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## And Miles to Go Before I Sleep: The Future of End-of-Life Law and Policy in Canada

Jocelyn Downie  
*Dalhousie University*

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*This paper reviews the legal status of a number of end-of-life law and policy issues that have, to date, been overshadowed by debates about medical assistance in dying. It suggests that law reform is needed in relation to palliative sedation without artificial hydration and nutrition, advance directives for the withholding and withdrawal of oral hydration and nutrition, unilateral withholding and withdrawal of potentially life-sustaining treatment, and the determination of death. To leave the law in its current uncertain state is to leave patients vulnerable to having no access to interventions that they want or, at the other extreme, being forced to receive interventions that they do not want. This can either inappropriately shorten life or extend suffering. It can also leave individuals at risk of being declared dead earlier than appropriate or much-needed organs not being available for transplantation because individuals are being declared dead later than appropriate.*

*L'auteure examine le statut juridique d'enjeux concernant les lois et les politiques en matière de fin de vie qui ont, jusqu'à maintenant, été éclipsées par les débats sur l'aide médicale à mourir. Elle avance qu'une réforme du droit s'impose pour ce qui est de la sédation palliative sans hydratation et nutrition artificielles, des directives anticipées concernant l'abstention et l'interruption d'hydratation et de nutrition par voie orale, la poursuite et l'abandon unilatéraux d'un traitement susceptible de maintenir la vie et la détermination de la mort. Laisser la loi dans son état actuel incertain équivaut à laisser les patients vulnérables au manque d'accès à des interventions qu'ils souhaitent ou, à l'autre extrême, à les forcer à subir des interventions dont ils ne veulent pas. L'une ou l'autre situation risque d'abrégé la vie ou de prolonger la souffrance de façon inappropriée. Elles peuvent également faire que des personnes à risque soient déclarées mortes trop tôt ou que des organes fort nécessaires ne soient pas disponibles pour transplantation parce que les donneurs potentiels sont déclarés morts trop tard.*

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\* University Research Professor, Schulich School of Law and Faculty of Medicine, Dalhousie University; Adjunct Professor, Australian Centre for Health Law Research, QUT; Fellow, Pierre Elliott Trudeau Foundation. Thanks to Kate Scallion for research assistance on this paper and Richard Liu for research and discussions on palliative sedation.

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*Introduction*

The future of end-of-life law and policy in Canada is a rapidly moving target because the field is changing so quickly. Indeed, by the time this paper has been published, parts of it will no doubt be out of date. Nonetheless, as Canada has just crossed the threshold of the most significant change in end-of-life law and policy in Canadian history, it is worth spending some time and effort to map the terrain for the future.

Although the shockwaves caused by the February 2015 Supreme Court of Canada decision in *Carter v. Canada (Attorney General)*<sup>1</sup> have largely died down, the significance of this decision has not. With the coming into force of the Quebec medical aid in dying legislation (*An Act Respecting End-of-Life Care*)<sup>2</sup> and the federal medical assistance in dying legislation (*An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*)<sup>3</sup>, medical assistance in dying (MAiD) is now legal throughout the country. The task of designing and implementing the surrounding regulatory framework for the newly permissive regime is well underway.

It is true that several open questions remain. Specifically, the government is required by the federal MAiD legislation to

initiate independent reviews of issues relating to requests by mature minors for medical assistance in dying, to advance requests and to requests where mental illness is the sole underlying medical condition.<sup>4</sup>

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1. 2015 SCC 5, [2015] 1 SCR 331 [*Carter 2015*].

2. RSQ c S-32.0001.

3. SC 2016 c3 [MAiD legislation].

4. *Ibid.*, s 9.1(1).

There has also already been a *Charter*<sup>5</sup> challenge launched against the restrictive nature of the federal legislation<sup>6</sup> and against the permissive nature of the Quebec legislation.<sup>7</sup> There is active litigation on the issue of a conscientiously objecting physician's duty to refer patients requesting MAiD.<sup>8</sup> Some "next gen" MAiD questions will no doubt arise. For example, should prisoners be allowed access to MAiD? And should changes be made to legal requirements regarding organ-harvesting protocols to accommodate the organ donation wishes of individuals who are accessing MAiD?

However, in this paper I focus on the non-assisted dying issues in the future of end-of-life law and policy. Now is a good time to turn our attention from fighting about whether or not to allow MAiD to working together on finding additional ways for society to better care for the dying. To this end, four main areas of end-of-life law and policy require attention: palliative sedation without artificial hydration and nutrition, advance directives for the withholding and withdrawal of oral hydration and nutrition, unilateral withholding and withdrawal of potentially life-sustaining treatment, and determination of death.

### I. *Palliative sedation without artificial hydration and nutrition*

Justice Smith, the trial judge in *Carter v. Canada*, defined palliative sedation as

the intentional administration of sedative medication to reduce a patient's level of consciousness, with the intent to alleviate suffering at the end of life. It includes both intermittent and continuous sedation, as well as both superficial and deep sedation. It may be accompanied by the withdrawal of artificial hydration and nutrition.<sup>9</sup>

In this paper, I am concerned with a subset of palliative sedation, specifically, deep and continuous palliative sedation combined with the withholding or withdrawal of artificial hydration and nutrition (PS $\bar{s}$ ANH).<sup>10</sup> There are three types of this kind of PS $\bar{s}$ ANH. First, where the interventions clearly *play no causal role* in the death (when death occurs within one

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5. *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [Charter].

6. *Lamb v Canada (AG)* (27 June 2016), Vancouver, SCBC, S-165851 (notice of civil claim) [Lamb].

7. See *Quebec (Procureur general) v D'Amico*, 2015 QCCA 2138, 2015 CarswellQue 12180.

8. See, e.g., Sean Fine, "Christian Doctors Challenge Ontario's Assisted-Death Referral Requirement," *Globe and Mail* (22 June 2016), online: <<http://www.theglobeandmail.com/news/national/christian-doctors-challenge-ontarios-assisted-death-referral-policy/article30552327/>>.

9. *Carter v Canada (AG)* 2012 BCSC 886, [2012] BCWLD 6899 at para 42 [Carter (Trial)].

10.  $\bar{s}$  is the symbol for "without."

or two days). Second, where the palliative interventions *may, but are not certain to* shorten life (when death occurs within two weeks). Third, where interventions *clearly cause* the death (when death would not otherwise have occurred for many weeks or even months).

1. *Types one and two PSsANH*

If someone were charged with a criminal offence in connection with the first type of PSsANH there would arguably be no liability—the conduct is legal as the first type clearly does not cause death.

The law on the second type is somewhat less clear—there are some statements from courts that might be taken to mean that it is (or may be) legal. For example, in *Rodriguez v. British Columbia (Attorney General)* Sopinka J. writing for the majority said:

The fact that doctors may deliver palliative care to terminally ill patients without fear of sanction, it is argued, attenuates to an even greater degree any legitimate distinction which can be drawn between assisted suicide and what are currently acceptable forms of medical treatment. The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active contribution to death by any standard. However, the distinction drawn here is one based upon intention—in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death. The Law Reform Commission, although it recommended the continued criminal prohibition of both euthanasia and assisted suicide, stated, at p. 70 of the Working Paper, that a doctor should never refuse palliative care to a terminally ill person only because it may hasten death. In my view, distinctions based upon intent are important, and in fact form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear.<sup>11</sup>

Unfortunately it is not clear whether Sopinka J. would have included Type Two PSsANH in his definition of “palliative care” (he appears to only be contemplating the potentially life-shortening effect of drugs, not the withholding of hydration and nutrition; as noted by Smith J. in *Carter (Trial)*, “[t]he majority in *Rodriguez* did not refer to palliative sedation”<sup>12</sup>). However, the logic of the passage suggests that, if he had turned his mind to it, he would have concluded that Type Two PSsANH is legal.

More recently, Smith J. noted in *Carter (Trial)*:

11. *Rodriguez v British Columbia (Attorney General)*, [1993] 3 SCR 519, 107 DLR (4th) 342 at para 57 [*Rodriguez*]. The position put forward by Sopinka J. has been criticized. See, for example, Jocelyn Downie, *Dying Justice* (Toronto: University of Toronto Press, 2004), at p 93-94, 139-140.

12. *Carter (Trial)*, *supra* note 9 at para 332.

So far as I am aware, palliative or terminal sedation has not been the subject of judicial consideration in Canada. It seems, however, to be a practice that may fall within the principles already described with regard to informed consent and potentially life-shortening symptom relief.<sup>13</sup>

However, Justice Smith's choice of language, in particular her use of "it seems" and "may fall," reflects and reinforces the ambiguity about the legality of Type Two PS $\bar{s}$ ANH. That ambiguity leaves health care providers contemplating providing Type Two PS $\bar{s}$ ANH in the shadow of potential criminal liability and leaves patients without a strong foundation upon which to base a request for access.

Looking deeper into Smith J.'s reasons does not provide greater clarity or certainty. Justice Smith certainly had before her the fact that "palliative or terminal sedation" may shorten life. She reported that both the plaintiffs<sup>14</sup> and the defendants<sup>15</sup> accepted that deep and continuous sedation combined with the withholding or withdrawal of artificial hydration and nutrition can be "death-hastening." She noted, without disagreeing with the submission, that the Crown had submitted, "the law permits death-hastening acts through refusal or withdrawal of treatment, or declining nutrition and hydration while under palliative sedation."<sup>16</sup> She might be taken as implying that PS $\bar{s}$ ANH is a form of suicide and so is not illegal.<sup>17</sup> She might also be taken as implying that PS $\bar{s}$ ANH is legal for individuals even when death is not imminent.<sup>18</sup> However, none of this is sufficient to have confidence in drawing conclusions regarding the legal status of Type Two PS $\bar{s}$ ANH.

On the appeal, the Supreme Court of Canada simply stated "The law allows people in this situation [with a grievous and irremediable condition] to request palliative sedation..."<sup>19</sup> Again, this provides no guidance on the boundaries of permissibility (for example, it is not clear whether the Supreme Court even turned its mind to the different types of palliative sedation or the range of different circumstances in which it might be sought).

The Quebec legislation directly addresses the issue of what it calls "continuous palliative sedation," understanding it narrowly as deep

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13. *Ibid* at para 226.

14. *Ibid* at para 321.

15. *Ibid* at para 1075.

16. *Ibid* at para 1075.

17. *Ibid* at para 1076.

18. *Ibid* at para 1159. For example, Gloria Taylor and Elayne Shapray were not imminently dying and yet Smith J. implies that they could legally have access to PS $\bar{s}$ ANH.

19. *Carter 2015*, *supra* note 1 at para 66.

and continuous sedation (with no reference to hydration and nutrition), restricting it to “end-of-life” patients, establishing the requirement of consent (from the patient or substitute decision-maker), and ensuring oversight through the establishment of a reporting system.<sup>20</sup> However, continuous palliative sedation is defined as part of “palliative care,” and “palliative care” is defined as “care delivered...without delaying or hastening death.” This suggests that Type Two PS $\bar{S}$ ANH would not be legal under the Quebec legislation as, by definition, it may hasten death.

The federal MAiD legislation in turn did not address the issue of palliative sedation at all. Of course, this all leaves many details of the legal status of palliative sedation woefully underdeveloped. Furthermore, in this state of uncertainty, there is reason to be concerned that some patients are being denied PS $\bar{S}$ ANH on contestable grounds. Consider the “Framework for Continuous Palliative Sedation Therapy in Canada.”<sup>21</sup> While the framework for continuous palliative sedation therapy (CPST) is a commendable effort to develop and advance guidance in the absence of clear law, it would be problematic to leave the uncertainties described above to be resolved through this framework. For example, it requires that “all other reasonable alternatives have failed or were reasonably rejected”<sup>22</sup> and that “there should be consensus that the harm of suffering warrants the harm of reduced consciousness.”<sup>23</sup> Contrast these conditions with the criteria for access to MAiD established in the federal legislation—the framework criteria are more restrictive. Under the federal legislation, there is no reasonableness standard for the rejection of treatments; the assessment of suffering is for the patient alone and is not subject to “consensus.”<sup>24</sup> On what basis could being more restrictive of access to Types One and Two PS $\bar{S}$ ANH than to MAiD be justified? In addition, while the Framework says, “decisions regarding CPST should conform to the national, provincial and institutional policies for decisionmaking and informed consent in law and medical ethics,”<sup>25</sup> it then requires “consensus” among the patient, family, and team. A consensus requirement is not consistent with the law on informed consent. Finally, there is reason to be

20. *An Act Respecting End-of-Life Care*, *supra* note 2.

21. Mervyn M Dean et al, “Framework for Continuous Palliative Sedation Therapy in Canada” (2012) 15:8 J Palliative Medicine 870 [Framework].

22. Framework, *supra* note 21 at 872.

23. *Ibid* at 871.

24. MAiD legislation, *supra* note 3, at s 241.2(2).

25. Framework, *supra* note 21 at 872.

concerned that some patients are being given PS $\bar{s}$ ANH without their or their substitute decision-maker's free and informed consent.<sup>26</sup>

Fortunately, there is a way to respond to this state of affairs. The federal government could amend the *Criminal Code*<sup>27</sup> to make it clear that: (1) the first two types of PS $\bar{s}$ ANH are not contrary to the *Criminal Code*, (2) access should not be restricted by the type of suffering or condition of the patient, and (3) like any medical treatment, free and informed consent from the patient or patient's substitute decision maker where the patient does not have capacity to make the decision is necessary and sufficient. To that end, the following could be added to the *Criminal Code*:

“palliative sedation” means the intentional administration of deep and continuous sedation combined with the withholding or withdrawal of artificial hydration and nutrition where the purpose is to alleviate suffering where this will not, or may but is not certain to, shorten the life of the person.<sup>28</sup>

No physician, other health care provider acting under the direction of a physician, or nurse practitioner is guilty of an offence under this Act where the physician, other health care provider acting under the direction of a physician, or nurse practitioner provides palliative sedation to a patient with a valid consent from the patient (if competent or through a valid advance directive if incompetent) or the patient's statutory substitute decision-maker (if incompetent and without a valid advance directive).

This *Criminal Code* amendment would provide clarity and certainty—enabling understanding and respect for the law—as well as access to much-needed symptom relief for patients.

In addition, all institutions in which the first two types of PS $\bar{s}$ ANH are provided could be encouraged to conduct an audit of practice to ensure that they are following best practices (and the *Criminal Code* amended as above), including getting free and informed consent from the patient or patient's substitute decision-maker.

Discussion of these and other suggestions for law reform is needed.

## 2. *Type three PS $\bar{s}$ ANH*

The law on the third type of PS $\bar{s}$ ANH is absolutely unsettled. Imagine a situation in which a patient is diagnosed with Amyotrophic Lateral

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26. E.g., M McKinnon et al, “Practice and Documentation of Palliative Sedation: A Quality Improvement Initiative” (2014) 21:2 *Current Oncology*, 100 at 102.

27. RSC 1985, c C-46.

28. Note that this definition does not include Type Three PS $\bar{s}$ ANH. A discussion of what should be done for that type follows below.



Sclerosis, a lethal degenerative neurological disorder. She lives with it for some while but, six months before her death is expected, she asks to be deeply sedated (thereby creating the need for artificial hydration and nutrition) *and* refuses all artificial hydration and nutrition. The cause of her death would be the lack of hydration and nutrition. Can a physician respect her wishes without facing criminal liability? If so, what eligibility criteria and procedural safeguards apply? What if the patient requested PS̄ANH through an advance directive completed long before any particular diagnosis or commencement of suffering?

There is no legislation or case law directly on point to provide clear answers to these questions. As noted in the earlier discussion of Type Two PS̄ANH, Smith J. in *Carter (Trial)* did contemplate “death-hastening” palliative sedation. She noted, without disagreeing with the submission, that the Crown had submitted that death-hastening acts are legal,<sup>29</sup> and her comments could be taken to imply Type Three PS̄ANH is legal. However, there is no clarity or certainty, and no discussion of the boundaries of permissibility (in particular, how near to death the patient must be, the nature of the suffering, etc.). We are therefore left wondering whether it is legal for a patient whose life has become intolerable to her but whose medical condition is not likely to cause her death for many years to access to Type Three PS̄ANH.

As noted earlier, there is no evidence that the Supreme Court of Canada appreciated the three types of palliative sedation, most particularly, that it even knew of the existence of this third type.

The only national framework for palliative sedation takes the position that “CPST is indicated only for refractory and intolerable suffering, usually in the last 2 weeks of life.”<sup>30</sup> The Framework acknowledges, “the longer the anticipated time before death the greater the ethical challenges and the more controversial the procedure, especially regarding decisions around nutrition and hydration during sedation.”<sup>31</sup> This means that the third type of PS̄ANH could be permissible under the Framework. It would be “unusual” outside of two weeks. But PS̄ANH with a life-expectancy beyond two weeks is not prohibited. And yet, the Framework does not tell health care providers how to determine when cases of the third type of PS̄ANH, while unusual, are nonetheless permitted.<sup>32</sup> Furthermore, the

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29. *Carter (Trial)*, *supra* note 9 at para 1075.

30. Framework, *supra* note 21 at 871.

31. *Ibid* at 871.

32. *Ibid*.

Framework has no authority: it is the result of a special task force of the Canadian Society for Palliative Care Physicians.

We need to address this legal lacuna. We need to wrestle with at least three very serious questions. First, *is* Type Three PS̄ANH legally permitted under the current law? To answer this, we must debate the application of first principles of criminal law to PS̄ANH (in particular, intention and causation). Second, *should* Type Three PS̄ANH be legally permitted? Third, if permitted at all, how should Type Three PS̄ANH be regulated? Through reform to the *Criminal Code*? Through guidelines for the exercise of prosecutorial discretion issued by provincial/territorial Attorneys General or Directors of Public Prosecutions?

Clear guidance is obviously needed on Type Three PS̄ANH so that patients receive adequate symptom control (i.e., those who should have access, do), the vulnerable are protected (i.e., those who should not have access, do not), and patients who qualify for MAiD but would prefer to die through PS̄ANH (rather than through ingesting or receiving an injection of a lethal medication) can do so. Given the current lack of clarity in and guidance from the law, we cannot be confident that any of these objectives are being met.

## II. *Advance directives for the withholding and withdrawal of oral hydration and nutrition*

Twenty-six years ago, the right to refuse potentially life-sustaining treatment first came before the courts in Canada.<sup>33</sup> It is now very clear that a refusal of potentially life-sustaining treatment made by a competent individual or their substitute decision-maker must be respected by health care providers. As noted by Sopinka J. in *Rodriguez*,

Canadian courts have recognized a common law right of patients to refuse consent to medical treatment, or to demand that treatment, once commenced, be withdrawn or discontinued (*Ciarlariello v. Schacter*, [1993] 2 S.C.R. 119). This right has been specifically recognized to exist even if the withdrawal from or refusal of treatment may result in death (*Nancy B. v. Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Que. S.C.); and *Malette v. Shulman* (1990), 72 O.R. (2d) 417 (C.A.)).<sup>34</sup>

However, a couple of years ago a twist on the issue of withholding or withdrawing treatment was brought forward in the case of Margot

33. *Malette v Shulman* (1990), 72 OR (2d) 417, [1990] OJ No 450 (CA); *Nancy B v Hotel Dieu de Québec* (1992), 86 DLR (4th) 385, [1992] RJQ 361 (Que SC); *Fleming v Reid* (1991), 4 OR (3d) 74, [1991] OJ No 1083 (CA).

34. *Rodriguez*, *supra* note 11 at para 41.

Bentley.<sup>35</sup> Given the anticipated wave of dementia in coming years,<sup>36</sup> this issue is likely to take on increased significance.

Margot Bentley was a woman with advanced Alzheimer's Disease. When she was well she completed an advance directive, that indicated the point at which she wished many things, including "nourishment and liquids" to be withheld or withdrawn. Once she reached that point, her substitute decision-maker directed the facility she lived in now to stop spoon-feeding her. However, this facility insisted on continuing to feed Margot and her family was unsuccessful at stopping the facility in court.<sup>37</sup> So Margot continued to be fed for years (she died in November 2016).

While there are disagreements in the Bentley case about various matters (e.g., was there another advance directive that expressed conflicting wishes? Was Margot competent? Was Margot consenting to being fed by opening her mouth when the spoon was tapped against her lip?), the case unquestionably raises a significant issue of end-of-life law and policy. The law is clear around refusing *artificial* hydration and nutrition through advance directives, but it is not so clear around refusing *oral* hydration and nutrition through advance directives. What should happen when a valid advance directive clearly states that, should the patient get into a particular condition, she does not want even food and water by mouth? Must a health care team respect that refusal? Might a health care provider who respects the refusal find themselves facing criminal liability for failing to "provide necessities of life"?<sup>38</sup>

Some provinces have already addressed this issue in legislation. For example, the Nova Scotia *Personal Directives Act* provides:

"personal care" includes, but is not limited to, health care, *nutrition, hydration*, shelter, residence, clothing, hygiene, safety, comfort, recreation, social activities, support services and any other personal matter that is prescribed by the regulations;<sup>39</sup>

Following an advance directive refusing oral nutrition and hydration would therefore be required in Nova Scotia under the *Personal Directives*

35. 2015 BCCA 91, [2015] 6 WWR 252 [*Bentley 2015*]; see also Thaddeus Pope, "Decision-Making: At the End of Life and the Provision of Pretreatment Advice" (2015) 12:3 J Bioethical Inquiry 389.

36. J Downie & G 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*, 1st ed, (New York: Springer International Publishing, 2015) 97 at 100-101.

37. *Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165, [2014] 7 WWR 808; *Bentley 2015*, *supra* note 35.

38. *Criminal Code*, *supra* note 27, s 215.

39. *Personal Directives Act*, SNS 2008, c 8, s 2(1) (emphasis added).

*Act* and would not violate the *Criminal Code* as the health care provider would have a “lawful excuse” for not providing the necessities of life.

Again, as a starting contribution to the policy debate needed to address this issue, I would argue that those provinces and territories lacking provisions similar to those found in Nova Scotia<sup>40</sup> need to reform their legislation to: (1) make the answer clear; and, specifically, (2) make it clear that health care providers must respect refusals of oral hydration and nutrition. This could be achieved through the inclusion of the following text in, for example, health care consent legislation:

“potentially life-sustaining care” means care that has the potential to sustain the life of a person including, but not limited to, health care and oral and artificial hydration and nutrition;

“withdrawal of potentially life-sustaining care” means intentionally ceasing care that has the potential to sustain a persons’ life;

“withholding of potentially life-sustaining care” means intentionally refraining from commencing care that has the potential to sustain a person’s life.

Except as otherwise provided by law, a capable patient may, at any time, refuse consent to potentially life-sustaining care or withdraw consent to such care. In the case of an incapable patient, the substitute decision-maker appointed under the [*provincial/territorial advance directives legislation and consent legislation*] may also refuse to authorize potentially life-sustaining care or withdraw authorization of such care. A free and informed refusal of consent or authorization made by an individual with legal decision-making authority must be respected.

It could also be achieved through the inclusion of the following text in advance directives legislation, as in Nova Scotia:

3 (1) A person with capacity may make a personal directive

(a) setting out instructions or an expression of the maker’s values, beliefs and wishes about future personal-care decisions to be made on his or her behalf....

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40. Alberta: *Personal Directives Act*, RSA 2000, c P-6, s 1(f); British Columbia: *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 1 & 19.2; Manitoba: *The Health Care Directives Act*, CCSM c H27, s 1; New Brunswick: *Infirm Persons Act*, RSNB 1973, c 1-8, s 40(1); Northwest Territories: *Personal Directives Act*, SNWT 2005, c 16, s.1; Ontario: *Substitute Decisions Act*, 1992, SO 1992, c 30, s.46(1), *Health Care Consent Act*, 1996, SO 1996, c 2, s 2(1); Prince Edward Island: *Consent to Treatment and Health Care Directives Act*, RSPEI 1988, c C-17.2, s 2(m)&(p); Quebec: *Civil Code of Québec*, CQLR c C-1991, s 11, 12 & 2166; Saskatchewan: *The Health Care Directives and Substitute Health Care Decision Makers Act*, SS 1997, c H-0.001, s 2(1) (d) & (h); Yukon: *Care Consent Act*, SY 2003, c 21, s 1.

18(3) A health-care provider shall follow

...

(b) where there is no delegate, the instructions or an expression of the maker's wishes contained in a personal directive.<sup>41</sup>

### III. *Unilateral withholding or withdrawal of potentially life-sustaining treatment*

Fortunately, as noted above, we have left behind the practice of keeping people alive against their express wishes. If a competent patient is ventilator-dependent and paralyzed in bed, his request to remove the ventilator must be respected. But what if a patient has sustained a traumatic brain injury, is now incompetent, and her family want treatment continued while the health care team have decided that treatment would be what they characterize as “futile”? Or what if a competent patient has advanced cancer and wants all interventions for a long enough window to see whether some traditional medicines might work, but the doctors want to put a Do Not Attempt Resuscitation Order on his chart?

These questions are not speculative in a pejorative sense. A recent Canadian study revealed a disturbing discordance between written orders regarding treatment and patients' expressed preferences for end-of-life care.<sup>42</sup> In addition, a significant number of conflicts between health care teams and patients' substitute decision makers have ended up in court<sup>43</sup> and in the media.<sup>44</sup>

41. *Personal Directives Act*, *supra* note 39.

42. Daren K Heyland et al, “The Prevalence of Medical Error Related to End-of-Life Communication in Canadian Hospitals: Results of a Multicentre Observational Study” (2015) *BMJ Quality & Safety*, DOI: 10.1136/bmjqs-2015-004567, online: < <http://qualitysafety.bmj.com/content/early/2015/11/08/bmjqs-2015-004567.full.pdf>>.

43. See, e.g., cases summarized in Jocelyn Downie & Karen McEwen, “The Manitoba College of Physicians and Surgeons Position Statement on Withholding and Withdrawal of Life-Sustaining Treatment (2008): Three Problems and a Solution” (2009) 17 *Health LJ* 115.

44. See, e.g., Robert Cribb, “Sunnybrook Case Raises Question of Who Decides Life Support,” *Toronto Star* (28 September 2012), online: <[https://www.thestar.com/news/gta/2012/09/28/sunnybrook\\_case\\_raises\\_question\\_of\\_who\\_decides\\_life\\_support.html](https://www.thestar.com/news/gta/2012/09/28/sunnybrook_case_raises_question_of_who_decides_life_support.html)>; John Gillis, “Family Wants Court to Keep Sick Man Alive,” *The Chronicle Herald* (17 November 2006); Tom Blackwell, “Who Says Doctors Know Best: Families Do Not Have Final Say in Pulling Plug,” *The National Post* (11 December 2006); Robert Cribb, “Family Sues Physician, Toronto Hospital over No-Resuscitation Order,” *The Toronto Star* (25 March 2015), online: <<https://www.thestar.com/news/gta/2015/03/25/family-sues-physician-toronto-hospital-over-no-resuscitation-order.html>>; Robert Cribb, “Lawsuit Could Set Precedent About End-Of-Life Decisions,” *The Toronto Star* (4 September 2010), online: <[https://www.thestar.com/news/gta/2010/09/04/lawsuit\\_could\\_set\\_precedent\\_about\\_endoflife\\_decisions.html](https://www.thestar.com/news/gta/2010/09/04/lawsuit_could_set_precedent_about_endoflife_decisions.html)>.

Unfortunately, the legal status of unilateral withholding and withdrawal of potentially life-sustaining treatment is profoundly unsettled in Canada. As noted by Smith J. in *Carter (Trial)*:

The law makes clear that consent is a sufficient condition for the withdrawal or withholding of treatment. But is consent also a necessary condition? Whether a physician or hospital can legally withhold or withdraw potentially life-sustaining treatment without the consent of either the patient or the patient's substituted decision-maker, is currently under much debate.

In some decisions, Canadian courts have held that it is not appropriate for a court to interfere with medical practitioners acting unilaterally in the best interests of a patient: for example, *Child and Family Services of Manitoba v. R.L.* (1997), 1997 CanLII 3742 (MB CA), 154 D.L.R. (4th) 409 (Man. C.A.); and *Re: I.H.V. Estate*, 2008 ABQB 250 (CanLII).

More commonly, however, courts faced with such issues have concluded that the law in Canada is not settled: for example, *Sawatzky v. Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 (Man. Q.B.); *Jin v. Calgary Health Region*, 2007 ABQB 593 (CanLII); *Golubchuk v. Salvation Army Grace General Hospital*, 2008 MBQB 49 (CanLII); and *Rotaru v. Vancouver General Hospital Intensive Care Unit*, 2008 BCSC 318 (CanLII).<sup>45</sup>

No doubt hoping that clarification of the law would be forthcoming, Smith J. noted that this issue was before the Supreme Court of Canada in *Rasouli v. Sunnybrook Health Sciences Centre*.<sup>46</sup> Unfortunately, the Supreme Court decision provided considerable (albeit not perfect) clarity for those who live in Ontario, but not much for those of us in the rest of Canada.

In Ontario, thanks to some unique provisions in their health care consent legislation,<sup>47</sup> the existence of a Consent and Capacity Board (CCB),<sup>48</sup> and the fact that the majority in the Supreme Court based its decision in *Rasouli* on statutory interpretation of the Ontario legislation and not on the common law,<sup>49</sup> the legal status of unilateral withholding and withdrawal of potentially life-sustaining treatment is somewhat clear (physicians do not have the authority to unilaterally withdraw potentially life-sustaining

45. *Carter (Trial)*, *supra* note 9 at paras 227-229.

46. *Rasouli (Litigation Guardian of) v Sunnybrook Health Sciences Centre*, 2013 SCC 53, [2013] 3 SCR 341 [*Rasouli*].

47. See *Health Care Consent Act*, SO 1996, c 2, Schedule A, s 2(1) "Plan of treatment" means a plan that...provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition."

48. Consent and Capacity Board, online: <<http://www.ccboard.on.ca/scripts/english/index.asp>>.

49. *Rasouli*, *supra* note 46.

treatment, but rather must go to the CCB to seek authorization to do so when the team believes treatment should not be provided and the patient's substitute decision-maker believes that it should).

At first blush, it might seem like the issue of unilateral withholding and withdrawal has, as in Ontario, been somewhat clarified for Yukon; because of apparent similarities between the Ontario and Yukon statutes, it might seem like the reasoning in *Rasouli* could be extended to Yukon. Similar (but not identical) to Ontario, the Yukon legislation includes "the withholding or withdrawal of health care" in its definition of "care plan" and Yukon has a Care and Consent Board. However, Yukon does not include "care plan"<sup>50</sup> within its definition of "health care."<sup>51</sup> The legislation requires consent to "care" and "care" is defined as "(a) health care, (b) admission to live in a care facility, and (c) personal assistance services."<sup>52</sup> Therefore, unlike Ontario, there is arguably no statutory requirement for consent to the withholding or withdrawal of potentially life-sustaining treatment (although, like the rest of country, there may still be a common law requirement for consent). Furthermore, even if "care plan" was read into "health care" and a requirement of consent to withholding and withdrawal of treatment established, Yukon does not then end up with the same clarity as Ontario. Unlike in Ontario, health care providers can only seek a decision from the Care and Capacity Board respecting "major health care" (it is all treatment in Ontario). Major health care is defined in s.1 of the *Care Consent Act* as:

- (a) major surgery,
- (b) any treatment involving a general anesthetic,
- (c) major diagnostic or investigative procedures, or
- (d) any health care designated by the regulations as major health care....

It is further defined in the regulations as:

- (a) radiation therapy;
- (b) intravenous chemotherapy;
- (c) peritoneal and kidney dialysis;
- (d) abortions under section 9;
- (e) electroconvulsive therapy under section 10;
- (f) removal of tissue under section 11;
- (g) experimental health care under section 12;

50. *Care Consent Act*, *supra* note 40, Schedule B.

51. *Ibid.*, s 1.

52. *Ibid.*

- (h) medical research under section 13;
- (i) laser surgery.<sup>53</sup>

Much contested potentially life-sustaining treatment will not qualify as “major health care” so health care providers will not have access to the Care and Capacity Board to resolve disagreements about such care. In these instances, if consent to withholding and withdrawal is required, health care providers would have to go to court under the *Adult Protection and Decision Making Act*<sup>54</sup> to seek to have the substitute decision-maker displaced through the appointment of a guardian (presumably on the grounds that the substitute decision-maker is not acting according to their duties under section 20 of the *Care Consent Act*.)

As the Supreme Court declined to settle the common law status of unilateral withholding and withdrawal of potentially life-sustaining treatment through its decision in *Rasouli*, most of the country remains mired in a controversial and corrosive state of confusion. We need provincial and territorial legislatures to step up, clarify the law, and establish efficient and affordable processes for the resolution of conflicts. Barring that, more litigation will be necessary.

Unfortunately, unilateral withholding and withdrawing of treatment is one of the most controversial issues facing end-of-life law and policy in the future.<sup>55</sup> Achieving the necessary law reform will not be easy as the issue implicates the patients’ and their families’ beliefs and values, as well as the beliefs and values of health care providers.<sup>56</sup> Costs to the health care system are also implicated. Autonomy, conscience, culture, and professional judgement along with economics can all come together in a singularly toxic clash. How the competing rights and interests will be reconciled is unclear; that they need to be reconciled is very clear.

#### IV. *Determination of death*

It might seem odd to suggest that the future of end-of-life law and policy should include a discussion of the issue of the determination of death. This issue was discussed in depth a number of decades ago and then largely subsided with the broad acceptance in practice of using brain death criteria

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53. Care Consent Regulation, YOIC 2005/80, 29 April 2005.

54. SY 2003, c 21, Sch A.

55. See, e.g., James Downar, Michael Warner & Robert Sibbald, “Mandate to obtain consent for withholding nonbeneficial cardiopulmonary resuscitation is misguided” (2016) 188:4 CMAJ 245; Hilary Young, “Why Withdrawing Life-Sustaining Treatment Should Not Require ‘*Rasouli*’ Consent” (2012) 6:2 McGill JL & Health 54.

56. J Downar, L Willmott & BP White, “Next Up: A Proposal for Values-Based Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment” [forthcoming Alberta Law Review].



for the determination of death. However, it needs to be revisited for at least two reasons.

First, there is a desperate need for organs for transplantation and there are some patients who do not progress to brain death while on cardiopulmonary support. Some have suggested (and indeed put into practice) that physicians should be allowed to turn off the artificial supports, wait 2, 5, 10, or 20 minutes, and, if the heart does not function, declare the person dead and then have the transplant team harvest the organs.<sup>57</sup> This practice is known as “controlled Donation After Circulatory Death (DCD).” A number of authors have raised concerns with the practice of DCD in Canada, both in terms of the content of the guidelines that established a five-minute wait period and the process of arriving at the guidelines.<sup>58</sup> Indeed there have been calls for a moratorium on the practice.<sup>59</sup>

Second, there are reasons to be concerned about actual or perceived inaccurate determinations of death. A recent study of hospitals in the United States concluded that “[h]ospital policies in the United States for the determination of brain death are still widely variable and not fully congruent with contemporary practice parameters.”<sup>60</sup> While this is an American study, there is no reason to presume Canadian results would be any better. Furthermore, we are now seeing cases in which the patient is declared brain dead by physicians, but the families dispute the declaration. While the high profile cases have been in the United States (e.g., Jahi McMath), there is some anecdotal evidence of such cases in Canada. One

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57. Institute of Medicine, *Non-Heart-Beating Organ Transplantation: Medical and Ethical Issues in Procurement* (Washington, DC: National Academies Press, 1997); University of Pittsburgh Medical Center. *UPMC Policy for the Management of Terminally Ill Patients Who May Become Organ Donors After Death* (Pittsburgh, Penn: University of Pittsburgh Medical Center, 1992); G Kootstra, “Statements on Non-Heart-Beating Donor Programs” (1995) 27:5 *Transplantation Proceedings* 2965; Margaret A Sanner, “Two Perspectives on Organ Donation: Experiences of Potential Donor Families and Intensive Care Physicians of the Same Event” (2007) 22:4 *J Critical Care* 296.

58. J Downie et al, “Eligibility for Organ Donation: a Medico-Legal Perspective on Defining and Determining Death” (2009) 56:11 *Can J Anesthesia* 851 [Downie et al, 2009]; Jacquelyn Shaw “A Death-Defying Leap: Section 7 Charter Implications of the Canadian Council for Donation and Transplantation’s Guidelines for the Neurological Determination of Death” (2012) 6:1 *McGill JL & Health* 41. See also CBC *The Fifth Estate*, “Dead Enough?” (21 March 2014), online: <[www.cbc.ca/fifth/episodes/2013-2014/dead-enough](http://www.cbc.ca/fifth/episodes/2013-2014/dead-enough)>.

59. AR Joffe et al, “Donation after Circulatory Death: A Call for a Moratorium Pending Full Public Disclosure and Fully Informed Consent” (2011) 6:1 *Philosophy, Ethics, & Humanities in Medicine* 17.

60. David Greer et al, “Variability of Brain Death Policies in the United States” (2016) 73:2 *JAMA Neurology* 213. Greer et al do note that “no legitimate reports of patients regaining any brain function after being declared brain dead according to the 1995 AAN guidelines have surfaced.” Or course, this is not surprising given the cessation of treatment, including artificial support for cardiac function, that almost always follows the determination of brain death. They do not acknowledge the controversy over the declaration of death of Jahi McMath.

significant concern arising from these cases is that the public may lose faith in the system and, if they do, the willingness to be organ donors will drop. Then the number of organs available for transplantation will drop and lives will be lost.

What is needed is a significant health law and policy intervention on the legal definition, criteria, and tests for the determination of death; robust consultation of experts and other stakeholders; legal clarification; education; and enforcement. This initiative need not start from scratch. Yet again, as a starting contribution to the policy debate needed to address this issue, I would argue that provinces and territories should embrace the following approach to the determination of death:

(1) Death is defined as the irreversible cessation of the functioning of the organism as a whole. (2) The criterion for the determination of death is the irreversible loss of the brain's capacity to control and coordinate the organism's critical functions. (3) Irreversible is defined as not physically possible to reverse without violating the law on consent. (4) The fulfillment of the criterion may be demonstrated by one or more medical tests (including neurological and cardiopulmonary). Specific tests are to be established by the medical profession.<sup>61</sup>

This could be achieved through the inclusion of the following text in organ donation legislation, as in Nova Scotia:

“death” means the irreversible cessation of the functioning of the organism as a whole as determined by the irreversible loss of the brain's ability to control and co-ordinate all of the organism's critical functions;

“irreversible” means not physically possible to reverse without violating consent law;<sup>62</sup>

The full argument for that legislative approach has been published elsewhere.<sup>63</sup> What is needed now is a multi-disciplinary and multi-sectoral engagement with that argument as well as the arguments in support of and against alternative approaches. Greater clarity and certainty could then be achieved through the adoption of provisions in either organ donation legislation or interpretation acts (surprisingly, most provinces and territories do not have a statutory definition of death).<sup>64</sup> Following on from this, rigorous education materials should be produced and education

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61. Downie et al, 2009, *supra* note 58.

62. *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 2 (not yet in force).

63. Downie et al, 2009, *supra* note 58.

64. Prince Edward Island, Manitoba, and New Brunswick have a statutory definition of death, while Quebec, Northwest Territories, Nunavut, Newfoundland and Labrador, Nova Scotia, Ontario, Saskatchewan, Alberta, British Columbia, and Yukon do not.

programs offered to ensure that physicians understand the legal definition of death and understand the criteria for the legal determination of death and the appropriate tests to assess whether the criteria have been met.

It should also be noted here that, at least in part as a result of the need for organs for transplantation, we may again be confronted with the argument that we should get rid of the dead donor rule—that is, the rule that says that physicians cannot remove organs from a person (even with consent) until after they are dead.<sup>65</sup> Individuals will soon be able to consent to their own death (MAiD). We have a desperate need for organs for life-saving transplantation. And the legal fiction that there is a moment of death (as opposed to a process of dying and decomposition) is struggling under its own weight as science advances. As a result of these facts, pressure may well mount to abandon the dead donor rule. Put concretely, for example, why can I not consent to the removal of my organs while I am in a persistent vegetative state? This too is a question that will require our considerable attention in the near future.

### *Conclusion*

The victory in *Carter 2015* and the passage of the federal and Quebec MAiD legislation has surely transformed the field of end-of-life law and policy in Canada and the implementation of the legislation will surely benefit many Canadians.<sup>66</sup> But there is still much more work to be done. We can and should now tackle these other issues that have long lived in the shadows of assisted dying.

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65. Downie et al, 2009, *supra* note 58.

66. It must be noted here that an argument can be made that the federal MAiD legislation does not benefit as many Canadians as it should; it is too restrictive and is not consistent with the *Charter*. Indeed, a court challenge has already been launched to make just this argument; see, e.g., *Lamb*, *supra* note 6. This case will no doubt end up in front of the Supreme Court of Canada in the not-too-distant future.