CHALLENGES TO CHOICE:

BILL C-14

ONE YEAR LATER

Dying With Dignity Canada

It's your life. It's your choice.

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Introduction

When Parliament passed an assisted dying law in June 2016, it signalled the start of a new era for Canada's right-to-die movement and for the country as a whole. No longer would the national discussion on medical assistance in dying (MAID) be centred on the pros and cons of legalization. The Supreme Court of Canada effectively settled that debate in 2015 when it struck down the decades-old federal ban on assisted dying. Instead, the passage of Bill C-14 challenged advocates, analysts and critics to shift their focus to evaluating the impacts and effectiveness of this controversial new law.

One year later, examining Bill C-14 is a central component of Dying With Dignity Canada's (DWDC) work. We continue to seek out as much information as we can about the implementation of MAID and what it means for Canadians. This intelligence comes to us via news reports and academic literature, the doctors on our Physicians Advisory Council, other allies and stakeholder groups, and through conversations with individuals and families who access our Personal Support Program. As a result, our assessments of Bill C-14 are rooted in a solid understanding of Canada's political landscape, as well as the personal experiences of people who are navigating their legal end-of-life options.

This report is a summary of our findings on the implementation of MAID in Canada one year after the passage of Bill C-14. It is divided into four major content areas:

- the impacts of Bill C-14's eligibility criteria;
- the practical effects of the safeguards laid out in the law;
- the structural barriers facing Canadians who wish to exercise their right to MAID;
- the state of the mechanisms that are in place to gather, monitor and report national MAID data.

The goal of this publication is to identify successes, gaps and challenges that have arisen after the passage of Bill C-14. DWDC will continue to work towards a framework for healthcare at end of life that puts patients first, respects their *Charter* rights and recognizes their inherent dignity as humans. These values inform our human-rights advocacy and education programs in general, and we believe they should be at the heart of any serious public policy discussion regarding the future of MAID in Canada.

Carter v. Canada and the road to choice

Our analysis of Bill C-14 and its impacts is heavily informed by the Supreme Court of Canada's landmark ruling in *Carter v. Canada.* On February 6, 2015, the nine justices of the

high court unanimously struck down the federal prohibition on medically assisted dying, arguing that the old law forced Canadians to endure intense suffering against their will and, in turn, violated their *Charter* rights.

DWDC has advocated for a framework for assisted dying that reflects the thoughtful, compassionate principles of the *Carter* decision, which set out guidelines for who is eligible for MAID. In striking down the old ban on assisted dying, the Supreme Court established MAID as a right for competent, consenting adults with a "grievous and irremediable" illness, disease or disability causing enduring suffering that is intolerable to the individual.[1] It was clear that the parameters given did not limit MAID access to only those Canadians who are at end of life.

Eligibility criteria

Bill C-14's parameters are more limited. The law defines "grievous and irremediable," a phrase borrowed from the *Carter* decision, in a way that renders the eligibility requirements both more restrictive and more difficult to interpret. According to Bill C-14, an individual qualifies as having a grievous and irremediable medical condition if they have satisfied all of the following criteria:

- "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;"
- "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."[2]

This definition, along with some of the procedural safeguards in Bill C-14, has substantially influenced who can access MAID and has raised questions about the law's constitutionality. Much of this report explores the human impact of these restrictions and how the rules should be changed to better reflect the spirit of the *Carter* decision as well as the *Charter.*

[1] Carter v. Canada (Attorney General), 2015. 35591 (Supreme Court of Canada, February 6), Para. 4.
[2] Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying),* 1st session, 42nd Parliament, 2016. S. 241.2(1) - 241.2(2).

Interpreting "reasonably foreseeable"

As of April 2017, more than 1,300 Canadians had availed themselves of a medically assisted death.[3] For these individuals, Bill C-14 afforded them a path to relieving their intolerable, enduring suffering. However, for one to be eligible to access MAID under Bill C-14, one's "natural death must be reasonably foreseeable." A year after the law's passage, this requirement continues to cause confusion among clinicians, patients and commentators alike. In turn, uncertainty over the term's exact meaning has led to significant inconsistencies in how Bill C-14's eligibility criteria are being applied.

The government's attempts to clarify the meaning of "reasonably foreseeable" have arguably done little to lessen the confusion. In a committee hearing in May 2016, Justice Minister Jody Wilson-Raybould said that "a patient must be on a trajectory towards death," but added that it would be left up to physicians and nurse practitioners to make that determination "based on their medical expertise, their ethics, and their closeness in terms of the individual patient's circumstances."[4] However, being on a trajectory towards death does not mean that the patient has to have a fatal or terminal condition in order to be eligible for MAID. According to a government backgrounder on Bill C-14, reaching the conclusion that a patient's natural death is reasonably foreseeable does not require "a specific prognosis as to the length of time a person has to live."[5]

As a result of the opaqueness of "reasonably foreseeable," combined with the latitude healthcare clinicians have been given to decipher it, there is not yet a standard definition for what the term means in a clinical context. Some clinicians are applying the criterion very conservatively, only approving MAID cases where the patient has a terminal or near-terminal prognosis, as the MAID team with the University Health Network in Toronto is doing.[6] Other MAID providers and assessors assert that an individual's natural death is "reasonably foreseeable" if he or she could reasonably be expected to die within the next five years. (This prognosis is similar to the one given to Kay Carter, a B.C. woman who accessed MAID in Switzerland and whose medical circumstances were considered at length as part of the *Carter* case.) It raises the spectre that two Canadians with the exact same set

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[3] Nicole Ireland, "1,300 Canadians have died with medical assistance since legalization." *CBC News*. April 20, 2017. http://www.cbc.ca/news/health/medically-assisted-dying-canadians-rob-rollins-1.4056700.
[4] Canada. Parliament. House of Commons. Standing Committee on Justice and Human Rights. *Minutes of Proceedings.* 1st Session, 42nd Parliament, Meeting No. 10, 2016. http://www.ourcommons.ca/DocumentViewer/en/42-1/JUST/meeting-10/evidence.
[5] Canada. Health Canada. *Legislative Background: Medical Assistance in Dying*, 2016. http://www.justice.gc.ca/eng/rp-pr/other-autre/adra-amsr/adra-amsr.pdf.
[6] Grant, Kelly. "Group of assisted-death providers publish clinical-practice guidelines." *The Globe and Mail.* June 2, 2017. http://www.theglobeandmail.com/news/national/group-of-assisted-death-providers-publish-clinical-practice-guideline/article35192103/.

of medical circumstances could be given radically different answers regarding their eligibility for MAID under Bill C-14.

However, a recent court ruling in Ontario may help to clear up some of the confusion surrounding this provision in the law. The ruling came in response to an application made by a 77-year-old Ontario woman who is suffering from severe osteoarthritis and has made a formal request for MAID. Two independent doctors had assessed her as eligible under Bill C-14, but the physician who initially agreed to provide her with life-ending treatment was not comfortable moving forward because of the disagreement in the medical community surrounding the reasonably foreseeable provision.

On June 19, 2017, Justice Paul Perell ruled that AB, whose identity is protected under a publication ban, satisfied this requirement, even though her primary medical condition was not fatal and she was not terminally ill. "The language reveals that the natural death need not be connected to a particular terminal disease or condition and rather is connected to all of a particular person's medical circumstances," Perell wrote in his judgment.[7] He also reiterated that, in assessing an individual's eligibility for MAID, a physician or nurse practitioner "need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime."[8]

The possible implications of this decision for individual patients and their loved ones are difficult to overstate. In many cases, whether a person's natural death is deemed "reasonably foreseeable" may currently hinge upon where she lives, who her assessing physicians are, or the particular lawyer who is advising her healthcare team — factors that are unrelated to the degree of the applicant's suffering or her capacity to choose MAID. This is unacceptable, and we hope Perell's decision will help to temper the inconsistencies that currently exist in how Bill C-14's eligibility rules are being applied.

Canadians discriminated against on the basis of their medical condition

In addition, the confusion surrounding Bill C-14's eligibility criteria is not the only reason Canadians are being unfairly denied access to their right to an assisted death. By design, the law excludes individuals who satisfy the eligibility criteria laid out in *Carter* but who are not yet on a course towards death. This approach has raised questions about the constitutionality of some of the provisions laid out in Bill C-14. In a written submission to the Canadian Senate, constitutional expert Peter Hogg wrote that, "[if] Bill C-14 is enacted in its present form, it can safely be predicted that a member of the newly excluded class — those who satisfy the *Carter* criteria and do not have an end-of-life condition — will bring a

[7] AB v. Canada (Attorney General), 2017. 3759 (Ontario Superior Court of Justice, June 19), Para. 81.
[8] Ibid., Para. 80.

constitutional challenge to the new legislation."[9] His words were prescient: on June 27, 2016, just 10 days after the legislation received royal assent, the notice of claim in *Lamb v. Canada*, the first civil case to challenge Bill C-14's eligibility criteria, was filed in a British Columbia court.

The plaintiffs' submissions in *Lamb v. Canada* shed light onto how Bill C-14's contentious eligibility requirements harm suffering Canadians whose natural deaths are not "reasonably foreseeable." For example, Julia Lamb, the 26-year-old lead plaintiff in the case, is afflicted with spinal muscular atrophy, a painful degenerative condition that causes the wasting of the muscles. According to a statement submitted to the court, Lamb fears that her condition could deteriorate to the point that she would no longer be able to breathe without a ventilator or to speak. Though she does not plan to access assisted dying in the near future, she does want the "peace of mind of knowing that… she has the right, should her medical condition bring her to the point of enduring and intolerable suffering, to seek medical assistance in dying to alleviate that suffering *regardless of how long she might survive in that state"* (emphasis ours).[10]

The law's eligibility criteria effectively exclude most, if not all, Canadians whose primary underlying medical condition is a mental illness. This ban is not made explicit in the wording of the law. However, in Parliamentary hearings on Bill C-14, government officials made it clear that Bill C-14's eligibility criteria, taken as a whole, were intended to prevent individuals whose suffering stems from severe mental illness from accessing MAID. "The proposed legislation also does not permit eligibility solely on the basis of suffering from mental illness," Health Minister Jane Philpott said on May 2, 2016, during her deputation to the House of Commons' Committee on Justice and Human Rights. "There's no denying that mental illness can cause profound suffering, but illnesses such as chronic depression, cognitive disorders, and schizophrenia raise particular concerns with respect to informed decision-making."[11]

A court decision handed down only two weeks after Philpott's deputation suggested that the government's approach to MAID for individuals with mental illness may have been cruel and legally risky. At the time, the country was in the midst of a four-month period in which individuals who wanted to die with a physician's help, but who couldn't wait for new federal legislation to be approved, could apply for a judge's permission to access MAID. One

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[9] Hogg, Peter. *Presentation to Standing Senate Committee on Legal and Constitutional Affairs Bill C-14 (medical assistance in dying).* June 6, 2016. https://sencanada.ca/content/sen/committee/421/LCJC/Briefs/LCJC_June_6_2016_SN_Hogg_e.pdf

[10] "Amended notice of civil claim." *British Columbia Civil Liberties Association.* June 27, 2017. http://bccla.org/wp-content/uploads/2016/06/2017-06-21-Amended-Notice-of-Civil-Claim.pdf.

[11] Canada. Parliament. House of Commons. Standing Committee on Justice and Human Rights. *Minutes of Proceedings.* 1st Session, 42nd Parliament, Meeting No. 10, 2016.

person to go to court to access MAID was an Alberta woman who, because of a court-ordered ban on the publication of her name, is known to the public as EF. At 58 years old, EF had lived for at least nine years with severe conversion disorder, and she had attempted several treatments in the hopes of alleviating her suffering.[12]

Though her medical condition was considered psychiatric at its root, EF's suffering was predominantly physical. A panel of three judges on the Court of Appeal of Alberta described her circumstances in the following terms:

> "She suffers from involuntary muscle spasms that radiate from her face through the sides and top of her head and into her shoulders, causing her severe and constant pain and migraines. Her eyelid muscles have spasmed shut, rendering her effectively blind. Her digestive system is ineffective and she goes without eating for up to two days. She has significant trouble sleeping and, because of her digestive problems, she has lost significant weight and muscle mass. She is non-ambulatory and needs to be carried or use a wheelchair. Her quality of life is non-existent."[13]

The question of EF's eligibility under the rules laid out in *Carter* appeared to be relatively straightforward. Without a doubt, her suffering was intolerable to her and resistant to the treatments she had attempted; EF's condition was deemed irremediable; she was unequivocal in her request for assistance in dying; and her medical team confirmed that she was clearly capable of providing informed consent for MAID. As a result, a judge on the Court of the Queen's Bench of Alberta approved EF's request to access her right to die with a physician's help.

That decision came at an inconvenient time for the federal government, which was working to pass Bill C-14 in Parliament. Justice department lawyers had argued in court that EF didn't qualify for MAID because she wasn't approaching end of life and because her condition was psychiatric at its root. Moreover, allowing EF to be approved for MAID would suggest that the government's interpretation of the Supreme Court's *Carter* decision — and by extension, the legal justification for Bill C-14's reasonably foreseeable requirement — was erroneous. Ottawa sent the decision to appeal, further delaying EF in her quest for an assisted death.

The appeal court's decision was no less embarrassing for the government. Ruling in favour of EF, a panel of three justices refuted the federal government's assertion that the *Carter* ruling only applied to individuals who were at or near end of life. In addition, the judges

[12] *Canada (Attorney General) v. EF*, 2016. 155 (Court of Appeal of Alberta, May 17), Para. 62.
[13] Ibid., Para. 7.

reasserted that the Supreme Court had established MAID as a right for anyone who qualifies under the 2015 decision. “Persons with a psychiatric illness are not explicitly or inferentially excluded if they fit the criteria,” they wrote.[14]

We will never know whether two doctors would have found EF eligible for MAID under a liberal interpretation of Bill C-14, as she died less than a month before the law would go into effect. However, as a result of the government's interventions in her case, we *do* know that Bill C-14 was designed to keep Canadians such as EF alive, in a state of intractable suffering, against their wishes, in violation of their *Charter* rights.

Safeguards

Ending a life is a profound, irrevocable act. And, as Bill C-14’s preamble wisely points out, “robust safeguards… are essential to prevent errors and abuse in the provision of medical assistance in dying.”[15]

Several procedural safeguards are built into Bill C-14 to ensure that only those individuals who qualify under the law’s eligibility criteria may access MAID. Among them:

- patients must make a formal written request for MAID;
- their request must be signed by two independent witnesses;
- their eligibility for MAID must be confirmed by two independent physicians or nurse practitioners;
- individuals must wait through a “cooling-off period” of at least 10 clear days between submitting their formal request for MAID and receiving assistance to die;
- patients must be informed that they can withdraw their request at any time;
- immediately before the provision of MAID, the attending physician or nurse practitioners must give the patient “an opportunity to withdraw the request and ensure that the person gives express consent to receive medical assistance in dying.”[16]

A year after the passage of Bill C-14, the emerging evidence suggests that the safeguards in Bill C-14 have been effective at protecting vulnerable Canadians from inducement and abuse. This is reassuring but hardly surprising. Data gathered in the Netherlands and in the U.S. state of Oregon — two jurisdictions where MAID has been legal for more than a decade

[14] *Canada (Attorney General) v. EF*, 2016. 155 (Court of Appeal of Alberta, May 17), Para. 59.
[15] Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, 1st session, 42nd Parliament, 2016. S. 241.2(3).
[16] Ibid.

— have repeatedly shown that the legalization of MAID does not put vulnerable residents (i.e., those who are poor, elderly or mentally incapable) at an increased risk of abuse.[17]

However, Bill C-14 contains a number of problematic safeguards that pose negative consequences — some expected and others not — for Canadians who want to access their right to MAID. The problems with the safeguards can be grouped into two broad categories: 1) impacts for individuals who qualify for MAID under Bill C-14's eligibility rules and whose health is extremely fragile; 2) and the impacts of safeguards that, combined with the law's eligibility requirements, function to deny MAID to groups of grievously ill Canadians who might have qualified under *Carter* but who are not imminently dying.

Impacts for individuals whose natural deaths are "reasonably foreseeable"

Requiring patients to consent to MAID immediately before assistance is provided imposes a heavy burden upon dying Canadians who want to exercise the right to choice. The unintended consequences of this rule are explored in a May 2017 paper written by clinicians with Toronto's University Health Network (UHN) and published in *The New England Journal of Medicine*. The article, which shares lessons learned from the first year of the hospital network's MAID program, identifies a stark dilemma posed by the ban on advance requests for assisted dying: "This stipulation… has unintentionally caused some patients to feel pressured to request MAID prematurely or to accept the risk of becoming incapacitated and thereby losing the right to receive MAID."[18] In addition, the authors note, individuals who request MAID while they are actively dying sometimes refuse pain medication — and thus, compromise efforts to control their symptoms — in order to maintain their capacity to consent.[19]

Bill C-14 *does* allow for the 10-day cooling-off period to be waived in cases where the patient's death or loss of capacity is considered imminent. But even with this legally available caveat, the authors' early experiences with MAID have demonstrated "that many patients who request MAID do not receive it because death or loss of capacity supervenes."[20] This reality, combined with concerns about consequences for symptom management, has led the UHN team to the following conclusion: "We have now taken the position in our MAID program that it is neither desirable nor practically feasible for MAID to be delivered on an emergency basis at the very end of life."[21]

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[17] Battin, Margaret P., et al., "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups." *Journal of Medical Ethics.* Vol. 33, No. 10 (2007): 591.
[18] Li, Madeline, et al., "Medical assistance in dying — Implementing a hospital-based program in Canada." *The New England Journal of Medicine.* Vol. 376, No. 21 (2017): 2087-2088.
[19] Ibid., 2087.
[20] Ibid., 2085.
[21] Ibid., 2085.

Independent witness requirement

At least one procedural safeguard in the bill has been found to cause unnecessary delays, creating additional stress for patients who are already at risk of losing capacity. Requiring the signatures of two independent witnesses has emerged as an unexpected barrier to access. In order for a witness to qualify as independent under Bill C-14, he or she must not "know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death."[22] Additionally, individuals who own or operate the facility where the patient resides are prohibited from serving as independent witnesses for MAID, as are health professionals who are directly involved in the applicant's care.

Finding suitable independent witnesses has at times proven difficult. Individuals who are dying tend to have a smaller social circle than those who are in better health. In some cases, the only people they interact with on a regular basis are the healthcare clinicians and support workers who are involved in their care, or close family members who stand to benefit financially from the individual's death. As a result, soon after the passage of Bill C-14, DWDC began receiving inquiries from healthcare practitioners and facility managers who were having trouble finding independent witnesses. The apparent need for independent witnesses prompted our organization to develop a policy that would allow DWDC volunteers to fulfill this statutory requirement. Between Fall 2016, when the policy was approved, and June 2017, our volunteers served as independent witnesses in a total of about 90 MAID cases.

The insights we have gleaned through this volunteer program lead us to conclude that the independent witness requirement in Bill C-14 should be removed or amended. This rule creates unnecessary and unreasonable delays, and it serves as a fundamental invasion of privacy for vulnerable Canadians who request MAID. DWDC questions the utility of asking ordinary Canadians who are not trained to assess for MAID eligibility to sign off on a patient's request. This situation poses security risks not only for the patient, but also for the witness, who may be required to enter a stranger's home to sign the documentation. We also question the appropriateness of requiring grievously ill individuals to share private health information with someone who is potentially a complete stranger. In Canada, individuals have a right to keep their health decisions private, and MAID should be no exception.

[22] Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, 1st session, 42nd Parliament, 2016. S. 241.2(3a).

Impacts for individuals whose natural deaths are not yet "reasonably foreseeable"

A strong majority of Canadians (80 per cent) believe that an individual diagnosed with a grievous and irremediable medical condition should be allowed to make an advance request for MAID that could be honoured at a later date, after the person has lost capacity.[23] Consequently, Bill C-14's explicit ban on advance requests for MAID came as a crushing disappointment for many Canadians, especially supporters of DWDC.

Bill C-14 discriminates against Canadians whose chronic medical conditions rob them of mental capacity as a matter of course. For some, the combined effects of the safeguard banning advance requests and Bill C-14's eligibility criteria mean that they will never qualify for MAID.

Consider, for example, Maria, a 60-year-old woman in the early stages of Alzheimer's disease. Still active in her community, she wants to access MAID in the future — after she has lost capacity but before her condition renders her bed-bound, incontinent and unable to express herself. Aware that making an advance request is not an option, Maria now fears she will never be able to access MAID, despite being competent and having a diagnosis for a "grievous and irremediable medical condition." Because of the nature of her illness, there is a strong chance that the sun will set on Maria's capacity to consent before she reaches "an advanced state of irreversible decline" or before her natural death becomes reasonably foreseeable. In effect, her right to MAID appears to be as out of reach today as it did before the Supreme Court announced its ruling in *Carter.*

Maria is not a real person, but the heartbreaking choices she would face are anything but imaginary for Canadians whose rights have been curtailed by the federal assisted dying law. Our organization is aware of at least four Canadians who travelled to Switzerland to access MAID after Bill C-14 was passed in Parliament. One was John Schreurs, a 54-year-old Ontario man with Huntington's disease, a degenerative condition that gradually immobilizes its victim and eventually erodes their mental faculties as well.

According to his wife, Erin, John decided in Spring 2016 that he was ready to end his own life with a physician's help.[24] At the time, the *Carter* ruling was about to come into effect, instilling John with the hope that he would be able to access MAID at home in Canada. Ostensibly eligible under the *Carter* rules, John soon learned he would no longer qualify for MAID with the passage of Bill C-14. Four separate doctors, all of whom were supportive of

[23] "8 in 10 Canadians support the right to advance consent for assisted dying." *Dying With Dignity Canada.* Feb. 11, 2016. http://www.dyingwithdignity.ca/advance_consent_assisted_dying_poll.
[24] Harris, Kathleen. "Frustrated widow wants Liberals to expand assisted dying rules two years after landmark decision." *CBC News*. Feb. 7, 2017. http://www.cbc.ca/news/politics/assisted-death-carter-schreurs-1.3970804.

his wish for MAID, determined that his death was not reasonably foreseeable.[25] John's suffering, along with the prospect of losing the capacity to consent, motivated him to travel in September 2016 to the Dignitas clinic near Zurich in order to access assistance in dying. His family's journey to Switzerland, it should be noted, came after John made unsuccessful attempts at suicide.[26]

Without the option to make an advance request for MAID, Canadians in John's position face a "cruel choice" similar to the one that led the Supreme Court to decriminalize assisted dying in the first place.[27] They may languish for months or years in the very same state of intolerable suffering that they desperately sought to avoid. They may end their own lives in a violent manner, potentially traumatizing their loved ones as well as the first responders who are called to the scene. Those who can afford it may choose to travel overseas, spending tens of thousands of dollars, as John did, to access a right that should be available at home.

Stories such as John's lead us to conclude that the ban on advance requests violates Canadians' *Charter* rights and the spirit of the *Carter* ruling. And unless federal lawmakers address this fundamental flaw in Bill C-14, we believe the law will remain vulnerable to constitutional challenges.

Structural barriers to access

Observers cannot at this point know the true scope and scale of the structural barriers to MAID access that exist one year after the passage of Bill C-14. However, it is already apparent that these barriers do exist, they are numerous, and they have created a landscape in which MAID is much less accessible to some Canadians who qualify under Bill C-14 than it is for others.

Public healthcare facilities that ban MAID on-site

One major barrier to access is the spate of public hospitals across Canada that refuse to allow the provision of MAID on their premises. These are facilities that accept taxpayer funds to provide public healthcare in communities across the country. Many but not all of these facilities cite their religious affiliation and principles as their motivation for banning MAID on-site. Some represent the only public hospital in the region they serve, meaning

[25] Grant, Kelly. "Group of assisted-death providers publish clinical-practice guidelines." *The Globe and Mail.* June 2, 2017. http://www.theglobeandmail.com/news/national/group-of-assisted-death-providers-publish-clinical-practice-guideline/article35192103/
[26] Harris, 2017.
[27] Carter v. Canada (Attorney General), 2015, Para. 13.

that an individual who requests an assisted death in one of those facilities would potentially have to leave their community in order to access MAID in an institutional setting.

Without comprehensive national data, it is impossible to assess the total effect of these institutional bans on MAID. That being said, early reports demonstrate that these prohibitions have subjected Canadians at end of life to unnecessary delays and gruelling patient transfers. In the most dramatic cases, these prohibitions result in a denial of care for individuals who have requested MAID.

A case last year in British Columbia has shed light on the harms of allowing public hospitals to ban the provision of MAID on their premises. An 84-year-old former accountant, Ian Shearer was dying of sepsis and suffering severe pain as the result of spinal stenosis when he made a request for MAID at St. Paul's Hospital in Vancouver.[28] Because the provision of MAID is not allowed at St. Paul's, Shearer had to be transferred to Vancouver General Hospital in order to fulfill his wish to die with the help of physician. According to Shearer's daughter, Jan Lackie, the transfer was excruciating. She said her father "yelled out in agony" when he was lifted from his bed at St. Paul's. Shearer "cried out going over every single bump" during the four-kilometre ambulance ride to Vancouver General, said Lackie, who spoke about her father's experience in an interview with the *National Post.*[29]

There is also evidence to suggest that patients who request MAID in facilities that refuse to allow it sometimes die of natural causes or lose capacity before a transfer can be arranged. A freedom-of-information request filed by Dying With Dignity Canada revealed that an individual who requested MAID last summer in a faith-based public hospital in Ontario was effectively denied their right to choice in part because of the facility's ban on MAID. According to provincial records, the patient at Hotel-Dieu Grace Hospital in Windsor had been approved for MAID and was informed that the procedure could not take place on the hospital's premises. Representatives of Hotel-Dieu Grace asked whether they could transfer the patient to Windsor Regional Hospital, a non-denominational hospital that permits the provision of MAID on-site. However, Windsor Regional refused the transfer, arguing that it doesn't provide MAID to patients who are not its own. The patient withdrew their request after Hotel-Dieu Grace failed to find a non-institutional setting where the provision of MAID could take place and then died in the hospital's care, according to a report in the *Windsor*

[28] Blackwell, Tom. "B.C. man faced excruciating transfer after Catholic hospital refused assisted-death request." *National Post.* Sept. 27, 2016. http://nationalpost.com/news/canada/b-c-man-faced-excruciating-transfer-after-catholic-hospital-refused-assisted-death-request/

[29] "Personal stories shed light on barriers to access." *Dying With Dignity Canada.* Dec. 1, 2016. http://www.dyingwithdignity.ca/personal_stories_go_mainstream

Star.[30] The Windsor case and others like it have drawn fire across Canada, adding fuel to the ongoing national debate about the appropriateness of allowing public hospitals to impose bans on assisted dying.

Additionally, they have begun to spark protest among members of the medical community. Dr. Jonathan Reggler, a family physician in B.C.'s Comox Valley, resigned from the ethics committee of St. Joseph's General Hospital over the facility's prohibition on MAID.[31] (Disclosure: As of June 2017, Reggler is a member of DWDC's board of directors and he is the chair of DWDC's Physicians Advisory Council.) In a resignation letter dated October 18, 2016 and addressed to the hospital's president and CEO, Reggler outlined the harms of requiring individuals at end of life to leave the hospital in order to access their right to MAID:

> "Even a patient so ill that they would, under different circumstances, be deemed unfit to be transferred must submit to an uncomfortable and unnecessary ambulance journey accompanied by distressed family members. In the case of patients who request an expedited medically assisted death due to the extremity of their condition, the delay caused by the need to make the arrangements for transfer may be sufficiently great that the patient loses legal capacity and thus, their right to a medically assisted death. This is the cruellest hospital policy that I have ever encountered in over thirty years of medical practice. St. Joseph's motto 'Care with Compassion' rings hollow now."[32]

Access to providers and physician referrals

Whether Canadians have timely, fair access to MAID in the future will depend significantly on the individuals who are the gatekeepers of public healthcare in this country. Medical doctors and nurse practitioners are the only healthcare professionals permitted under Bill C-14 to conduct assessments for and provide MAID. Consequently, their participation in MAID — or lack thereof — will inevitably have an impact on the availability of MAID to residents in their local communities.

Though comprehensive national data on how many physicians and nurse practitioners are involved in MAID are not currently available, the rate of participation appears to be extremely low. In February 2017, a provincial referral list of Ontario doctors who could be

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[30] Jarvis, Anne. "Searching 'along the 401' for a place to die." *The Windsor Star.* Feb. 17, 2017. http://windsorstar.com/columnists/jarvis-searching-along-the-401-for-a-place-to-die

[31] Hager, Mike. "B.C. doctor takes stand against Catholic hospital's assisted dying policy." *The Globe and Mail.* Oct. 18, 2016. http://www.theglobeandmail.com/news/british-columbia/doctor-takes-stand-against-catholic-hospitals-assisted-dying-policy/article32436426/

[32] Reggler, Jonathan. Letter to Jane Murphy. Oct. 18, 2016.

called on to provide MAID listed only 30 names, according to records obtained by the *National Post*.[33] An additional 107 physicians and nurse practitioners had indicated that they could be called upon to provide assessments for MAID but were not willing to administer life-ending medication. These figures do not reflect healthcare professionals who participate in MAID but have chosen not to add their names to the referral list. Nevertheless, the dearth of healthcare practitioners on the referral list represents a major potential barrier to access in Ontario, Canada's most populous province and one of its largest by land mass.

The consequences for rural and remote communities are of particular concern. In late March of 2017, France Gélinas, a Member of Provincial Parliament and health critic for the Ontario New Democracy Party, told a legislative committee that none of the physicians and nurse practitioners on the referral list resided in the North East Local Health Integration Network (LHIN), an administrative region covering 400,000 square kilometres in Ontario's mostly rural north.[34] The LHIN's geography already poses significant challenges in terms of access to healthcare; the existing gaps will only be compounded in the context of MAID unless more physicians and nurse practitioners in the LHIN opt to participate in this service.

Whether an individual can access MAID also depends on how their request is handled by the attending doctor or nurse practitioner. In Ontario, physicians who refuse to participate in MAID are required by regulation to, in a timely manner, provide the patient with an "effective referral" to a medical practitioner or agency willing to facilitate the request. The College of Physicians and Surgeons of Ontario (CPSO), the province's medical regulator, implemented the policy to ensure that doctors who conscientiously refuse to provide MAID "do so in a manner that respects patient dignity" and that does not unfairly impede patient access to MAID.[35] Similar policies are in place in at least two other provincial-territorial jurisdictions.

The CPSO's policy on effective referral has come under fire from a group of religious doctors who oppose MAID. In June 2016, the Christian Medical and Dental Society of Canada filed a court challenge against the referral requirement, arguing that it violates their *Charter* right to freedom of religion. In response, the CPSO has committed to

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[33] Kirkey, Sharon. "'Take my name off the list, I can't do any more:' Some doctors backing out of assisted death." *National Post.* Feb. 26, 2017. http://nationalpost.com/news/0227-na-euthanasia/

[34] Canada. Legislative Assembly of Ontario. Standing Committee on Finance and Economic Affairs. *Minutes of Proceedings.* 2nd Session, 41st Parliament, Mar. 30, 2017.

[35] "Medical assistance in dying." *College of Physicians and Surgeons of Ontario*. June 6, 2016. http://www.cpso.on.ca/Policies-Publications/Policy/Medical-Assistance-in-Dying.

"vigorously defending patients' rights to access care."[36] The outcome of this case promises to have major implications for assisted dying access across Canada.

Dying With Dignity Canada supports the CPSO's position and acted as an intervener in favour of the defence when arguments in the case were heard in court in June 2017. We believe that the effective referral requirement strikes a suitable balance between a physician's right to conscientious objection and a patient's right to care. The policy takes into account the fact that the Ontarians who are eligible for MAID and wish to access it are among the province's most vulnerable patients. It is unreasonable to expect these individuals — those who are approaching end of life, are suffering intolerably and may be severely physically compromised as a result of their medical condition — to strike out on their own to find a provider or agency who will handle their request. Refusing them an effective referral may lead to a denial of care.

Collecting and reporting national data on MAID

On April 26, 2017, the federal government released a report containing initial findings about the implementation of MAID in Canada in the first six months after the passage of Bill C-14.[37] This interim update revealed a number of inconsistencies and deficiencies in how national data about MAID are being collected.

Currently, the federal government is collecting basic MAID data from the provinces and territories. We know how many individuals received an assisted death in the first six months after Bill C-14 was passed, we know the gender and the average age of those individuals who accessed MAID, and we know their general underlying medical conditions. However, more needs to be done to ensure that reporting for MAID is consistent from one province or territory to the next. We can see in the interim update that some provinces, such as Alberta, Saskatchewan and Manitoba, are collecting more detailed MAID data than other provinces are. For example, while Ontario and B.C. reported the total number of MAID deaths within their respective jurisdictions, the Prairie provinces are reporting that figure along with the total number of MAID requests that took place and the total number of requests that had been declined. Ontario and B.C. must take steps to bring their reporting measures in line with the Prairie provinces' while the federal government prepares its national framework for MAID monitoring.

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[36] "CPSO defends patients' rights to access health services." *College of Physicians and Surgeons of Ontario.* June 13, 2017. http://www.cpso.on.ca/Whatsnew/News-Releases/2017/CPSO-defends-patients%E2%80%99-rights-to-access-health-ser.

[37] Canada. Health Canada. *Interim update on medical assistance in dying in Canada: June 17 to December 31, 2016*, 2017. https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html.

Fortunately, the federal government has committed to developing a national monitoring framework in order to more adequately collect and track MAID data. According to the interim update, the federal monitoring structure will report relatively detailed information, including "findings regarding the application of the eligibility criteria and safeguards."[38] This data will come from the physicians, nurse practitioners and pharmacists involved in the provision of MAID, who will report the information either to their respective provincial-territorial authorities or to Health Canada directly. The government has also committed to asking for the public's input in the shaping of the draft regulations. This is a positive step.

DWDC will be looking closely to see if the new monitoring system will make it possible for us to accurately assess how the eligibility criteria and safeguards are affecting Canadians who request MAID. Major gaps in our current understanding include the reasons why certain people are being denied MAID. Are people being denied because their deaths are not "reasonably foreseeable?" Are they not in an "advanced state of irreversible decline?" At the moment, we do not have the answers.

Currently, we are also left in the dark about other outcomes that can arise after a person requests MAID and is approved. How many people are withdrawing their requests after being approved for MAID? How many have died of natural causes after being approved for MAID? Are some losing capacity while they're waiting to be assessed or for their application to be signed by an independent witness? What is the impact for patients of allowing public healthcare facilities to ban MAID on their premises? These are vital public policy questions, and they must be reflected in the national system for collecting and reporting data about MAID.

Looking ahead

One year after the passage of Bill C-14, we continue to learn more about how the law empowers and, in some cases, obstructs Canadians who want access to a full range of end-of-life choices. However, we can say with confidence that the promise of a Canada that fully respects residents' end-of-life rights — a promise that was made when the Supreme Court delivered its earth-shaking decision in *Carter* — has yet to be realized. We believe that destination is on the not-too-distant horizon, but we fear we will arrive there too late for people in our movement for whom time is of the essence.

[38] Ibid.

As our understanding of Bill C-14 deepens, we will continue to identify opportunities to bring our country closer to fully respecting Canadians' right to MAID. The *Lamb* challenge, along with a similar court action launched in Quebec, represents a promising path toward restoring the eligibility rules laid out in *Carter.* We will be following developments in these cases very closely and will be looking for ways to support the plaintiffs in their bid to defend their own *Charter* rights and those of all Canadians.

Changes to Canada's MAID rules could also come through federal legislation. A clause in Bill C-14 required the federal government to commission independent reviews into the future of the right-to-die law. Six months after the legislation passed in Parliament, federal leaders announced they had tapped the Council of Canadian Academies (CCA) to study the possible expansion of Bill C-14's eligibility criteria to include three groups who don't qualify for access under the current rules: mature minors; individuals whose primary medical condition is a mental illness; and individuals who will continue to be excluded unless the law is changed to allow for advance requests for MAID.[39] The three working groups, composed of a total of more than 40 experts in the fields of health, ethics and law, have already begun their work and are scheduled to submit their findings to the government by the end of 2018.

It's not yet evident whether ordinary Canadians whose rights are being violated will be consulted as part of these studies. Omitting their perspectives could damage the credibility of the committees' research in the eyes of our supporters. Also of concern is the fact that government leaders explicitly asked the CCA working groups *not* to include recommendations for legislation in their final reports. This directive raises serious questions about the sincerity of the federal Liberals' commitment to respecting Canadians' right to a peaceful death.

Finally, another opportunity for change has presented itself in the province of Quebec. In March 2017, provincial Health Minister Gaétan Barrette revealed that a panel of experts would be tasked with studying the possibility of opening up Quebec's MAID law to allow for advance requests.[40] This announcement is significant in part because of the province's track record on the MAID file. In June 2014, months before the Supreme Court heard arguments in the *Carter* case, members of Quebec's National Assembly voted 94 to 22 in favour of approving Bill 52, a law that allows terminally ill Quebecers to end their own lives

[39] Laucius, Joanne. "Reviews on expanding assisted dying to mature minors, those with mental illness, to begin in new year." *Ottawa Citizen.* Dec. 27, 2016. http://ottawacitizen.com/news/national/reviews-on-expanding-assisted-dying-to-begin-in-the-new-year.
[40] Woods, Allan. "Quebec considers assisted death for dementia patients." *The Toronto Star.* Mar. 4, 2017. http://www.thestar.com/news/canada/2017/03/24/quebec-considers-assisted-death-for-dementia-patients.html.

with a physician's help.[41] The law positioned Quebec as a national leader in the field of end-of-life choice — a tradition that continues with the launching of the study on advance requests.

For DWDC's part, keeping up with the assortment of court cases, academic studies and parliamentary debates that have been sparked by the passage of Bill C-14 has been both challenging and rewarding. Further complicating our work are the obstacles facing Canadians who qualify for MAID under the federal rules and who want to exercise their rightful choice. Structural barriers to access include but are not limited to: public healthcare institutions that refuse to allow MAID on their premises; physicians who oppose MAID who refuse to refer patients who request it to a willing provider or referral agency; and a lack of supports for healthcare practitioners who want to include MAID as part of their practice. Addressing these concerns is as much a part of our human-rights advocacy work as our efforts to push for eligibility rules that respect the *Charter* and the Supreme Court's decision. After all, if we as an organization are to live up to our commitment to *putting the person first,* then we cannot act in the interest of only one group of Canadians whose right to choice is at risk. We must act to defend them all.

[41] "Quebec passes landmark end-of-life-care bill." *CBC News.* June 5, 2014. http://www.cbc.ca/news/canada/montreal/quebec-passes-landmark-end-of-life-care-bill-1.2665834.

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