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Navigating “Assisted Dying”

Harvey Schipper

Abstract

Carter is a bellwether decision, an adjudication on a narrow point of law whose implications are vast across society, and whose impact may not be realized for years. Coupled with Quebec’s *Act Respecting End-of-life Care* it has sharply changed the legal landscape with respect to actively ending a person’s life. “Medically assisted dying” will be permitted under circumstances, and through processes, which have yet to be operationally defined. This decision carries with it moral assumptions, which mean that it will be difficult to reach a unifying consensus. For some, the decision and *Act* reflect a modern acknowledgement of individual autonomy. For others, allowing such acts is morally unspeakable.

Having opened the Pandora’s Box, the question becomes one of navigating a tolerable societal path. I believe it is possible to achieve a workable solution based on the core principle that “medically assisted dying” should be a very rarely employed last option, subject to transparent ongoing review, specifically as to why it was deemed necessary.

My analysis is based on

1. The societal conditions in which have fostered demand for “assisted dying”,
2. Actions in other jurisdictions,
3. *Carter* and Quebec Bill 52,

4. Political considerations,
5. Current medical practice.

Leading to a series of recommendations regarding

1. Legislation and regulation,
2. The role of professional regulatory agencies,
3. Medical professions education and practice,
4. Public education,
5. Health care delivery and palliative care.

Given the burden of public opinion, and the legal steps already taken, a process for assisted-dying is required. However, those legal and regulatory steps should only be considered a necessary and defensive first step in a two stage process.

The larger goal, the second step, is to drive the improvement of care, and thus minimize assisted-dying.

The laws of biology can only be understood and obeyed
The laws of man are fungible¹

Introduction

Some Supreme Court decisions can be considered bellwethers. While such a decision may be narrow in respect to a particular point of law, its context and implications may have enormous, and unpredicted societal impact over time. Though they are decisions made at a moment in time, their effects may not become fully apparent for generations, for it is the broad societal response to those decisions which define their impact. As examples, *Dred Scott* (1857), a U.S. Supreme Court decision that held that no African American, whether slave or free, could be a citizen directly catalyzed Lincoln's *Proclamation of Emancipation*. In Canada, the 1970 *Drybones* decision drew on the *Bill of Rights*, reflecting a societal concern that fundamental rights be superimposed on the vicissitudes of the political process. This led ultimately to the *Canadian Charter of Rights and Freedoms*. The longer horizon view of *Morgentaler* (1988) may well be that the legal process has little place in the most intimate issues at the bedside.

The recent Supreme Court of Canada decision, *Carter* may be such a case. It is the first such decision, at a national level, in a common law jurisdiction. In a country in which there is no provision for a death penalty, it explicitly opens a unique legal pathway to ending a life. Moreover, this is not a decision incumbent on a new technology. On the contrary, the proposed methods are old, simple and inexpensive. *Carter* is about shifting societal values. While the legal decision could be argued to have been many years in the making, the intense conversations and soul searching following *Carter* engaging the health professions, faith-based organizations, regulators, human rights activists and federal and provincial governments, to name a few, suggests that like *Dred Scott*, *Drybones* and *Morgentaler*, *Carter* (along with Quebec's *Act respecting end-of-life care*) rather than settling the issue, opens a more far-reaching Canadian values re-assessment.

Judging from media coverage, one might sense broad support for decisions setting the stage for decriminalization of assisted death in what are intended to be very tightly defined circumstances.

The focus now appears to be one of effective implementation: who legislates, who regulates, who decides and who provides the service. However, I think there is another way to look at this. We may be putting the cart before the horse by focusing on legal process to the exclusion of addressing the underlying impetus for the growth of the death with dignity movement. What are the societal conditions that have engendered the decision? Are there historical perspectives which may add value? What is happening elsewhere, and how does our political structure affect the outcome? The decision has serious implications for the practice of medicine. In that respect, those closest to the scene professionally, palliative care practitioners can provide important lessons. Those lessons require articulation and advocacy, because they are relevant across all of the healing disciplines, and by extension to our communities.

The Impact of Social Conditions

The notions “suicide”, and “assisted suicide” are not new. The issue has been debated for millennia. Seneca, Socrates, the mediaeval philosophers, and theologians of all religious persuasions have taken up the debate. Suicide has been seen as honourable, or a legitimate moral choice when faced by the spectre of torture or social degradation, or the ultimate sin. Some commentators offer that transient increase in suicide may follow on stories of notable figures taking their lives. Emile Durkheim’s 1897 “Suicide”² is considered by many the first modern analysis of suicide, and as such is one of the founding documents of contemporary sociology. His model speaks to public perceptions of societal breakdown, loss of a sense of connectedness and intimacy with a community, of loss of individual self-worth, and fear that compassion and succor will be lacking in times of gravest need. The Durkheim model remains deeply influential.

Some will also argue that calls for the legal termination of life, in the face of unrequited suffering,

also are loudest when religious faith is on the wane, for, as those who would make the point have it, absent a belief in some higher being there is no value in the suffering, there is no prospect of peace at the end. The theologians would make two further points. The first is that no person is truly alone. Every person’s being is felt by others, and to unilaterally extract oneself from this subtle web is to weaken the whole community. The argument then concludes that since life is the gift of an unfathomable higher power, for man to take unto himself the power to end life, as an expression of autonomy, is the ultimate act of hubris.

Most enduring, for physicians, is Hippocrates, whose Oath enshrines the notion of physician as healer in the sole interest of the patient. The relationship is characterized as sacred and explicitly proscribes the taking of a life.

I think we are in one of those times. I will go so far as to suggest that if there was one word to characterize why we are in this spot it is “hubris”. Hubris is excessive pride or self-confidence, or in Greek tragedy excessive pride toward or defiance of the Greek gods, leading to nemesis or downfall. Hubris is not synonymous with malevolence. The hubris I speak of is that of good intent.

The Hubris of Medicine

As an engineer and physician I have embraced my professions with great excitement, and practiced medicine for more than four decades with a sense of fulfillment and joy that I can’t imagine in any other endeavour. To receive the trust of the vulnerable and ailing is a great responsibility. To bring modern medicine, an ancient art profoundly influenced by science, to the bedside and the clinic to reverse previously fatal diseases, or prolong life or ease suffering is an inestimable privilege. Our scientific methods and learning have extended lifespans by more than 30 years in a century, improved in a measurable way the quality of life of millions, and spawned technologies which allow us

to see and record phenomena never before imagined. We are beginning to understand the subtle underpinnings of life itself. And yet...I am uneasy. As with many scientific and technologic advances, progress can be a double-edged sword.

Medicine's embrace of Science is full throated, albeit no more so than was the dominance of the Humoural Theory of Galen's time, and other models of medicine we now dismiss as primitive.

Science is a framework for understanding, and a very powerful one. However, it is but a tool. As with any tool, we employ it better when we fully appreciate its properties, strengths and weakness. We need to appreciate its great acuity, and its areas of blindness.

Our model, science, is disciplined observation. It is a rigorous curiosity coupled with dispassionate hypothesis testing. Karl Popper, the noted philosopher of science, devoted a lifetime to emphasizing that science creates models, abstractions of an unfathomable reality, based on observation and testing. Proper science challenges those models. Overturning them in the face of new information is the basis of progress.

However, within the scientific method as applied to human biology lie two fundamental weaknesses. First, science, derived from observational physics, cannot accept what it cannot measure. And it cannot measure what it cannot observe. So we are dismissive of observations and learning from other systems of observation, be it Ayurvedic medicine, or the wisdom of our grandmothers. Medicine dismissed bacteria as the cause of disease until we could see them. Peyton Roos' virally induced sarcoma in chickens was dismissed as an anomaly until we developed technologies to visualize viral changes in the genome. We dismissed as quaint generations of societal observation that adolescent brains deconstruct and re-assemble, leading us to treat adolescent mental illness as adult mental illness in a smaller brain, until the visualization

technologies of the past two decades showed that our grandmothers were right.

Second, science is reductionist. This reductionist property of science, the tool, deconstructs a living person into a series of organs. It emphasizes the physical at the expense of the emotional, spiritual and communal. For many years much of medicine has treated the mind body relationship with deep skepticism.³ The result, translated into a health care system, is fragmentation of care, and a certain abandonment of the whole for the much lesser sum of the parts. It is depersonalizing.

The Scientific Method is good at characterizing independent, linear, dominant forces. It has yet to come to terms with non-linear, interdependent, time and context-variable multifactorial forces that are the hallmarks of biology. Moreover, a first principle of the Scientific Method is to establish an experiment with homogenous subjects, in an environment where all relevant influences are identified and controlled, and in which one variable is changed while we observe what happens to everything else. The Randomized Clinical Trial (RCT) is thus valued highest in the hierarchy of observational evidence. These trials we exalt as our benchmarks mask profound individual differences by resorting to large numbers to see small differences. We then extrapolate to the individual, in some respects, a logical nonsense. Though science is intended as the antithesis of dogma, large clinical trials foster dogma, because they tempt us to dismiss outlying data in a kind of perverse and unintended "law of large numbers".⁴ Whether it be statins, the purported hazards of estrogens, or any other of our numerous medical enthusiasms, we are afflicted by hubris when we forget how ultimate biological understanding is the goal, and that our concepts are but models—transient approximations that are useful for a time. There are many examples of conclusions drawn from clinical research only to be overturned when it is later revealed that

unrecognized characteristics of the illness were unequally distributed in the randomization. The answer is not to abandon trials. Rather, take into account the individual consequence.

Our technological prowess depersonalizes in another way. Machines become the interface between the caring and the cared for. The American surgeon and writer William Nolen⁵ traced the beginnings of this distancing between doctor and patient to the invention of the stethoscope. Before that doctors listened to hearts and lungs by putting their ears to the patient's chest. Now we shortcut the hands-on essence of healing—the physical examination—by feeding our patients through claustrophobic MRI machines. What we have certainly gained in information, we have lost in intimacy and connectedness, and even trust in the most difficult moments.

The obvious power of science in medicine, coupled with our enthusiasm to bring progress to the bedside leads us to overpromise, and all too often under-deliver. However well-intentioned, the daily reports of great breakthroughs are seldom tempered by sober perspective. John Ioannidis, Professor of Health Research and Policy at Stanford has deftly demonstrated that most reported breakthroughs are at best incremental, and translate slowly into clinical reality. So we leave our patients frustrated by the Tantalus' Cup of cure, and figuratively dissociated into their component parts. In their time of greatest vulnerability, it is difficult to find someone who understands the full breadth of the patient's needs and concerns.

Not infrequently our ability to prolong life through supportive technology, such as dialysis and mechanical ventilation, leads to a confusion between the withdrawal of support and the active ending of life. In my interviews with patients and the lay community, quite often they express support for assisted dying because, as they understand it, it will facilitate the withdrawal of life support. It is an important nuance that needs to be addressed.

The Hubris of Government

In the 1870s, Bismarck united the German States, in part with the promise of social welfare. It took the form of pensions. It was a major step beyond earlier models of the social contract that provided physical security in return for loyalty and some form of taxation. With the end of the Second World War, social welfare moved into health, initially hospitals, and then gradually into other elements of health services: physicians, other medical professionals, drugs and disability allowances. Implicit in government's emerging role was a major shift in a very long-standing power relationship—namely, that between the physician and the patient. There was now an intermediary who increasingly assumed authority over both the roster of services provided and the payment mechanism. In the beginning, that worked well. Those who previously could not afford hospital care gained unfettered access, relieving a social inequity. In most of the industrialized world, the provision of at least basic health services became a capstone of the social welfare state. However, the very success of the concept pre-determined its current challenges. Governments found themselves held responsible for what was really an undefined element of the social contract, unfettered access to health care. The promise was perceived as open ended. The reality was unachievable, constrained not least by cost. Politicians have been frozen by the fear that any overt efforts at constraint would render them un-electable. So the rationing has been largely by stealth.

There is a confusion and conflation of intent between two necessarily distinct medical perspectives, that of the population and that of the individual. Government must act in the interest of the population. The individual has, as first priority, personal well-being. It is by definition a continuing tension. The challenge is to align those often opposing imperatives. We have not done that well.

Thus, having with the best of intent and near-sighted enthusiasm, seized credit for health care, governments have not been able to deliver. With little transparency, accountability has been shuffled between levels of government like the proverbial hot potato. The hubristic assertion of Jean Chretien, only a few years ago, that we had, “The best health care system in the world”, and another Supreme Court Decision, *Chaoulli*,⁶ only deepened the concern of many that when the time of need comes, access would be denied.⁷

The Hubris of Institutions

A cynical economist once observed that a corporation is a legally created person characterized by potential immortality and lacking a soul, in other words a Tin Man. It doesn't matter whether it is a for-profit or not-for-profit entity; it is driven by the need to survive. Survival depends on the proverbial bottom line, and that means revenue must at least match expenditure over time. The best way to assure revenue is to satisfy those you serve: customers, clients ... patients. One of the unintended consequences of health insurance schemes, be they public or private, is that they tend to separate the revenue stream from the intended beneficiary, the patient. In Canada, hospital revenue does not follow the patient. It is the result of a negotiation between the health institution and government, the driver being the highest possible throughput for a largely fixed sum. In some jurisdictions, the distancing of accountability from the patient goes even further. There, the CEO is held primarily accountable not to the Board of the hospital, but to the Minister of Health. The result is, at one level, closed wards and expert services rationed well below capacity. At a more profound level, the hospital becomes a body shop where once the immediate physical malfunction is addressed, the patient is trucked out the door in all haste. The notion of “hospice”, caring and the relief of suffering bringing an opportunity for rest and healing is lost. The

population health argument—namely, how best to allocate our limited resources across our entire population—has by stealth, silenced the equal right of individuals to seek the best outcome in their own interest. Government population goals reflected in health institutions whose mission should be primarily individual creates a confusion of purpose that is damaging to all parties. Yet, the institutional confusion is mainstream thinking across the industrialized world. The patient has lost all voice in the place of resort for illness. In times of greatest need this can only contribute to an existential despair.

The Hubris of Individuals and Groups

We now assume good health and long lifespan. While as a society we are only recently embracing health lifestyle changes, the advances in medicine and public health have provided a veneer of belief that our health is very much in our control. We also have a distorted understanding of risk, in particular a tendency to focus risk around an individual adverse event rather than in the context of a broader living experience. There is an emphasis on proportionate risk, losing sight of the absolute risk. Thus a 50 per cent chance of reducing a 2 per cent likely occurrence often weighs more heavily than a 10 per cent chance of a virtually certain adverse effect. More specifically, we believe health system has the knowledge and the technology to provide a full and productive life until we die peacefully at an advanced age. Our relentless drive to define more and more illnesses at the earliest or precursor or purported high risk stages creates a life more focused on avoiding illness than on living. As the 20th Century Austrian existentialist philosopher Martin Buber famously said, “Man plans; God laughs.” So when a less controllable reality becomes manifest, and we become ill, we are often perceived to have failed. When our treatments don't work, we often say, the sufferer, the patient, “failed treatment”. To die amidst suffering is becoming unpardonable.

I do not suggest for a moment that we should be fatalists, accepting all manner of misfortune and suffering as beyond our control. Far from it! But we have become a society of often lonely individualists. The family unit, long the basis of social stability has been dispersed. Though we likely feel the same sense of caring for those closest, the generational changes in lifestyle and our geographic separation have those middle aged and beyond worried that we'll be on our own when we become frail and ill.

It is worth noting that the cases that have driven permissive assisted dying legislation, in Canada and elsewhere, have not been those where death was imminent. Rather they have been in circumstances such as the neurodegenerative diseases where the sufferer fears a long period of disability prior to death. In contrast, palliative care emerged in response to control of pain and suffering, usually related to cancer, where death was presumed close at hand. One thus might argue that the expansion of assisted dying may represent some confusion of intent. Are we easing the suffering of those dying, or are we ending the lives of those who might otherwise live a long time, albeit in difficult circumstances? Or both? If the answer is both, in that it is our autonomous right to control the time of our dying, then why establish narrow criteria at all?

Much of the public discourse takes as a given some commonly accepted definition of “autonomy”. There is none, as I am aware.⁸ Yet such a definition, or at least understanding of the range of definitions is fundamental to the concept of assisted dying, and any legislation or regulation. Clearly, as an example, if autonomy were understood as a person's right to action without regard to others, the practical outcome of any administrative structure would be different than were the definition to expect some accord with the wishes of those who might be affected. I am concerned that neither the public nor our lawmakers are sufficiently aware of this core issue.⁹

Other Jurisdictions

The matter of assisted dying has become, over the past year, a major public discussion in the West. *The New Yorker*, *Newsweek*, and *Time* have weighed in with major reviews. On June 27, 2015, *The Economist* came out boldly in favour, stating on its cover “The right to die: Why assisted suicide should be legal”. Public opinion particularly in Europe and North America has moved toward acceptance. According to Gallup, support for some form of euthanasia in the United States has risen from about 36 per cent in the 1950s to around two-thirds today.

In one form or another, assisted dying is legally enabled in the Netherlands, Belgium, Switzerland, Colombia and six American states, most notably Oregon. Absent specific, and unlikely, intervention at the federal level, it will become legal in Canada within the year. Several other countries such as Australia have bills pending. The Supreme Court of British Columbia judgment in *Carter* provides an excellent review of the landscape at the date of decision.

Of particular note is the suggestion of a relationship between criteria and oversight, and the expansion of completed assisted deaths. There are no published statistics citing the reasons for application to assisted dying assessment processes, which link to the associated outcomes. For example, while the medical diagnosis may be listed, motivating issues such as access to care are not routinely documented. Thus, the information is fragmentary and anecdotal, and not amenable to analysis from a societal and motivational perspective.¹⁰ Nonetheless, it would appear that where the criteria are broadest, the use is growing most. That is not surprising, though the lack of transparency about oversight is troubling for such a new and controversial intervention. The most rapid expansion would appear to be in the Netherlands where, in 2013, 4,829 people

chose assisted suicide, a trebling of numbers since 2002, amounting to about 4 per cent of recorded deaths. In Belgium, Dr. Wim Distelmans is a charismatic advocate for assisted dying, having founded Life ending information Forum (LEIF), and interestingly, serving as Chair of the Belgian Federal Commission on Euthanasia. The criteria in Belgium are broad and particularly focused on individual autonomy. Family members are not necessarily informed that such as process is under way.

Thus, it would be a mistake to conclude that since assisted death provisions seem to be working without much fuss in a few jurisdictions, such as the Netherlands and Oregon, the issue is at least operationally if not morally resolved. There are evident issues of access to appropriate and comprehensive care in all of those jurisdictions. We know something of numbers, but little of circumstances. To pose a plausible question, what ought to be our response if it turns out that lack of access to care is a common basis for requests for “assisted suicide”? What if, as was the case in the 1980s in Canada, the issue is inadequate skill in providing pain relief and supportive care? Clearly both the shorter-term regulatory mechanisms and the long-term solutions require such specific information.

The Supreme Court Decision

As with *Morgentaler* a generation ago, the Court, in *Carter* has vacated in a specific circumstance the general provision against taking a life that is one of the underpinnings of our society. The Court has adjudicated a circumstance wherein the person in question is, for themselves, asking that there be a means by which their earthly life be actively ended, lawfully. You may ask, what circumstances distinguish *Carter* from *Rodriguez*? It is noteworthy that the medical setting is the same—namely, a debilitating and irreversible neurological disease wherein the patient has clearly said there will come a time when they no longer wish to continue what they perceive to be an undignified life suffused with

suffering. The biology is the same. It is the legal construct that has changed.

As cited in the decision, “Trial courts may reconsider settled ruling of higher courts in two situations: (1) where a new legal issue is raised; and (2) where there is a change in the circumstances or evidence that fundamentally shifts the parameters of the debate”. In both *Rodriguez* and *Carter*, the plaintiffs (patients) wanted to have some control over their means of passage, such that they will not find themselves forced to take their own lives *earlier* than would otherwise be the case, because with the advance of their illness they will no longer be physically capable of ending their lives at their own hand. In other words, allowing for some form of physician-assisted suicide/death serves to extend life because it provides a means to alleviate otherwise interminable suffering. The legal argument that followed was built around another fundamental principle of our judicial system—namely, the protection of the vulnerable. In most circumstances, the strictest sanctions against taking a life are an obvious effect of that concept. In *Carter*, that argument is, in fact, inverted. To force an incapacitated person to continue to suffer amounts to an assault on a vulnerable person. To use a term not in the judgment, one might argue it is a form of torture. It was on the basis of this new legal formulation that the Court was able to determine that the blanket, and almost invariably correct, strict prohibition on taking a life was overly broad. Hence, the Court said, the prohibition could be set aside, given specific circumstances.

Much has been made of the decision having been handed down in the name of The Court, rather than the more usual listing of names citing the vote. Some have argued that this represents unanimity, only more so. It is hard to believe that on an issue as delicate and contentious as assisted suicide, the issues were so clear and unambiguous that there was no dissent, no nuance of difference. After all,

Rodriguez was decided at 5:4. The issue is intensely debated in many jurisdictions, and as of this date, only a few have opened the possibility of legal assisted death. A unanimous decision would have had equal legal force.

I suspect something else. Our societal values are legally articulated by our elected governing bodies, who have written laws such that the foundational principles are entrenched by millennial Parliamentary tradition and precedent, and/or the process required to alter them requires much more than simple Parliamentary majority. The role of the Court is to make sure the rules are followed, and measure the law against the Charter.¹¹ Even activist courts are sensitive to the concern that they may be making laws rather than interpreting them.

Carter is a decision at a very high level of abstraction. It has accepted and invoked a novel legal construct to very narrowly permit an exception to the prohibition against killing. That goes to the core of our societal values. The Court has stated what those values are and has reiterated to the legislatures their responsibility to make the rules. As I have come to understand this, what the Court is saying by the format of its decision is that there is no ultimate right and wrong to be discerned here. The positions can never be definitively reconciled. What does matter is that we fully understand what we are doing and take explicit societal responsibility.

The text of the decision makes clear the fundamental conditions that must be met in one compact sentence (emphasis mine) "... for a **competent adult** person who (1) **clearly consents** to the termination of life and (2) has a **grievous and irremediable medical** condition (including **illness, disease or disability**) that causes **enduring suffering** that is **intolerable to the individual** in the circumstances of his or her condition". Later in the text, the following, "**Nothing in this decision would compel physicians** to provide assistance in dying. **The Charter rights of patients and physicians will**

need to be reconciled in any legislative or regulatory response to this judgment".

Those two sentences are the core of the judgment, and each highlighted word, while at first glance definitive, names a foundational issue. Each one will require operational translation. Who is to do the translating, and by what process? How precisely can these foundational terms be articulated, and by inference, how much room is to be left to interpretation? Who are to be the deciders, and with what processes and oversight? Who is to be permitted to act on the decision, and what is to be that process, its documentation, and its nature of indemnity?

Lessons of Palliative Care

Focus on assisted dying as a dichotomous, legal or illegal, matter denies a fundamental reality of the practice of medicine. Physicians take therapeutic responsibility, every day, for decisions whose intent may be to cure or alleviate suffering, but whose outcome is, by way of adverse side-effect, a worsening of a patient's condition, and even death. Hence, the question: what is the intent? Ethicists use the term "double intent" to describe the situation. The "double" refers to benefit versus harm. "Intent" refers to the objective of the treatment. According to this formulation, interventions whose first objective is benefit will be found moral and in keeping with a healer's obligations. Treatments whose intent is specifically to end life by deflecting its natural trajectory are considered a harm, and hence not permitted. We have always used pain relief, sedation, touching, counseling and other treatments to ease one's passage. They work well most of the time. Contrary to public myth, the burden of data says such treatment eases death, but likely does not measurably advance it.

Palliative care physicians are the medical specialty most troubled by the provision of assisted dying. They hew very closely to the distinction between actively ending life, and easing suffering, with the

possible/likely consequence that death will be hastened. This distinction follows rather closely the concept of “Double Intent”, wherein a treatment intended to benefit may cause harm. The therapeutic expression of Double Intent is palliative sedation, a procedure in which a consenting terminally ill adult is heavily sedated to the point of marginal consciousness. Typically, death follows in a few hours or days.

More important, in the eyes of practitioners of palliative care, is their holistic, expansionist view of medicine. Palliative care represents, somewhat paradoxically, a return to the longest held principle of medicine, the relief of suffering as primary intent. The focus is the person, not the disease. Somehow, along the way of our enormous advances in clinical medicine we started treating diseases rather than persons. “Did you see the gall bladder in 103?” was a common sort of discourse among physicians. I also recall being asked to see a patient with an advanced colorectal cancer whose pain was not relieved by radiation delivered by a superb radiation therapist, whose focus was more the disease than the patient. This woman had the face of the tortured. She could not concentrate enough to answer simple questions as she writhed. It had been that way for weeks. I can’t recall why I chose a numorphone suppository, but within 20 minutes her pain had largely dissipated and she reconnected with this world. Years disappeared from her face. She and her family were able to come to terms with her illness, consider treatment options and make plans. In fact, she was able to return to work for a short while, a source of great satisfaction.

Palliative care practitioners had to buck a lot of dogma in order to ease suffering due to physical pain. I well recall the days when giving more than about 20 mgm of morphine every four hours was considered akin to malpractice. Patients might become addicted. Respiration might be compromised. These shibboleths led to some strange public policy moments. Around 1984, Dr. Ken Walker, known

widely as Dr. Gifford-Jones for his popular medical writing, mounted a high profile campaign to legalize heroin. Legislators were in a dither. Pharmacists were concerned about robberies in their stores. I even received a call from a mother worried that such legalization might lead to a rush of street heroin. In the end the legislation was passed, but with an important caveat. It was paired with intense focused education for health professionals about modern, evidence-based principles of pain relief. That came from palliative care. The result was wiser use of effective existing therapy. A few years down the line, heroin was largely phased out for lack of use. Palliative care thinking made that possible.

Lesson number 1:

It’s not the disease, it’s the patient.

I wrote an op-ed in the *Globe and Mail*¹² in advance of *Carter*, taking the position that permitting “assisted suicide” was both unnecessary and wrong. The element that drew the most comment was the anecdote about the young man whose suffering turned out to be caused by a fear that he would not get to see his dog before he died. His apparently intractable pain was relieved when we were able to arrange a hospital visit for the pet. Suffering and loss of dignity are synergistic. Not all suffering takes root in physical pain. What great palliative care teaches is holistic medicine. It seeks to relieve suffering by understanding it individually. That takes time, and more important a sense of availability.

Lesson number 2: Take the time to understand the cause of “pain” and suffering.

Many years ago, I was privileged to work with Dr. Paul Henteleff who led the palliative care unit at St. Boniface Hospital in Winnipeg. The inpatient unit had about 20 beds. He was a firm believer in helping patients remain at home, the hospital being a place of almost last resort. He built a robust home care program, but still had difficulty convincing

patients to accept discharge, until he experienced a eureka moment. What if he guaranteed any patients on the program immediate access to the unit upon request? The hospital authorities were flabbergasted. They thought it an impossible promise, whose delivery would compromise every other department. What happened? In-patient demand dropped. On only a couple of occasions were patients bed-spaced on other wards. He was able to increase the capacity of the program greatly with no additional beds. Why? Patients and families were explicit. They no longer feared for lack of care.

Lesson number 3: Access relieves suffering.

Paul and I had a big argument one day over the management of a young woman dying of breast cancer. Leptomeningeal metastases were causing painful spasms that we couldn't relieve with analgesics. She was an inpatient on the palliative care service. I wanted to try intrathecal methotrexate, given by lumbar puncture. The procedure was simple, but the drug was considered chemotherapy, not something to be done on a palliative care ward. She invited us both to her bedside and said she had no expectation that this would alter her overall prognosis, but that it might restore some element of dignity. She went on to say there should be no distinction between "active care" and "palliative care" when it comes to relieving suffering. The balancing of effect and side effect might be different, but the goal was the same. She received the injections and the policy was changed, if only incrementally. Her pain got better.

Lesson number 4: The goals of medicine are a continuum. There should not be a discontinuity between active and palliative care.

Around the same time, we were developing the Functional Living Index for Cancer, which has since formed the basis of quality of life assessment around the world. Patients completed a 22-item questionnaire at regular intervals. We were careful to explain that missed forms meant missed data that

could not be recovered. One day, my research coordinator came to my office perplexed. She had some conflicting data about a patient. There were several completed QOL questionnaires, and a death notice. The death notice antedated the questionnaires. We needed an explanation. It turned out that the patient was so committed to this simple reporting that she instructed her survivors to meet at the designated intervals, and as it were, channel her for her answers. We had learned that physical and occupational function, psychological state, social interaction and freedom from pain are globally consistent constructs that patients understand. Those measures provide a much richer appreciation of patients' overall well-being than do the size of tumours, or the quantum of some blood test. Observing, measuring and recording provide the basis of greater understanding. Atul Gawande's eloquent *New Yorker*¹³ comparison of traditional medical therapy and palliative care for two women with lung cancer is based on relevant measurement. His recent book *Being Mortal*¹⁴ is based on data. It is data that says there is more to life than medicines. Absent that data, we will remain frozen in our paradigms.

Lesson number 5: Measurement opens avenues to relieving suffering.

An Approach to Common Ground

My thesis is that the impetus toward legalization of some form of assisted dying reflects societal maladjustment. Unless we are prepared to accept an ever-broadening application of life-ending therapies, the underlying drivers need to be addressed. That will take time. That, in turn, suggests a two-phase solution. The first is to establish legal and regulatory processes that both limit the use of life-ending treatment and, more importantly, provide a constantly refreshed understanding of exactly what is taking place. Those processes will provide an element of safety, while we address the societal issues. The second step, of a much longer horizon,

is to ameliorate those pressures that drive people to seek to end their lives when faced with illness.

Step One—Legal and Regulatory Approaches

It is important to acknowledge that there is no universally acceptable solution to the legal and regulatory challenge posed by the Supreme Court decision, *Carter*, and its Quebec counterpart. The issue cuts too deeply into the moral core of our communities to other than leave people divided. Likely, some reconciliation of patients' and physicians' rights as mandated by *Carter* will be acceptably achieved, though I doubt fully embraced. As a distinguished legislator explained, "I don't think the law has a place at the bedside in these situations. However, it is right that the people, through their elected leadership, have a say in sanctioning the principle of assisted dying".¹⁵

Taken as a whole government has several options:

1. The federal government might invoke the "notwithstanding clause", which would serve to set aside the decision thus leaving matters, legally, unchanged. Since the criminal law is a federal matter, assisted dying would remain a criminal offense. Invoking the "notwithstanding clause" is a Cabinet prerogative, understood to be fraught with unforeseeable consequences. It would mark a first use of the clause, moreover around a deeply contentious issue projecting federal politicians into a debate that, from their perspective, offers no satisfactory outcome. From many conversations with those close to the matter, that's an unlikely course of action.
2. The federal government could determine it would undertake to provide legislation and regulatory processes. Acting federally would achieve one important effect—there would be consistency across the country. We already experience a troubling, though at present small amount of jurisdiction shopping, particularly for cancer treatments. Nobody relishes the prospect of similar shopping for assisted death. The provinces would likely object, if only half-heartedly, because assisted dying would be seen as a health matter, thus within their jurisdiction.
3. The federal government could stand aside, taking the position that the Court has vacated the criminal provision and laid out a framework whose implementation belongs to the provinces. It would thus fall to provincial legislatures and MLA's to stake out positions at considerable political peril. Doubtless there would be attempts to find common ground between provinces, perhaps using Quebec's *Act* as the model, but the process would be prolonged and likely little coordinated as to time of effect. To anticipate an argument that appears later, full divestment to the provinces leaves them exposed to a potential fiscal and human resource challenge. If one takes the position that much of the current demand for assisted death derives from either the experience or anticipation of limited access to medically and scientifically available services, one must ask what it would take to provide those services to all who required them, especially regardless of geography.
4. The provinces could do more than seek the input of the health professions. They could turn the process over to their professional standards mechanisms, in effect saying assisted suicide is an approved service, subject to specific criteria, but nonetheless no different from any other (major) medical intervention. The likely outcome would be another post-*Morgentaler* scenario where the medical standards appear to be high, from a safety and efficacy perspective, but there are wide disparities in process, criteria and availability.
5. What if nobody acts? What if the Colleges of Physicians simply state that physicians must comply with the law, to the policies of their

health institution and be demonstrably current in their skills? (It appears Carter allocates this role to allopathic physicians. That being said, the judgment leaves open the possibility that other classes of physician, for example, Traditional Chinese Medicine practitioners). I suspect the problem would temporarily go away, only to re-surface after examples of mis-application come to light, perhaps reminiscent of Dr. Kevorkian.

Legislative and Regulatory Process

Ideally, federal and provincial jurisdictional issues ought to be reconciled in this matter. *Carter* is very much in the abstract, and as has been pointed out, leaves unmentioned other provisions of the *Criminal Code* which could be brought to bear against a physician providing such ending of life intervention. Those ambiguities require resolution before any but the most naïve advocates for “assisted suicide” risk their careers. The Quebec *Act* is more explicit but still remains quite detached from bedside reality. In the end, it is most likely that the Medical Colleges will find themselves obligated to establish procedures within the ambit of professional standards.^{16 17} Those standards are by their nature quite different from most regulatory processes, in that they offer boundaries of action rather than tick boxes of compliance. Within that framework, the following principles ought to govern the legal and regulatory realization of *Carter*:

1. That all related processes be placed in the context of the overall delivery of health care, thus broader in application than strictly within palliative care. This addresses generally the concern expressed regarding adjustments to medical education etc.;
2. That all related processes be nationally consistent. Jurisdiction shopping cannot be an inadvertent outcome;
3. That each jurisdiction establish an enduring oversight process, in the form of a broadly composed committee whose mandate is¹⁸

- i. To provide by example or otherwise more specific guidelines¹⁹ with respect to eligibility and assessment criteria. It is understood that ultimately decisions will be made by a local panel, and will of necessity require the exercise of clinical judgment beyond that which can be legally or specifically and exhaustively defined. The deliberation process needs to be transparent, and while many discussions will necessarily be *in camera*, the guidelines should be publically accessible. Issues to consider would include

- 1) **Competence:** how rigorous should the tests be; at what point in relation to the course of illness (raising the issue of advance directives); application in mental illness
- 2) **Adult:** by age? By ability to comprehend? (age of consent issues seriously confound effective treatment in adolescent mental health, by way of caution); should there be a mechanism for children?
- 3) **Clearly consents:** at what point, and how enduring? Who is qualified to initiate and document the conversation(s)? (it is my view that *only the patient* may initiate the conversation); must consent be multiply obtained, and if so, by whom and at what interval?; how deeply must we explore the basis of the consent?; (I believe we must explore motivations. As a provocative example, what might be our response if the patient claimed financial drivers that could not be immediately remediated?²⁰); to what extent and by what mechanisms are family or close friends to be involved? (it is my view that this decision should involve those who have, during the proximate illness, been closely involved)

Do we mean **clearly** or do we mean **freely**, and how is this achieved within complex family situations?

- 4) **Grievous and irremediable**: in whose eyes, the patient or others such as health professionals, and if so what degree of concordance is required?; over what time frame? Does the disease, illness or disability have to be fatal in the near term, or could it be chronic not affecting lifespan? (my view is that this should be restricted to circumstances where the condition may persist for an extended time. Note that the triggering examples in each legal case have been chronic neurodegenerative diseases, not painful cancers); what about mental illness? (a 25-year-old with a history of severe depression, resistance to accepting treatment and multiple, unsuccessful suicide attempts. Would we consider “forced” treatment in preference to assisted dying?)
- 5) **Enduring suffering that is intolerable to the individual** in the circumstances of his or her condition. This is most difficult formulation. Suffering is the end manifestation of numerous influences: physical pain, loneliness, fear, anger, loss, social pressure, economic or legal challenges, to name a few. Any of these can motivate suicide. For which ones are we prepared to sanction assisted dying?
 - ii. To audit compliance and performance of the assisted dying processes, within the context of palliative care and overall system performance;
 - iii. To make specific recommendations as to systemic changes suggested by the review in i. above

4. That all permissive aspects of regulations have renewable five-year terms, with mandated full review. Within that limitation all instances of assisted dying not found otherwise in breach of professional or legal standards, which have taken place prior to lapse of such permissive regulations would be indemnified against suit.

The Oversight Process

Oversight with respect to assisted death has three distinct purposes: to prevent abuse, to assure quality, and to drive improvement. There is no consistency regarding such oversight across those jurisdictions where assisted death is permitted. Quebec, through Bill 52, provides two avenues, one at the hospital level:

8. ...

The executive director of the institution must report annually to the board of directors on the carrying out of the policy. The report must include the number of end-of-life patients who received palliative care, the number of times continuous palliative sedation was administered, the number of requests for medical aid in dying, the number of times such aid was administered as well as the number of times medical aid in dying was not administered, including the reasons it was not administered.

The report must also state, where applicable, the number of times continuous palliative sedation and medical aid in dying were administered at the patient’s home or in the premises of a palliative care hospice by a physician as a physician practicing in a centre operated by the institution

and another at the Provincial level, through a “*Commission sur les soins fin de vie*”. The *Commission* mandate is broader, though more detail is provided with relation to the medical aid in dying elements of the legislation:

45. The Commission may require of institutions, palliative care hospices, physicians practising in a private health facility and agencies that they supply, in the manner and within the time specified, the statements, statistical data, reports and other information it needs for the performance of its functions under the first paragraph of section 42, provided it is not possible to link that information to any specific patient having received end-of-life care or to any specific health or social services professional having provided the care.

46. A physician who administers medical aid in dying must give notice to the Commission within the next 10 days and send the Commission, in the manner determined by government regulation, the information prescribed by regulation. This information is confidential and may not be disclosed to any other person, except to the extent that is necessary for the purposes of this section and section 47.

Any person who notes that a physician has contravened this section must bring the breach to the attention of the Collège des médecins du Québec so that it can take appropriate measures.

47. On receiving the notice from the physician, the Commission assesses compliance with section 29 in accordance with the procedure prescribed by government regulation. On completion of the assessment, if two thirds or more of the members present are of the opinion that section 29 was not complied with, the Commission sends a summary of its conclusions to the Collège des médecins du Québec and, when the physician provided the medical aid in dying as a physician practising in a centre operated by an institution, to the institution concerned so that they can take appropriate measures.

Drawing on this data, my recommendations for the oversight process thus have three elements:

1. With respect to abuse, discipline appears to rest with the Professional Colleges,²¹ who of course retain the right to access the criminal process where (one presumes rarely) required.
2. With respect to quality assurance:
 - a. Each case requires *a priori* review by a formally constituted multi-disciplinary panel;
 - b. There should be specific certification of both the process and the responsible physician, subject to renewal at five-year intervals;
 - c. While the counseling and support activities ought to be remunerated by a specific and restricted billing code, the specific act of assisted dying should **not** be remunerated;
 - d. Each application for medical aid in dying should be fully documented, including the nature and context of the request, the reasons for approval **or** denial, an assessment specifically of any system deficiencies which may have

occasioned or added impetus to the request, and a report of the manner and outcome of the means of medical aid in dying;

- e. **Separate and distinct from the *a priori* review, each** documented report should be reviewed by a **duly constituted review panel at the institution** in the manner of morbidity and mortality rounds which are confidential, and not subject to subpoena. The anonymous abstract, citing material content should be part of publically available review, on an annual basis at the institution.²²

3. With respect to system improvement:

- a. The permanent jurisdictional panel earlier defined, reporting to the highest political authority in the province, exercises two of its mandates:
 - i. To audit compliance and performance of the assisted dying processes, within the context of palliative care and overall system performance;
 - ii. To make specific recommendations as to systemic changes suggested by the review in i. above.

This process must be public, advertised and the information freely available.

Restoring a Healthier Context— Reducing the Hubris

These are complex issues, and their resolution will take years. They affect education, the relations of professional groups, the organization of hospitals and clinics. We have to educate public expectation and curb our enthusiasms without compromising innovation. It's a tough agenda. Here are some specific suggestions:

To the hubris of medicine.

1. Restore the balance of art and science in medicine, without compromising the power and

discipline of science. Broaden medical experience before specialization. We overspecialize too soon, and thus lose sight of the humanity of our patients. We treat organs and diseases rather than fostering wellness and the ability to make the most of our lives.

2. Extend the palliative care concept of relief of suffering across clinical medicine. Palliation is not only for the dying. The relief of suffering is not only about physical pain. We need to train our health professionals to be healers, and that means listening before touching, touching before probing, and human contact before machine intervention. This is perhaps the great lesson that palliative care has yet to fully share.
3. Restore continuity of health management. We need to better balance the requirement for specialization with the over-riding requirement that each of us, as a patient, has someone we know and trust as our agent. We may not be able to return to the days of Marcus Welby, the paternalistic physician who knows all, but surely we can create a role for the healer whose view is holistic, long term and patient centred.
4. Overcome the professional silos that leave patients confused, and limit our flexibility as health providers. Common early years of training for nurses, physicians, pharmacists and other core health professionals will bring a more holistic medicine.
5. A new scientific method for human biology is a grand challenge. It will expand our understanding beyond what can now assess to include those, subtle non-linear time and context-dependent processes that we can't yet observe, leaving them lost in statistical noise. It will be able encompass emotion, and social interaction. The new science will help reconcile the inherently contradictory visions of individualized medicine, driven by genetics, and the homogenization of groups which underlies the randomized clinical trial.

6. A new scientific method coupled with a humbler way of expressing our excitement at new observations will relieve our patients of the emotional roller coaster of endless dashed breakthroughs. We understand the drivers of reportorial excess: recognition, money, and perhaps being a little too close to the forest to see the larger picture. Modesty will regain our patient's confidence.

The Right Role for Government

Repeatedly, I heard my respondents say their motivation for allowing an assisted dying process was a fear that should the time come, they would not be able to access existing, established means of relieving suffering. The impediments could be education, geography, lack of professional resources or the availability of medications and treatments. Modern government's role is to set the context for the health and wellness of its citizens. One element of such context setting is to assure reasonable access to services. That does not mean it has to be the sole provider. However it cannot be seen to be the impediment.

The current structural relationship wherein government is seen as insurer, standard overseer, arbiter and provider of services is inherently conflicted. It puts patient's needs at the bottom of the priority list. Allow the money to follow the patient. Couple that with public reporting of institutional performance and outcome (rather than inputs) and the system will become more responsive.

Public expenditure involves choices, which, at least in the public perception, are being made by stealth. Since some form of rationing cannot be avoided, the principles of that rationing must be explicit and publically achieved, and the execution must be transparent. If we believe that relieving suffering for those seriously ill, and/or with life-ending irreversible diseases is the right thing to do, governments role should be to set that expectation and bring public and private energies to bear. More than money, governments' role is to mobilize the

creativity and innovation to meet the need. Our ability to innovate is stifled by a false assumption that health expenditure is a sunk cost. A better conceptualization would be to emulate President John Kennedy's 1960 challenge to get to the moon in a decade.

Patient-Centred Institutions

The next generation health institution will be wall-less, and capable of serving its patients across their lifespans, and across geography. Its capability will extend from wellness, through illness and to life's end. The great challenge will be continuity of care, made more so by the spectre of genetic predisposition testing, with its very long horizons. As with any enterprise, its success will depend on the satisfaction of those it serves. Thus, the bottom line measure will have to be successful outcomes in the eyes of the patient and the providers, attached to the revenues which they bring. They will have to achieve alignment of interests of their employees and contractors, in keeping with a patient-centred mission. Programs which succeed should be allowed to grow. Those whose goals are less achieved will be revised or wound down. Excellence merits reward.

These institutions will require the freedom to collaborate widely, not necessarily limited by geography. If continuing excellence is to be realized, they will have to both nurture and foster research and innovation. Doing that implies partnerships of a different sort, between innovators and suppliers, and the corporate ability to take risks. To be clear, those risks are not about patient lives, but around new forms of therapy and new health delivery structures. This offers the potential of diversified revenue streams, making possible cross-subsidization of worthy otherwise unaffordable elements of care.

As pertains to difficult moral issues, such as assisted dying, institutions will have to manage their own

reconciliation of competing values. That reconciliation has been achieved in some jurisdictions for abortion, but may prove much more challenging when it comes to assisted dying. Those seeking abortion can usually go elsewhere, but those so debilitated as to seek assist in death may already be resident in the institution, and would face an unsightly cruelty if forced to go elsewhere for a final medical act.

Changing Public Expectation

There are no ready answers to the unrealizable expectations our communities have with respect to health. In the largest sense, it is about education. I do have an optimistic, perhaps somewhat naïve, belief that when given clarity on the issues and choices our society will evolve responsibly. It is a long-term prospect. Meanwhile, somehow it is the role of our leaders and teachers to adhere to long term goals. We need to find the balance between individual responsibility and public and/or private safety nets.

Summary

Our country, by virtue of both *Carter* and Quebec's *Act* has created a pathway to assisted dying that is both nationally provocative, and thus far a minority legal practice within industrialized nations. Only time will reveal whether the trend continues.

Great danger attaches to assisted dying programs considered in isolation, divorced from the existing health care system, and the social context. To that extent *Carter* is problematic. The focus must be on the drivers of the apparent need, and on their relief.

Within, and only within that understanding, the most important element of any future assisted dying process is its intent. That goal should be to eliminate the need for such a possibility. It should not be to make it easier to realize. The technology of assisted dying is quite simple. The method is straightforward and efficient. It is inexpensive,

arguably saving money. Therein lies the paramount need to continuously monitor its use **not** against standards of safety, efficacy, and efficiency. The analytic outcome is the case-by-case understanding of why such a course became necessary.

The hazard of individual abuse is likely small compared to the hazard of societal abuse: easing the passage of those who suffer relieves the pressure to do better at relieving the suffering. Both monitoring the process and addressing the shortcomings require long-term vigilance and long-term investment. The conversation cannot be limited to health care delivery, although one of the recurring themes is concern that there might not be access when needed. It goes beyond that to transforming health professional training, health institutions, and even broader societal issues. Make no mistake, it will be politically and economically expedient to establish a process of assisted death that operates quietly in the background sheltered by some degree of indemnity for those who approve and undertake the act. After all, those no longer with us can no longer speak.

Better to think deeply and invest for the long term by using this most fundamental moral dilemma to impel us continually aspire to do better. Only time will tell whether *Carter* comes to be seen as a *Dred Scott*, or a *Drybones*. The *Court* has put out the challenge. It is for us to shape history.

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¹ This essay draws on preparatory work for the 18th Sandra Goldberg Lecture, *Public Choice, Private Lives: An End-of-Life Conversation*. The Council on Palliative Care, McGill University, May 5, 2015. I have met groups and individuals who have uniformly and repeatedly enriched my understanding through the diversity of their views and perspectives. All of our conversations have been either off the record, or where they took place in groups, within Chatham House rules. The assurance of confidentiality

opened the dialogue, for I learned quickly that “assisted death” however titled drew on deep and personal experiences, fears and questions. I spoke with patients, families, and caregivers. I was taken into the confidence of senior political leaders, lawyers, jurists, hospital administrators, policy analysts, ethicists, insurers, spiritual leaders, journalists and the person on the street. I am appreciative more than words can express.

- ² Emile Durkheim (1897) [1951]. *Suicide: a study in sociology*, The Free Press. ISBN0-684-83632-7. There is a broad and specialized literature including, among others: S. Stack (2000), “Suicide: A 15-Year Review of the Sociological Literature Part II: Modernization and Social Integration Perspectives”, *Suicide and Life-Threat Behaviour*, 30: 163–176. doi: 10.1111/j.1943-278X.2000.tb01074.x; *History of Suicide: Voluntary Death in Western Culture*, Georges Minois, translated by Lydia G. Cochrane, Paperback, 400 pages, ISBN:9780801866470, March 2001.
- ³ The conundrum was well articulated by a magnificent mentor, the late engineering professor, Arthur Porter who once said to me, “If the body and mind weren’t connected, why did God create necks?”
- ⁴ Knowledge, belief and dogma form a sort of intellectual continuum. The knowledge end of the spectrum is characterized by an appreciation of both the limits of the knowledge, and openness to other possibilities. Dogma is certain and close-minded.
- ⁵ *The Making of a Surgeon*, Random House, 270 pp. 1970
- ⁶ *Chaoulli v Quebec (AG)*, [2005] S.C.J. No. 33, [2005] 1 S.C.R. 791, 2005 SCC 35.
- ⁷ I was reminded also of the apparent increase in PTSD suicides among military veterans and charges of lack of recognition and resources.
- ⁸ There is, of course, a s. 7 of the *Charter* definition. However the concept is broadly debated in both medicine and law. For example: J. Coggon, Miola J. “Autonomy, Liberty, and Medical Decision-Making”, *The Cambridge law journal*. 2011;70(3):523-547. doi:10.1017/S0008197311000845., and G. Dworkin, *The Theory and Practice of Autonomy*. Cambridge: 1988.
- ⁹ Rachel Aviv, “The Death treatment: When should people with a non-terminal illness be helped to die?”, *New Yorker*, June 22, 2015, <<http://www.newyorker.com/magazine/2015/06/22/the-death-treatment>>. This article offers a perspective from Belgium which appears to have the most permissive view.
- ¹⁰ <<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>> ; and MJ Shariff, “Assisted death and the slippery slope—finding clarity amid advocacy, convergence, and complexity”. *Current Oncology*. 2012;19(3):143-154. doi:10.3747/co.19.1095.
- ¹¹ As Peter Hogg writes, there is a constant dialogue between the courts and the legislatures in such matters: Peter W. Hogg and Allison Bushell, “Charter Dialogue between Courts and Legislatures (Or Perhaps the Charter of Rights Isn’t Such a Bad Thing after All)”. *Osgoode Hall Law*

- Journal* 35.1 (1997): 75–124, <<http://digitalcommons.osgoode.yorku.ca/ohlj/vol35/iss1/2>>.
- ¹² <<http://www.theglobeandmail.com/globe-debate/assisted-suicide-context-is-everything/article19012073/>>
- ¹³ <<http://www.newyorker.com/magazine/2010/08/02/letting-go-2>>.
- ¹⁴ Atul Gawande, *Being Mortal, Medicine and What Matters in the End*, 282 pages. Metropolitan Books/Henry Holt & Company. \$26.
- ¹⁵ Veronique Hivon, the minister in the PQ government of Quebec who introduced their *Act* has expressed this view on several occasions.
- ¹⁶ This invokes a certain irony. Many physicians have observed that the clinical experience of end-of-life management has always been a medical issue, properly not a legal matter. This perspective, these days, often draws the rebuttal of antediluvian paternalism. Nonetheless, those whose profession is at the bedside quickly learn that few such decisions are dichotomous. Rather they are cloaked in the enveloping uncertainties that constitute clinical judgement.
- ¹⁷ As of the publication date provincial Colleges of both pharmacy and medicine are publishing draft or first guidelines; as examples: Nova Scotia <<http://www.cpsns.ns.ca/Portals/0/PDFpoliciesguidelines/DRAFT%20Standard%20of%20Practice%20-%20Physician-Assisted%20Death.pdf>>, and Quebec, *Medical Aid in Dying Practice Guidelines 11/2015*, College des medecins du Quebec, ISBN 978-2-9815140-7-3.
- ¹⁸ The jurisdictional review committee membership should include physicians, members of the allied health professions, legal, and lay representation. The Chair might well be a sitting or retired senior court judge.
- ¹⁹ There already exist several formalized guidelines related to end-of-life care. Not surprisingly, they vary somewhat.

- There is concern that unless new jurisdictional guidelines are consistent with current practice confusion will result. One hospice director posited a scenario where in current practice of “terminal sedation” would not be allowed, to be replaced by “assisted dying” in the form of lethal injection of some sort.
- ²⁰ Case examples illustrate the difficulties to be encountered. Consider, for example, a patient requiring much support, though not mechanical, who expresses some interest in advancing death. The patient is generally lucid, but not always. Two children have deeply opposing views, and the patient’s views shift after each encounter with the child.
- ²¹ There seems little formal interest in extending the clinical role of assisted dying beyond those practitioners regulated by Colleges of Physicians and Surgeons. It may be that no one wishes to assume the role, only that physicians have become the *de facto* agents. This does leave open the question of whether others might assume the role (presumably at patient request) in whole or in part. Margaret Wentz, the *Globe and Mail* columnist has raised the notion of “death doulas”, (<http://www.theglobeandmail.com/globe-debate/should-doctors-be-allowed-to-kill/article26428075/>). Also, it relates to the question as to whether the supervising physician must be present during administration of the lethal cocktail.
- ²² The institutional review committee membership should have a majority of physicians (the profession-assigned responsibility for enacting assisted dying provisions) representing, absent the extremes, the spectrum of views regarding assisted dying. In addition other health professionals and lay representation from the institution governing body should be present.

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