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Jocelyn Downie

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MEDICAL ASSISTANCE IN DYING: LESSONS FOR AUSTRALIA FROM CANADA

JOCELYN DOWNIE*

I INTRODUCTION

Canada has recently witnessed dramatic changes in end of life law and policy. Most notably, we have moved from a prohibitive to a permissive regime with respect to medical assistance in dying (MAiD). As a number of Australian states are actively engaged in debates about whether to decriminalise MAiD,¹ it is worth reviewing the Canadian experience and drawing out any lessons that might usefully inform the current processes in Australia.

II MEDICAL ASSISTANCE IN DYING IN CANADA (VOLUNTARY EUTHANASIA AND ASSISTED SUICIDE)²

A *The Past*

Until 2016, assisted suicide was clearly illegal in Canada. It was an offence under s 241(b) of Canada's *Criminal Code*.³ Euthanasia was also clearly illegal in Canada—it was murder under the *Criminal Code*.⁴ In the early 1990s, Sue Rodriguez, a woman with amyotrophic lateral sclerosis (ALS, a degenerative neurological condition), challenged the prohibitions under the *Canadian Charter of Rights and Freedoms* ('*Charter*'),⁵ but was unsuccessful at the Supreme Court of Canada (by the merest 5–4 margin).⁶ Over the years, there were a number of failed attempts made to pass legislation that would permit some assisted dying.⁷ There was also a Special Senate Committee on Euthanasia and Assisted Suicide, but it too did not end up

*BA Hons (Philosophy) (Queens University), MA (Philosophy) (Queens University), MLitt (Philosophy) (University of Cambridge), LLB (University of Toronto), LLM (University of Michigan, SJD (University of Michigan). Jocelyn Downie is a University Research Professor in the Faculties of Law and Medicine at Dalhousie University. She is a Fellow of the Royal Society of Canada, the Canadian Academy of Health Sciences, and the Pierre Elliott Trudeau Foundation. She is also an Adjunct Professor at the Australian Centre for Health Law Research at the QUT Faculty of Law. Thanks to Kate Scallion for her meticulous and dogged research assistance, and to Ben White and Lindy Willmott for always challenging and stimulating conversations about end of life law and policy in Australia.

¹ See eg, Samantha Hutchinson, 'Andrews Victorian Government to Debate Assisted Dying Law Bill', *The Australian* (online), 25 July 2017 <www.theaustralian.com.au/national-affairs/state-politics/andrews-victorian-government-to-debate-assisted-dying-law-bill/news-story/4ef6b947c57efe05daee184c6bba50d>; Death with Dignity Bill 2016 (SA); 'Voluntary Euthanasia Laws Fail to Pass South Australian Parliament by One Vote', *Australian Associated Press* (online), 16 November 2016

<www.theguardian.com/society/2016/nov/17/voluntary-euthanasia-laws-clear-hurdle-in-south-australian-parliament-after-15th-attempt>; Voluntary Assisted Dying Bill 2016 (Tas); 'Assisted Dying Bill Fails to Pass Tasmanian Parliament', *Australian Associated Press* (online), 24 May 2017 <www.theguardian.com/australia-news/2017/may/25/assisted-dying-bill-fails-to-pass-tasmanian-parliament>.

² This section is a modified extract from my book chapter: Jocelyn Downie, 'End of Life Law and Policy in Canada' in Joanna Erdman, Vanessa Gruben and Erin Nelson (eds) *Canadian Health Law and Policy* (LexisNexis, 5th ed, 2017).

³ *Criminal Code*, RSC 1985, c C-46, s 241(b).

⁴ *Ibid* s 229.

⁵ *Canada Act 1982* (UK) c 11, Sch B Pt 1 'Canadian Charter of Rights and Freedoms'.

⁶ *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519.

⁷ Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84.



recommending changes to the law.⁸ However, for decades, there was strong majority public support for the decriminalisation of assisted dying.⁹ There was also a growing body of evidence from permissive regimes demonstrating that the feared slippery slopes had not materialised.¹⁰ Additionally, there were significant new decisions from the Supreme Court of Canada on various sections of the *Charter* (for example, introducing new ‘principles of fundamental justice’ and thereby opening up the possibility of new arguments to be made in court that were not available at the time of *Rodriguez*).¹¹ Finally, an Expert Panel of the Royal Society of Canada on End of Life Decision-Making recommended the decriminalisation of assisted dying.¹²

B Three Recent Developments

Against this historical backdrop, dramatic reform came in the shape of three major developments. Quebec introduced legislation to regulate medical aid in dying,¹³ the Supreme Court of Canada ruled that the *Criminal Code* prohibitions on physician-assisted dying violate the *Charter*,¹⁴ and the federal Parliament passed legislation to establish a federal regulatory framework for MAiD.¹⁵

1 Quebec’s Legislation

The first development hailed from Quebec. On 12 June 2013, following a truly extraordinary process of expert and public consultation,¹⁶ the Quebec government introduced *An Act Respecting End-of-life Care* (‘the Act’) to allow medical aid in dying.¹⁷ After some skirmishes in court, the legislation came into force in December 2015.¹⁸ The Act establishes a right to ‘end-of-life care’, defined as ‘palliative care provided to end-of-life patients and medical aid

⁸ Canada, Senate Special Committee on Euthanasia and Assisted Suicide, *Of Life and Death – Final Report* (1995).

⁹ See eg, Ipsos News Center, ‘As Dr Kevorkian Released, Just One Quarter (25%) Believe Doctor-Assisted Suicide Should Be Illegal’ (Media Release, 10 June 2007) <www.ipsos-na.com/news/pressrelease.cfm?id=3526>.

¹⁰ See eg, Frances Norwood, Gerrit Kimsma and Margaret P Battin, ‘Vulnerability and the “Slippery Slope” at the End-of-Life: a Qualitative Study of Euthanasia, General Practice and Home Death in The Netherlands’ (2009) 26(6) *Family Practice* 472; Margaret P Battin et al, ‘Physician-Assisted Dying and the Slippery Slope: the Challenge of Empirical Evidence’ (2008) 45 *Willamette Law Review* 91; Georg Bosshard, Esther Ulrich and Walter Bär, ‘748 Cases of Suicide Assisted by a Swiss Right-to-Die Organisation’ (2003) 133 *Swiss Medical Weekly* 310.

¹¹ *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519. See eg, *R v Demers* [2004] 2 SCR 489; *R v Heywood* [1994] 3 SCR 761; *Canadian Foundation for Children, Youth and the Law v Canada (Attorney General)* [2004] 1 SCR 76; *R v Marmo-Levine* [2003] 3 SCR 571.

¹² Udo Schuklenk et al, ‘The Royal Society of Canada Expert Panel: End-of-Life Decision-Making’ (Final Report, Royal Society of Canada, November 2011) 6-7 <www.rsc-src.ca/en/expert-panels/rsc-reports/end-life-decision-making>; concurrently published as ‘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(S1) *Bioethics* 1.

¹³ *An Act Respecting End-of-Life Care*, RSQ c S-32.0001.

¹⁴ *Carter v Canada (Attorney General)* [2015] 1 SCR 331.

¹⁵ *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, SC 2016, c 3, 2411.1.

¹⁶ The consultation included 32 experts, 273 briefs, 239 individuals and organisations at public hearings, 114 individuals during ‘open mic’ sessions, 6 558 completed online questionnaires, 16 000 comments, 21 meetings during a mission in Europe, and 51 deliberative meetings of the Committee. Details are available in *Select Committee on Dying With Dignity Report* (Assemblée National Quebec, March 2012) 12-14 <www.assnat.qc.ca/en/travaux-parlementaires/commissions/CSMD/mandats/Mandat-12989/index.html>.

¹⁷ *An Act Respecting End-of-Life Care*, RSQ c S-32.0001.

¹⁸ See *D’Amico c Québec (Procureure Générale)* [2015] QCCS 5556; *Quebec (Procureur General) c D’Amico* [2015] QCCA 2138; ‘Quebec Court of Appeal Rules Assisted Dying Law Can Stand’, *CTV News* (online), 22 December 2015 <montreal.ctvnews.ca/quebec-court-of-appeal-rules-assisted-dying-law-can-stand-1.2709907>.

in dying'.¹⁹ Under the legislation, 'medical aid in dying' is defined as: 'care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death'.²⁰

The Act permits medical aid in dying for patients who meet all of the following criteria, i.e the patient:

- (1) is an insured person within the meaning of the Health Insurance Act;
- (2) is of full age and capable of giving consent to care;
- (3) is at the end of life;
- (4) suffers from an incurable serious illness;
- (5) suffers from an advanced state of irreversible decline in capability; and
- (6) suffers from constant and unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable.²¹

Considerable safeguards are built into the legislation. These include:

- The patients must meet the criteria for access outlined above;
- The patient must request medical aid in dying themselves, in a free and informed manner;²²
- Only physicians may provide medical aid in dying;²³
- Physicians must ensure provision of information, confirmation of conditions being met, second independent opinion, and recording of all information;²⁴
- Physicians must report medical aid in dying;²⁵
- Institutions must report on continuous palliative sedation and medical aid in dying;²⁶
- Inspection powers;²⁷ and
- Oversight by a Commission sur les soins de fin de vie [Commission on end-of-life care].²⁸

In an effort to protect access to medical aid in dying and respect conscience, the legislation requires:

- Physicians who object to medical aid in dying must report requests for medical aid in dying to the executive director (or designate) of their institution (if they work in a public institution) or the local authority (if they work in a private facility) or the local community centre (if the patient lives somewhere with no local authority). The executive director must then find an alternative physician for the patient who has made the request.²⁹

¹⁹ *An Act Respecting End-of-Life Care*, RSQ c S-32.0001, s 3(3).

²⁰ *Ibid* s 3(6).

²¹ *Ibid* s 26.

²² *Ibid* s 26.

²³ *Ibid* s 30.

²⁴ *Ibid* s 29.

²⁵ *Ibid* ss 36, 46.

²⁶ *Ibid* s 8.

²⁷ *Ibid* s 21.

²⁸ *Ibid* ss 38–47.

²⁹ *Ibid* s 31.

- Institutions must offer medical aid in dying unless they offer only palliative care (in which case they may opt out).³⁰

Between December 2015 and June 2016, there were 253 requests made for medical aid in dying and 166 cases in which it had been administered. Reasons for requests not (yet) resulting in administration include: the person did not meet the criteria at the time of making the request (27); the person did not meet the criteria during the assessment process or when administration was set to take place (9); the person withdrew the request (24); the person died prior to the scheduled administration (21); the evaluation was still pending (5); and the person rescheduled the administration (1).³¹ Between June and December 2016, the number of requests for MAiD increased to 468 and 295 patients received it; as of 31 December 2016, a total of 461 patients were granted MAiD of the 721 who requested it.³²

2 *Carter v Canada (Attorney General)*

The second development was *Carter v Canada (Attorney General)* ('Carter').³³ Kay Carter was a woman with an extremely painful degenerative condition (spinal stenosis) who decided her suffering had become too much; she asked her family to take her to Switzerland for an assisted suicide. They did, and they also became the first named plaintiffs in the case that would change the law in Canada. Then, Gloria Taylor, a woman with amyotrophic lateral sclerosis ('ALS') who wanted an assisted death, joined the case and the British Columbia Civil Liberties Association, representing suffering Canadians more generally, effectively carried the case.

The plaintiffs argued that the *Criminal Code* prohibitions on assisted suicide and voluntary euthanasia violate ss 7 and 15 of the *Charter*.³⁴ The plaintiffs were successful at trial,³⁵ lost the appeal (but only on the issue of *stare decisis* — whether the trial judge was bound by the 1993 Supreme Court of Canada decision in *Rodriguez*),³⁶ but were then successful again at the Supreme Court of Canada,³⁷ which ruled 9–0 that the *Criminal Code* prohibitions violated the *Charter* and were void. The Supreme Court found that the prohibitions on physician-assisted dying³⁸ violated s 7 as they limited the right to life, liberty, and security of the person and were

³⁰ Ibid ss 7, 72.

³¹ Pierre Deschamps, 'Medical Aid in Dying in Quebec: A Status Report' (Webinar presented to the Canadian Bar Association, 23 November 2016).

³² 'Over 450 Quebec patients received medical aid in dying last year', *CBC News* (online), 14 March 2017: <<http://www.cbc.ca/news/canada/montreal/medical-assisted-death-cases-first-year-1.4023851>>.

³³ *Carter v Canada (Attorney General)* [2012] BCSC 886; *Carter v Canada (Attorney General)* [2013] BCCA 435; *Carter v Canada (Attorney General)* [2015] 1 SCR 331.

³⁴ *Canada Act 1982* (UK) c 11, Sch B Pt 1 'Canadian Charter of Rights and Freedoms' s 7 provides that 'Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.' Section 15 provides that 'Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.'

³⁵ *Carter v Canada (Attorney General)* [2012] BCSC 886.

³⁶ *Carter v Canada (Attorney General)* [2013] BCCA 435; *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519. The issue of *stare decisis* is discussed by Smith J in *Carter v Canada (Attorney General)* [2012] BCSC 886, [898–910].

³⁷ *Carter v Canada (Attorney General)* [2015] 1 SCR 331.

³⁸ At trial, Justice Smith defined 'physician-assisted dying' and 'physician-assisted death' as 'generic terms that encompass physician-assisted suicide and voluntary euthanasia that is performed by a medical practitioner or a person acting under the direction of a medical practitioner': [2012] BCSC 886 [39]. She defined 'physician-assisted suicide' as 'the act of intentionally killing oneself with the assistance of a medical practitioner, or person acting under the direction of a medical practitioner, who provides the knowledge, means, or both': [2012] BCSC

overly broad.³⁹ The limit on s 7 rights was not saved by s 1 as the prohibitions did not minimally impair the right.⁴⁰ Therefore, the prohibitions were 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’. ‘Irremediable’, [they added] ..., does not require the patient to undertake treatments that are not acceptable to the individual.⁴¹

The Supreme Court made no comment on whether health care institutions could decline to provide physician-assisted dying. The court commented on, but did not resolve the issue of conscientiously objecting providers:

In our view, nothing in the declaration of invalidity which we propose to issue would compel physicians to provide assistance in dying. The declaration simply renders the criminal prohibition invalid. What follows is in the hands of the physicians’ colleges, Parliament, and the provincial legislatures. However, we note — as did Beetz J. in addressing the topic of physician participation in abortion in *Morgentaler* — that a physician’s decision to participate in assisted dying is a matter of conscience and, in some cases, of religious belief (pp. 95–96). In making this observation, we do not wish to pre-empt the legislative and regulatory response to this judgment. Rather, we underline that the *Charter* rights of patients and physicians will need to be reconciled.⁴²

The Supreme Court suspended their declaration of invalidity for 12 months (to February 2016) to give the government time to craft new legislation should they wish to do so.⁴³ There was a federal election after the *Carter* decision was released and subsequently a change in government. When the new Liberal government took office in November 2016, they asked for an extension on the suspension of the declaration of invalidity and were given four months (to 6 June 2016).⁴⁴ The Supreme Court also made provisions for individuals to be able to access physician-assisted dying through the courts during the period of the extension. These cases

886 [37]. She defined ‘euthanasia’ as ‘the intentional termination of the life of a person, by another person, in order to relieve the first person’s suffering’: [2012] BCSC 886 [38].

³⁹ One principle of fundamental justice under s 7 is overbreadth: ‘restrictions on life, liberty, and security of the person must not be more broadly framed than necessary to achieve the legislative purpose’: *Carter v Canada (Attorney General)* [2012] BCSC 886 [1339].

⁴⁰ Section 1 of the *Charter* is a limitation clause as it subjects the rights and freedoms set out in the *Charter* to ‘reasonable limits prescribed by law’, that can be ‘demonstrably justified in a free and democratic society’. The test for s 1 test includes a proportionality analysis, which asks whether the infringement of the right is minimally impairing of it. As noted by Justice Smith in *Carter v Canada (Attorney General)* [2012] BCSC 886 [1232]: ‘The question, then, is whether there is an alternative means for the legislature to achieve its objective in a real and substantial way that less seriously infringes the Charter rights of Gloria Taylor and others in her situation.’

⁴¹ *Carter v Canada (Attorney General)* [2015] 1 SCR 331 [127].

⁴² *Ibid* [132].

⁴³ The government was under no obligation to legislate. It could simply have left the regulation of MAiD consistent with the declaration in *Carter* to the provinces and territories as a matter of health (which is under provincial and territorial jurisdiction). Indeed, there is precedent for this approach as the federal government has never passed legislation to replace the restrictions on access to abortion struck down by the Supreme Court of Canada in *R v Morgentaler* [1988] 1 SCR 30. Abortion is currently regulated by the provinces and territories as any other health service.

⁴⁴ ‘Supreme Court Gives Federal Government 4-Month Extension to Pass Assisted Dying Law’, *CBC News* (online), 15 January 2016 <www.cbc.ca/news/politics/assisted-dying-supreme-court-federal-1.3406009>.

followed the *Carter* criteria and there were 17 reported cases of people accessing physician-assisted dying in that way.⁴⁵

The Supreme Court's decision ultimately took effect 6 June 2016, and, until the new federal legislation was passed (see below), the *Criminal Code* no longer prohibited physician-assisted dying where the *Carter* criteria were met.

Before moving on to the final development in this area, it is worth returning briefly to the trial decision in *Carter*. In her decision, Justice Lynn Smith made a number of important findings of fact (these are important as they were settled at trial and, as is most commonly the case, not unsettled by the Supreme Court of Canada). It is important to repeat them here, as they are the factual foundation for the current Canadian legal framework for medical assistance in dying.

On palliative care, Justice Smith found:

Adequate palliative care can reduce requests for euthanasia or lead to their retraction.⁴⁶

However, despite the best possible palliative care, some patients suffer pain that cannot be alleviated As well, symptoms can cause suffering other than pain (such as nausea, vomiting, and shortness of breath) that cannot be alleviated even by the best palliative care.⁴⁷

Further, high quality palliative care is far from universally available in Canada.⁴⁸

On ethics, she found:

The preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death.⁴⁹

On the slippery-slope arguments, she found:

[T]he research does not clearly show either a negative or positive impact in permissive jurisdictions on the availability of palliative care or the physician-patient relationship.⁵⁰

No evidence of inordinate impact on vulnerable populations⁵¹

Risks (eg, re: ability to make well-informed decisions, freedom from coercion or undue influence, physicians' ability to assess patients' capacity and voluntariness) exist, but they can be largely avoided through carefully-designed, well-monitored safeguards.⁵²

A system with properly designed and administered safeguards could, with a very high degree of certainty, prevent vulnerable persons from being induced to commit suicide while

⁴⁵ See Jocelyn Downie, 'Court Cases, Judicial Authorizations', *End-of-Life Law and Policy in Canada* (Health Law Institute, Dalhousie University) <eol.law.dal.ca/?page_id=242>.

⁴⁶ *Carter v Canada (Attorney General)* [2012] BCSC 886 [189].

⁴⁷ *Ibid* [190].

⁴⁸ *Ibid* [192].

⁴⁹ *Ibid* [335].

⁵⁰ *Ibid* [9].

⁵¹ *Ibid*.

⁵² *Ibid* [10].

permitting exceptions for competent, fully informed persons acting voluntarily to receive physician-assisted death.⁵³

3 Federal Legislation

As federal, provincial and territorial governments contemplated how to respond to the *Carter* decision, three groups were tasked by various levels of government with studying the question of how best to regulate assisted dying: a Federal Expert Panel on Options for a Legislative Response to *Carter*, appointed by then Prime Minister Stephen Harper; a Provincial–Territorial Expert Advisory Group on Physician-Assisted Dying; and a Special Joint Committee [of the federal House and Senate] on Physician-Assisted Dying. They all issued reports (the latter two with recommendations).⁵⁴ The Provincial–Territorial Expert Advisory Group recommended that governments: not have narrower eligibility criteria than those set out in *Carter*; permit access to MAiD for mature minors, individuals whose sole underlying condition is a mental illness, and those whose requests were made in advance of loss of capacity; and establish a duty to transfer care from conscientiously objecting providers.⁵⁵ The Special Joint Committee issued similar recommendations varying only in recommending a two-year delay in the coming into force of the permissive elements regarding mature minors.⁵⁶

Ultimately the federal government introduced Bill C-14 in April 2016.⁵⁷ Most notably, the government adopted narrower eligibility criteria than those set out in *Carter* as the Bill did not permit access to MAiD for mature minors and requests made in advance of loss of capacity (at least not yet); and did not establish a duty to transfer care (although, it must be noted, that lies outside their jurisdiction).⁵⁸ A furious federal parliamentary debate ensued.⁵⁹ Attempts were made through the House of Commons (in Committee and on the floor) to amend the Bill to be less restrictive.⁶⁰ They failed.⁶¹ The Senate sent an amended (less restrictive) Bill back to the

⁵³ Ibid [1367].

⁵⁴ External Panel on Options for a Legislative Response to *Carter v Canada*, *Consultations on Physician-Assisted Dying: Summary of Results and Key Findings: Final Report* (Government of Canada, 2015) <www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/index.html>; Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final Report* (Ontario Department of Health, 2015) <www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf>; Special Joint Committee on Physician-Assisted Dying, Parliament of Canada, *Medical Assistance in Dying: A Patient-Centred Approach* (2016).

⁵⁵ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, above n 54, 5–11.

⁵⁶ Special Joint Committee on Physician-Assisted Dying, above n 54, 21.

⁵⁷ Bill C-41, An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), 42nd Parl, 1st Sess, 2016 (first reading as passed by the House of Commons, 14 April 2016) <eol.law.dal.ca/wp-content/uploads/2016/05/C-14_1.pdf>.

⁵⁸ Under the Canadian Constitution, provinces and territories have jurisdiction over the administration of health, and regulation of healthcare providers falls within that jurisdiction: *Canada Act 1982* (UK) c 1, Sch B ‘*Constitution Act 1982*’.

⁵⁹ See eg, Canada, *Parliamentary Debates*, House of Commons, 42nd Parl, 1st Sess, Vol 148, No 45 (22 April 2016), 1005 (Jody Wilson-Raybould); 1035 (Michael Cooper), 1255 (Murray Rankin); see also Vol 148, No 57 (17 May 2016), No 60 (20 May 2016), No 61 (30 May 2016); Canada, *Parliamentary Debates*, Senate, 42nd Parl, 1st Sess, Vol 150, No 42 (2 June 2016) 1450 (George Baker), 1650 (Serge Joyal); see also Vol 150, No 41 (1 June 2016), No 45 (8 June 2016), No 47 (10 June 2016), No 49 (14 June 2016).

⁶⁰ House of Commons, Standing Committee on Justice and Human Rights, Bill C-14 An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying) (31 May 2016) <www.parl.gc.ca/Committees/en/JUST/StudyActivity?studyActivityId=8874111>.

⁶¹ Ibid.

House,⁶² but the House rejected the more permissive amendments.⁶³ Finally the Senate conceded and passed the House's restrictive Bill.⁶⁴

After its tumultuous ride through the House and Senate, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*⁶⁵ was passed and immediately came into force on 17 June 2016. It is worth repeating that the law as passed is narrower than that recommended by the Royal Society of Canada Expert Panel on End of Life Decision-Making,⁶⁶ the Provincial–Territorial Expert Advisory Group, the Special Joint Committee, and the amendments sought by the Senate.

The key elements of the federal legislation are as follows:

- Medical assistance in dying is the umbrella term that includes both voluntary euthanasia and assisted suicide.⁶⁷ It is defined in the legislation as:
 - (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.⁶⁸
- Recognising the scarcity of physicians in Canada (especially in rural and remote communities) as well as the competencies and accountability of nurse practitioners, both physicians and nurse practitioners are allowed to provide MAiD.⁶⁹
- Recognising that health care is provided in teams and few physicians or nurse practitioners would be acting completely alone and also recognising that some patients would want their loved ones to be the ones to help them at the end, any person is permitted to assist the providers. So pharmacists, nurses, and friends and family members are all permitted to assist.⁷⁰
- Recognising that patients may well ask a whole range of health care providers about assisted dying and that these providers could be very appropriate sources of information, information can be provided by social workers, psychologists, psychiatrists, therapists, medical practitioners, nurse practitioners, and other health care professionals.⁷¹

According to s 241.2(1) of the new legislation, only those who meet the following criteria can have access to medical assistance in dying. Patients must:

⁶² Bill C-41, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, 42nd Parl, 1st Sess, 2016 (third reading as passed by the Senate 15 June 2016) <eol.law.dal.ca/wp-content/uploads/2016/07/Senate-amendments-sent-to-House.pdf>.

⁶³ Canada, *Parliamentary Debates*, House of Commons, 42nd Parl, 1st Sess, Vol 148, No 74 (16 June 2016) 1035 <www.parl.gc.ca/HousePublications/Publication.aspx?Pub=Hansard&Doc=74&Parl=42&Ses=1&Language=E&Mode=1>.

⁶⁴ Canada, *Parliamentary Debates*, Senate, 42nd Parl, 1st Sess, Vol 150, No 52 (17 June 2016) 910 <sencanada.ca/en/Content/Sen/chamber/421/debates/052db_2016-06-17-e#16>.

⁶⁵ SC 2016, c 3 ('*Medical Assistance in Dying Act*').

⁶⁶ Schuklenk et al, above n 12, 6–7.

⁶⁷ *Medical Assistance in Dying Act*, SC 2016, c 3, s 241.1.

⁶⁸ *Ibid.*

⁶⁹ *Ibid* s 227.

⁷⁰ *Ibid* s 241.

⁷¹ *Ibid.*

- be eligible for health services funded by government in Canada (or would be, but for a minimum period of residence or waiting period);
- be at least 18 years old;
- be capable of making decisions with respect to their health;
- have made a voluntary request;
- have given informed consent to receive medical assistance in dying after having been informed of means available to relieve suffering, including palliative care; and
- have a grievous and irremediable medical condition.

This is further explained in s 241.2(2) as:

- they have a serious and incurable illness, disease or disability;
- they are in an advanced state of irreversible decline in capability;
- that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

The following procedural safeguards must also be met:

- A medical practitioner or nurse practitioner must be of the opinion that the person meets all of the eligibility criteria;⁷²
- A request must be made in writing, signed and dated after the patient has been informed of their grievous and irremediable condition;⁷³
- There must be two independent witnesses to the request;⁷⁴
- A second independent medical practitioner or nurse practitioner must confirm that the eligibility criteria have been met;⁷⁵
- There must be a 10-day waiting period between the day the request was signed and the day MAiD is provided (unless death or loss of capacity is imminent);⁷⁶ and
- The patient must be given the opportunity to withdraw consent and, indeed, must explicitly reconfirm the consent required immediately before MAiD is provided.⁷⁷

Freedom of conscience was, of course, the subject of enormous debate in relation to the legislation. Some health care providers want to be able to opt out of MAiD entirely (including not providing information, transfers of care, or referrals to willing providers) and some institutions want to be able to opt out of allowing MAiD within their walls.⁷⁸ Patients and patient advocates in turn worry about lack of access if opting out is allowed. The legislation

⁷² Ibid s 241.2(3)(a).

⁷³ Ibid s 241.2(3)(b).

⁷⁴ Ibid s 241.2(3)(c).

⁷⁵ Ibid s 241.2(3)(e).

⁷⁶ Ibid s 241.2(3)(g).

⁷⁷ Ibid s 241.2(3)(h).

⁷⁸ A transfer of care and a referral have the same result (a patient gains access to a provider who is willing to assess whether she meets the criteria for MAiD and, if so, to provide MAiD). However, some providers believe that a referral implies that the provider approves of MAiD while a transfer of care does not and therefore involves no (or less) moral compromise on the part of the provider. See Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, above n 54, 45.

itself does not resolve this conflict as it says only the following: ‘nothing in this Act affects the guarantee of freedom of conscience and religion’;⁷⁹ and ‘nothing in this section compels an individual to provide or assist in providing medical assistance in dying’.⁸⁰

The legislation also establishes the foundation for retrospective oversight as providers have a duty to file information on every written request for MAiD⁸¹ (once the conditions for coming into force are met), there are penalties for non-compliance with the legislation,⁸² and there will be a Parliamentary review of the provisions of Act and the state of palliative care in Canada, scheduled to start on 18 June 2021.⁸³

The legislation also imposes some obligations on the Minister of Health as she must make regulations regarding provision, collection, analysis, and reporting of data,⁸⁴ and, after consultation with provinces and territories, she must establish guidelines on information to be included on death certificates.⁸⁵ The legislation also provides that the Ministers of Justice and Health must initiate one or more independent reviews of issues relating to mature minors, advance requests, and requests where mental illness is the sole underlying condition.⁸⁶ In addition, no more than two years after the initiation of the reviews (ie, by 14 December 2018), they must present one or more reports on the reviews to both Houses of Parliament.⁸⁷

Finally, while not in the legislation itself, the federal government also promised to increase support for palliative and end of life care, and to work with the provinces and territories to establish a pan-Canadian system for access, a) to facilitate transfers of care; b) to protect the conscience of objecting providers; and c) to protect the privacy of willing providers.⁸⁸

Despite the passage of the federal legislation, there remain some challenges: first, implementing the legislation; and, second, dealing with several outstanding legal issues. The implementation challenges include: gathering data (eg, standardizing what goes on medical certificates of death⁸⁹ and determining what information needs to be reported and to whom⁹⁰);

⁷⁹ *Medical Assistance in Dying Act*, SC 2016, c3, Preamble.

⁸⁰ *Ibid* s 241.2(9).

⁸¹ *Ibid* s 241.31(2).

⁸² *Ibid* ss 241.3-4ff.

⁸³ *Ibid* s 10.

⁸⁴ *Ibid* s 241.31(3).

⁸⁵ *Ibid* s 241.31(3.1).

⁸⁶ *Ibid* s 9.1(1). These reviews will be conducted by an independent panel appointed by the Council of Canadian Academies (the umbrella organisation for the Royal Society of Canada, the Canadian Academy of Engineering, and the Canadian Academy of Health Sciences). Canadian Council of Academics, ‘Council of Canadian Academies to Undertake Studies Related to Medical Assistance in Dying’ (What’s New, 14 December 2016) <www.scienceadvice.ca/en/news.aspx?id=186>.

⁸⁷ *Medical Assistance in Dying Act*, SC 2016, c 3, s 91(2).

⁸⁸ Department of Justice Canada, ‘Government of Canada Moves Motion to Amend Bill C-14 – Medical Assistance in Dying’ (News Release, 16 June 2016) <https://www.canada.ca/en/departement-justice/news/2016/06/government-of-canada-moves-motion-to-amend-bill-c-14-medical-assistance-in-dying.html>.

⁸⁹ The Canadian government now has non-binding guidelines for death certificates with respect to MAiD that recommend recording both the immediate cause of death (eg toxicity of drugs administered for MAiD) and the underlying cause of death (eg ‘the disease or condition that initiated the train of morbid events leading to the medically-assisted death’); see ‘Guidelines for Death Certificates’ (online): <www.canada.ca/en/health-canada/services/publications/health-system-services/guidelines-death-certificates.html>. However, inconsistencies in practice across Canada remain.

⁹⁰ Draft regulations are due this fall. See Government of Canada, ‘Interim update on medical assistencing in dying in Canada June 17 to December 31, 2016’ (31 May 2017), online: <www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html>.

establishing MAiD protocols (eg, what drugs, dosages, etc.); ensuring that the most appropriate drugs for MAiD are available in Canada;⁹¹ determining who pays for the drugs and the services of the health care providers; managing the promised system for transfers of care in the face of conscientious objections; and educating health care professionals, lawyers, and the public. The key outstanding legal issues to be resolved are conscientious objection and the eligibility criteria.

Federal, provincial and territorial governments, and regulatory bodies will be challenged to clarify whether health care providers have a legal obligation to inform patients about MAiD, transfer care to a provider willing to conduct an assessment and provide assistance to a patient if eligible, and/or arrange an effective referral to a willing provider. The battlegrounds for these issues will be health professional regulatory bodies revising their guidelines and provincial and territorial governments deciding whether to introduce legislation to create statutory obligations for providers.⁹² Litigation has already started as the Ontario College of Physicians and Surgeons Guidelines establishing a duty of effective referral are being challenged by a consortium of religious groups.⁹³ Federal, provincial and territorial governments will also be challenged to clarify whether publicly funded health care institutions have a legal duty to transfer patients, allow the provision of MAiD within their walls, or provide MAiD. Provincial and territorial governments will have to decide whether to insist upon provision by institutions (eg, through legislation,⁹⁴ their memoranda of understanding, or funding agreements). Patients may in turn litigate if it turns out that access is being severely hampered by claims of freedom of conscience by institutions. It seems increasingly likely that this will be an ongoing and growing source of friction as a significant number of institutions appear to be opting out without facing any consequences from the provinces or territories.⁹⁵

The federal Parliament must also deal with outstanding issues concerning the eligibility criteria. As noted earlier, Parliament decided to exclude but undertake further study on issues

⁹¹ Eg, the preferred drug for self-administered MAiD (oral secobarbital) is not available in Canada. See, Sheryl Ubelacker, 'Drugs for Physician-Assisted Death: What Will they Cost and Who Will Pay?' *Canadian Press* (online), 13 June 2016 <www.theglobeandmail.com/news/national/drugs-for-physician-assisted-death-what-will-they-cost-and-who-will-pay/article30414929/>; Health Canada, *Drug Product Database* <www.hc-sc.gc.ca/dhp-mps/prodpharma/databasdon/index-eng.php>.

⁹² See eg, College of Physicians and Surgeons Alberta, *Standard of Practice: Medical Assistance in Dying* (June 2016) <www.cpsa.ca/standardspractice/medical-assistance-dying/>; College of Physicians and Surgeons Nova Scotia, *Professional Standard Regarding Medical Assistance in Dying* (2016) <www.cpsns.ns.ca/Standards-Guidelines/Medical-Assistance-in-Dying>.

⁹³ See Alex McKeen, 'Doctors challenge Ontario policy on assisted-death referrals', *Toronto Star* (online), 13 June 2017 <<https://www.thestar.com/news/gta/2017/06/13/group-of-doctors-challenge-policy-requiring-referral-to-services-that-clash-with-morals.html>>. The case was heard 13-15 June 2017. A decision has not yet been released. Court documents, including the notice of claim by the Christian Medical and Dental Society of Canada (CMDS), the Canadian Federation of Catholic Physicians' Societies, Canadian Physicians for Life, and intervener documents submitted by Dying with Dignity are available online: <www.dyingwithdignity.ca/cpso_court_challenge>.

⁹⁴ For contrasting approaches, see *An Act Respecting End-of-Life Care*, RSQ c S-32.0001, ss 7, 13, 17; Medical Assistance in Dying Statute Law Amendment Act, 2017, SO 2017 C7; and Bill 41, Patients First Act, 2016, SO 2016 C30;; and Bill 41, Patients First Act, 2016, SO 2016 C30; *Local Health System Integration Act*, 2006, SO 2006, c 4, s 20.2(4); *Public Hospitals Act*, RSO 1990, c P40, s 8.1(2).

⁹⁵ See eg, Sharon Kirkey, 'Ontario Hospitals Allowed to Opt Out of Assisted Dying, Raising Conscientious Accommodation Concerns', *National Post* (online), 10 June 2016 <news.nationalpost.com/news/ontario-hospitals-allowed-to-opt-out-of-assisted-dying-raising-conscientious-accommodation-concerns>; Tom Blackwell, 'BC Man Faced Excruciating Transfer After Catholic Hospital Refused Assisted-Death Request', *Globe and Mail* (online), 27 September 2016 <news.nationalpost.com/news/canada/b-c-man-faced-excruciating-transfer-after-catholic-hospital-refused-assisted-death-request>. Dying with Dignity Canada has launched a campaign to expose barriers that may prevent Canadians from accessing MAiD; see 'The Shine a Light Campaign' (online): <www.dyingwithdignity.ca/shinealight>.

of mature minors and requests made in advance of loss of capacity.⁹⁶ As required by the legislation, between now and December 2018, there are independent reviews of the questions of mature minors, advance requests, and mental illness as the sole underlying condition. Advocates on all sides of these issues will ultimately attempt to persuade Parliament to ensure that the legislation reflects their positions on these issues.

The Parliament also decided to exclude, with no promise of further study, those whose conditions are ‘incurable’, who are in an ‘advanced state of irreversible decline in capability’, and whose ‘natural death’ has become ‘reasonably foreseeable’. There will be two kinds of challenges to these criteria. First, there will be cases questioning what the key terms or phrases mean. For example, in *AB v Canada (Attorney General)*, a woman sought clarification of the meaning of ‘reasonably foreseeable’.⁹⁷ Second, there will also be *Charter* challenges to the exclusion criteria. In particular, there will be challenges to the requirements that the patient’s condition must be incurable, the patient must be in an advanced state of irreversible decline in capability, and their natural death must have become reasonably foreseeable. Recall that the Supreme Court of Canada, in one voice, declared the *Criminal Code* prohibitions on MAiD void because they violated the *Charter* insofar as they prohibited 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. ‘Irremediable’, [they added] ..., does not require the patient to undertake treatments that are not acceptable to the individual.⁹⁸

Contrast this with the federal legislation. There is no reference to ‘incurable’ in the *Carter case* declaration. There is no reference to ‘advanced state of irreversible decline in capability’ in the *Carter* declaration. There is no reference to ‘reasonably foreseeable’ in the *Carter* declaration. In sum, the following hypothetical people would be allowed access to MAiD through the *Carter* declaration and, as is already being argued, the *Charter* would require them to have access, but they would be denied access by the legislation: someone who has had three unsuccessful rounds of chemo and is refusing a fourth (if her disease is not considered incurable);⁹⁹ someone who had a traumatic injury five years ago (as there is no decline in

⁹⁶ Individuals whose sole underlying condition is mental illness are not included in this list of excluded groups because I am persuaded that, contrary to the assumption of some, the legislation does not exclude them. See Jocelyn Downie and Justine Dembo, ‘Medical Assistance in Dying and Mental Illness under the New Canadian Law’ (2016) 9 *Journal of Ethics in Mental Health* VI(iv) <http://www.jemh.ca/issues/v9/documents/JEMH_Open-Volume_Benchmark_Medical_Assistance_in_Dying_and_Mental_Illness_Under_the_New_Canadian_Law-Nov2016.pdf>, for an argument in support of the position that individuals whose sole condition is a mental illness are not excluded from accessing MAiD under the legislation (as long as they meet the s 241.2(2) criteria). There is no published rebuttal of this argument.

⁹⁷ 2017 ONSC 3759.

⁹⁸ *Carter v Canada (Attorney General)* [2015] 1 SCR 331 [127].

⁹⁹ It should be noted here that the Minister of Health and Department of Justice Senior Counsel both stated when appearing before the Senate that ‘incurable’ should be interpreted as including the phrase ‘by any means acceptable to the patient’: Canada, *Parliamentary Debates*, Senate, 42nd Parl, 1st Sess, Vol 150, No 41 (1 June 2016) 1650 (Dr Jane Philpott) <www.parl.gc.ca/Content/Sen/Chamber/421/Debates/041db_2016-06-01-e.htm> and Evidence to Senate Standing Senate Committee on Legal and Constitutional Affairs, Parliament of Canada (6 June 2016) (Chair: Bob Runciman) <www.parl.gc.ca/content/sen/committee/421/LCJC/52666-E.HTM>. Their position is grounded in the well-established right to refuse treatment. However, this phrase is not explicitly included in the legislation in conjunction with the ‘incurable’ criterion. The phrase is explicitly included in the legislation in conjunction with the alleviation of suffering criterion (‘... suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable’). The logic of the defence for not explicitly

capability); someone with Chronic Obstructive Pulmonary Disease (as death is too uncertain); someone with Parkinson's Disease, ALS, multiple sclerosis, or Huntington's disease (when death is too far off); and even someone in Kay Carter's situation, who is only 60 instead of 89 (as death is too far off).

One *Charter* challenge to the new legislation was launched in *Lamb v Canada (Attorney General)*¹⁰⁰—by the same legal team that argued and won the *Carter* case. Julia Lamb is a 25-year-old woman with spinal muscular atrophy. This is a degenerative muscle-wasting condition that is slowly depriving Julia of a wide range of muscular functions and, consequently causing considering pain and suffering. She does not wish to access MAiD now, but can anticipate a time at which she would find her suffering to be enduring and intolerable; however, her physicians would not be able to predict with sufficient certainty that her death is reasonably foreseeable. She is arguing that the new federal legislation violates her s 7 and s 15 rights under the *Charter*. This case will focus on Julia and other people who, the Supreme Court of Canada said in *Carter*, must not be prevented from having access to MAiD, but who do not have access under the federal legislation.

A second *Charter* challenge, *Jean Truchon and Nicole Gladu v Attorney General (Canada) and Attorney General (Quebec)*,¹⁰¹ has been launched arguing that both the federal and Quebec laws are too restrictive. Jean Truchon has cerebral palsy, and Nicole Gladu, has post polio syndrome.

Governments and practitioners are also going to have to wrestle with the on-the-ground consequences of some of the provisions in the federal legislation. These include (but are not limited to):

- A patient is in agony from spinal stenosis but refuses pain medication at dosages sufficient to control the pain, in order to be competent at the time of the request and at the time of provision of MAiD.¹⁰²
- A patient has advanced bone cancer pain that can be managed by such deep sedation that she is in a semi-conscious state. She has her sedation lightened (and is thereby returned to a state of experiencing severe pain) so that she will regain capacity at the time of provision of MAiD.¹⁰³
- A patient has completed all of the requirements (including the 10-day waiting period) on a Friday afternoon, her MAiD provider is not available until Monday, she loses capacity on the weekend, and so becomes ineligible for MAiD and remains stranded in a state of enduring and intolerable suffering until she dies from her underlying condition months later.¹⁰⁴

including 'by any means acceptable to the patient' for 'incurable' would also apply to the alleviation of suffering (in which case 'under conditions that they consider acceptable' is redundant in s 241.2(2)(c)). Since the principles of statutory interpretation require courts to read legislation in such a way as to avoid redundancy, it might be argued that a court would not be permitted to read the limit into s 241.2(2)(a).

¹⁰⁰ *Lamb v Canada (Attorney General)* (27 June 2016), Vancouver, SCBC, S-165851 (notice of civil claim).

¹⁰¹ *Jean Truchon and Nicole Gladu v Attorney General (Canada) and Attorney General (Quebec)* (13 June 2017), Montreal, CQ (Civ Div) (notice of Application to Proceed for Declaratory Relief) filed 13 June 2017, online: <www.menardmartinavocats.com/documents/file/demande-introductive-da%C2%80%C2%99instance-en-jugement-d%C3%83%C2%89claratoire.pdf>.

¹⁰² *Medical Assistance in Dying Act*, SC 2016, c 3, ss 241.2(1)(b) and (3)(h).

¹⁰³ *Ibid* s 241.2(3)(h).

¹⁰⁴ *Ibid* ss 241.2(1)(b) and (3)(h).

- A patient was diagnosed with Alzheimer’s disease three years ago and made an advance request for MAiD and, if that wasn’t available, an advance directive refusing all oral hydration and nutrition once she reached stage seven of the disease. She is now stage seven, incapable and therefore ineligible for MAiD, and so the institution stops giving her food and liquids and waits while she dies of dehydration.¹⁰⁵
- A patient has multiple sclerosis but, although experiencing enduring and intolerable suffering, her death is not reasonably foreseeable. She decides to stop eating and reduce liquids in order to get close enough to death to qualify for MAiD while still retaining capacity. It takes 50 days without food and four days without liquid before her physician determines that she meets the eligibility criteria.¹⁰⁶
- A patient has Huntington’s disease and while experiencing enduring and intolerable suffering, her death is not likely for a number of years. She asks her physician to provide her with deep and continuous sedation and she refuses artificial hydration and nutrition. She dies 14 days later.¹⁰⁷

As the public continues to learn of these situations that result from the way in which the legislation has been drafted, there is likely to be increased pressure on governments to revisit the provisions that create such situations and on providers to find ways to avoid the consequences while respecting the provisions.¹⁰⁸

Finally, the inconsistencies between the Quebec legislation, the *Carter* decision, and the federal legislation will need to be addressed. For example, the Quebec legislation requires that patients be ‘at the end of life’, which is a much narrower criterion than *Carter*’s criterion of ‘grievous and irremediable condition’. The federal legislation also requires a 10-day waiting period between the request and the provision of MAiD while the Quebec legislation does not.¹⁰⁹

III LESSONS FOR AUSTRALIA

What then can Australia learn from the Canadian experience with decriminalising medical assistance in dying? First, *be patient and adaptable*. In Canada, advocates of law reform concurrently worked on litigation, legislation, and prosecutorial charging guidelines.¹¹⁰ They wanted to be able to go through any crack in any window of opportunity that opened. If one

¹⁰⁵ Ibid.

¹⁰⁶ Ibid ss 241.2(1)(b) and (2)(d).

¹⁰⁷ Ibid.

¹⁰⁸ Eg, could impending provision of palliative sedation be taken to mean that loss of capacity is imminent and therefore a shortening of the 10-day waiting period is permissible? Could all patients with diagnoses involving future dementia who want MAiD be advised to explicitly refuse oral feeding and liquids through advance directives?

¹⁰⁹ Rather, the Quebec legislation requires at s 29(1)(c) ‘verifying the persistence of suffering and that the wish to obtain medical aid in dying remains unchanged, by talking with the patient at reasonably spaced intervals given the progress of the patient’s condition’. The Deputy Minister of Health of Quebec instructed health care institutions to comply with the 10 day requirement. However, the Executive Director of the Conseil pour la Protection des Malades has filed a complaint with the Quebec Ombudsperson about this instruction. See Aaron Derfel, ‘Dying with Dignity: Quebec Paves Way, but Critics Point to Problems’ *Montreal Gazette* (online), 21 October 2016 <montrealgazette.com/news/local-news/medial-aid-in-dying-quebecs-experience>; Isabelle Paré, ‘Six Ordres Professionnels Demandent un Appel sur L’aide à Mourir’, *Le Devoir* (online), 6 December 2016 <www.ledevoir.com/societe/sante/486444/aide-a-mourir-six-ordres-professionnels-demandent-un-renvoi-en-cour-d-appel>.

¹¹⁰ See eg, Jocelyn Downie and Simone Bern, ‘Rodriguez Redux’ (2008) 16 *Health Law Journal* 27, 44–54; Jocelyn Downie and Ben White, ‘Prosecutorial Discretion in Assisted Dying in Canada: A Proposal for Charging Guidelines’ (2012) 6(2) *McGill Journal of Law and Health* 113.

waits for the window to open before developing the arguments, drafting legislation, etc, then by the time the work is done, the window will have closed again. So the advocates prepared for all eventualities, were patient, and then took the litigation path when it opened and the legislation path when that followed.

Second, ***prepare the foundations for law reform initiatives***. It was essential to the plaintiffs' success in the *Carter* case that they were able to access robust empirical evidence on the experience with assisted dying around the world¹¹¹ as well as well-developed legal and ethical arguments on why assisted dying should be decriminalised.¹¹² Very clear strong public support for both the *Carter* decision and assisted dying were also important for the legislative process.¹¹³

Third, ***consult and engage broadly***. As noted earlier in this paper, this principle was embraced by the Quebec Select Committee on Dying with Dignity and is in no small part a reason for the widespread support for their medical aid in dying legislation. It was also respected (albeit on an abridged timeline) by the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and the Special Joint Committee on Physician-Assisted Dying and, again, probably played a role in the strong positive response their reports received from the majority of Canadians. However, the perils of not consulting were also manifest in the Canadian process. For example, the Canadian government did not consult with the regulators of physicians, but rather just consulted with the Canadian Medical Association.¹¹⁴ If they had consulted with those who are tasked with regulating physicians, they would have been advised not to use the criterion that 'natural death' be 'reasonably foreseeable'¹¹⁵ and, had they followed that advice,

¹¹¹ See eg, the impact of the expert evidence provided by Johannes J M van Delden, Luc Deliens, and Linda Ganzini in the trial decision in *Carter v Canada (Attorney General)* [2012] BCSC 886.

¹¹² See eg, Jocelyn Downie, *Dying Justice: A Case for Decriminalizing Euthanasia and Assisted Suicide in Canada* (University of Toronto Press, 2004); Downie and Bern, above n 110. See also the impact of the expert evidence provided by Wayne Sumner, Margaret Pabst Battin, and Marcia Angell in the trial decision in *Carter v Canada (Attorney General)* [2012] BCSC 886.

¹¹³ See eg, results of Ipsos Poll: Ipsos Public Affairs, *Dying with Dignity Canada*, (February 2016), <d3n8a8pro7vbm.cloudfront.net/dwdcanada/pages/480/attachments/original/1455165944/DWDC-Ipsos_-_Feb_2016_poll_-_final.pdf?1455165944>.

¹¹⁴ Senate Standing Senate Committee on Legal and Constitutional Affairs, Parliament of Canada, *Proceedings*, Issue No 9, Evidence, 42nd Parl, 1st Sess (10 May 2016) <www.parl.gc.ca/Content/SEN/Committee/421/lcjc/09ev-52575-e.htm?Language=E&Parl=42&Ses=1&comm_id=11>. Senator Joyal asked the Federation of Medical Regulatory Authorities of Canada (FMRAC) whether or not they had been consulted on Bill C-14 and FMRAC said they had not. Likewise the same question directed to the College of Physicians and Surgeons of Ontario revealed they had not been consulted. FMRAC is mandated 'to advance medical regulation on behalf of the public through collaboration, common standards and best practices': see FMRAC, *Mission* <fmrac.ca/about-us/>. The Canadian Medical Association (CMA) is 'a national association of physicians that advocates on behalf of its members and the public for access to high-quality health care' and 'provides leadership and guidance to physicians': see CMA, *History, Mission, Vision and Values* <www.cma.ca/En/Pages/history-mission-vision.aspx>. The CMA had historically been opposed to MAiD and so, despite the fact that the official position had become neutral on decriminalisation (see CMA, *CMA Policy: Euthanasia and Assisted Death: Update 2014* <www.cma.ca/En/Pages/end-of-life.aspx> 3), it came as no surprise that they were actively lobbying in support of a restrictive approach to the eligibility criteria.

¹¹⁵ See Evidence to Senate Standing Senate Committee on Legal and Constitutional Affairs, Parliament of Canada, 42nd Parl, 1st Sess, Issue No 9, 10 May 2016, 9:47, (Dr Douglas Grant) <sencanada.ca/Content/SEN/Committee/421/lcjc/pdf/09issue.pdf>, where FMRAC rejects 'reasonably foreseeable' and 'natural death'; FMRAC, 'Bill C-14, Medical Assistance in Dying: Submission to the Senate Standing Committee on Legal and Constitutional Affairs' (What's New, 10 May 2016) <fmrac.ca/federation-of-medical-regulatory-authorities-of-canada-bill-c-14-medical-assistance-in-dying/>.

they would have avoided the firestorm that greeted their draft legislation and the *Charter* challenge to the legislation that has now been commenced.¹¹⁶

It is also essential to *be respectful of heterogeneity in communities*. The loudest voice does not necessarily articulate the most widely held or only held position. A good example of this phenomenon in Canada is with respect to persons with disabilities. There was a very vocal group representing persons with disabilities and arguing for as restrictive an approach as possible.¹¹⁷ Yet there are many other people with disabilities who believe that the most restrictive approach is patronising, paternalistic, and infantilising.¹¹⁸

Remember also to *consult with indigenous communities*. In Canada, indigenous communities lack access to health services, are confronting a higher rate of suicide than non-indigenous populations, and have a range of different cultural values and beliefs relevant to end of life decision-making.¹¹⁹ In Canada, they were not adequately engaged in the conversations about decriminalisation and implementation of MAiD.¹²⁰ As a result, policy-makers and providers are now playing catch-up and trying to undo misinformation and mistrust.

Fourth, ***prepare the infrastructure for assisted dying***. It is essential to develop a mechanism for identifying willing providers, as providers can feel at risk of stigmatisation by their colleagues and attack from opponents of assisted dying, and so may not make their willingness known. But, in order to ensure access for patients, it is essential to know who and where the willing providers are. Some physicians in Canada have been very open about being willing

¹¹⁶ *Lamb v Canada (Attorney General)* (27 June 2016), Vancouver, SCBC, S-165851 (notice of civil claim).

¹¹⁷ Vulnerable Person Standard, *Materials Related to Bill C-14* <www.vps-npv.ca/materials-related-to-bill-c14/>; Senate Standing Senate Committee on Legal and Constitutional Affairs, *Proceedings*, Issue No 9, Evidence, 42nd Parl, 1st Sess (10 May 2016) (Michael Bach) <www.parl.gc.ca/Content/SEN/Committee/421/lcjc/09ev-52575-e.htm?Language=E&Parl=42&Ses=1&comm_id=11>; Evidence to Senate Standing Committee on Justice and Human Rights, Parliament of Canada, 42nd Parl, 1st Sess, No 12, 3 May 2016, 1950 (Michael Bach); and 42nd Parl, 1st Sess, No 13 (4 May 2016) 1800 (Dianne Pothier); Dianne Pothier, Submissions to the Senate Standing Committee on Legal and Constitutional Affairs, *Consideration of Bill C-14*, 28 April 2016, <www.vps-npv.ca/s/Pothier-Senate-Committee-submissions-on-C-14.pdf>; Senate Standing Committee on Justice and Human Rights, Parliament of Canada, *Evidence*, 42nd Parl, 1st Sess, 5 May 2016, (David Baker) <sencanada.ca/en/Content/Sen/committee/421/lcjc/52552-e>.

¹¹⁸ Canada, *Parliamentary Debates*, Senate, 3 June 2016, 1st Sess, 42nd Parl, Vol 150, Issue 43 (Chantal Petitclerc) 1100: <www.parl.gc.ca/Content/Sen/Chamber/421/Debates/043db_2016-06-03-e.htm>; Senate Standing Committee on Justice and Human Rights, *Evidence*, 42nd Parl, 1st Sess, No 12, (3 May 2016) 1715 (Angus Gunn); *Carter v Canada* [2015] 1 SCR 331 (Factum of the Intervenor the Alliance of People with Disabilities who are Supportive of Legal Assisted Dying Society) <www.scc-csc.ca/WebDocuments-DocumentsWeb/35591/FM130_Intervener_Alliance-of-People-with-Disabilities.pdf>.

¹¹⁹ For access to health services, see Jeff Reading and Regine Halseth, *Pathways to Improving Well-Being for Indigenous Peoples: How Living Conditions Decide Health* (National Collaborating Centre for Aboriginal Health, 2013) <www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/102/pathways_EN_web.pdf>; for suicide, see Sherry Bellamy and Cindy Hardy, *Understanding Depression in Aboriginal Communities and Families* (National Collaborating Centre for Aboriginal Health, 2015) <www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/150/2015-10-07-RPT-MentalHealth03-Depression-BellamyHardy-EN-Web.pdf>; for cultural beliefs and values, see Elaine Anselmi, 'Physician Assisted Dying: Offering a Choice Means Making Tough Decisions', *Northern Public Affairs* (online), 22 February 2016 <www.northernpublicaffairs.ca/index/physician-assisted-dying-offering-a-choice-means-making-tough-decisions/>.

¹²⁰ There was some engagement, but no community consultation. See eg, House of Commons Special Joint Committee on Physician-Assisted Dying, Parliament of Canada, *Evidence*, 42nd Parl, 1st Sess, No 9 (1 February 2016) 1715 (Dr Carrie Bourassa); No 10 (2 February 2016) 1900 (Dr. Alika Lafontaine). Alika Lafontaine, Carrie Bourassa and Melanie MacKinnon engaged with the Federal Expert Panel.

providers.¹²¹ Some provinces and territories have set up a central team that can be contacted by patients.¹²² Access is further enhanced if some entity capable of protecting provider privacy is given the mandate and resources necessary to act as a go-between to ensure patients have access to willing providers.¹²³ It is also essential to develop a transfer of care system if any conscientious objection by providers and/or publicly funded health care institutions will be permitted. Many provinces and territories in Canada have set up such systems and as a result some patients can access MAiD even when their own health care providers object to it.¹²⁴

It is also necessary to make sure the most appropriate drugs are licensed. It was only realised after the fact that secobarbital (the drug preferred by Canadian providers, for self-administered MAiD) is not available in Canada, so patients who wish to self-administer may face real barriers to doing so (for example, an oral protocol is available in Alberta but not in Nova Scotia).¹²⁵ Australian patients could find themselves in the same bind if the barriers to access to secobarbital (or pentobarbital which may be preferred in Australia) are not removed when or before MAiD is decriminalised.

It is also important to establish educational programs for health professionals, lawyers, and the public. Everyone needs to understand what the law is and what their rights and obligations are, and providers need to know how to deliver MAiD. Support systems must also have been put in place for providers as well as patients and families. Canada is playing catch-up on both of these infrastructure pieces—MAiD is legal but not everybody has the information or support they need.¹²⁶

It is also essential to establish the infrastructure for the oversight system: for the sake of accountability, transparency and trust, all cases should be reviewed; and death certificate forms

¹²¹ See eg, Elizabeth Church, 'Ellen Wiebe is the Doctor Seeking a Smoother Path to Assisted Death', *Globe and Mail* (online), 2 March 2016 <www.theglobeandmail.com/news/national/ellen-wiebe-is-the-doctor-seeking-a-smoother-path-to-assisted-death/article29006968/>; Shannon Proudfoot, 'Q&A: Stefanie Green on Helping Doctors Navigate Assisted Dying', *Maclean's* (online), 25 November 2016 <www.macleans.ca/news/canada/qa-stefanie-green-on-helping-doctors-navigate-assisted-dying/>; Sandra Martin, 'Patients Should Talk Frankly With their Doctors about Assisted Dying', *Globe and Mail* (online), 12 November 2015 <www.theglobeandmail.com/life/health-and-fitness/health/patients-should-talk-frankly-with-their-doctors-about-assisted-dying/article27234624/>.

¹²² See eg, Winnipeg Regional Health Authority, *Accessing Medical Assistance in Dying* (2016) <www.wrha.mb.ca/maid/contact.html>.

¹²³ See eg, Alberta Health Services, *Medical Assistance in Dying Care Coordination Services* (14 July 2016) <www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-coordination-service.pdf>; Nova Scotia Health Authority, *Medical Assistance in Dying: Frequently Asked Questions for the Public* (4 July 2016) <www.nshealth.ca/sites/nshealth.ca/files/faq_for_public_2016_07_04.pdf>.

¹²⁴ Nova Scotia Health Authority, above n 123; Alberta Health Services, *Medical Assistance in Dying: Frequently Asked Questions for Patients and Family Members* <www.albertahealthservices.ca/assets/info/pf/if-pf-maid-faqs-public.pdf>.

¹²⁵ The Health Canada Drug Product database shows no results for secobarbital, indicating its licence has lapsed. Health Canada, *Drug Product Database* <<https://health-products.canada.ca/dpd-bdpp/index-eng.jsp>>. This drug was cancelled post-market in 2004. Janet French, 'Nearly 80 Alberta Doctors Have Stepped Forward to Offer Physician-Assisted Death' *Edmonton Sun* (online) 13 March 2016 <www.edmontonsun.com/2016/03/13/nearly-80-alberta-doctors-have-stepped-forward-to-offer-euthanasia-physician-assisted-death>; Alberta Health Services, above n 124; Alberta Health Services, *Medical Assistance in Dying — Phase Four Action Phase* (26 August 2016) <www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-process-admin-medication.pdf>.

¹²⁶ One group filling this void is the Canadian Association of MAiD Assessors and Providers, <<http://camapcanada.ca/>>. It has been set up by a small group of MAiD providers on a voluntary mutual-assistance basis. It would have been better if such an organisation could have been set up prior to the coming into force of the legislation and with sufficient government support to enable it to play a robust role in education and support from the outset.

need to be modified and instructions given on the completion of death certificates (what is the manner of death, the underlying cause of death, etc).¹²⁷ These steps enable robust data gathering, analysis and reporting, which again is essential for accountability and transparency, and having and deserving the trust of the public. They also enable research to be conducted on a range of issues aimed at improving end of life care. Unfortunately, Canada did not get its oversight infrastructure in place prior to the legalisation of MAiD. Indeed, more than a year after the legislation came into force, there is no pan-Canadian oversight system; there is considerable variability with respect to who is conducting case reviews (where any case review is being done), and there is no standard approach to what information is being reported and to whom. Even the death certificate forms and instructions are not consistent across the country.¹²⁸

More positive lessons can be learned from other permissive jurisdictions, for example, the Netherlands and Belgium have robust systems for reviewing and reporting on all cases and the Netherlands, Belgium, and the permissive American states all gather and report on robust data sets.¹²⁹ The Netherlands also commissions a major end of life decision-making research study every five years rather than (as in Belgium) leaving this to researchers to find their own funding independently (and therefore somewhat irregularly).¹³⁰ However, nobody yet has developed a system that gathers reliable data on all requests (which can provide important evidence on a variety of issues such as patient access) or that facilitates research in an efficient, reliable, and cost-effective manner (eg, by linking MAiD cases through death certificates with large health information databases). Again, while these issues were flagged for the Canadian authorities, they did not get out ahead of them and so we are in a sense building the ship while sailing it—and this is definitely not ideal.

Fifth, ***beware of negative consequences*** that can accompany particular turns of phrase in legislative drafting and particular positions taken on substantive issues in the debate about criteria for access and procedural safeguards. In particular, as illustrated earlier, there are serious negative consequences flowing from the following elements of the Canadian

¹²⁷ Jocelyn Downie and Kacie Oliver, 'Medical Certificates of Death: First Principles and Established Practices Provide Answers to New Questions' (2015) 188(1) *Canadian Medical Association Journal* 49.

¹²⁸ Eg, until Ontario passed Bill 84 (above n 94), coroners in Ontario completed the medical certificates of death for MAiD cases and they are instructed to report 'combined drug toxicity' as the cause of death with reference to the underlying medical condition that qualified the person for MAiD and with 'suicide' as the manner of death (with reference to MAiD): the attending physician now prescribes what is written on the medical certificate of death; e-mail communication from Cheryl Mahyr, Issues Manager, Office of the Chief Coroner of Ontario Forensic Pathology Service, 31 January 2017 and 14 August 2017. Providers in Nova Scotia are being instructed to report the drugs as the immediate cause, the grievous and irremediable condition as the underlying cause, and whatever would have been recorded as the manner of death had the person died from the grievous and irremediable condition. MAiD is also noted at the bottom of the form: telephone communication from Krista Dewey, Deputy Registrar General, Nova Scotia.

¹²⁹ Eg, information for the Netherlands is available at Regionale Toetsingscommissies Euthansie, *Frequently Asked Questions* <www.euthanasiecommissie.nl/uitspraken/publicaties/faq-engels/faq/faq/frequently-asked-questions>; section 5 of the Belgian Euthanasia Act requires physicians to complete Federal Control and Evaluation Commission form (*Belgian Act on Euthanasia of May 28, 2002* <eol.law.dal.ca/wp-content/uploads/2015/06/Euthanasia-Act.pdf>; Oregon State publishes annual dying with dignity reports: see Oregon Health Authority, *Annual Reports* <public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>; Washington State also publishes data: see Washington State Department of Health, *Death with Dignity Data* <www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData>.

¹³⁰ A van der Heide et al, 'End-of-Life Decisions in the Netherlands over 25 Years' (2017) 377(5) *New England Journal of Medicine* 492, doi: 10.1056/NEJMc1705630.

legislation: capacity required at time of provision; mandatory waiting periods; access limited to those for whom death is ‘reasonably foreseeable’;¹³¹ and allowing providers and institutions to opt out. This is not to say that legislators must avoid all of these elements (although I would argue for that). Rather, it is to say that legislators must be aware of the consequences of proceeding with those elements. It might be argued that the Canadian government did not know and therefore should not be blamed for the consequences of their legislative drafting. However, any jurisdiction that follows Canada will have been forewarned and will therefore bear the responsibility for the suffering that ensues.

Sixth, take the opportunity of assisted dying being on the legislative agenda to also **address related end of life issues**. The Canadian legislation only deals with MAiD, so it did not resolve the following issues: unilateral withholding or withdrawal of potentially life-sustaining treatment (can a physician withhold or withdraw potentially life-sustaining treatment without the knowledge of or against the wishes of the patient or patient’s substitute decision-maker?);¹³² palliative sedation (can you provide deep and continuous sedation and respect a refusal of artificial hydration and nutrition for a patient with a neurodegenerative condition who is not expected to die for years but whose suffering has become enduring and intolerable?);¹³³ and voluntary stopping of eating and drinking (can patients stop eating and drinking until death and can they refuse not only artificial hydration and nutrition but also oral feeding through an advance directive?).¹³⁴ End of life decision-making is best seen as a spectrum of care and countries should have clear laws about the entire spectrum so that they can care best for all patients at the end of life. Canada does not. Australia does not. Yet both countries can and should.

The final lesson to be drawn from the Canadian experience is that **the hard work that it takes to decriminalise MAiD is worth it**. Approximately 970 people have been able to access MAiD as of 31 December 2016.¹³⁵ Some (a much larger number) will have made a request for MAiD and qualified, but never self-administered or had a physician or nurse practitioner administer it. An unknown number (but still higher) have been comforted to know that MAiD would or will be available to them, should, or when, they reach the point of enduring and intolerable suffering. Still others (a much, much larger number) will never have made a request but will

¹³¹ This lesson is immediately relevant to the Australian context as drafts of legislation in different states have relied upon variations on the criterion of ‘terminal illness’. If this criterion is defined in terms of a life expectancy rather than lethality of the condition, the legislation will likely generate the same negative consequence as has accompanied the Canadian criterion of ‘reasonably foreseeable’ (ie, patients starving themselves to get close enough to death to qualify).

¹³² Lindy Willmott, Ben White and Jocelyn Downie, ‘Withholding and Withdrawal of “Futile” Life-Sustaining Treatment: Unilateral Medical Decision-Making in Australia and New Zealand’ (2013) 20 *Journal of Law and Medicine* 907.

¹³³ Jocelyn Downie, ‘And Miles to Go Before I Sleep: The Future of End-of-Life Law and Policy in Canada’ (2016) 39 *Dalhousie Law Journal* 413.

¹³⁴ Thaddeus Pope and Lindsey Anderson, ‘Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life’ (2011) 17 *Widener Law Review* 363; Thaddeus Pople and Amanda West, ‘Legal Briefing: Voluntarily Stopping Eating and Drinking’ (2014) 25(1) *Journal of Clinical Ethics* 68; Nataša Ivanović, Daniel Büche and André Fringer, ‘Voluntary Stopping of Eating and Drinking at the End of Life – a “Systematic Search and Review” Giving Insight into an Option of Hastening Death in Capacitated Adults at the End of Life’ (2014) 13(1) *BMC Palliative Care* 1.

¹³⁵ Government of Canada, ‘Interim update on medical assistencing in dying in Canada June 17 to December 31, 2016’ (31 May 2017), online: <www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html>. The most regular, up-to-date, and comprehensive (within a province) data are available on the Alberta MAiD website: Alberta Health Services, *Medical Assistance in Dying: Data* <www.albertahealthservices.ca/info/Page14930.aspx>.

have been relieved just to know that the option would be there for them to pursue should their suffering ever become enduring and intolerable.

Obviously much still remains to be done in Canada. But these are at least some of the lessons that can be learned so far. My hope is that Australian states can take the good, leave the bad, and thereby profoundly enhance end of life care in Australia.