, the law recognises that a competent, informed adult patient may refuse medical treatment in advance, even when their physician believes that treatment is “clinically indicated” or “medically appropriate.” For example, the law recognises that a patient may refuse a blood transfusion even if, absent that medical intervention, the patient will die. In *Malette v. Shulman*, the Ontario Court of Appeal upheld a decision finding a physician liable for battery because he administered a blood transfusion to an unconscious patient in a life-threatening situation even though it had come to his attention that she was carrying a card in her purse that stated “No Blood Transfusions...under any

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41. *Ibid* at 37. Instruction directives (stating treatment preferences) are also known as living wills, whereas proxy directives (designating an SDM) are also called durable powers of attorney for healthcare. Terms for advance directives vary across Canada (*e.g.*, healthcare directives in Manitoba and personal directives in Nova Scotia). See *supra* note 4 (outlining the various legislative schemes addressing advance directives across the country).

42. *Constitution Act, 1867*, 30 & 31 Victoria, c 3 (UK), ss 91-92. See Alana Klein, “Jurisdiction in Canadian Health Law” in Joanna N Erdman, Vanessa Gruben & Erin Nelson, eds, *Canadian Health Law and Policy*, 5th ed (LexisNexis Canada, 2017) 29. Provincial power over health does not preclude Parliament from legislating on MAID because health is in fact “an area of concurrent jurisdiction.” *Carter v Canada (Attorney General)*, 2015 SCC 5 at para 53 [*Carter* SCC].

43. See *Bentley v Maplewood Seniors Care Society*, 2015 BCCA 91 at para 5 [*Bentley* BCCA].

44. See Udo Schüklenk et al, *supra* note 34 at 23.

circumstances,” on the basis of her religious convictions as a Jehovah’s Witness.<sup>45</sup> At trial, the physician noted that he had doubts as to whether the signed but undated card provided a sufficient basis to refuse treatment. Unable to confirm that the patient’s refusal to consent to treatment was informed or that her refusal had not arisen from family or peer pressure, the physician chose not to rely on it. The trial judge found that “Dr. Schulman’s doubt about the validity of the card, although honest, was not rationally founded on the evidence before him.”<sup>46</sup> The Court of Appeal noted that if the patient could not have issued such a refusal in anticipation of such a medical emergency she would have had no way to ensure her religious beliefs were respected; thus, the court ruled that “[a] doctor is not free to disregard a patient’s advance instructions any more than he would be free to disregard instructions given at the time of the emergency.”<sup>47</sup> Although Canadian common law recognises the right to refuse treatment, even by advance directive, it also acknowledges a difference between refusing and demanding specific medical treatment.<sup>48</sup>

Furthermore, acute challenges arise when the patient has lost decision-making capacity but their prior competent wishes are not evident. The advance directive may not lay out the patient’s preferences very clearly, or the difficulty may lie in determining whether the wishes as expressed still apply in the present circumstances. For example, did the patient change their mind since writing the directives? Are the present circumstances what the patient had in mind when

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45. See *Malette*, *supra* note 1. There is not, however, a right to receive whatever medical treatment one demands if that treatment has no medical benefit. See Young, “Contrary to Clinical Judgment”, *supra* note 28; Downie, Willmott, & White, *supra* note 32 at 826 (arguing no duty to provide treatment that does not work).

46. *Malette*, *supra* note 1 at 44. But see Norman Siebrasse, “Malette v. Shulman: The Requirement of Consent in Medical Emergencies” (1989) 34 4 McGill LJ 1080 at 1098. Siebrasse argues that:

in a pressing emergency, such as that faced by Dr. Shulman, it seems clearly unreasonable, especially in view of the reaction of judges [in a number of cases in the United States] when faced with conscious and contemporaneous refusals, to ask a doctor to overcome training and instinct to rely on a refusal card, even if it would seem in retrospect to represent the true wishes of the patient.

47. *Malette*, *supra* note 1 at 14. But see Siebrasse, *supra* note 46 at 1095, citing *US v George* 239 FS 752 (noting that in *US v. George*, the patient refusing consent to a blood transfusion nevertheless assented to the procedure once the judge had authorized it, indicating that, with the court order signed, “his conscience would be clear and he would not resist the transfusion in any way”).

48. See Young, “Contrary to Clinical Judgment”, *supra* note 28; Downie, Willmott, & White, *supra* note 32 at 826.

they provided their directives, or were they not anticipating this situation and therefore not addressing it in their instructions?

In *Rasouli*, where the SCC refused to give an order affirming any common law right of physicians to take their patient off life support, there was no relevant advance directive from Mr. Rasouli. His SDM's authority to refuse consent on his behalf blocked the physicians from unilaterally withdrawing life-sustaining treatment and from acting on their own professional medical judgment.

As noted, an SDM's authority is not absolute, however. The legislation provides that if the SDM "knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age," then the SDM must give effect to that wish.<sup>49</sup> This applies to any treatment including contraindicated treatments.<sup>50</sup> If the SDM does not know of any prior competent wish (or the wish expressed is impossible to comply with), then "the question for the substitute decision-maker is not what the patient would have decided in light of the change, but rather what is in the best interests of the patient."<sup>51</sup> If the health practitioner who proposed the treatment thinks that the SDM did not fulfill their obligations under section 21 of the *HCCA*, the health practitioner may apply to the CCB for a determination to this effect<sup>52</sup> and to direct the SDM to make the decision that, in the CCB's view, reflects the patient's best interests regarding the proposed treatment.<sup>53</sup>

The *HCCA* requires the SDM to consider several factors when deciding what is in the patient's best interests.<sup>54</sup> First is whether the treatment is likely to: (i) improve the incapable person's condition or well-being; (ii) prevent the incapable person's condition or well-being from deteriorating; or (iii) reduce the extent

49. *HCCA*, *supra* note 4, s 21(1).

50. *Ibid*, s 21(1)1; *Rasouli*, *supra* note 30 at paras 143-44 (noting "[t]here is no provision that gives the Board authority to permit a substitute decision-maker to ignore known wishes and to determine and act on the best interests of the patient if the patient, over the age of 16 years, expressed a clear and applicable wish" at para 148).

51. *HCCA*, *supra* note 4, s 21(1)2; *Conway v Jacques*, 214 DLR (4th) 67.

52. *HCCA*, *supra* note 4, s 37(1). See Robert W Sibbald & Paula Chidwick, "Best interests at end of life: A review of decisions made by the Consent and Capacity Board of Ontario" (2010) 25 J Critical Care 171.e1; Paula Chidwick & Robert Sibbald, "Physician Perspectives on Legal Processes for Resolving End-of-life Disputes" (2011) 14 Healthcare Q 69; Paula Chidwick, Robert Sibbald & Laura Hawryluck, "Best interests at end of life: an updated review of decisions made by the Consent and Capacity Board of Ontario" (2013) 28 J Critical Care 22; Laura Hawryluck, Robert Sibbald & Paula Chidwick, "The Standard of Care and conflicts at the End of Life in critical care: Lessons from medical-legal crossroads and the role of a quasi-judicial tribunal in decision-making" (2013) 28 J Critical Care 1055.

53. *HCCA*, *supra* note 4, s 37(3).

54. *Ibid*, s 21(2).

to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate. The second factor is whether the incapable person's condition or well-being is likely to improve, remain the same, or deteriorate without the treatment. Third is whether the benefit that the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her. Finally, the SDM is required to consider whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

The provisions do not explicitly reference death, as the legislation applies to all medical treatment scenarios, not just the end-of-life context. Despite the general nature of the criteria and the wide variety of situations to which they may be applied, the SCC in *Rasouli* stressed the objective character of the best interests question:

The substitute decision-maker is not at liberty to ignore any of the factors within the best interests analysis, or substitute her own view as to what is in the best interests of the patient. She must take an objective view of the matter, having regard to all the factors set out, and decide accordingly.<sup>55</sup>

In the SCC's view, the SDM either gets the answer right or not; thus, "[t]he Board must apply a standard of correctness in reviewing the decision of the substitute decision-maker...[and] consider the matter de novo."<sup>56</sup> The SCC distinguishes, however, between this matter of correctness and "the correctness of the physicians' professional opinion that sustaining life...confers no medical benefit."<sup>57</sup> It notes that the CCB must "duly consider the physician's professional opinion and submissions on what would be of medical benefit to the patient,"<sup>58</sup> but the CCB has the authority to reach a decision that effectively compels physicians "to continue providing life support, even where they consider it to provide no medical benefit to, or even to harm, the patient."<sup>59</sup>

According to Downie, Willmott, and White, what may appear to be a drawback to Ontario's legislative approach actually speaks to one of its chief advantages: the law locates "the decision-making power with the patient and substitute decision-maker."<sup>60</sup> This demands that the doctor and health system engage with the SDM, by conveying information, responding to questions,

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55. *Rasouli*, *supra* note 30 at para 88.

56. *Ibid* at para 99.

57. *Ibid* at para 38.

58. *Ibid* at para 97.

59. *Ibid* at para 71.

60. Downie, Willmott & White, *supra* note 32 at 826.

and maintaining transparency.<sup>61</sup> It also underscores one of the *HCCA*'s most important objectives: "to promote communication and understanding between health practitioners and their patients or clients."<sup>62</sup> Furthermore, the burden of challenging a decision about the provision of treatment ends up falling on those in the best position to discharge it: the physician and health care institution, rather than the SDM or the patient.<sup>63</sup> Lastly, distinguishing the best interests standard from the question of medical benefit makes room for "non-clinical values, and limits the role of medicine and doctors accordingly."<sup>64</sup> That said, the authors insist that the right to request treatment contrary to medical benefit is not absolute: "There are circumstances in which a doctor should not be obliged to provide necessities of life and these should be clearly articulated."<sup>65</sup> Thus, in their view, authorization of the CCB "provides a lawful excuse" to health care professionals to depart from the requirement of patient or SDM consent; nevertheless, Downie, Willmott, and White do not describe how an authoritative decision-maker ought to determine when this lawful excuse should be applied.<sup>66</sup>

In the 2017 Ontario decision, *H.M.*, Presiding Member Nina Lister noted:

It is important to underscore a fundamental difference between a capable person making treatment decisions on his or her own behalf, and a SDM making decisions on behalf of an incapable person...[A] capable person has the right to make foolish or selfish decisions – this is an inviolable attribute of individual liberty and personal autonomy protected by our laws...In contrast, a SDM does not have the right to make unwise decisions on behalf of an incapable person; a SDM must make decisions in accordance with the principles of consent set out in the *HCCA*...If the SDM strays from the *HCCA* principles, the [CCB] is empowered to intervene and compel the SDM to comply with those principles, in accordance with Board's perception of the person's best interests, as revealed by the evidence.<sup>67</sup>

The SCC's extensive analysis of the *HCCA* in *Rasouli* has understandably impacted the way the CCB interprets the *Act*. Between the Court's decision in 2014 and November 2020, the CCB made seventeen decisions regarding whether an SDM complied with the principles outlined in the *HCCA* when refusing a treatment plan that omits all life-saving medical interventions for a

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61. *Ibid.*

62. *HCCA*, *supra* note 4, s 1(d).

63. Downie, Willmott & White, *supra* note 32 at 826.

64. *Ibid* at 825-26.

65. *Ibid* at 826-27.

66. *Ibid* at 827.

67. 2017 CanLII 34282 (ON CCB) at 28-29 [*HM (Re)*].

patient with irreversible and advanced neurological damage.<sup>68</sup> In six decisions, the CCB ruled that the patient's physician was not able to prove, on a balance of probabilities, that the SDM's refusal to consent to the physician's treatment proposal—to provide palliative care but abstain from life-sustaining medical interventions—contravened the legislative requirements.<sup>69</sup> In these cases, the CCB agreed with the SDM that it was in the patient's best interests to continue life-sustaining treatment, even though the physician contended that it would be of no medical benefit. Only one of the six cases involved an elderly person—in that case, a retired 86 year-old professor of medicine whom the CCB concluded had clearly expressed a competent wish to be resuscitated.<sup>70</sup> The other decisions involved an infant,<sup>71</sup> a 6 year-old,<sup>72</sup> a middle-aged father,<sup>73</sup> a young man in his 20s,<sup>74</sup> and a 36 year-old man with strong religious views.<sup>75</sup> In each case, the SDM's evidence, expectations, and perceptions conflicted with those of the medical team, contributing to the CCB's determination that the SDM had complied with the *Act*. In the eleven other cases, where the CCB ordered the

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68. *CN (Re)*, 2014 CanLII 53714 (ON CCB); *SS (Re)*, 2015 CanLII 44140 (ON CCB); *SL (Re)*, 2016 CanLII 46386 (ON CCB); *PS (Re)*, 2017 CanLII 34288 (ON CCB); *JEP (Re)*, 2017 CanLII 49299 (ON CCB); *NS (Re)*, 2017 CanLII 141943 (ON CCB); *LL (Re)*, 2017 CanLII 70035 (ON CCB); *HM (Re)*, *supra* note 67; *AH (Re)*, 2018 CanLII 119741 (ON CCB); *AC (Re)*, 2018 CanLII 57652 (ON CCB); *GL (Re)*, 2018 CanLII 132242 (ON CCB); *MO (Re)*, 2019 CanLII 110013 (ON CCB); *VB (Re)*, 2019 CanLII 47034 (ON CCB); *HC (Re)*, 2019 CanLII 47097 (ON CCB); *SH (Re)*, 2019 CanLII 79248 (ON CCB); *NA (Re)*, 2019 CanLII 129081 (ON CCB); *AW (Re)*, 2020 CanLII 32608 (ON CCB).

69. *CN (Re)*, *supra* note 68; *SS (Re)*, *supra* note 68; *PS (Re)*, *supra* note 68; *JEP (Re)*, *supra* note 68; *NS (Re)*, *supra* note 68; *MO (Re)*, *supra* note 68.

70. *JEP (Re)*, *supra* note 68.

71. *CN (Re)*, *supra* note 68.

72. *SS (Re)*, *supra* note 68.

73. *PS (Re)*, *supra* note 68.

74. *NS (Re)*, *supra* note 68.

75. *MO (Re)*, *supra* note 68.

SDM to consent to the withdrawal or withholding of life-sustaining treatment, the average age of the patients was considerably higher.<sup>76</sup>

In 2014, James Downar et al noted that “in the two years since the Rasouli decision...[the CCB] has been consulted for only three end-of-life cases, compared with 24 cases in the four years before the decision.”<sup>77</sup> Although there was a precipitous drop in cases immediately following *Rasouli*, the numbers have increased consistently. Further empirical research would be necessary to verify Downar et al’s conclusion that “[t]he Rasouli decision did not lead to more conflict resolution; it led to conflict avoidance and the provision of more aggressive life-sustaining therapy, even in cases to which the decision did not apply.”<sup>78</sup> More modestly, *Rasouli* may be interpreted as merely recognizing the CCB’s jurisdiction to hear end-of-life cases involving demands for treatment with no medical benefit. Since that SCC decision, however, the CCB has been interpreting the law differently. The contrast is evident in CCB Vice Chair Michael Newman’s decision in *JR (Re)*—made prior to the SCC ruling in *Rasouli*—and his subsequent decisions, which quote *Rasouli* extensively.

Thus, in the pre-*Rasouli* decision of *JR (Re)*, Vice Chair Newman notes that according to the *Act*, “only health practitioners...could propose Treatment, although patients or their substitute decision makers could suggest or request

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76. One of the eleven decisions does not state the patient’s age (although based on the information it may be inferred that they are a senior). See *AC (Re)*, *supra* note 68. The average age of the other ten patients is 73.5 years. See *AH (Re)*, *supra* note 68 at 22 (involving a 90-year-old woman whose son insisted on full code, stating “I will not change my plan under any circumstances & this is the wish of my mother”); *HM (Re)*, *supra* note 67 (involving an 81-year-old man); *LL (Re)*, *supra* note 68 (involving an 88-year-old man); *SL (Re)*, *supra* note 68 (involving a 92-year-old man); *GL (Re)*, *supra* note 68 (involving a 70-year-old woman); *VB (Re)*, *supra* note 68 (involving a 71-year-old woman); *HC (Re)*, *supra* note 68 (involving a 62-year-old woman); *SH (Re)*, *supra* note 68 (involving a 75-year-old woman); *NA (Re)*, *supra* note 68 (involving a 56-year-old man); *AW (Re)*, *supra* note 68 (involving a 50-year-old man). In all seventeen cases, the medical evidence was that the patient was never going to recover. In every case, also, one may detect a breakdown in communication and trust. One defensible reading of the difference between those decisions supporting the SDM and those that do not is that the reason for the communication breakdown and distrust did not owe to the actions of the SDM alone. Unsurprisingly, where the CCB found in the SDM’s favour, the actions and perspective of the SDM are portrayed more sympathetically than in decisions that came down the other way.

77. Downar, Warner & Sibbald, *supra* note 28 at 246.

78. *Ibid.* But see *Rasouli*, *supra* note 30; Laura Hawryluck et al, “The Perils of Medico-legal Advocacy in ICU Conflicts at the End of Life: A Qualitative Study of What Happens When Advocacy and Best Interests Collide” (2019) 51 J Critical Care 149.

treatments.”<sup>79</sup> In fact, Newman relies on the reasoning of the Ontario Court of Appeal in its decision in *Rasouli*, which the SCC would later end up rejecting:

[W]e have difficulty accepting that the legislature intended to include within the definition of treatment measures that attending physicians consider to be of no medical value and therefore worthless. More to the point, if the legislature intended that consent was required to the withholding or withdrawal of life support measures that are considered to be medically ineffective or inappropriate, we would have expected clearer language to that effect.<sup>80</sup>

Furthermore, depending on the case at hand, as well as the composition of the CCB that hears it, the analysis and outcome of the CCB’s decision may vary. For example, Vice Chair Newman concluded in *NS* that a mother’s insistence on “full code” for her son was in his best interests, notwithstanding the consensus medical opinion that the patient would remain in a vegetative state and should therefore be allowed to die if he were to go into cardiac arrest.<sup>81</sup> The decision of the CCB reads:

NS was a fighter. His mother knew that. We all know that about him. In his time in hospital he has demonstrated that. He has been fighting back, no longer requiring life support. In spite of the predictions of medicine NS has continued to fight back.<sup>82</sup>

Evidence that NS’s doctors had made other predictions that never came true influenced the CCB’s analysis in this respect. At the same time, the decision offers no scientific basis for equating survival in a persistent vegetative state with a person’s level of will-power and yet the perception of the patient as a “fighter” ends up being decisive, outweighing the clinical judgment that prolonging the patient’s death would be medically futile. By contrast, in another 2017 post-*Rasouli* decision (that of *HM (Re)*) the CCB, constituted differently, states:

I felt that [the SDMs’] faith in HM’s potential recovery was akin to a fantasy, which distorted their rational consideration of HM’s best interests. Their unrealistic faith in HM’s potential recovery led [the SDMs] to dismiss the medical evidence that contradicted their fantasy, and also blinded them to HM’s current suffering. Their

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79. 2013 CarswellOnt 10236 at 14-15 (Ont CCB).

80. *Ibid* at 16, citing *Rasouli v Sunnybrook Health Sciences Centre*, 2011 ONCA 482 at para 41. In support of the Court of Appeal for Ontario’s view, see Robert Sibbald, Paula Chidwick & Laura Hawryluck, “Standard of care and resource implications of the *Cuthbertson v. Rasouli* ruling” (2014) 186 CMAJ 327 at 328 (arguing that “if the professional judgment of a group of physicians is that a treatment lies outside the standard of care...the board should have no role in questioning that judgment”).

81. *HM (Re)*, *supra* note 67.

82. *Ibid* at 36.

approach was to justify HM's current suffering because he might eventually wake up and enjoy life once again.<sup>83</sup>

Such differences in the CCB's language and approach reflect the margin for maneuver and no doubt wrenching difficulty each presiding Board member must encounter in these kinds of cases. The meaning of a patient's best interests may be blurry, only coming into focus in the eye of the beholder. *JEP*, another 2017 decision by Newman, nevertheless illustrates just how sharply the clinical position and the requested treatment may contrast.<sup>84</sup> Dr. D'Egidio, the patient's physician, testified before the CCB that even though the patient's SDMs recognised that their 86 year-old father was dying, "they were insisting on Full Code status because they were respecting JEP's wishes, values, and beliefs."<sup>85</sup> In the doctor's view, however, those wishes "were now impossible to respect because they violated physician ethical principles" and following them would only cause the patient harm.<sup>86</sup> Despite Dr. D'Egidio's view that providing CPR and dialysis would be medically futile and "ethically at odds with his physician's oath to do no harm," the CCB concluded that the SDMs were acting in accordance with the principles for substitute decision making set out in the *HCCA*.<sup>87</sup>

Even though, generally speaking, a patient's specific advance instructions take precedence, an SDM may nonetheless have to interpret them. The instructions themselves, and the circumstances in which they must be applied, can pose difficulties, giving rise to conflicting interpretations. For example, in the 2014 British Columbia case of *Bentley v. Maplewood Seniors Care Society*, the family of Margot Bentley, an 83-year-old Alzheimer's patient, sought a declaration requiring the seniors' home to stop giving her food and water.<sup>88</sup> The judge ruled that providing the patient with food and water (as opposed to artificial nutrition and hydration) constituted "personal" rather than "medical" care. Refusal to be given food or drink could not therefore fall within a set of valid healthcare directives. Moreover, because the patient had issued two sets of instructions at different times which were inconsistent, the judge deemed them inconclusive. Ultimately, the judge found that Margot Bentley's receptivity to eating and drinking demonstrated her present wishes, and that as a matter of common law,

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83. *Ibid* at 40.

84. *JEP (Re)*, *supra* note 68.

85. *Ibid* at 28.

86. *Ibid*.

87. *Ibid* at 28-29, 38.

88. 2014 BCSC 165 [*Bentley* BCSC].

one's current competent wishes, expressed through one's conduct, trump advance directives as well as SDM authority.<sup>89</sup>

Margot Bentley was in a long-term care facility in the final stage of Alzheimer's. Having lost all speech and basic psychomotor skills, her brain appeared "to no longer be able to tell the body what to do."<sup>90</sup> Years prior to her diagnosis, Margot Bentley had signed a "statement of wishes" asking that she be allowed to die should she end up suffering from an extreme disability with no expectation of recovery, and that she not be provided with nourishment or liquids. She had, however, authored a subsequent document stating she did not want to be kept alive "by artificial means such as life support systems, tube feeding, antibiotics, resuscitation or blood transfusions" and that "any treatment which has no benefit other than a mere prolongation of [her] existence" should be withheld or withdrawn.<sup>91</sup> Because of this discrepancy, the judge did not conclude that the patient had given advance consent to be deprived of food and water once she reached an advanced stage of her illness. Meanwhile, although Margot Bentley was no longer capable of eating independently, the staff at the facility would hold food and water up to her mouth which she would eat and drink. The judge ruled that by accepting the oral nutrition and hydration, Bentley was providing her consent.<sup>92</sup> The Court of Appeal upheld the trial judge's decision, noting that "a court of law will be assiduous in seeking to ascertain and give effect to the wishes of the patient in the 'here and now,' even in the face of prior directives, whether clear or not."<sup>93</sup> In reaching this conclusion, the BC Court of Appeal cited the SCC's decision in *Carter v. Canada*, "where the Court emphasized that when assisted suicide is legalized, it must be conditional on the 'clear consent' of the patient."<sup>94</sup>

According to Jocelyn Downie, since the BC Court of Appeal accepted the trial judge's finding that Margot Bentley was making a presently competent decision, *Bentley* "was not, in the end, a case of a presently incompetent vs. previously

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89. *Ibid* at paras 59-60. See *HCCA*, *supra* note 4, s 5(3) (in Ontario, "[l]ater wishes expressed while capable prevail over earlier wishes").

90. *Bentley* BCSC, *supra* note 88 at para 23.

91. *Ibid* at para 9.

92. *Ibid* at para 153.

93. *Bentley* BCCA, *supra* note 43 at para 18. Similarly, the Regional Disciplinary Tribunal in The Hague has noted that a written advance euthanasia directive "must be extremely clear," and, "at the time of the euthanasia procedure, no matter how advanced the patient's dementia, their views and their reaction to the situation must be considered." See *CCA*, "Advance Requests", *supra* note 2 at 74.

94. *Bentley* BCCA, *supra* note 43 at para 18, citing *Carter* SCC, *supra* note 42 at para 127.

competent person.”<sup>95</sup> Thus, in Downie’s view, the common law principle that a patient’s previously expressed capable wishes trump the preferences they express in their current, incompetent state, persists. Therefore, “health care providers have a legal obligation to respect a previously competent person’s prior capable informed expressed wishes not to be offered or given oral or artificial nutrition or hydration after losing capacity.”<sup>96</sup> Furthermore, based on her interpretation of the corresponding statutory scheme in Nova Scotia, Downie argues that even where an incompetent patient asks for food or water, “the substitute decision-maker must...refuse consent to artificial nutrition or hydration in accordance with that person’s prior capable wishes; further, the health care providers must respect that refusal.”<sup>97</sup> Under Downie’s account of the common law, and accommodation of the BC Court of Appeal’s decision in *Bentley* within it, whether a patient is deemed to have capacity for the purpose of receiving oral nutrition and hydration will determine whether their SDM has a right—and in effect, a duty—to deny them food and water in accordance with their previously expressed, capable wishes. Based on the decision in *Bentley*, however, an advance directive will not justify denying food and water to a conscious person still willing to eat and drink. Notwithstanding arguments as to whether a person at such an advanced phase of cognitive deterioration is aptly characterized as capable of *willing* anything, it appears that in Canadian law, a patient’s prior instructions do not nullify the duties their caregivers owe to them or override the patient’s current expression of preferences.

Thus, the proposition that, at law, a previously competent wish always supersedes a current incompetent wish, has limited determinative value in situations, including this case, involving voluntarily stopping eating and drinking, where the expression of a preference constitutes a current, competent wish. For example, a willingness to eat and drink is all that needs to be demonstrated to show that the patient is competent in respect to these activities. Capacity assessment is always context and task specific.<sup>98</sup> People do not forfeit their experiential interests or the right to pursue them simply because they have been determined to have lost legal capacity. Just because one is incompetent to make decisions about life-sustaining medical treatment or lacks the legal capacity to request

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95. Jocelyn Downie, “An Alternative to Medical Assistance in Dying? The Legal Status of Voluntary Stopping Eating and Drinking (VSED)” (2018) 1 Can J Bioeth 48 at 50.

96. *Ibid* at 52.

97. *Ibid*.

98. See Ellen Wiebe et al, “Assessment of capacity to give informed consent for Medical Assistance in Dying (MAiD): A qualitative study of clinicians’ experience” (2021) CMAJ Open [forthcoming].

medical assistance in dying does not mean that one is no longer competent to decide whether to eat and drink. Of course, the problem arises in respect of what constitutes offering food and drink (the only way to facilitate the otherwise incompetent person to do the thing they want to do in the present moment) and force-feeding, which frustrates the patient's expression of autonomy.<sup>99</sup>

Evidently, when patients consent in advance rather than immediately before treatment, questions are more likely to arise "as to the clarity or currency of the wishes, their applicability to the patient's present circumstances, and whether they have been revoked or revised by subsequent wishes or a subsequently accepted treatment program."<sup>100</sup> In other words, the less ambiguous one's advance instructions are, the more regularly one re-iterated them, and the less time one had to alter them, the more they merit respect.

### III. IMPORTANCE OF INFORMED CONSENT IN JUSTIFYING ACCESS TO MAID

Informed consent has played an important role in justifying MAID. First, the value of autonomy represented by the consent principle is a crucial element in the argument for legalizing MAID; furthermore, informed consent is presented as a safeguard against mistake and abuse in the regulation of this "end-of-life practice."<sup>101</sup> Until 2015 and the SCC's decision in *Carter*, there was an important, bright-line distinction in Canadian law between consent to the withholding and withdrawal of life-sustaining medical treatment (*i.e.*, "passive" MAID), and consent to physician-assisted suicide or voluntary euthanasia (*i.e.*, "active" MAID.) Evidence disputing the ethical salience of the active/passive distinction

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99. See Thaddeus Mason Pope & Lindsey E Anderson, "Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life" (2011) 17 *Widener L Rev* 363 at 406-07 (observing in U.S. case law that, how a caregiver offers food to a patient who is voluntarily stopping eating and drinking, may affect whether the conduct constitutes battery); Paul T Menzel & M Colette Chandler-Cramer, "Advance Directives, Dementia, and Withholding Food and Water by Mouth" (2014) 44 *Hastings Center Report* 23 at 25 (arguing in favour of withholding oral nutrition and hydration to incompetent patients who have made an advance directive to that effect only once the dementia has become severe and problems with eating and drinking have already arisen).

100. *Fleming*, *supra* note 3 at 318.

101. This is the Court's characterization. See *Carter* SCC, *supra* note 42 at para 127 (requiring evidence the patient "clearly consents to the termination of life"). See *Bentley* BCCA, *supra* note 43. For relevant statutory provisions, see *Criminal Code*, *supra* note 1, s 241.2(1) (e), 241.2(3)(h).

contributed to the SCC's invalidation of laws criminalizing active MAID under certain circumstances.<sup>102</sup> The SCC ruled that these laws are void

insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.<sup>103</sup>

One of the government's arguments supporting the blanket ban on voluntary euthanasia and assisted suicide was the difficulty of developing adequate safeguards to protect vulnerable individuals from being induced to choose an assisted death. In its judgment, the SCC observed that there already are safeguards in place when it comes to "end-of-life medical decision-making in Canada."<sup>104</sup> The Court stated:

[T]here is no reason to think that the injured, ill and disabled who have the option to refuse or to request withdrawal of lifesaving or life-sustaining treatment, or who seek palliative sedation, are less vulnerable or less susceptible to biased decision-making than those who might seek more active assistance in dying. The risks that Canada describes are already part and parcel of our medical system.<sup>105</sup>

In an important respect, therefore, the judicial contribution to legalization of active MAID in Canada was justified as an extension of the principles governing passive MAID. If respect for patient autonomy in medical decision-making means recognizing the right to refuse life-sustaining treatment, patients suffering intolerably should be able to request assistance in dying. By logical extension—one might argue—since a person may instruct their SDM to refuse consent to life-sustaining interventions on their behalf, they should also be able to issue an advance directive for MAID.

In contrast, when Parliament passed Bill C-14, it modified aspects of the SCC's remedial declaration in *Carter*, notably by defining "grievous and irremediable condition" (the SCC's language) to include the requirement that a patient be in "an advanced state of irreversible decline in capability" and their

102. *Carter* SCC, *supra* note 42 at para 23; *Carter v Canada (Attorney General)*, 2012 BCSC 866 at para 357 [*Carter* BCSC]. See also John Keown, "A Right to Voluntary Euthanasia--Confusion in Canada in *Carter*" (2014) 28 *Notre Dame JL Ethics & Pub Pol'y* 1 at 23; L W Sumner, *Assisted Death: A Study in Ethics and Law* (Oxford University Press, 2011).

103. See *Carter* SCC, *supra* note 42 at para 127.

104. *Ibid* at para 115.

105. *Ibid*.

“natural death has become reasonably foreseeable.”<sup>106</sup> Julia Lamb and the BC Civil Liberties Association brought a *Charter* challenge against both eligibility criteria in British Columbia, whereas Jean Truchon and Nicole Gladu challenged the “natural death has become reasonably foreseeable” criterion and the provincial “end-of-life” requirement in Québec.<sup>107</sup> In its response to the statement of claim in B.C.’s *Lamb* case, the government argued that:

[t]he purpose of the legislation is to allow those who are in decline and whose natural death has become reasonably foreseeable the choice of a medically assisted death. It does not provide a general right to medically assisted death as a response to suffering in life. Nor does anything in the Carter decision provide for such a right.<sup>108</sup>

Indeed, while recognizing “the autonomy of persons who have a grievous and irremediable medical condition that causes them enduring and intolerable suffering and who wish to seek medical assistance in dying,” the Preamble to the law affirms “the inherent and equal value of every person’s life” while denouncing “negative perceptions of the quality of life of persons who are elderly, ill or disabled.”<sup>109</sup> Thus, the legislative dimension of Canadian law reform on MAID, effected in 2016, places more emphasis on the ways in which voluntary euthanasia and assisted suicide differ from existing end-of-life medical practices than the SCC did in its reasoning in *Carter*. In that decision, the Court decried the “cruel choice” that the blanket prohibition on lawful physician-assisted dying was imposing on Gloria Taylor, and those like her, “between killing herself while she was still physically capable of doing so, or giving up the ability to exercise

106. *Criminal Code*, *supra* note 1, ss 241.2(2)(b), 241.2(2)(d).

107. *Truchon c Procureur général du Canada*, 2019 QCCS 3792 [*Truchon*] (where the Quebec Superior Court declared both the federal “natural death has become reasonably foreseeable” and the provincial “end of life” requirements unconstitutional). See Kelly Grant, “B.C. woman drops challenge of MAID law after learning she qualifies for assisted dying” *The Globe and Mail* (18 September 2019), online: <[www.theglobeandmail.com/canada/article-bc-woman-challenging-reasonably-foreseeable-clause-in-maid-law/](http://www.theglobeandmail.com/canada/article-bc-woman-challenging-reasonably-foreseeable-clause-in-maid-law/)> (reporting on how evidence from the federal government’s medical expert on the plaintiff’s MAID eligibility resulted in *Lamb v. Canada* not proceeding to trial). See *Lamb v Canada*, (*Attorney General*), 2017 BCSC 1802 [*Lamb*]. See also Thomas McMorrow, “MAID in Canada? Debating the Constitutionality of Canada’s New Medical Assistance in Dying Law” (2018) 44 *Queen’s LJ* 69. For a discussion of the constitutionality of MAID law in Canada from competing perspectives, see Hamish Stewart, “Constitutional Aspects of Canada’s New Medically-Assisted Dying Law” (2018) 85 *SCLR* (2d) 435; Trudo Lemmens, “Charter Scrutiny of Canada’s Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice” (2018) 85 *SCLR* (2d) 459.

108. *Lamb*, *supra* note 107 (Response to Civil Claim at part 3, para 9), online (pdf): <[bccla.org/wp-content/uploads/2016/08/2016-07-27-Response-to-Civil-Claim.pdf](http://bccla.org/wp-content/uploads/2016/08/2016-07-27-Response-to-Civil-Claim.pdf)>.

109. Bill C-14, *supra* note 6.

any control over the manner and timing of her death.”<sup>110</sup> Although Parliament amended the *Criminal Code* to lift the blanket ban, the law continues to impede people from exercising control over the manner and timing of their death through medical assistance.

The “grievous and irremediable medical condition” standard provides a legal criterion for distinguishing between legitimate and illegitimate forms of medically assisted death. Limiting access in this way is meant to help prevent error and abuse: to stop MAID being inflicted on people absent their “true consent.”<sup>111</sup> It may also reflect the SCC’s reluctance to view MAID as totally interchangeable with other end-of-life healthcare decision-making practices. Along with “the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition,” the SCC in *Carter* did acknowledge the important, competing values of “the sanctity of life and the need to protect the vulnerable.”<sup>112</sup> It made no pronouncement as to the constitutionality of permitting incompetent patients to receive MAID through advance directives.<sup>113</sup>

Nevertheless, the question of whether inflicting death on someone is intrinsically wrong—and rightfully prohibited under criminal law—(whether that person has voluntarily consented to be killed or not) received cursory attention from the SCC’s *per curiam* judgment in *Carter*. The Court’s reasoning suggests that when a person is suffering intolerably from a grievous and irremediable medical condition, it is wrong to take their life insofar as doing so infringes upon that person’s individual autonomy. In other words, what is morally wrong in killing another human being is reducible to violating the principle of informed consent in medical decision-making. If protecting individual autonomy is the only point of prohibiting killing, then no competent person who clearly consents to the termination of life should be constrained by the criminal law from exercising their autonomy in this way. Why should the criminal law constrain anyone from receiving assistance in ending their life? The SCC in *Carter* does not address this question at the same time as it abstains from recognizing the right of every person to receive physician assistance “to bring a peaceful end to their lives at a time and in a manner of their own choosing.”<sup>114</sup> Rather, it stipulates competency,

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110. *Carter* SCC, *supra* note 42 at 13.

111. *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519 at para 621 [*Rodriguez*].

112. *Carter* SCC, *supra* note 42 at para 2.

113. *Ibid* at para 127.

114. *Ibid* at para 14.

voluntariness, adulthood, intolerable suffering, and a grievous and irremediable medical condition as prerequisites.

The collection of opinions in the split SCC decision in *Rodriguez v. British Columbia (Attorney General)*, rendered twenty two years before *Carter*, displays a greater range of tensions in reasoning.<sup>115</sup> For example, writing for the majority, Justice Sopinka argued that the blanket ban reflected the “consensus...that human life must be respected and we must be careful not to undermine the institutions that protect it.”<sup>116</sup> Meanwhile, dissenting, Justice McLachlin (as she then was) disputed this assertion of a consensus, arguing that the criminal law does not contain an absolute prohibition on killing and should not proscribe assistance of suicide when suicide itself is already legal.<sup>117</sup>

In Justice McLachlin’s view, permitting MAID was about respecting individual choice. Prohibiting MAID frustrates how certain individuals wish to exercise their autonomy. Conversely, for Justice Sopinka, the problem with permitting MAID lay in the risk that doing so would not only satisfy but in fact spur demand. Whereas Justice McLachlin regards the criminal law as wanting when it comes to facilitating individual choice, Justice Sopinka sees it as needing to offer the right guide to autonomous decision-making. Justice Sopinka expressed worry that legally authorizing medical assistance in dying “would send a signal that there are circumstances in which the state approves of suicide.”<sup>118</sup> According to him, by “upholding the respect for life, [the prohibition] may discourage those who consider that life is unbearable at a particular moment, or who perceive themselves to be a burden upon others, from committing suicide.”<sup>119</sup>

Counsel for the plaintiffs in *Carter* succeeded in persuading the trial judge, however, that the singularity and power of this message could not be taken for granted. Justice Lynn wrote:

I accept that suicide and attempts at suicide are serious public health problems that governments are trying to address. To that end, the absolute prohibition may have some of the salutary effects the defendants allege, for example, sending an anti-suicide message and a message about the value of every life, including the lives of those who are elderly or disabled. Nevertheless, I note that by thwarting the wishes of persons who are physically disabled, grievously ill and suffering intractably, the law sends a negative message that their wishes, and their suffering, are not as important as are other considerations. The law’s positive general message about the

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115. *Rodriguez*, *supra* note 111.

116. *Ibid* at 608.

117. *Ibid* at 620-21.

118. *Ibid* at 608.

119. *Ibid*.

value of human life must be weighed against its negative message specific to the people whom it most directly affects.<sup>120</sup>

In both the SCC's judgment in *Carter*, and the amendment to the *Criminal Code*, physical disability rendering one incapable of independently ending one's own life is not an eligibility requirement for MAID. Although the Court refers to a person physically unable to terminate their life at the moment of their choosing while elaborating its reasoning behind invalidating the blanket ban<sup>121</sup>, neither the SCC nor Parliament proposed limiting MAID eligibility to patients in these kinds of circumstances alone. Nonetheless, Parliament's access regime under C-14 for MAID presents a skeptical posture towards the claim that assistance in dying is actually the help that each person needs when they ask for it. It reflects a concern that in making MAID legal, it reduces roadblocks deterring people from executing their current, but potentially temporary, wish to die. Making MAID available may affect whether and how people with illnesses, diseases, and disabilities view the choice to die as an alternative to their suffering.

Indeed, Trudo Lemmens argues:

Normalization of a practice can create subtle pressures when it becomes seen as the standard procedure in specific situations. It may increasingly be seen as the norm, and thus people may indirectly come to expect those who are elderly or dependent on others to opt for euthanasia...A key concern is the effectiveness of measures to protect those who may otherwise have preferred to live longer; those who, perhaps, may not have had a stable and authentic desire to end their lives (which is itself of course very difficult to determine); those who may have felt under pressure in the circumstances of their illness or disability, and in specific socio-economic circumstances, to opt for earlier termination of life; and those who may be vulnerable because of mental illness.<sup>122</sup>

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120. *Carter BCSC*, *supra* note 102 at paras 1265-66.

121. *Carter SCC*, *supra* note 42 at para 126. The Court's remedial declaration contains the phrase: "To the extent that the impugned laws deny the s. 7 rights of people like Ms. Taylor." It also concludes with the following sentences: "The scope of this declaration is intended to respond to the factual circumstances in this case. We make no pronouncement on other situations where physician-assisted dying may be sought." *Carter SCC*, *supra* note 42 at para 127. Canada did not persuade the court in *Truchon*, however, that these statements constrict the effect of the Court's remedial declaration. "Si la Cour suprême voulait établir ou imposer un lien temporel entre l'administration de l'aide médicale à mourir et l'imminence de la mort, elle l'aurait certainement écrit de manière précise dans les considérants de son jugement alors qu'elle prend soin d'élaborer les conditions qui y donne ouverture." *Truchon*, *supra* note 107 at para 495.

122. Lemmens, *supra* note 107 at 480-81.

Being able to end one's life immediately, painlessly, confidently, lawfully, with friends and family present, and with a doctor or nurse practitioner's assistance, may render the decision to terminate one's life at a time of one's choosing more attractive and legitimate. In this sense, the critique at issue does not concern outright coercion, unconscious bias, or deliberate manipulation. Each of these is doubtless a concern in its own right and why the law requires MAID assessors to verify that the patient's request is voluntary.<sup>123</sup> Rather, here the point is that the law creates room for an interior sense of obligation to develop, according to which one feels one ought to spare others (or oneself) the burden of one's being. The more MAID is perceived as the way for a person with a deteriorating cognitive condition to die with dignity, the more dying naturally in such circumstances appears as the undignified, inconsiderate, even selfish thing to do.

Of course, having MAID as an option is not going to have the same impact on the way everyone perceives and experiences their end-of-life choices. Still some people may want to be saved the choice that others ardently wish to make. This tension is also present when it comes to the matter of advance requests for MAID. Welcome relief from barriers to access may also import an unwelcome burden to justify why one is not choosing MAID. What further complicates and therefore distinguishes the advance request scenario is the expanded role of those acting on patients' behalf. In voluntary euthanasia, the patient does not execute their decision on their own. The MAID provider acts as their agent. When provision does not immediately follow the patient's communication of informed consent, the agent must decide where, when, why, and how to give effect in the present to a request that a no longer competent individual made in the past.

To prevent the potential of error and abuse, the law requires the person who receives MAID to express their consent immediately prior to the physician or nurse practitioner administering or prescribing the lethal substance. The problem with implementing an advance request for MAID is that it blurs the line between self-initiated death and death imposed by another. The idea is that the patient expresses their autonomy through the agency of the MAID provider acting in the future. The passage of time, change of circumstances, and limitations to what the patient can know or predict at the moment of their request can complicate the ways in which the provider merely acts as an instrument of the patient's present freely expressed informed consent to MAID. Questions that arise already for SDMs, health care providers, and adjudicative bodies responsible for making treatment decisions on behalf of incompetent patients adopt a different character when the power to give that patient MAID on the strength of their advance

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123. Bill C-14, *supra* note 6, s 241.2(1)(d).

request is legally recognised. At law, the patient's informed consent is crucial to the provision of MAID in a way that sets it apart from other end-of-life decisions resulting in a patient's death. There are already circumstances where medical decisions leading to a person's death are made on a person's behalf, absent any advance request. Barring evidence of a patient's previously expressed wishes, evaluations of the patient's best interests serve transparently as the reference point for determining whether efforts will be made to keep them alive. The more the contemporaneous consent requirement is diminished, the more that MAID will appear to be just another mode of clinical intervention, like turning off a ventilator, and the more appropriate it will feel to predicate the delivery of MAID on the range of considerations, beyond mere evidence of an advance directive, that currently inform end-of-life decisions on behalf of persons lacking capacity.

A further complication lies in the range of circumstances in which patients are eligible for MAID; for example, outside Québec,<sup>124</sup> one need not be at the end of one's life to receive MAID in Canada. Québec's "end-of-life" criterion is not the same as the *Criminal Code*'s requirement that "natural death has become reasonably foreseeable." In striking down the two provisions, the Québec Superior Court in *Truchon* treated them as if they were the same, but MAID assessors determine eligibility more restrictively in Quebec—subject as they are to an additional provincial statutory regime—than they do in the rest of Canada. Clinical guidelines of the Canadian Association of MAID Providers,<sup>125</sup> scholarly studies of the MAID law,<sup>126</sup> the Ontario Court of Justice's decision in *AB*,<sup>127</sup> and empirical research<sup>128</sup> reveal that the requirement in the *Criminal Code* and the one in Québec's *Act Respecting End-of-life Care* are not equivalent. This owes in part to the ambiguity of the phrase, "natural death has become reasonably foreseeable," and the absence of oversight bodies like Québec's Commission

124. See *Act Respecting End-of-Life Care*, CQLR c S-32.0001.

125. Canadian Association of MAID Assessors and Providers, *Clinical Practice Guideline: The Clinical Interpretation of "Reasonably Foreseeable"* (CAMAP, June 2017).

126. Jocelyn Downie & Kate Scallion, "Foreseeably Unclear: The Meaning of the 'Reasonably Foreseeable' Criterion for Access to Medical Assistance in Dying in Canada" (2018) 41 Dal LJ 23.

127. *AB v Canada (Attorney General)*, 2017 ONSC 3759.

128. Thomas McMorow et al, "Interpreting the Medical Assistance in Dying Law: The Experiences of Physicians and Nurse Practitioners" (2020) 14 McGill JL & Health 51. This article reports findings from interviews with twenty-four MAID providers and assessors from across the country, including eight in Québec, that reveal that while patients in Québec may be deemed eligible with a prognosis of up to twelve months, a patient outside the province may nevertheless satisfy the reasonably foreseeable natural death requirement if their manner of death is predictable but it is still not expected to happen for ten, or even fifteen years.

on End-of-life Care in the other provinces and territories. The fact Julia Lamb ended up being assessed as eligible makes it highly probable that the plaintiffs in *Truchon* would have qualified for MAID, satisfying the clinical standard of interpretation of the “natural death has become reasonably foreseeable” as applied in practice outside Québec.<sup>129</sup> Notably, while declaring these provisions invalid and suspending the declaration of invalidity for six months, Madam Justice Baudouin nonetheless stated:

It is clear from the legislative regime in place that a patient’s capacity to consent to medical assistance in dying is a *sine qua non* condition to its administration. The person making the request must be able to consent thereto in a free and informed manner, in addition to satisfying the other requirements.<sup>130</sup>

Following advance directives presents an important but nonetheless imperfect way to honour a person’s autonomy and respect the principle of informed consent. The image of the SDM serving as an extension of the patient’s agency is necessary to maintain respect for autonomy while keeping up the pretense that autonomy is something all human beings are able to exercise to the same extent at all times in their lives. Allocating the authority to an SDM or the instructions in a legal document to determine when one’s life will be ended by a MAID provider would alter the circumstances in which clinicians provide MAID, further erode the criminal prohibition on intentional killing, and expand the reliance on advance directives, SDMs, and authoritative bodies tasked with determining the best interests of incapacitated patients, in order to maximize the power of competent patients to determine when they die after losing capacity. When a patient lacks capacity, it becomes incumbent on others to exercise this decision-making authority on their behalf. There is a value in honouring previously expressed wishes. How much weight it should be accorded depends on other factors, including the need to respect a person in their current condition.<sup>131</sup>

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129. *Ibid.*

130. *Truchon*, *supra* note 107 at para 254. Justin Trudeau made the announcement during the French-language leaders’ debate during the federal election campaign, after the Québec government had announced its decision not to appeal *Truchon*. Christopher Reynolds, “Trudeau says he would look at ways to improve medical assistance in dying law,” (3 October 2019), online: *National Post* <[nationalpost.com/pmn/news-pmn/canada-news-pmn/trudeau-defends-use-of-two-planes-calls-tory-criticism-a-far-right-tactic](http://nationalpost.com/pmn/news-pmn/canada-news-pmn/trudeau-defends-use-of-two-planes-calls-tory-criticism-a-far-right-tactic)>.

131. *Bentley BCCA*, *supra* note 43.

#### IV. ADVANCE REQUESTS FOR MAID

Thus, while the principle of informed consent may appear like the germ of legal growth in end-of-life decision-making in Canada, it also seems to constrain the extension of access to medical assistance in terminating life on compassionate grounds. General distrust and specific difficulties attending advance directives (both instruction-giving and proxy-appointing facets) as a means of realizing the principle of informed consent become especially acute in the context of MAID. Indeed, as Gina Bravo et al observe, when it comes to the question of making it legal to comply with advance directives requesting MAID—especially in the case of patients rendered incompetent by advanced dementia—arguments centre on the failure of advance directives to reflect patient wishes when patients never communicate them sufficiently clearly in the first place, when patients articulate threshold conditions that are difficult for family members or physicians to assess, when such wishes may change, or previously expressed preferences appear in conflict with what a patient appears to accept now.<sup>132</sup> Indeed, such conflicts raise the question of whether “a request made by a previously competent person should have any authority over the life of a person who now has severe dementia.”<sup>133</sup>

A patient’s previous competence (or precedent autonomy) may certainly conflict with their present autonomy.<sup>134</sup> Not only may a person’s considered wish to die vanish with the loss of competence, but a person who dreaded the thought of living in dementia may nevertheless end up enjoying life in (at least the earlier stages of) dementia. Thus, Paul Menzel and Bonnie Steinbock argue:

It is one thing for someone to write an AD [advance directive] directing their treatment in case of permanent unconsciousness; the AD has full authority because later there is no current active agent. It is quite different to write an AD to apply in case of dementia, when there will still be a valuer, though one with different interests.<sup>135</sup>

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132. Gina Bravo et al, “Should Medical Assistance in Dying Be Extended to Incompetent Patients With Dementia? Research Protocol of a Survey Among Four Groups of Stakeholders From Quebec, Canada” (2017) 6 JMIR Res Protoc 208.

133. *Ibid.*

134. Paul T Menzel & Bonnie Steinbock, “Advance Directives, Dementia, and Physician-Assisted Death” (2013) 41 JL Med & Ethics 484 at 490. See Ronald Dworkin, *Life’s Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (Alfred A Knopf, 1993). Cf Agnieszka Jaworska, “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value” (1999) 28 Phil & Pub Aff 105. See also JK Davis, “The Concept of Precedent Autonomy” (2002) 16 Bioethics 114; JK Davis, “Precedent Autonomy and Subsequent Consent” (2004) 7 Ethical Theory & Moral Practice 267.

135. Menzel & Steinbock, *supra* note 134 at 491.

After the SCC handed down its decision in *Carter*, but before the government tabled Bill C-14, a non-partisan expert advisory group and a special joint parliamentary committee both recommended legalising advance requests for MAID. The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying concluded in 2015 that requiring patients with degenerative diseases to be “competent at the time physician-assisted dying is delivered would force many of them to trigger the act earlier in the course of their disease than necessary.”<sup>136</sup> Likewise, the 2016 Special Joint Parliamentary Committee expressed concern “that by excluding individuals who want access to MAID but have lost competence, such individuals will be left to suffer or end their lives prematurely.”<sup>137</sup> In the Committee’s view, “[t]his situation was exactly what the *Carter* decision sought to avoid. Allowing advance requests also provides comfort to individuals, reducing their psychological suffering, knowing that their lives will not end in a way that is against their wishes.”<sup>138</sup> It recommended limiting the option of advance directives to individuals who already have a diagnosis to ensure the request would be more informed. The Committee also alluded to additional safeguards, including the possibility of requiring “health care practitioners to communicate regularly with their patients while they are still competent to ensure that their advance requests continue to reflect their wishes.”<sup>139</sup> It stopped short of further elaboration on these measures.

But the specifics matter. Minor differences in the legislative scheme have the potential to yield significant consequences. If contemporaneous consent is no longer required in every case, then the conditions under which advance consent for MAID is valid must be defined. If consenting in advance to MAID is not going to be binding in every situation, who it is that has the authority to make that determination—and on what basis—must be established clearly. In November 2019, the interdisciplinary expert group commissioned by Quebec’s Ministry of Health and Social Services published a report and set of fourteen recommendations titled, *L’aide médicale à mourir pour les personnes en situation d’inaptitude: le juste équilibre entre le droit à l’autodétermination, la compassion et la prudence*.<sup>140</sup> Their position is that barring advance requests does not strike

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136. See Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final Report* (November 2015) (Co-Chairs: Jennifer Gibson and Maureen Taylor) at 31 [*Final Report*].

137. House of Commons, *Medical Assistance in Dying: A Patient-Centred Approach, Report of the Special Joint Committee on Physician-Assisted Dying* (February 2016) (Joint Chairs: Kelvin Kenneth Ogilvie and Robert Oliphant) at 24.

138. *Ibid.*

139. *Ibid.*

140. *Québec Report*, *supra* note 9.

the right balance between the values of self-determination, compassion, and prudence.<sup>141</sup> The authors maintain that respecting the right to self-determination demands permitting advance requests for MAID.<sup>142</sup> Enabling a person to consent to receive MAID in the future—when they will no longer be competent to request it—extends that individual’s capacity to exercise autonomy.<sup>143</sup> Nevertheless, the authors acknowledge that the requirement of contemporaneous consent controls for a range of risks that advance consent does not. Consequently, the authors endorse the legalization of advance *requests* rather than *directives*, meaning they would not be equipped with executory force, binding health care professionals to provide the patient with MAID.<sup>144</sup> The report also recommends excluding SDMs from initiating a MAID request on a patient’s behalf.<sup>145</sup> In addition, it would limit eligibility to those patients who have already received a specific diagnosis and satisfied all of the eligibility requirements. In Québec, that means the patient must be at the end of their life.<sup>146</sup> Thus, while making some allowance for MAID via advance request, the Québec expert group’s proposal still restricts a range of people who may feel just as deserving. Simultaneously, the proposal shifts responsibility for determining who is entitled to receive MAID on the strength of an advance request onto the shoulders of physicians.

The need to make some allowance for people to access MAID after they have lost capacity stems from a sense of duty to facilitate the self-determination of individuals for whom avoiding the kind of death they do not want is felt to be integral to their life project.<sup>147</sup> According to Menzel and Steinbock, demonstrating compassion and respect for people with dementia who communicated, before they lost capacity, that once their condition reaches a certain point they want to have their lives ended through MAID, may demand complying with their request. They note:

The desire to die to avoid sustained dementia...need not stem from ignorance and prejudice, lack of imagination, failure to appreciate adaptation, and fear of poor nursing home care...[I]t can be based on profound convictions about the meaning and narrative of one’s life...What makes survival into severe dementia to many so

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141. *Ibid* at 65.

142. *Ibid* at 4.

143. *Ibid*.

144. *Ibid*.

145. *Ibid* at 127. Although the report proffers the idea of the patient designating a third party in their advance request whose role would be to remind the care givers about the request for MAID and to give it due consideration. *Ibid* at 117.

146. *Ibid* at 124.

147. *Ibid* at 102-04. See also Davis, “Alzheimer”, *supra* note 8.

valueless, and to some even horrifying, is the thought that...they will no longer be themselves, and yet others will have to relate to them.<sup>148</sup>

To deflect what they call the “disability critique,” Menzel and Steinbock attempt to distinguish patients whose incompetence stems from their experience of dementia from other individuals who lack legal capacity due to a cognitive disability.<sup>149</sup> Menzel and Steinbock assert that whereas other people with profound disabilities can be helped to lead meaningful lives, patients with dementia cannot, since “[t]hey do not hold jobs, engage in volunteer activities, or socialize with family and friends.”<sup>150</sup> While Menzel and Steinbock may certainly say what they themselves would consider a meaningless existence, what constitutes a meaningful or meaningless life varies from person to person. In fact, it is really the *prospect* of experiencing cognitive decline that renders life with dementia meaningless for the person imagining it. A person may experience the life they had imagined as unlivable quite differently when they are actually living it. Menzel and Steinbock are on more solid ground when they stress how strongly some individuals desire to determine their own life course right up to the end. Suggesting that life with degenerative neurocognitive impairment is pointless ignores what medical anthropologist Janelle S. Taylor describes as the ways in which ordinary people in everyday life are “experimenting with how to best continue to connect and to live together as fully and well as possible in the presence of dementia.”<sup>151</sup> For Taylor, “personhood is not a property of individuals alone, but rather is a collective accomplishment, created in and through relationships as these are lived out in everyday life.”<sup>152</sup> The question of whether to permit advance requests for MAID depends in part on how best to reconcile competing conceptions—as well as past and present experiences—of personhood.

Even though Menzel and Steinbock see advance requests for MAID as morally justifiable, they argue that “the question of whether people should be

148. Menzel & Steinbock, *supra* note 134 at 487, 493.

149. An important consideration is that allowing advance requests for MAID makes it impossible for people who have lost legal capacity but retain what is referred to in the literature as “experiential interests,” to withdraw their consent to have their life ended. In this way, the possibility that a person’s “disability may be the condition that sustains the move into a very different form of affirmative becoming” is foreclosed. Margrit Shildrick, “Deciding on Death: Conventions and Contestations in the Context of Disability” (2008) 5 *J Bioethical Inquiry* 209 at 218.

150. Menzel & Steinbock, *supra* note 134 at 488.

151. Janelle S Taylor, “Engaging with Dementia: Moral Experiments in Art and Friendship” (2017) 41 *Culture Medicine Psychiatry* 284 at 286.

152. *Ibid* at 285-86.

able to create AEDs [advance euthanasia directives] to avoid prolonged life in dementia does not have a simple yes-or-no answer but depends on the details of cases.”<sup>153</sup> Complying with an advance request means evaluating the quality of the prior directive as well as the individual’s current quality of life. Indeed, for Menzel, it is not only in situations of “unbearable suffering, but when the experiential value of survival is so minimal that it is outweighed by the strong critical interests reflected in a clear and persistent AED” that advance requests for MAID should be implemented.<sup>154</sup>

If a prior competent wish (or failing that, an SDM’s interpretation of what is in the patient’s best interests) bears such weight at present when it comes to end-of-life decision-making, transposing advance requests for MAID onto the existing legal landscape would result in situations where such demands end up prevailing over the clinical objections of the patient’s physicians. It is significant that the law in the only jurisdictions to permit advance requests for MAID (the Netherlands, Belgium, Luxembourg, and Colombia) reflects a higher degree of deference to medical professional authority than Canadian law does. Dutch law, for example, specifies a set of due care criteria that physicians must meet before they may provide a patient with euthanasia. These include being satisfied that: the patient’s request is voluntary and well considered; the patient’s suffering is unbearable, with no prospect of improvement; there is no reasonable alternative in the patient’s situation, after coming to this conclusion along with the patient.<sup>155</sup> It is also noteworthy that the most persuasive arguments for legalizing MAID through advance requests acknowledge that context matters; whether and how to implement them depends on the circumstances as well as features of the directives themselves.

Indeed, advance requests for MAID reflect but also compound some of the ethical questions already raised by advance requests to withdraw or withhold life-sustaining treatment. Rebecca Dresser highlights the practical issues with advance directives and the problems that come with according them trump status.<sup>156</sup> Louise Bernier and Catherine Régis’ study of the advance medical

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153. Menzel & Steinbock, *supra* note 134 at 485.

154. *Ibid* at 494.

155. *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, s 2(1) cited in Regional Euthanasia Review Committees, “Annual Report 2015” (April 2016) online (pdf): <[www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2015/april/26/jaarverslag-2015/Jaarverslag2015ENG.pdf](http://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2015/april/26/jaarverslag-2015/Jaarverslag2015ENG.pdf)>.

156. See Dresser, “Precommitment”, *supra* note 8 (arguing that relying exclusively on a patient’s prospective determinations for reaching end-of-life decisions on their behalf discounts the social and ethical complexity that characterize these kinds of situations).

directives regime in Québec shows how efforts to increase the use of advance directives have led to the adoption of a form-filling approach that magnifies several of the concerns Dresser highlights.<sup>157</sup> There is always room for judgment. Whether the legal jurisdiction locates it with the SDM, the physician, the adjudicative tribunal, or the courts, deciding how to apply a person's previous wishes in their present circumstances is never an automatic exercise, especially when it concerns whether that person's life is to be terminated.

Therefore, the question is what the default should be. Making access contingent on contemporaneous consent bans MAID through advance request. A permissive model would make advance requests for MAID lawful in the same manner as other death-hastening medical interventions or abstentions. A third approach would incorporate formal requirements, substantive requirements, or both, relating to how the request would have to be made and under which circumstances it could be applied. The first approach prohibits ending a person's life when that person is resisting what is happening to them. It also forbids terminating the life of an individual who is no longer capable of understanding and supporting this action, even if they once expressed a sincere desire for it. The rationale is that if people want to end their lives through MAID, the public is justified in requiring them to do it while they are conscious and have capacity. Otherwise, people will have their lives ended at a time that others judge appropriate. Sometimes the difference may not seem consequential. A person who loses capacity after their MAID request has been accepted but is still awaiting the ten clear days before they are permitted, by C-14, to receive it, is in a unique situation. It is highly unlikely that a person in these circumstances would have an abrupt change of heart. Ending their lives after their loss of capacity or consciousness, as per their signed and approved request for MAID, would appear to honour their wishes.

Still, if the patient who is awaiting their approved MAID request loses capacity but remains conscious, the act of terminating their life will be conditional on imputing an intentionality on their part that is no longer there. Of course, this move is made when withdrawing, withholding, or performing a medical intervention, which has the effect of hastening a patient's death, in accordance with wishes the patient previously expressed but now lacks the present capacity to confirm them. The difference here is that the health care practitioner is

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157. Louise Bernier & Catherine Régis, *Improving Advance Medical Directives: Lessons from Quebec* (Institute for Research on Public Policy, 2019).

actively ending the person's life;<sup>158</sup> that is, hastening what is ultimately inevitable for all human beings but in an immediate fashion. It is technically an act of non-voluntary euthanasia. *Technically* because, in the circumstances where the MAID request has been approved and the patient has lost capacity while waiting for the procedure, the lack of contemporaneous consent here closely resembles the lack of contemporaneous consent given by an incapacitated patient to palliative sedation. By abolishing the "ten clear days" requirement, Bill C-7 renders the passage of time between MAID approval and provision indefinite.

It has been claimed that a perverse effect of the "ten clear days" requirement is that, to ensure they can satisfy the capacity requirement, patients may forego high dosages of pain relief when they need it most. This is despite the fact that the law does permit the MAID provider to proceed if there is concern the patient will lose capacity before the ten days have elapsed. In Québec, where the "end-of-life" criterion is interpreted more stringently than the "natural death has become reasonably foreseeable" standard in the rest of the country, a greater proportion of patients have likely been near death, suffering from somatic pain, and in need of analgesics when deemed eligible for MAID.<sup>159</sup> If palliative sedation relieves suffering, while the cessation of artificial hydration and nutrition hastens a patient's death, the question is why MAID should be added as a clinical tool in these kinds of scenarios. The primary reason for barring a doctor or nurse practitioner from administering MAID in this type of situation is the concern that its erosion of the contemporaneous consent requirement for MAID could have negative ramifications in other clinical contexts. The law could be modified to permit the provision of MAID to patients who have lost capacity during the ten-day waiting period, but not indefinitely. At present, there is no legal provision requiring a person who has been approved for MAID to renew that approval even if they do not go through with their decision to receive MAID for months, even years. Depending on the quality and clarity of the advance request, the kind of ethical quandary that non-voluntary euthanasia presents varies. Acknowledging

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158. As noted in the CCA report, another contrast (at least with withholding life-saving treatment) is that MAID involves bodily intrusion; absent consent, this may constitute the tort of battery or the criminal offence of assault. Where consent is unclear, because the AR's applicability is uncertain, or because the patient appears to resist, not performing MAID may be seen as erring on the side of non-intrusion. CCA, "Advance Requests", *supra* note 2 at 38.

159. See *Act Respecting End-of-Life Care*, *supra* note 124. With the Québec Minister of Health and Social Services Danielle McCann's announcement that the end-of-life requirement will no longer apply, it remains to be seen what eligibility regime will follow the federal government's consultations and planned modifications to the MAID law before the suspension of the declaration. See *Truchon*, *supra* note 107.

that there may be circumstances where the previously expressed wishes of a patient to receive MAID should not always be given effect after they have lost capacity, the question is: What requirements would have to be established as a substitute for the current provision that patients must always give informed consent—and therefore have capacity—immediately prior to receiving MAID?

One reason to retain the safeguard is that permitting MAID in one kind of case where the patient is not capable of consenting in that moment will make it harder to argue that contemporaneous consent has value in other contexts. It is surely more difficult to justify refusing MAID to people whose situations involve a slow, protracted and horrific decline than it does for patients with days, months or even years of unconscious subsistence. If we deem it ethically acceptable, even legally required, to terminate someone's life without their current (but with only their advance) consent, we cross a line that numerous other sets of circumstances may produce pressure to breach. Once it is lawful for someone to determine the moment of MAID provision on the patient's behalf, it is much harder to justify denying MAID to other incompetent patients who did not make an advance request but who appear to be suffering or whose previous wishes appear to be known.<sup>160</sup> Requiring a patient to communicate their informed consent right up to the end may appear to place inordinate weight on a *pro forma* eligibility criterion for accessing MAID. It will no doubt appear equally absurd, legalistic, and cruel when patients with advanced Alzheimer's are denied what their loved ones feel would be a dignified death merely on the basis that the patient never completed a formal request.

Permitting MAID by advance request is about: alleviating a patient's present anxiety at the prospect of losing capacity and having no choice but to experience what they view as an undignified end; respecting the patient's "precedent autonomy" by honouring the wishes they expressed when they had the capacity to form and articulate them; and relieving what the SDM interprets as the patient's intolerable suffering (in light of explicit instructions or an understanding of that person's values and preferences). Arguments in favour may presume any one of a variety of scenarios, ranging from a cancer patient on their death bed, refusing pain relief for fear of losing the lucidity they need to remain eligible to follow through on their decision to receive MAID, to a man horrified by his spouse's condition with dementia, knowing she never would have wanted to live like this and wanting to relieve her of this low quality of life. There are many more

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160. See *R c Cadotte*, 2019 QCCS 1987 (where the defendant was convicted of homicide for ending his partner's life out of what he maintained—and which no one disputed—was compassion for his loved one's suffering and respect for her wishes).

potential circumstances. Surely not all are the same. While it may be possible to modify the law to account for the more significant ways in which they differ, it is important to recognise that changing the law will have an impact on how we perceive, articulate, and address those differences.

Conversely, prohibiting MAID by advance request is about preventing patients whose previous instructions no longer reflect their wishes from: having their lives ended; foreclosing the choice to spare others the burden of being one's caregiver in the wake of a deteriorating cognitive condition; sheltering end-of-life decision making from the force of consequentialist reasoning; preventing SDMs and MAID providers from deciding to terminate a patient's life based on an ascertainment of that person's previously expressed wishes and interpretation of the person's experience of the present circumstances (when that individual is not taking any steps to initiate their death themselves).

Is it right to terminate someone's life—even if, when they were still able, they expressed the wish to have this done for them—if they are not now seeking to end their lives themselves? One might argue that in some cases, it is—or at least, that the state is not justified in interfering with individual choices about what is right and wrong. Whether one will die by MAID—or assist someone to die in this manner—is a personal decision, but the standards that society sets for lawful killing reflect the public interest. When a person is no longer capable of deciding for him or herself whether he or she wishes to receive MAID, advance consent should not satisfy the demand for voluntariness that voluntary euthanasia requires.

If the Dutch experience is any indication, cases of conscious patients receiving MAID in accordance with an AED may encounter SDM and physician ambivalence.<sup>161</sup> The case law and tribunal decisions relating to advance directives in Canada show the considerable grey area that can exist when it comes to applying a patient's prior capable wishes. Furthermore, Ontario's current statutory regime governing the application of advance directives contrary to clinical judgment sets the default in favour of SDMs getting the treatment for the patient that they deem is in their best interests. Absent the legal rules (such as the due care requirement) in the Netherlands, which appear to militate against a high rate of compliance with advance directives, current conditions in Canada (or, at least, Ontario) favour physicians granting advance requests for MAID, even where it goes against their clinical or ethical judgment.

The absolute ethical distinction between MAID and other forms of life-terminating conduct always depended on convention—a convention at once

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161. See CCA, "Advance Requests", *supra* note 2.

reliant on, and responsible for, the criminal law on the matter. That convention no longer persists in the same manner, as the lawful practice of voluntary euthanasia and assisted suicide under prescribed circumstances indicates. Changes in the views of the public, the courts, health care professionals, and parliamentarians have produced a shift. Although the change is reflected (and in no small part caused) by the amendments made to the *Criminal Code*, the law itself provides room for interpretation. This means that the norms governing access to MAID are in flux at the same time as wider societal expectations and values continue to change.

It is possible for a person to issue advance directives that, once their cognitive state deteriorates to a certain point, they are to be deprived food and water no matter how hungry, thirsty, or receptive to eating and drinking they appear to be. Whether or how such directives will be followed through with is another question. In the case of Margot Bentley, tension lay between her family's sense of obligation to respect their mother's previously expressed wishes and her caregivers' sense of duty to provide the necessities of life to a person rendered completely dependent due to advanced Alzheimer's disease.<sup>162</sup> Of course, just as concerns about the prospect of legal liability may have inflected Maplewood Seniors Care Society's motives, the Bentley family may have been as motivated by compassion for their mother and distress at her condition as a sense of obligation to follow her advance instructions to a tee. The principle of informed consent—and its approximations vis-à-vis advance directives and SDMs—does not only serve as a necessary bulwark against violations of personal autonomy and bodily integrity; it may also serve as a warrant for justifying difficult decisions ultimately predicated upon other considerations.

## V. CONCLUSION

In Canada, recognition of principles such as patient autonomy—and more specifically—the right of competent, adult patients to refuse to consent to medical treatment (even if such refusal will result in their deaths) has not only justified developments in the law facilitating advance directives; it has also played an important role in justifying the legalization of voluntary euthanasia and assisted suicide under specific circumstances. Now, it also figures in debates over current legal restrictions on these practices. The question of who should be permitted to access MAID remains highly contested, especially in the case of advance requests

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162. *Bentley BCCA*, *supra* note 43.

(where public opinion is more positive and the interests affected better resourced and more organized than in the case of the other two excluded groups: mature minors and individuals whose sole underlying condition is a mental disorder).<sup>163</sup>

People fear the effects that dementia will have on them, their relationships to the people they care about, and the lives of those who will be obliged to care for them; understandably, to the extent they could, people would want to avoid the worst that a degenerative neurological condition can do. Rather than pre-empt the whole business and end one's life now, it sounds quite reasonable to set out in advance under what circumstances one would no longer wish to live, and to have the person one trusts the most decide when those conditions have been met and consent to having the MAID provider follow through with one's advance request. The problem, though, is that an advance request has the potential to present difficulties that a patient's immediate expression of informed consent does not. Moreover, MAID is not just any medical treatment; it may sometimes differ in important respects from other forms of medical decision-making at the end-of-life, such as the withholding or withdrawal of life-sustaining treatment and cessation of artificial hydration and nutrition.

A recent Dutch case brings these unique features into relief.<sup>164</sup> The case concerned an Alzheimer's patient, Mrs. A., whose advance directives did not clearly indicate whether she herself was to be the one to determine when it was time to receive MAID or if that determination was to be made on her behalf based on an evaluation of her quality of life. David Miller, Rebecca Dresser and Scott Kim describe the circumstances leading up to Mrs. A's death:

While Mrs. A lived in the nursing home, things generally went well for her in the mornings. During the afternoons, however, she 'exhibited signs of restlessness, and she appeared deeply unhappy'. The case report states that Mrs. A 'was continuously occupied with directing and instructing her fellow residents as though they were

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163. See Council of Canadian Academies, *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition* (CCA, 2018) [CCA, *Mental Disorder*]; Council of Canadian Academies, *The State of Knowledge on Medical Assistance in Dying for Mature Minors* (CCA, 2018). But see Bill C-7, *supra* note 12 (containing a provision, excluding mental illness as the qualifying medical condition for MAID eligibility, to expire two years after the legislation is passed).

164. See "Physician permitted to grant a written request for euthanasia from individuals suffering from advanced dementia: summary" (24 April 2020), online (pdf): *Hoge Raad Der Nederlanden* <[www.hogeraad.nl/publish/pages/797/summary\\_conclusion\\_euthanasia\\_case.pdf](http://www.hogeraad.nl/publish/pages/797/summary_conclusion_euthanasia_case.pdf)> ["Physician Granted Requests for Euthanasia"]. See David Gibbes Miller, Rebecca Dresser, & Scott YH Kim, "Advance Euthanasia Directives: a Controversial Case and Its Ethical Implications" (2019) 45 J Med Ethics 84 (providing a detailed summary of the facts in the case).

children' (she had worked with children in the past). If the caregivers intervened in conflicts between Mrs. A and other nursing home residents, Mrs. A sometimes 'hit, kicked, scratched and bit' the caregivers. She regularly told her caregivers that she wanted to die. But when she was asked whether she wanted to die, several times she answered, 'But not just now, it's not so bad yet!' Mrs. A's geriatrician thought that her inconsistent wishes reflected a loss of insight into her illness. Mrs. A also 'missed her husband and wandered around looking for him until late at night'. Mrs. A felt better during her husband's daily visits, but she became 'restless and sad' when he left the nursing home. Based on these findings, the geriatrician believed that Mrs. A was suffering unbearably for most of the day, and that euthanasia was appropriate given her advance directive.<sup>165</sup>

From her physician's perspective, Mrs. A's lack of mental competence meant that whatever she said had no bearing on the decision to fulfill her advance euthanasia directive. Indeed, the physician indicated that she would have proceeded with the provision, even if, at the moment she was injecting Mrs. A with the needle, the patient had said, "I don't want to die." In fact, during the provision, Mrs. A's family restrained her after she unexpectedly tried to get up.

The Dutch public prosecutor subsequently opened an investigation into Mrs. A's death. The Dutch Supreme Court ultimately affirmed the decision of the District Court that the physician had acted with due care and therefore was not liable to criminal prosecution. According to the Supreme Court's reasons, a patient who can no longer express their will due to advanced dementia may receive euthanasia in accordance with an advance, written request. All legal requirements must be satisfied, including the physician's obligation to act with due care and to "impart the substance in a way that does justice to the special nature of situations involving advance dementia."<sup>166</sup> If the patient's conduct or verbal expression indicates that the present situation does not correspond with the circumstances envisaged in the directive, it may be a situation where the request cannot be granted but the court "must exercise reticence when assessing the physician's medical actions."<sup>167</sup> Moreover, the Dutch Supreme Court points out that the physician providing MAID may wish to sedate the patient in advance to avoid the possibility of the patient engaging in irrational or unpredictable behaviour.<sup>168</sup>

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165. Miller, Dresser & Kim, *supra* note 164 at 85.

166. "Physician Granted Requests for Euthanasia", *supra* note 164.

167. *Ibid.*

168. *Ibid.*

The Canadian government's Bill C-7 reflects certain features of the law in the Netherlands.<sup>169</sup> Bill C-7 allows patients to consent in advance to MAID—currently prohibited by the contemporaneous consent requirement—so long as their natural death has become “reasonably foreseeable.”<sup>170</sup> Under the proposed legislation, eligible patients may receive MAID whether they continue to express a wish to die or not. Once approved, the only prerequisite is that they have scheduled a date for the provision with their provider. The bill does not prescribe a time limit, so it is possible that the patient and provider could arrange a provision days, weeks, months, or even years in the future.

Bill C-7 also does not indicate whether the use of sedatives or deception on the patient to help facilitate the procedure is permitted, but it does establish some limits. For example, the bill provides that “the medical practitioner or nurse practitioner may administer a substance to a person to cause their death...if the person does not demonstrate, by words, sounds or gestures, refusal to have the substance administered or resistance to its administration.”<sup>171</sup> The bill specifies that “involuntary words, sounds or gestures made in response to contact” do not count as refusal.<sup>172</sup> The bill does not say what the MAID provider must do if the patient does refuse or resist. Are they permitted to try again later that day or the next? The bill notes that the substance will be “administered to the person in accordance with the terms of the arrangement” so perhaps that could include a contingency plan.<sup>173</sup> At any rate, the statutory parameters remain under-specified.

Given the practical, as opposed to purely abstract problems and stressors patients would encounter, one may look to precedent to find workable ways to address potential conflicts. Nowhere—not in Switzerland, the Netherlands, Belgium, Luxembourg, Colombia, or any U.S. state that has legalized physician assisted suicide—may a proxy decision-maker initiate a request for MAID on their own. When it comes to jurisdictions that do permit advance directives, the approaches differ markedly. The Dutch allow physician compliance with advance directives only when patients who have lost capacity are still conscious, whereas in Belgium and Luxembourg, the law permits it only for patients who

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169. Bill C-7, *supra* note 12. Elements of this analysis of Bill C-7 are published in Thomas McMorrow, “Bill C-7 lacks adequate limits for advance MAiD requests” *Policy Options* (11 November 2020), online: <[policyoptions.irpp.org/magazines/november-2020/bill-c-7-lacks-adequate-limits-for-advance-maid-requests](http://policyoptions.irpp.org/magazines/november-2020/bill-c-7-lacks-adequate-limits-for-advance-maid-requests)>.

170. Bill C-14, *supra* note 6, s 241.2(2)(d).

171. Bill C-7, *supra* note 12, cl 3.2(c).

172. *Ibid*, cl 3.3.

173. *Ibid*, cl 3.2(d).

are irreversibly unconscious (*e.g.*, in a persistent vegetative state).<sup>174</sup> Besides, as of October 2019, only eight cases in the Netherlands of patients registered as decisively incompetent receiving euthanasia based on advance directives have been reported.<sup>175</sup> Two of these cases resulted in the responsible oversight body issuing a reproof of the physician's actions. Furthermore, there is considerable evidence of physicians and SDMs not complying with advance directives. It turns out that "the very situations for which [advance directives] were developed (*i.e.*, when patients can no longer communicate their wishes) are also the situations in which they are not being followed."<sup>176</sup>

How does one decide to put an end to another's life when that person is no longer able to confirm or deny that this is what they want? Requiring a state of irreversible unconsciousness is preferable to requiring that the patient retain consciousness since it avoids having to make a determination, based on an incompetent patient's conduct, as to whether that person ought to receive MAID. It is unconscionable to cause the death of patients who do not understand what is happening to them, or do not currently wish to receive MAID. If the lethal procedure would have to be abandoned if the patient were to resist, surely it would also have to be avoided if the patient could not appreciate to what they were assenting. On the other hand, Dutch lawmakers and medical professional regulators have reasoned that, since the primary rationale for euthanasia is to relieve suffering, where a person is no longer suffering due to an irreversible loss of consciousness, then euthanasia is not justified. In all likelihood, were advance directives to be permitted, a great number of people who would expect

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174. See Jan L Bernheim & Kasper Raus, "Euthanasia embedded in palliative care. Responses to essentialistic criticisms of the Belgian model of integral end-of-life care" (2017) 43 *J Medical Ethics* 489. For a more critical perspective on the Belgian model, see Trudo Lemmens, Heesoo Kim & Elizabeth Kurz, "Why Canada's Medical Assistance in Dying Legislation Should Be C(h)arter Compliant and What It May Help to Avoid" (2018) 11 *McGill JL & Health* S61 at S119-S148. See also Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst, *The role of the physician in the voluntary termination of life* (KNMG, June 2011); Paul Mevis et al, "Advance directives requesting euthanasia in the Netherlands: do they enable euthanasia for patients who lack mental capacity?" (2016) 4 *J Medical L & Ethics* 127.
175. Regional Euthanasia Review Committees, "Annual Report 2018" (April 2019), online (pdf): <[www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2018/april/11/jaarverslag-2018/RTE\\_jv2018\\_English.pdf](http://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2018/april/11/jaarverslag-2018/RTE_jv2018_English.pdf)>. See also CCA, "Advance Requests", *supra* note 2 at 175 (indicating the total as six but not including the 2018 RTE report).
176. ME de Boer et al, "Advance directives for euthanasia in dementia: Do law-based Opportunities Lead to More Euthanasia?" (2010) 98 *Health Pol'y* 256 cited in CCA, "Advance Requests", *supra* note 2 at 123.

to receive MAID would nevertheless find their hopes dashed due to the cautious, case-by-case approach that such an untested, risk-laden way of governing end-of-life decision-making would necessarily demand.

The loss of capacity has the potential to pose quite practical problems. Issues of principle are in play, certainly. The tension is not, however, between abstract proposition and personal concern. Neither the value of autonomy nor the principle of informed consent can, of itself, offer a solution since different ideas and applications of these concepts yield different results. Qualifying the distinction in Canadian criminal law between active and passive forms of medical aid in hastening death means more detailed and specific justificatory work is needed when defending restrictions on access to MAID. Since the law permits patients suffering from a grievous medical condition to receive medical assistance in dying—and for some time, advance requests have been a standard means to ensure patient treatment preferences are respected at the end of life—losing capacity appears tantamount to having “the right to a peaceful, dignified death” taken away.<sup>177</sup> With an aging population, and rates of neurodegenerative diseases on the rise, the demand for MAID through advance request is only going to grow.

The principle of informed consent plays a critical role in respect to the law governing both advance directives and MAID. It does not yield a clear, obvious answer to the question of whether to permit MAID through advance requests. In its 2018 report, *The State of Knowledge on Advance Requests for Medical Assistance in Dying*, the expert working group of the Council of Canadian Academies (CCA) acknowledged that individuals facing the prospect of neurodegenerative decline may want to receive medical assistance in dying before experiencing the full extent of their illness in order to spare their families the considerable strain it brings: “It is financially, emotionally, and physically challenging to provide round-the-clock care and it is reasonable to want to avoid burdening loved ones with years of caring for someone with severe dementia.”<sup>178</sup> Indeed, given the choice, many parents, grandparents, spouses, and friends may feel like they should spare their loved ones by opting for an assisted death. In this way, permitting MAID through advance request would not just allow individuals to exercise their autonomy in ways heretofore constrained under pain of state sanction; it also shifts societal expectations, clearing the way for a sense of personal obligation to act in a way that the criminal law had previously foreclosed. As a consequence—the CCA working group report notes—“[t]here is concern...that [advance requests] for MAID...could become a release valve for the societal failure to provide adequate

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177. CCA, “Advance Requests”, *supra* note 2 at 138.

178. *Ibid* at 146.

support or care for those with neurocognitive declines and their families.”<sup>179</sup> MAID thereby becomes the answer to complicated problems society is failing to face head on. The tenor of such arguments is nothing new to those familiar with debates over euthanasia in general.

Indeed, the Council of Canadian Academies’ working group report on eligibility for MAID solely on the basis of mental disorder acknowledges that the authors themselves disagree about when MAID is legitimate. The report notes that some of the working group members contend that, even if an individual is seeking MAID due to a systemic lack of medical, social, or economic resources, for example, depriving them of the opportunity to decide the manner and timing of their death forces that person to bear the brunt of society’s failings and disrespects their agency.<sup>180</sup> Applied to the present discussion, the argument would be that while efforts to de-stigmatize dementia, enhance financial and emotional supports for caregivers, and improve the quality of care for people with neurological conditions may reduce the level of demand for MAID through advance request, it does not justify restricting access until such changes are realized.<sup>181</sup> That, say these expert working group members, is a form of paternalism that devalues the self-determination of people trying to “make do as best they can in an imperfect world.”<sup>182</sup> In their view, the goal should be to ensure “maximal freedom for the self-determination of capable people within constrained circumstances, while

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179. *Ibid.*

180. CCA, *Mental Disorder*, *supra* note 163 at 99.

181. This echoes the opinion of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying that “palliative care should not be seen as a pre-condition for the development of a system that permits physician-assisted dying, but rather as a complement to improved end-of-life care.” See *Final Report, supra* note 136 at 20. Of course, introducing MAID, a one-off intervention with permanent consequences, as part of the suite of treatments for mental disorders, presents a greater rupture in established practice than in the palliative care context where the deliberate withholding and withdrawing of medical treatment already hastens death. But see The Halifax Group, *MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition* (Institute for Research on Public Policy, 2020), online: <on-irpp.org/2uGgID4>. Cf. Expert Advisory Group on Medical Assistance in Dying, *Canada at a Crossroads: Recommendations on Medical Assistance and Dying and Persons with a Mental Disorder- An Evidence-Based Critique of the Halifax Group IRPP Report* (EAG, 2020), online: < www.eagmaid.org/report>. Also, it is noteworthy that throughout the COVID-19 pandemic, Parliament has not invested anywhere near the time and energy it has spent on expanding access to MAID, on enhancing access to mental health services or improving supports for patients living with dementia and their carers (whether in a home or institutional setting). Bill C-7 does not earmark any money for such initiatives either.

182. CCA, *Mental Disorder*, *supra* note 163 at 99.

also seeking to remedy unjustified inequalities.”<sup>183</sup> In the abstract, it is difficult to disagree with this proposition. In practice, the legislative challenge of striking such a balance is even more difficult than the adjudicative task that the CCB performs every time it must determine whether it is in a person’s best interests to be allowed to die while that patient’s loved ones adamantly insist that it is not. Establishing prospective rules with general applicability has broader repercussions than rendering a decision in an individual case.

Maximizing freedom means setting safeguards that prevent patient autonomy from being disrespected. Although compliance with the informed consent principle may offer an invaluable means of respecting this value—and the concept of advance consent an indispensable proxy—the MAID context presents unique challenges. Recognizing why the temptation is so strong to discount these differences is important. It is precisely because removing the requirement for contemporaneous consent seems to be the answer to such vexing problems—the suffering of patients anticipating the horrors their condition will bring, the sheer wastefulness of so many wasting away when they would never have wanted such an end for themselves, the families financially and emotionally taxed to the brink, and the health care system stuck having to do more for more, for longer, with less—the temptation to allow advance requests for MAID appears overwhelming.

That, in and of itself, offers, if not reason to resist, then reason to pause, review relevant (and still largely forthcoming) research, and reflect on the implications of untethering MAID access from contemporary informed consent. There will always be restrictions on accessing MAID by advance request, so long as respect for patient autonomy and the value of voluntariness retain primacy. Requesting to have one’s life ended at a point in the future, no matter the specificity of the conditions identified in the request, is more complicated and more vulnerable to error and abuse than is giving contemporaneous consent. Removing the current consent requirement to permit advance requests for MAID demands its replacement with an alternative regulatory scheme. Some restrictions will apply, so invariably some people with very particular ideas of how they do (and more precisely, how they do not) want their lives to end, would end up with their autonomy interests thwarted. Repudiating the imperfect but nonetheless principled approach to determining lawful access to voluntary euthanasia would erode the system of safeguards in addition to inflating and ultimately frustrating the expectations of many people who wish to have MAID provided for them when they are no longer able to request it themselves.

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183. *Ibid.*

Under Bill C-7, those who are eligible but not yet ready to die would then be able to receive MAID on a specified date in the future. Advocates of the Bill C-7 MAID consent waiver argue these patients will thereby be spared the “cruel choice” of either ending their lives when they still have capacity or enduring the passage through advance dementia to death.<sup>184</sup> And yet, there is an element of cruelty built into any law that makes the compassionate termination of one’s suffering hinge on filling out the requisite paperwork. Witnessing an apparently contented person receive MAID may make it hard to see why another patient, appearing to suffer more and expressing their wish to die, would not also be able to receive MAID. Evidence of a patient’s wishes or values both prior to, and after, losing capacity may seem just as sound a basis to provide them with an assisted death as a formally approved advance MAID request; but then we have drifted away entirely from respecting the principle of informed consent. Any statutory effort at distinguishing permissible versus impermissible forms of non-voluntary euthanasia will be rife with difficulty—not least, one as under-specified as Bill C-7. The contemporaneous consent requirement offers a clearer, more certain and predictable threshold of legality.

Once it is lawful for others to decide when a patient in neurocognitive decline should have their life terminated through MAID, it becomes increasingly difficult to justify restricting this practice in any way that sets it apart from decisions to withhold or withdraw life-sustaining treatment. But no one suggests that these established forms of end-of-life decision-making might require concealing from the patient what is happening to them. The fact that sedation may be considered necessary before providing conscious patients with MAID via advance requests—and, as the Dutch Supreme Court suggests, even part of the standard of care—places the informed consent principle under significant strain. To the extent that the principle of informed consent may serve as a normative bulwark against health care professionals interfering with a patient’s bodily integrity, its value as a safeguard diminishes once a person lacks the legal capacity to give or refuse consent. Permitting the provision of MAID on the basis of advance consent reduces the level of legal protection for the lives of people lacking legal capacity, including those experiencing dementia.

The ethics of how we treat people who have lost capacity due to neurocognitive deterioration demands seeing them not simply as shadows of their former selves,

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184. Jocelyn Downie, “Medical assistance in dying bill an important step forward for Canadians with dementia” *Policy Options* (27 October 2020), online: <[policyoptions.irpp.org/magazines/october-2020/medical-assistance-in-dying-bill-an-important-step-forward-for-canadians-with-dementia](http://policyoptions.irpp.org/magazines/october-2020/medical-assistance-in-dying-bill-an-important-step-forward-for-canadians-with-dementia)>.

but also as individuals with the spark of life; that is, as persons owed due regard. Granting to a person the assisted death that they previously expressed to be their due must be balanced against the public interest in prohibiting the act of terminating someone's life on their behalf. The alternative is to develop an ethics of life termination—as to whose moral, political, economic, and cultural ramifications one may speculate with curiosity, optimism, or dread.