



Commentary

February 2020

The Bed We've MAiD: Moving Too Quickly and Without Evidence Down the Path of Medical Assistance in Dying

Harvey Schipper

We are now over five years since the Supreme Court of Canada decision *Carter v Canada* was released. That decision created a narrow legal opening in the otherwise absolute prohibition of actively ending a human life for certain medical conditions, allowing for a procedure that has come to be called Medical Assistance in Dying (MAiD).

The Supreme Court decision required a parliamentary response. The result, one year later, was Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. Since that date, around 7,000 Canadians have ended their lives through these provisions.

Legal action to further broaden eligibility criteria continues, most recently in a Quebec Superior Court decision, *Truchon*, which removes the provision that death must be “reasonably foreseeable,” which had been included in Bill C-14.

Neither the provincial nor federal governments saw fit to appeal that single judge decision. Government was given three months to respond with amended legislation. In addition, we are fast approaching the five-year review mandated by legislation when presently excluded provisions, including advance directives and extending access to MAiD to mature minors and those with mental health issues as the sole illness, are to be re-considered.

The author of this document has worked independently and is solely responsible for the views presented here. The opinions are not necessarily those of the Macdonald-Laurier Institute, its Directors or Supporters.

We should reject calls to expand MAiD, particularly since we do not yet understand what we are dealing with. We are moving too quickly, without evidence or understood experience, down a pathway of immense societal consequence.

What is posited as a simple question – namely an individual’s, ostensibly autonomous, right to end one’s life on one’s own terms – is not that simple. Its ramifications extend across society.

How do we protect the vulnerable? How do we know that when MAiD is offered and provided it fully meets what inevitably must be stringent requirements? What does it mean to be a healer, physician, nurse, or alternative health provider who is involved in a medically assisted death? Where do we prioritize our resources and energies in the provision of health and the fostering of a quality life? What are the moral and ethical principles that underlie our social norms, behaviours, laws, regulations, even traditions? How do we value a life?

In 2014, as a cancer researcher, administrator, and physician, I wrote an opinion piece for the *Globe and Mail* (Schipper 2014) in anticipation of and well before the Supreme Court *Carter* decision. I made the point that if we properly understood and paid attention to patients’ suffering, we could relieve it almost all the time. Almost all the time, not always. To do so, we had to take the time to understand that suffering is not necessarily physical pain. It can be loneliness, fear, psychological distress, even the inability to say goodbye.

My contention was, and remains, that there can be no perfect solution to relieving all suffering, including the active ending of a life.

I cited the large historical experience which culminated in the Nuremberg Trials at the end of the Nazi era. It is the slippery slope concern. It is real. It is bioethics 101. That was prescient, as the recent *Truchon* case from Quebec amply illustrates. Now, it appears, death does not even have to appear reasonably foreseeable for one’s life to be terminated. We are down the slippery slope.

We have entered uncharted territory, and therefore must proceed cautiously, with great attention to the detail of each and every instance. The fact is, despite frequent statements in the press that this is an emerging worldwide trend, fewer than two percent of people in the Western world live in jurisdictions that permit what we have come to call MAiD. The work of the Council of Canadian Academies (CCA 2018) Expert Panel documented that there is very little lived experience to go on.

If MAiD is to find a proper place in our society, we are going to have to address the fundamental challenges described in the sections below.

Misleading simplicity

Relieving unendurable suffering, with no end in sight, would seem intuitively obvious. It makes a brilliant and effective sound bite. The legal pathway to MAiD is built on cases that appear quite straightforward, usually a nasty neurodegenerative disease leaving a fit mind trapped in a frozen body.

“ We have entered uncharted territory, and therefore must proceed cautiously, with great attention to the detail of each and every instance.”

Such records as we have from Canada and elsewhere show that most requests for MAiD come from those with other conditions, such as cancer or heart disease. Often there are multiple co-morbidities. If the neurodegenerative disease is straightforward, most others are not. What motivates someone who has heart disease, some arthritis, difficulty hearing and seeing to seek MAiD? Is it the sum of small infirmities, and have these been addressed?

I clearly recall patients seemingly depressed, perhaps considered demented, and who, in current days, might request MAiD. After their poor hearing and retinal disease were treated, they returned to apparent vibrant normality. In other words, the neurodegenerative diseases, for all their clinical horror, are not representative of those who seek MAiD.

At the bedside, the experience seems to be that the vast majority of patients who open the conversation, in the end, do not receive MAiD. Often the consultation uncovers roots of suffering that were neither appreciated nor attended to beforehand, and now could be mitigated. Recent data from Oregon and Washington show that even among those who actually take possession of the lethal drugs, many do not use them (Al Rabadi, LeBlanc, et al. 2019).

There is another common clinical experience. It appears that the public in general and patients in particular are confused by the MAiD issue. I have encountered many who believe that MAiD is about the right to have a voice in their care, to refuse further treatment, or to request palliative care. They expect and want that. They misunderstand that these rights are long established. When we separate out that misunderstanding, often the conversation changes.

I have also had the uncanny and repeated experience, including during my work as a member of the Council of Canadian Academies Expert Panel, that people who start the conversation quite favourably disposed to MAiD often evolve into having serious misgivings when confronted with the complexity of the issue. This is not to say that the view swings from “yea” to “nay.” Rather it speaks to a desire for deep and detailed learning and great caution.

Divergent epistemologies

I introduce this arcane term because the irreconcilable differences between ways of thinking, the evaluation of evidence, and the making of rules are at the heart of the MAiD debate. Epistemology is the study of knowledge: What is it, what is its structure and limits, what is its language, what do we count as evidence?

In the MAiD debate, we face several structures of knowledge and evidence: medical, legal, and sociological, to name but three. The approaches are divergent, if not in direct conflict. What may be evidence in one framework may not make much sense in another.

For example, a lawyer looks backwards from the safety of retrospect and bases decisions on both black letter law and prior opinion or precedent. Precedent may not make much sense to a clinician at the bedside, who must make forward-looking decisions amid uncertainty.

The defining paragraph of the *Carter* decision reads:

...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. (*Carter v Canada* 2015, emphasis added)

As black letter law, this is clear. However, the clinical reality is that each of the highlighted terms is ambiguous, context dependent, changeable from moment to moment, and not measurable against any valid scale. As an example, “clearly consents” depends on the individual’s capacity to consent. Even simple words such as “capacity” are understood profoundly differently.

From a legal perspective, capacity is a binary state, you have it or you don’t. Yet, a physician or psychologist or public school teacher knows that capacity is highly context dependent and that different levels of capacity are required to make different types of decisions. In fact, we know very little about capacity when people are suffering unbearably.

Research commissioned by the Law Commission of Ontario revealed there to be little if any robust understanding of the capacity to consent in the face of severe suffering (Cartagena, Thompson, et al. 2016). Just imagine being asked to make a very nuanced assessment of your risk and prognosis while writhing in pain, having just been hit by a truck or in the middle of a heart attack. Nowhere is that considered. Yet capacity to consent is fundamental to the entire MAiD process.

It can be subtler than that. I was asked to see a patient of advanced age who had had a fall. There were no other significant medical issues. The patient wanted MAiD, and in the eyes of all who were present, the conversation was lucid and consistent. It turned out the patient had a large subdural haematoma, a slow bleed onto the surface of the brain that gradually squeezed the brain within its bony box. A neurosurgeon convinced the patient to have the haematoma drained, a simple procedure. A few days later when the topic of MAiD came up, the patient said that could not have been proper thinking on her part: “My brain was not working properly, and it is now fixed.”

Every black letter word in the defining paragraph of *Carter* is ambiguous to the bedside clinician, the patient, and those in the circle of concern. What is grievous? What is irremediable? What is suffering? Medicine, under the rubric of science, views prior opinion as low-quality evidence. Yet it is the bedrock of legal reasoning.

I was once asked how Bill C-14 influenced me at the bedside. My answer was, it doesn’t. I am bound by the Hippocratic Oath. I am bound in my obligation to my patient, and to the preservation of life and its dignity. I am a healer. It is not my job to parse the law at the bedside. Decisions at the bedside are not a matter of “settled law.” That is language divorced from its proper context.

Pierre Trudeau famously said that “government has no business in the bedrooms of the nation.” He was talking about epistemologies of moral conduct, which ought not be forced into a legal framework. The same may be true here. Which is to say that until the languages and evidence structures of the diverse professions intent on focusing on the active ending of life can come to much more than a superficial understanding of fundamental principles, we ought to move very cautiously.

“What is grievous? What is irremediable? What is suffering?”

Assertions of moral “neutrality”

There is a moral confusion in the legal framing of MAiD. What is posited as “neutral” is not. It is a decided point of view. The moral value is autonomy, and individual autonomy at that. That derives from the *Charter of Rights and Freedoms*. It is posited as a kind of “pure,” values-independent construct. It is a secular notion, a counter-cultural response, perhaps, to what some would consider a too powerful Church in earlier times. The only values are my values, inchoate, often not articulated, and independent of anyone else’s or the society at large. It dismisses community, and the web of connections that build a diverse, tolerant society. Without saying so, it privileges a single value.

That narrow conception in the *Charter* may have been of inestimable value in attempting to rebalance what can be the oppressive power of the state. Not so at the bedside, where it resonates across the society, from concern about families, to the allocation of scarce health resources, to the direction of research and the training of healers. The application is overly broad. Section 1 of the *Charter* balances individual autonomy against the need for a cohesive collective reality as well. If MAiD only affected the sufferer at the centre of the discussion, one could feel comfortable. But it does not.

A simple question: Can one name a stable modern society in which its core societal values do not derive from faith? That is not to say that religious entities have not from time to time ignored their own professed values, been corrupted or downright evil. In fact, we have been most contemptuous of religious orders that have acted in disregard of their principles, abusing their flock. In a way that may explain why we have excluded the faith voice from the MAiD discussion. But the worldly corruption of institutions is quite different from their underlying moral codes. We confuse human failings with the deep structures faith may teach.

My large and growing regret about the MAiD conversation has been the exclusion of that voice. Not because it should dominate, but to provide balance.

The libertarian, highly individualistic view has been well and capably represented, in the report of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (Ontario 2015) and the CCA Expert Panel Report. The other end of the spectrum was systematically excluded. The clergy have deep experience across the arc of life, especially during times of trouble, including the end of life.

Within denominations, their views are diverse, even competing. In many ways, from my conversations, faith voices allowed themselves to be cowed, regrettably. In the CCA process, they were invited to provide written submissions, but they were not at the table. The only spiritual voice that was drawn into the conversation has been that of our First Nations. If Canada is to come to some accommodation about a role for MAiD, then moral voices have to have equitable standing.

What is to be allowed in MAiD is entirely driven by values – not science, not technology, not even evidence, but the moral code of each participant. There is no new technology involved.

“What is posited as “neutral” is not. It is a decided point of view. The moral value is autonomy, and individual autonomy at that... If Canada is to come to some accommodation about a role for MAiD, then moral voices have to have equitable standing.”

Zealotry

The root ethos of medicine has always been to relieve suffering while preserving life. The legalization of active euthanasia changes that. The new ethos would be, I may ease your suffering by ending your life.

As one distinguished palliative care physician who has provided MAiD commented: “Before MAiD was available, there was greater focus on suffering relief. After C-14, there was less pressure to relieve suffering and more to do what the patient wants.” The more one contemplates that, the more consequential it becomes. This is not simply an individual autonomy question. It cuts to the root of societal values. Does it mean that we will come to choose our physicians by their willingness to include euthanasia as a therapeutic option?

How does that translate at the bedside? Let’s be clear, no medical advice in the MAiD context is values free. However attentive to unpacking the roots of a patient’s suffering, physicians who take a more liberal view of relieving suffering by ending life, in subtle ways at least, will communicate differently than those whose perspective is more restrictive.

In the Hippocratic tradition, he or she can begin the painstaking task of unpacking the roots of the suffering in order to mitigate the perceived need to die. Their frame of assessment will be to take a holistic view of the patient’s overall circumstance, and present MAiD as a last option, having carefully and laboriously considered and tried the options. On the other hand, as things currently stand, if a patient meets current (shifting and imprecise) regulations, a provider strongly disposed to providing MAiD is able to tick the procedural boxes and proceed.

What we are really talking about is trust in the most intimate and consequential of matters. There is no way that a patient, when facing a serious medical decision, can muster the knowledge and necessary objectivity to be on equal terms with the physician, in strictly medical terms. The physician’s role is to provide care, to relieve suffering in a way that brings together the physiologically doable with the humanly possible.

A physician’s obligation is to consider the full range of possibilities, take account of the patient’s condition, and suggest an approach. The patient makes the choice. However, it is in the connection with the patient and the presentation of the options where the imbalance of knowledge and dispassion come to the forefront.

There is a vital distinction between advocacy, in this case for broadened access to MAiD, and the clinical provision of the service. Advocacy requires focus and determination. There is a need to render complex issues simple so that decision-makers understand. Complexity and nuance can come later, after the goal is reached. That leads to the well-trodden path of first seeking a narrow application, and then widening the avenue.

When that distinction is lost, advocacy edges on zealotry. Nuances and complexity are set aside, countervailing concerns and evidence ignored or dismissed, displaced by a faith that the core principles can be more generalized.

The history of medicine is rife with such stories. As I am an oncologist, my benchmark story takes place in the 1990s. In the 1980s, there was a belief that high-dose chemotherapy leading to bone marrow transplant would save the lives of women with high-risk breast cancer. There were passionate medical advocates, arguing on theory and belief. There was public demand.

“What we are really talking about is trust in the most intimate and consequential of matters.”

The scientific establishment urged study and confirmation before widespread use. The advocates countered that in face of strong theoretical evidence and belief, such trials would be unethical, for the outcome was obvious and pre-ordained. The advocates then turned to the legal system, and, using argument similar to that in *Carter*, forced providers and insurers to provide the procedure. By then, 95 percent of marrow transplants performed in the United States were for breast cancer.

When, after years of political manoeuvring, four clinical trials were conducted, the results were deeply sobering. Three of the trials showed that those who received the treatment did worse. The fourth trial, published as a positive outcome, was quickly shown to be overtly fraudulent.

The cloud hangs over cancer treatment to this day. We can all think of circumstances when our intuitive enthusiasm gets ahead of us only to cause later regret.

Who should be the providers of MAiD?

I recall a day in medical school when, at the end of a physiological experiment on an anaesthetized dog, it fell to me to euthanize the animal with a dose of opioid. It left me with a lingering strange sensation, almost euphoria. Years later, in the MAiD context, I've been part or read of conversations with MAiD providers who speak of a great sense of peace, perhaps even a special gift or euphoria, that they experienced in providing MAiD.

I juxtapose this to conversations with cutting-edge clinicians who speak of the thrill of taking the highest risk patients to the edge of possibility in a new surgical approach or therapy. They have a drive, and express euphoria too. But, and this is the important distinction, their euphoria is tempered by the real chance of getting it wrong and the haunting fear and dismay that follows failure. There is no such tempering with MAiD provision.

How do we choose MAiD providers? At present it amounts to self-selection. Yet, for this most irreversible and counter-traditional role, how are we to be assured that providers have the expertise and psychological sophistication to assume this role? How do we ensure that MAiD is a carefully considered option among several, and given the sanctity of life as held by the medical profession, that it be held out as a last resort?

Put another way, is MAiD to be a singular exception to the practice of medicine, or a normalized one of the options?

There is accumulating data from the Low Countries that this concern is real (Lemmens 2018). If our society is to have confidence in its active euthanasia processes, this selection must be rigorous. It is not now.

Moreover, what is the process of oversight? At present we have an oversight and enforcement problem. The penalty for wrongful provision of MAiD falls back to the criminal code into the realm of "murder." Perhaps in some cases this will prove appropriate. More likely, and of more consequence, this rash bifurcation prevents the careful analysis of each and every case, making it very difficult to learn from our experience.

“For this most irreversible and counter-traditional role, how are we to be assured that providers have the expertise and psychological sophistication to assume this role?”

If it is the societal view that MAiD is to be the exception rather than the rule, as would appear to be the thrust of both *Carter* and C-14, then the way we motivate providers requires careful thought. The emphasis is on maintaining dignity and relieving suffering, less on the active ending of life. Perhaps we ought to compensate generously for the assessment and evaluation process, and not at all for the relatively simple business of administering the drugs.

MAiD has divided health providers. It is doubtful there will ever be a broadly satisfying resolution simply because it is a values rather than scientific or economic or partisan political issue. From that perspective, health providers are another vulnerable class to consider. *Carter* also made clear:

[132] 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.** (*Carter v Canada* 2015, emphasis added)

To the extent that the eligibility criteria for MAiD are broadened, the provisions for conscientious objection for health providers must also be broadened.

Individual vs collective rights

Lawyers will tell you that the reason we have MAiD in Canada derives from the *Charter of Rights and Freedoms*, specifically section 7 addressing individual autonomy. That is a particular, but not the only, concept of autonomy. Relational autonomy denotes something different. Its premise is that few if any actions are truly autonomous, in that they affect no others. There is a web of relationships and dependencies that is altered.

The large hazard of the individual autonomy argument is the risk of perversion of that autonomy to ulterior purposes. That's the slippery slope argument raising the risks of cost saving, devaluing the disabled, eugenics, and worse. Both the Court and the Legislature considered these downstream implications of MAiD in expressing two important caveats.

The first is that the vulnerable must be protected against abuse. The hazard is that the normalization of MAiD for those with disabilities will relieve the obligation to provide and continue to develop supports for those with disabilities. Moreover, the issue extends well beyond the individual rights of someone with a disability. We have to be very careful about avoiding a negative perception of the value of people with disabilities. That includes the elderly, a growing segment of Canadians. That's us, all of us. This is not readily dealt with by "safeguards" because they are deeply embedded in community values. The balancing of individual and societal rights comes into play here.

Archie Rolland had a slowly progressive neurodegenerative disease requiring substantial mechanical and professional support. He was resident in a Quebec health care facility. Institutional pressures led him to be moved, against his will, to another facility, which could not provide the supports. After an extended period of futile pleading for the care he had previously received, he requested and was provided MAiD.

Likewise, the wrenching recordings of hospital officials in London, Ontario, pressuring Roger Foley, a similar patient, toward MAiD can only be understood as coming from corporate needs to maximize efficiency and optimize expenditure across the system.

In financial terms, it is reasonable to postulate that liberalization of MAiD will save money. In fact, a study reported shortly after C-14 came into effect intended to estimate the *added* costs of MAiD in Ontario, and concluded that liberal use would save between \$34.7 million and \$138.8 million per year (Trachtenberg and Manns 2017). That's in keeping with the long known and accepted fact that the majority of health care costs come in the last five years of life. As our society ages, the pressures to mitigate those costs will only increase, and an argument can be made that the normalization of active euthanasia opens very difficult policy issues.

The second of the two caveats I refer to above is that means must be found to decrease the need for MAiD, expressed in the requirement for better palliative care. Some have taken this to mean, simply, better pain management at the end of life. In reality, it is not so.

As we contemplate loosening the “reasonably foreseeable” condition in C-14, or broach the mental health criterion, the whole argument leaps beyond the bounds of what we think about when we say “palliative care.” That means addressing suffering much more broadly: physical, psychological, social, and occupational. It demands a much deeper understanding of what's happening in our communities.

Thus an overbalanced focus on individual autonomy is likely to have broad societal effects, more extensive than we can anticipate. This is another reason to examine deeply and move slowly.

“ Thus an overbalanced focus on individual autonomy is likely to have broad societal effects, more extensive than we can anticipate. This is another reason to examine deeply and move slowly.”

The myth of efficiency and the pressure to improve

In the early 1960s, pediatric leukemia carried a 95 percent six-month mortality. The prevailing wisdom was to support families and provide comfort for the end of life. A minority of determined physicians, and their brave patients and families, were of a different mind. They subjected very sick children to painful, invasive, and uncertain treatments in an attempt to alter the natural history of the disease. It was expensive, and institutions struggled to justify the costs.

Today, 95 percent of those children are cured. That is the story of modern medicine. The stark face of failure drives us to innovate. To look at euthanasia as a success, even a higher virtue, is to deny the core goals of medicine and society – valued full lives with dignity. Rather, we should view MAiD as a last-option intervention that reflects our failure as caregivers. That sets it in a humbler, more constructive, frame.

It is not “normal,” nor should it be.

Learning from our experience

The Quebec government framed MAiD as a medical treatment. That framework provided the avenue to move in advance of the *Carter* carve-out of the criminal law. New medical treatments require oversight, ethical approval, close monitoring for effects beyond the simple and immediate, and a broad understanding of the context of each case. These days economic and resource factors are also considered. Social impact has become an active consideration.

All that for a drug, or procedure, or even reallocation of resources. None of that is in place for MAiD, a strange double standard. It is tougher to introduce a new antibiotic or diuretic than MAiD.

There are three kinds of evidence relevant to MAiD. The first, and simplest, is *process evidence*. Have the steps been followed by the right people, in the right order, and in a timely and appropriate manner? It is important, but of very limited value. It speaks to propriety and efficiency in an accountant's sort of way. It is also low risk for the overseers. It is currently the only data collected.

The second form of evidence is *context and outcome*. This is tougher, because in the context of MAiD, each player has different understanding of what constitutes evidence. That's the epistemological gulf that is so troubling. That can be solved, over time, by being perhaps overly inclusive.

Here's a minimum. The model from my lived experience is the morbidity and mortality round in a good hospital. It is time consuming, expensive, and anxiety inducing for the participants. There are mechanisms in place to allow errors to be recognized and learned from without purposeless censure. (Parenthetically, it is the process that has driven airline safety.)

For each and every case of MAiD, we ask what was the process, path of engagement, and outcome? What, in rich detail, were the elements of suffering, or fear, or worry that motivated the request, and how fully were those concerns recognized and addressed? Who participated in the conversations, what professionals, who from the patient's circle of caring? What was done to mitigate the desire to die? Where did what we provided fall short? What were the side effects (not just for the patient, because the procedures are simple and well known) for caregivers, for those close to the deceased, broadly understood. What are the consequences of failure? This is the most revealing of evidence.

The third stream of evidence is *epidemiological*. Why has the desire for MAiD come to such public attention? While active euthanasia is only legal in a small number of jurisdictions, polling suggests an increase in support in several Western countries. We ought to understand why.

Our struggle to find an acceptable balance of access cannot be based on either deft legal argument, or skillful advocacy, or values-driven reasoning. This is a public health problem requiring public health understanding. We hear anecdotes citing lack of resources, loneliness and ennui, financial concerns, expressions of a desire for control, and fear, to name a few.

“ It is tougher to introduce a new antibiotic or diuretic than MAiD.

Roughly seven thousand Canadians have chosen MAiD since Bill C-14 came into effect. Had those deaths been from medical errors, or a new infectious disease, or a rash of household fires, we would want to understand those circumstances and mitigate them. Why not with MAiD?

Absent this tripartite level of understanding, implementing a social policy of this magnitude is unconscionable.

Who decides?

Whatever one thinks of the legal march to MAiD, *Carter* and C-14 do represent a balancing of legislative and judicial powers. Along my path of involvement, I interviewed many Canadians, including health professionals, patients, academics, jurists, and politicians. I wanted to understand the roots of the growth of interest in medical euthanasia.

In a paper published in *Health Law in Canada* (Schipper 2016), one of the consistent messages was that politicians wanted no part of this topic. A former political leader said that if the football landed on the desk, it would be punted – and it would be punted far: “There are no votes in this.”

Advocates for MAiD knew this, and accordingly chose the legal route. It was a careful, deliberate, and patient journey. MAiD is now legal in Canada. The balancing of individual and collective rights, and the concerns about the vulnerable were precisely articulated in the Preamble to C-14. The legislation was not buried in some omnibus bill, nor debated briefly, nor without heat. The key departure from *Carter* was, as highlighted:

C-14: **Grievous and irremediable medical condition**

(2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

- (a) they have a serious and incurable illness, disease or disability;
- (b) they are in an advanced state of irreversible decline in capability;
- (c) 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
- (d) 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. (Canada 2016, emphasis added)

Nobody was entirely satisfied. What remains very unclear is what exactly that means: For whom? By whom?

The Quebec Superior Court decision *Truchon* overturned the “reasonably foreseeable” clause as unconstitutional on the grounds it discriminated against the sick. What makes that decision from Quebec deeply troubling is its apparent clever disregard for that balancing of individual and collective rights, along with a subsequent lack of political will to assume what must be a parliamentary responsibility.

A litigator colleague of mine mused that one could perhaps remove all restrictions, on the basis that the existing legislation discriminates against the healthy.

There is a philosophical notion of “the fence within the fence.” It holds that there are certain precepts that are sacrosanct, perhaps like honouring one’s parents. Those precepts are within the inner fence. Between that and the outer fence are issues related, such as how one might express honour, or, in the opposite, reflect revulsion within that frame. You argue around the outer fence. You do not puncture the inner fence, because the consequences may be vast and unknowable.

In a way that's what has happened with MAiD in Canada. It will be years before we make sense of this, for it changes more things than we know. What do those few, critical words in *Carter* and C-14 mean in the real world, among those suffering and those trying to palliate? How does this change the healing professions? How are societal moral principles evolved and reflected?

I have an abiding concern that a narrowly legal approach to this values-based health care problem is dangerous. We have ample experience that misapplying knowledge, evidence, and practice structures from one discipline to another has led to serious policy mistakes, even death and societal breakdown.

Given our laws, I have come to the view that MAiD may well find an acceptable place in care. I don't know what that ought to or will be. Neither does anyone else. What I do know is that we are going to have to learn deeply about misleading simplicity, divergent epistemologies, moral neutrality, zealotry, the balance of individual and collective rights, the tension between efficiency and the drive for progress, the way we accrue learning and use it, and the balance of legislative and judicial powers.

That takes time, and should be done dispassionately, and with ample data to support our actions. It is the fool who races forward with blinders on and passions in full command.

About the Author



Dr. Harvey Schipper is both an engineer and a physician who has combined disciplines to bring innovation to the health and life sciences sector. He brings prescient strategic subject matter expertise to bear on complex problems ranging from legal case management to corporate governance and public policy.

His career has bridged five continents as cancer specialist, innovator, health systems designer, businessman and advisor to government, academe and the corporate sector. As a physician he was Professor of Medicine and Director of the Regional Cancer Care system in Manitoba and has helped design cancer programs around the world. He established the WHO Collaborating Centre for Quality of Life Research in Cancer, which reframed outcome research from tumour focused to patient-centred on a global basis. Later he served as Corporate Vice-President of MDS, a health and life sciences multinational in a strategic portfolio. As Vice-Chair of the Institute of Corporate Directors in Ontario he led the creation of the Not for Profit programs which remain national standard setters. He is currently Professor of Medicine and Adjunct Professor of Law at the University of Toronto.

Over more than 35 years he has helped companies and organizations transition to the emerging health economy. As corporate director or expert advisor, his particular skill has been setting each initiative in the broad context of the health care environment. His work with governments and large health systems focuses on future orientation and transformation.

Out of a long-standing interest in the interface of medicine, law and public policy, he has played a substantive role in critical issues. These include the tainted blood crisis, where he was a Founding Director of Canadian Blood Services, and recently in the deliberations around 'assisted dying', as a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying.

References

- Al Rabadi, Luai, Michael LeBlanc, Taylor Bucy, Lee M. Ellis, et al. 2019. "Trends in Medical Aid in Dying in Oregon and Washington." *JAMA (Journal of the American Medical Association) Network Open* 2(8): e198648. Available at <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2747692>.
- Canada. 2016. *Bill C-14 (Royal Assent)*. Parliament of Canada. Available at <https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>.
- Cartagena, Rosario G., Alison K. Thompson, Kaveh Katebian, Trudo Lemmens, et al. 2016. *Understanding the Relationship between Suffering and Capacity at the End-of-life: A Pilot Study*. Law Commission of Ontario. Available at <https://www.lco-cdo.org/wp-content/uploads/2010/10/Cartagena%20et%20al.pdf>.
- Carter v Canada* (Attorney General). 2015 SCC 5. Available at <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>.
- CCA [Council of Canadian Academies]. 2018. *Expert Report on Medical Assistance in Dying*. Ottawa. Available at <https://cca-reports.ca/reports/medical-assistance-in-dying/>.
- Constitution Act*. 1982. Schedule B to the *Canada Act 1982* (UK), 1982, c 11.
- Lemmens, Trudo. 2018. "Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice." *85 Supreme Court Law Review (2nd)*: 453-539.
- Ontario. 2015. *Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report*. Ontario Ministry of Health. Available at http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf.
- Schipper, Harvey. 2014. "With Assisted Suicide, Context Is Everything." *Globe and Mail*, June 6. Available at <https://www.theglobeandmail.com/opinion/assisted-suicide-context-is-everything/article19012073/>.
- Schipper, Harvey. 2016. "Navigating Assisted Dying." *Health Law in Canada* 36 (February): 120-138.
- Trachtenberg, Aaron J., and Braden Manns. 2017. "Cost Analysis of Medical Assistance in Dying in Canada." *CMAJ: Canadian Medical Association journal = journal de l'Association medicale canadienne* 189(3): E101-E105. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5250515/>.



Critically Acclaimed, Award-Winning Institute

The Macdonald-Laurier Institute fills a gap in Canada's democratic infrastructure by focusing our work on the full range of issues that fall under Ottawa's jurisdiction.

- One of the top five think tanks in Canada and No. 1 in Ottawa according to the University of Pennsylvania.
- Cited by five present and former Canadian Prime Ministers, as well as by David Cameron, the British Prime Minister.
- First book, *The Canadian Century: Moving out of America's Shadow*, won the Sir Antony Fisher International Memorial Award in 2011.
- *Hill Times* says Brian Lee Crowley is one of the 100 most influential people in Ottawa.
- The *Wall Street Journal*, the *Economist*, the *Globe and Mail*, the *National Post* and many other leading national and international publications have quoted the Institute's work.



"The study by Brian Lee Crowley and Ken Coates is a 'home run'. The analysis by Douglas Bland will make many uncomfortable but it is a wake up call that must be read."
 FORMER CANADIAN PRIME MINISTER PAUL MARTIN ON MLI'S PROJECT ON ABORIGINAL PEOPLE AND THE NATURAL RESOURCE ECONOMY.

Ideas Change the World

Independent and non-partisan, the Macdonald-Laurier Institute is increasingly recognized as the thought leader on national issues in Canada, prodding governments, opinion leaders and the general public to accept nothing but the very best public policy solutions for the challenges Canada faces.



About the Macdonald-Laurier Institute

What Do We Do?

When you change how people think, you change what they want and how they act. That is why thought leadership is essential in every field. At MLI, we strip away the complexity that makes policy issues unintelligible and present them in a way that leads to action, to better quality policy decisions, to more effective government, and to a more focused pursuit of the national interest of all Canadians. MLI is the only non-partisan, independent national public policy think tank based in Ottawa that focuses on the full range of issues that fall under the jurisdiction of the federal government.

What Is in a Name?

The Macdonald-Laurier Institute exists not merely to burnish the splendid legacy of two towering figures in Canadian history – Sir John A. Macdonald and Sir Wilfrid Laurier – but to renew that legacy. A Tory and a Grit, an English speaker and a French speaker – these two men represent the very best of Canada’s fine political tradition. As prime minister, each championed the values that led to Canada assuming her place as one of the world’s leading democracies. We will continue to vigorously uphold these values, the cornerstones of our nation.



Working for a Better Canada

Good policy doesn’t just happen; it requires good ideas, hard work, and being in the right place at the right time. In other words, it requires MLI. We pride ourselves on independence, and accept no funding from the government for our research. If you value our work and if you believe in the possibility of a better Canada, consider making a tax-deductible donation. The Macdonald-Laurier Institute is a registered charity.

Our Issues

The Institute undertakes an impressive program of thought leadership on public policy. Some of the issues we have tackled recently include:

- Aboriginal people and the management of our natural resources;
- Making Canada’s justice system more fair and efficient;
- Defending Canada’s innovators and creators;
- Controlling government debt at all levels;
- Advancing Canada’s interests abroad;
- Ottawa’s regulation of foreign investment; and
- How to fix Canadian health care.



CONTACT US: Macdonald-Laurier Institute
323 Chapel Street, Suite #300
Ottawa, Ontario, Canada
K1N 7Z2

TELEPHONE: (613) 482-8327

WEBSITE: www.MacdonaldLaurier.ca

**CONNECT
WITH US:**



@MLInstitute



[www.facebook.com/
MacdonaldLaurierInstitute](http://www.facebook.com/MacdonaldLaurierInstitute)



[www.youtube.com/
MLInstitute](http://www.youtube.com/MLInstitute)

What people are saying about the Macdonald- Laurier Institute

In five short years, the institute has established itself as a steady source of high-quality research and thoughtful policy analysis here in our nation's capital. Inspired by Canada's deep-rooted intellectual tradition of ordered liberty – as exemplified by Macdonald and Laurier – the institute is making unique contributions to federal public policy and discourse. Please accept my best wishes for a memorable anniversary celebration and continued success.

THE RIGHT HONOURABLE STEPHEN HARPER

The Macdonald-Laurier Institute is an important source of fact and opinion for so many, including me. Everything they tackle is accomplished in great depth and furthers the public policy debate in Canada. Happy Anniversary, this is but the beginning.

THE RIGHT HONOURABLE PAUL MARTIN

In its mere five years of existence, the Macdonald-Laurier Institute, under the erudite Brian Lee Crowley's vibrant leadership, has, through its various publications and public events, forged a reputation for brilliance and originality in areas of vital concern to Canadians: from all aspects of the economy to health care reform, aboriginal affairs, justice, and national security.

BARBARA KAY, NATIONAL POST COLUMNIST

Intelligent and informed debate contributes to a stronger, healthier and more competitive Canadian society. In five short years the Macdonald-Laurier Institute has emerged as a significant and respected voice in the shaping of public policy. On a wide range of issues important to our country's future, Brian Lee Crowley and his team are making a difference.

JOHN MANLEY, CEO COUNCIL
