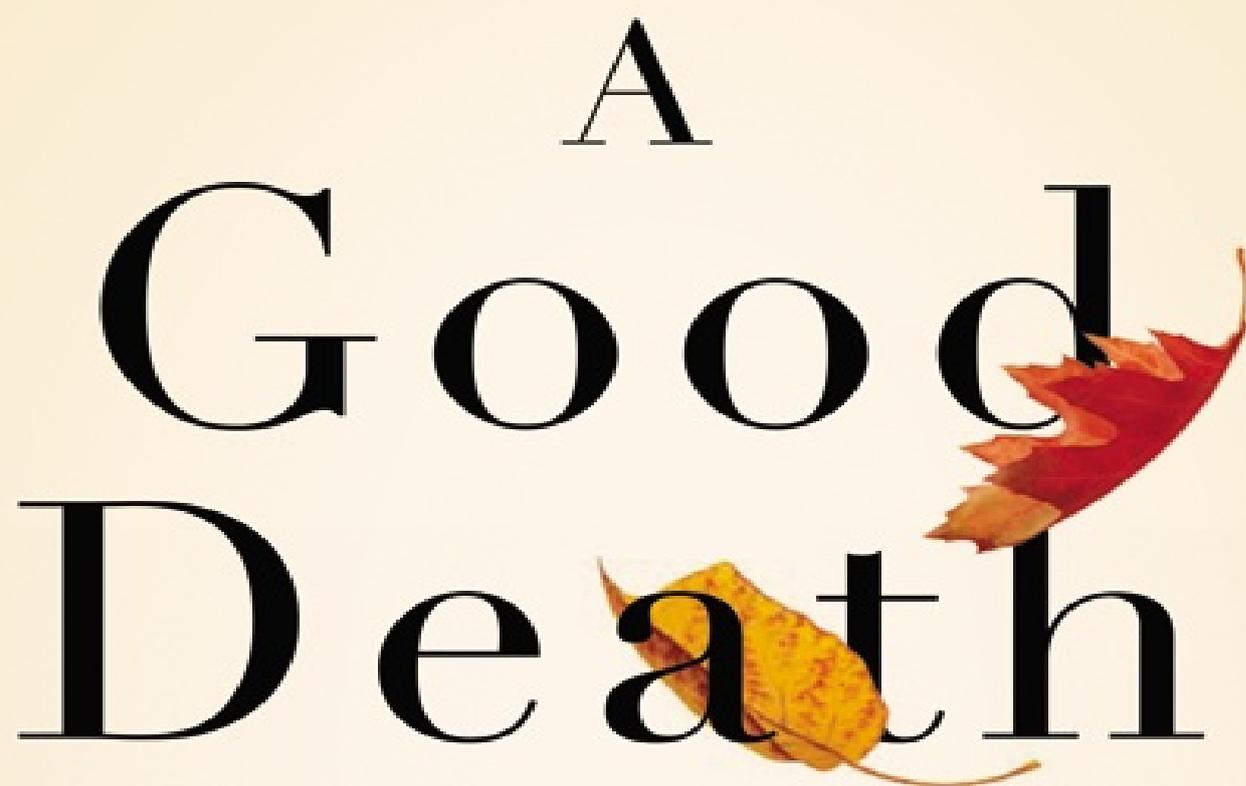


"A timely and deeply felt account of assisted dying: the histories, the issues." —MARGARET ATWOOD VIA @MARGARETATWOOD

A Good Death



*Making the Most
of Our Final Choices*



Sandra Martin



With a foreword by Margaret MacMillan



Sandra Martin

A GOOD DEATH

Making the Most of Our Final Choices



Patrick Crean Editions
An imprint of HarperCollins Publishers Ltd

DEDICATION

*For Roger, who will be there
at the end, I hope*

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Dedication

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FOREWORD

Sandra Martin is quite right. We don't do dying and death well in our present age. We will share intimate details about our lives with complete strangers on the Internet, but we shrink from confronting our own mortality or that of others. We hope, against all evidence, that we ourselves will not get old and die. The quest for the fountain of youth, after all, runs through Western civilization. One sip of its waters, so legend had it, would bring eternal life. The Spanish explorer Juan Ponce de León thought he would find it in Florida. Today, we put our faith in exercise classes, cosmetic surgery, or special diets. Advances in genetic modification (so we are told) open the possibility for extending the human life span, perhaps for centuries. Already, some optimists—rich ones—have arranged for themselves to be frozen at the time of death until the cure for whatever has ended their lives can be found.

We prefer to ignore the inconvenient and inevitable arrival of death—that of others and of our own—as much as we can. We don't even like the word, talking instead about “passing” as though it were a temporary, reversible process. We find those who are recently bereaved awkward to be around. Should we say something about those they are mourning? Might that seem tactless, upsetting—heartless even? So we send a card, mutter a few brief words, and then, with relief, turn to another subject.

Other generations and other cultures have dealt with death more robustly. For the Victorians, death was something to be expected. Mourning was not perfunctory, but prolonged, and it came with its own rules: Funerals were as elaborate as the families could afford. The living who had been left behind wore black for a stated period to signify their loss. Their stationery featured a black border. Women had mourning brooches or rings into which the hair of the loved one was often woven, while men wore black arm bands. Queen Victoria carried that to extremes and wore mourning clothes for the rest of her life to grieve her beloved Albert. Writers—think of Charles Dickens—wrote movingly about death and mourning. Artists painted death scenes or sculpted effigies.

As a consequence of our own squeamishness, we do not have the sorts of conversations that the Victorians had about the moral and practical implications of death. How should we arrange our affairs so that we don't leave a muddle for our heirs? What is a good death? How can we make the last months, days, and moments tolerable for those who are dying? How can we help to comfort those left behind? Martin is starting a conversation that is long overdue.

In the West, the demographic makeup of our populations is increasingly weighted towards the elderly. By 2024, more than 20 per cent of Canadians will be seniors, imposing an increasing burden on the state and—as families grow smaller—on the young. Perhaps technology will take up some of the slack, but the news that Japan is experimenting with robots programmed to be unfailingly chirpy and kind is not necessarily comforting. The fact that we are living longer also causes another set of problems. Medical care can now prolong life, but often at a cost to society (by making the last years so expensive) and the elderly themselves (by burdening them as their illnesses accumulate). We need to think about what happens in those last years before we die when, as in so many cases, we might be physically and mentally incapable. One encouraging development is that palliative care (the easing

much as possible of the last moments of life) is now both a respected part of the medical profession and more widespread. Its availability remains patchy, however, and dependent on local decisions rather than national policy.

We have both individual and collective choices to make, and we should be grateful to Martin for a clear and thoughtful guide to the recent history of dying and death in the West, and to the changing attitudes and debates on how to deal with that part of life. The issues she raises range from policy to those of moral dilemma. At present, many countries (including Canada) have far too many of the old or chronically sick in expensive hospital wards—bed-blockers, in the unkind phrase—when they could be in protected living. Yet there is not enough room in homes with adequate medical and other support, and not enough help for those who are caring for family members at home. The case that Martin makes for government, and indeed society as a whole, to rethink how it allocates and uses resources seems irrefutable. And we as individuals need to confront our own difficult decisions which we still can: where to live, how to stay as independent as possible, and how to keep the burden placed on our nearest and dearest, who may be getting old themselves, from becoming intolerable.

Martin, known for the perceptive and thoughtful obituaries she has long been writing for the *Globe and Mail*, started this book to find out what she herself thought about dying, and to address the difficult issue of whether one should have the right to die at a time of one's own choosing. Her journey has taken her from court rooms to bedsides to assisted death clinics in Switzerland. It is both chastening and heartening to see the courage, determination, and sheer practicality with which so many of the people whose deaths Martin describes have faced the end. This cannot have been an easy book to write, but we should be grateful to her for taking it on. As she would say herself, we have got to stop avoiding what we find distressing. Let us hope that this advice is heard by individuals embarking on their own journeys towards the end and equally by those who make the policies that must follow. Martin reminds us that we all need to manage dying and death better than we are doing now.

Margaret MacMillan
St. Anthony's College, Oxford
February 2011

CHAPTER ONE

Death: The Final Dilemma

A decade ago I made a visit to a family friend I will call Eleanor. Frailty and a complex series of physical maladies had forced her to give up the house she had built in rural Prince Edward Island after retiring from an executive position in the airline industry. She had stayed at home with 24/7 care as long as she could afford it and the system could supply her with nurses and personal care workers. Then she had moved into a nursing home in Charlottetown. Eleanor sat in her wheelchair, her hands resting in her lap, sculpted fingernails painted a familiar soft rose colour.

Much was the same as on my last visit, when she was still living in her comfortable bungalow with its stunning view over PEI's hills and dales, but much was different. Her conversation was stimulating, her mind sharp, her grooming elegant, but Eleanor was clearly bored and finding the day long and frustrating. Another resident, who was suffering from dementia, kept wandering into her room and interrupting our conversation. Eleanor was embarrassed and frustrated, but far too polite to speak sharply to the other resident or to summon a nurse. We sat in silence as we waited for the intruder to leave, only to have her reappear a few minutes later. Is this the future, I wondered, warehoused in an institution waiting for my body to conclude its sorry decline?

I had a plane to catch, so I made my goodbyes. "Is there anything I can get you before I leave?" I asked. "Something quick and painless," she responded quietly, with an enigmatic smile. I was shocked that I didn't answer, but I have never forgotten that naked glimpse into the ravages of infirmity in a woman I had always admired for her independence. It was another two years before she died, mourned by family and friends.

Every so often I think of Eleanor and wonder what she would make of the 2015 Supreme Court decision allowing patients with "a grievous irremediable condition" causing intolerable suffering the constitutional right to ask, under certain conditions, for a doctor to end their lives. The ruling on physician-assisted death came too late for Eleanor. Besides, she probably wouldn't have qualified for help in dying because what was she suffering from really, other than being tired of life? Moreover, Eleanor, who had been raised on stoicism and good manners, likely wouldn't have thought her situation was worth bothering the doctor about. I have encountered far more heartrending stories and situations, but I'm beginning this book with Eleanor because she was the first person who ever mentioned dying to me as a rational choice.

So who or what is worth bothering about? And how far are we willing to go in allowing patients to ask their doctors for help in ending their lives? Is there such a thing as rational suicide, or deliberate choosing death over life, as some bioethicists argue? We tend to delude ourselves that our end-of-life wishes will be honoured if we make out advance care plans. Nothing could be further from the truth as I point out later in this chapter in dispelling some common myths about the right to die. If we are to achieve the gentle deaths we want and deserve, we must abandon complacency and squeamishness and launch a public conversation about death and dying. Now is the time to fight for our final human right: a good death.

Death today is far too often like sex was for the Victorians: a taboo topic. We know it occurs and may even find a prurient pleasure in hearing gruesome details, but most of us don't want to talk about the prospect of our own deaths, and certainly not in public. Palliative care for the dying was introduced as a medical specialty forty years ago in this country. Yet only about 30 per cent of Canadians (and their families) have access to symptom relief and psychosocial counselling when they need it most, and that number plunges outside urban areas.

That isn't good enough for the current generation of middle-aged Canadians—the largest and most activist cohort ever. Baby boomers, reared on choice and autonomy, are radically restructuring the landscape of death, not only for themselves but for their elderly parents and the children coming behind them. Demographics play a big role in changing social attitudes and in this book. Choice about how we die is as pressing an issue today as abortion was in the 1970s and 1980s. It is the final campaign for a generation that fought for reproductive rights, sexual equality, and protections against racial, gender, and religious discrimination.

Why don't people just commit suicide if they want to die? many naysayers—some of them doctors—ask me. After all, that is what Vancouverite Gillian Bennett did in August 2014, when she swallowed a lethal overdose three years after she was diagnosed with dementia. Anybody who has talked with Bennett's family, as I have, knows that she didn't wake up one morning and decide to end her life on a whim. She had talked about it for decades and made covert preparations carefully so she wouldn't implicate her family. "I don't know where she got the Nembutal," her husband told the police when they questioned him. They believed him, but they could just as easily have declared the garden where Bennett died a crime scene and arrested her husband for aiding a suicide.

It isn't easy to kill yourself without resorting to violence in an era when drugs are tightly regulated and doctors and pharmacists have very little flexibility in the prescriptions they write. Assisting suicide carries a potential fourteen-year prison sentence in Canada. Unwilling to risk implicating the loved ones, many suffering people resort to "self-deliverance" using plastic hoods and helium machines, ropes, or shotguns. Others root around in medicine cabinets and swallow expired drugs or botched attempts that leave them in worse condition than before they attempted to end it all.

For two years I have been researching and writing about end of life, palliative care, and the legal challenges to the Criminal Code prohibition against assisted suicide. I have studied legislative accepted practices, and aberrations in other countries and undertaken research trips to interview experts in U.S. and European jurisdictions that allow assisted suicide and euthanasia. I've also observed makeshift and secretive arrangements in Canada. My interview list includes doctors, legislators, ethicists, politicians, lawyers, patients, and a right-to-die activist, a self-styled Canadian Jack Kevorkian, who operated an underground service helping people die.

Attitudes to death have changed as antibiotics, chemotherapy, medical technology, and surgical interventions have extended, although not necessarily improved, life. The concept of life everlasting is in danger of becoming a fearful secular nightmare rather than a religious solace, as most people in an aging demographic spend the last ten years of their lives coping with chronic and complicated diseases that force them into long-term care. What value are autonomy rights if you must live, like Eleanor did, in an institution where health care workers schedule most aspects of your days? In such an atmosphere, death the deliverer is less personal, more mechanized. If we want choices about how we spend our last days and how we die, we must be willing to accept responsibility for making our wishes and our choices not only clear, but legally binding. Those essential conversations and actions can only begin after a vigorous debate about our attitudes to death and dying.

Canada is a much more diverse country than it was when the abortion law was declared

unconstitutional in 1988, but there are many legal, moral, religious, cultural, and emotional similarities in the pro-choice and right-to-die campaigns. Is there a moral difference between a woman's right to choose to terminate an unwanted pregnancy and a patient's right to have help ending a life that has become unbearable? That is only one of the philosophical and practical dilemmas facing us.

Suicide is at least as old as classical antiquity. The arguments for and against what biblical scholars Arthur J. Droge and James D. Tabor call "voluntary death" in their book, *A Noble Death: Suicide and Martyrdom among Christians and Jews in Antiquity*, have changed mightily over the centuries, seeing an upsurge in acceptance in secular times and a downturn in eras dominated by religions that promise eternal life for the devout. Droge and Tabor point out that suicide is never "proscribed" in the Bible. "In fact," they write, "there are at least seven individuals in the Bible who take their own lives, and none of them is condemned for the act."

It wasn't until the fifth century, when the early Christian philosopher Augustine reinterpreted the commandment against killing to include oneself as well as others, that suicide was condemned. It gradually became an offence under church and state law, as both a sin and a crime, and was only decriminalized in this country in 1972, a decade before the Charter of Rights and Freedoms was promulgated. Aiding and abetting a suicide remained a crime.

The growth of individual autonomy in Canada under the Charter brought the issue of assisted suicide to the fore: Should medical help be available for people enduring a slow and agonizing death or for those who are so disabled by illness or injury that they can't put an end to their own suffering? Under such circumstances, is physician-assisted death simply part of health care or is it a human right? That's the fundamental question. The answer depends on your perspective.

Wayne Sumner, professor emeritus of philosophy at the University of Toronto, thinks a very strong human rights case can be made. "The foundational value behind most human rights documents, whether domestic or international, is respect for human dignity, respect for human autonomy," he told me. "We should have the same autonomy over the end of our lives as we have over the rest of our lives."

We are hard-wired to survive. Wanting to die is not an easy decision to make or, for those of us who are healthy and clear-headed, to understand. And yet, seeking an end to unbearable physical suffering is a fervent wish for many people. In 1992, Sue Rodriguez asked, "If I cannot give consent to my own death, whose body is this? Who owns my life?" in an impassioned video plea for help ending her life. The Victoria, British Columbia, resident was suffering from amyotrophic lateral sclerosis (ALS), an incurable neurodegenerative condition commonly known as Lou Gehrig's disease. It causes severe muscle wasting until a patient can no longer speak, swallow, or breathe unaided. Death from ALS, which has been described as drowning in your own phlegm, is usually caused by pneumonia.

Rodriguez argued that she wanted to end her life when her suffering became unbearable—to her. By that point, she would almost certainly be physically incapable of committing suicide by herself. Therefore, she argued, she needed help to do what able-bodied people could do legally, and a law that prevented her seeking a doctor's help was discriminatory. The Supreme Court agreed that her human rights under the Charter were violated, but found in a narrow 5–4 ruling that the discrimination was justified because making assisted suicide legal for the disabled would imperil vulnerable people and deny the supremacy of the sanctity of life.

Besides, as Justice John Sopinka wrote for the majority back in 1993, it would allow a constitutional right that goes "beyond that of any country in the western world" and "cannot be said

represent a consensus by Parliament or by Canadians in general that the autonomy interests of those wishing to kill themselves is paramount to the state interest in protecting the life of its citizens.” Less than a year later, Rodriguez died in secret after swallowing a lethal potion, with politician Sven Robinson holding her in his arms as her breathing stopped.

And there the Rodriguez judgment rested, while human rights law evolved, public and even professional attitudes softened, and assisted suicide and euthanasia were decriminalized and regulated in a number of jurisdictions in Europe and the United States. In the interim the principle of respect for autonomy has gained strength in Canada and abroad. That growth, experts suggest, is helping to tip the scales toward decriminalization.

As many public opinion polls have indicated, the people have always been ahead of the politicians in this debate. A poll released by Angus Reid in December 2014 showed that 79 per cent of respondents answered in the affirmative when asked, “Do you approve or disapprove of proposals to change the Criminal Code of Canada to allow physicians to assist with the suicide of their patients by prescribing lethal drugs?”

Clearly, an overwhelming majority of Canadians believe they should have the right to control their deaths in the same way they make decisions about procreation, marriage, and other life choices. Anecdotally, many of us believe that compassionate doctors have often quietly hastened or eased the deaths of patients in extreme pain, but the decision depended on the doctor’s discretion, not the patient’s wish. What does it mean for patients to control their deaths? Who gets to choose when enough is enough? Is psychic suffering the equivalent of the uncontrollable physical pain of a terminal cancer patient? Does a living will or another form of advance care directive made when a person is competent still have binding authority years later, if dementia has struck? Does a person have the right to change his or her mind? Should a terminally ill infant starve to death or be allowed a medically hastened death? What about a mature minor? These are deeply personal and troubling questions for doctors, patients, and society.

I interviewed many Canadians, including suffering patients and members of the medical profession, both supporters and opponents of assisted dying. How do doctors themselves want to die? In a now famous video, Donald Low, the Toronto microbiologist who was the calming voice during the SARS epidemic, implored doctors to imagine themselves in his position, not as physicians, but as dying patients. Suffering from a lethal brain tumour, he had the best palliative care available, but being sedated into unconsciousness was not the quick and autonomous death he wanted. How willing are doctors to engage in conversations about death? Finally, what are our responsibilities as individuals to ourselves, to our families, and to those who come after, in thinking about our deaths and making our wishes known?

For centuries people suffering from terrible illnesses and seemingly unendurable situations have concluded that suicide is the only rational solution to a life that has become unbearable. Mostly they die in the shadows. Some, like Rodriguez, decide to move into the spotlight. All campaigns need figureheads, people who are willing to commit themselves to a larger and all-consuming cause. For the dying it is often a way of staring down death by filling what remains of a foreshortened life with energy, passion, and meaning, to transform a horrible diagnosis into a legacy. They willingly sacrifice anonymity and a private life in a final grand act of defiance against the shutting down of the light.

The reasons are as complicated and as personal as the individuals, but they seem to share a common thread: “Yes, I am going to die, but I will make my mark first.” You can see it in the way teenaged Terry Fox brought cancer out of the closet when he began his one-legged run across the country in 1980. Or how Nancy B, a twenty-five-year-old quadriplegic, told a Quebec Superior Court

judge in 1992 that she wanted to end a life that was being artificially prolonged. “I am fed up with living on a respirator. It’s no longer a life,” she explained when the judge decided to visit her bedside rather than simply listening to pro and con arguments in the courtroom. The court ruled in her favour and she died after being disconnected from life support in a case that helped to establish in Canadian law that a competent adult has the right to refuse life-sustaining medical treatment.

The Netherlands is the country that has led the way in establishing euthanasia as an end-of-life option. It enacted its Termination of Life on Request and Assisted Suicide (Review Procedures) Act in 2002, following an extensive period of consultation and a series of legal cases in which charges were laid against doctors who helped their patients die, but the courts did not convict. Instead they established “due care” criteria specifying the circumstances under which doctors would not face criminal liability. The Dutch experience, including more than a decade of statistics about how the law was applied and the development of due care criteria, offers a primer for other countries wrestling with end-of-life choices and responsibilities. Why the right to die took hold in the Netherlands rather than, say, France or England is a fascinating question that I will argue (in chapter 9) found its roots in the Reformation.

On this side of the Atlantic, Oregon was the first American state to pass an assisted suicide law. Between 1997, when the law took effect, and the end of 2014, 1,327 terminally ill Oregon residents who met specific criteria, had asked a doctor for a lethal prescription to end their lives. Of that number, only 859 patients actually used the prescriptions, with many of the others stating that knowing they had an exit plan brought them peace and comfort. Oregon doesn’t allow euthanasia, so the patient has to be physically and mentally competent to request and then ingest the lethal potion.

That self-administered death appealed to Californian Brittany Maynard, one of the most famous examples of an ordinary citizen stepping into the public spotlight for the right to die. She was twenty-nine and suffering from frequent and vicious headaches when she was diagnosed with brain cancer in January 2014. By April the cancer had morphed into aggressive stage four glioblastoma multiforme and she was given fewer than six months to live. Unfortunately for Maynard, her home state of California didn’t allow medically assisted suicide. She had three options: wait and die what she feared would be a “terrible, terrible” death, blind, paralyzed and unable to speak; fly to a death clinic in Switzerland that allows assisted suicide for foreigners; or move to Oregon and hope to qualify for residency under that state’s Death with Dignity law before time ran out.

She chose the final option and relocated to Portland, Oregon, where she died in November 2014. Since Maynard’s assisted death, dying with dignity legislation has been introduced in several states and passed in California. As we will see, Maynard, a woman who died far too young, helped increase the death options for everybody else in the most populous state in the Union.

As I waded through the morass of documentation regarding slippery slopes, protection of the vulnerable, and freedom of the individual, I was also charting my own intellectual and emotional journey. Oregon, which is the basis for most American dying with dignity legislation, could provide a basic model that might work here, I thought early in my research. Still, I had serious qualms about whether the Oregon model could help people with degenerative diseases such as ALS or Huntington’s. Would they have to suffer, perhaps for decades, until they were classified as terminally ill? What if they were no longer physically or mentally capable of having the prescription filled or raising the glass to their mouths? I feared some of them would resort to guns, ropes, or illicit drugs, or the slow suicide of refusing food and drink. They could die alone and in pain or, worse, botch their suicide and be condemned to live even longer and in perhaps worse condition.

When I began my research, suffering was definitely part of my lexicon, but I was thinking mainly

of physical infirmity and pain, and the despair and hopelessness it could cause. And then I read *All My Puny Sorrows* by Miriam Toews, shortly after the novel was published in 2014.

As a writer, Toews is often funny, sometimes sad, and frequently lyrical. She writes autobiographical novels about sisters, mental illness, and the strictures of a Mennonite upbringing in a small Manitoba town. *All My Puny Sorrows* is more explicit than most of Toews's novels about the deep depression that her father tried to camouflage all his working life as an elementary teacher. After he retired, he committed suicide by kneeling on the tracks on the edge of town and waiting for the freight train to deliver him from his oppressive despair.

His elder daughter, Marjorie, who is called Elfrieda in the novel, had the same intractable mental illness. Talented and happily married, Elfrieda is paralyzed by depression. She tries several times in ever more horrifying ways to kill herself, and eventually begs her younger sister, Yolanda, to take her to Dignitas in Switzerland so she won't have to die violently and alone. Yolanda, relentless in her campaign to save her sister, refuses.

"She wanted to die and I wanted her to live and we were enemies who loved each other," Toews writes in the novel. It is a battle Yolanda can't win. Elfrieda's desperation to die can be thwarted only by stripping away all her autonomy, independence, and choice. Yolanda, who values her own freedom, doesn't realize that she is trying to deny Elfrieda that same liberty. She harangues the hospital to keep her sister institutionalized. Of course Yolanda fails. Elfrieda is far too wily. A dozen years almost to the day after her father's death, Elfrieda makes her own solitary trek to the train tracks and dies the horrific death everyone had tried to prevent. This is exactly how Marjorie Toews ended her life in 2010.

As a non-fiction writer I have always believed that fiction can be truer than the most comprehensive marshalling of facts and evidence. Fiction can hit you between the eyes with an emotional wallop that cool, dispassionate non-fiction can rarely achieve. Of course I knew people who suffered from depression, but not to this extent. That's why Toews's novel was a revelation to me. It made me realize that I had not given enough thought to intractable psychological suffering. At least with terminal cancer, you know there is a time limit. With psychological suffering, you can be condemned to the tyranny of life for decades. On the other hand, because patients suffering from refractory depression aren't physically dying, they may miss out on a miracle breakthrough drug or treatment that is discovered after they have successfully petitioned for physician-assisted death. There is the dilemma: hope for a future cure versus diabolical suffering now. Many herald electroconvulsive therapy (ECT, which was formerly called shock treatment). It works in about 50 per cent of cases, but it is not widely available, it can cause memory loss and cognitive deficits, and it is not a cure but only a periodic treatment for what is a chronic disease.

I'm not saying that I eschewed legal, ethical, and medical evidence in favour of fictional accounts, only that *All My Puny Sorrows* made me understand that suffering comes in many forms. Who am I to judge whether your suffering is unbearable?

"There is but one truly serious philosophical problem and that is suicide," Albert Camus famously wrote in *The Myth of Sisyphus*. "Judging whether life is or is not worth living amounts to answering the fundamental question of philosophy. All the rest . . . comes later." Elfrieda in *All My Puny Sorrows* is not the only example of somebody with major depressive disorder who has committed suicide. The American comedian and actor Robin Williams battled addiction and mental illness for decades before finally ending his life in 2014 shortly after he was diagnosed with Parkinson's disease. An autopsy showed the presence of diffuse Lewy body disease in his brain, a neurodegenerative disease that leads to a frightening form of dementia and hallucinations.

To have a new foe join forces with the old enemies must have been unbearable for Williams, much as it was for writer Virginia Woolf when she feared darkness was about to engulf her again. “Dearest, I feel certain that I am going mad again: I feel we can’t go through another of those terrible times. And I shan’t recover this time. I begin to hear voices, and can’t concentrate. So I am doing what seems the best thing to do,” she wrote to her husband, Leonard, in March 1941 before filling her pockets with rocks and walking into the river to drown.

Why am I combining fictional characters with real people, I can hear you protesting. Fair enough. Yes, Elfrieda is an invention, but she is carefully modelled on real events and a real person. Refractory depression links Elfrieda, Williams, and Woolf. They all suffered and died violently and alone because they feared that the people who loved them wouldn’t let them die. Toews and her older sister had made a pact after their father died, a promise that neither of them would kill themselves the way he had done—“the violence of it,” Toews explained, shuddering, in an interview. “I continue to have nightmares periodically about the battered, horrible bodies.” Despite the pact, Marjorie tried to kill herself several times from starvation, pills, and even by drinking bleach after slitting her wrists.

“I was in total denial,” Toews told me, as we talked about life, death, and fiction over coffee in a Vancouver hotel on an unusually sunny winter morning early in 2015. Helping her sister die was a “preposterous” notion to her. “Absolutely not. I am not going to accompany you to a place [Switzerland] where you are going to die. I can’t do that,” she remembered insisting. Now Toews realizes that she was in “such denial.” After Marjorie killed herself so brutally in 2010, Toews, while trying to deal with her own grief, tried to think “of ways that I could have made things different for her,” which included “Should I have taken her?” Eventually she “realized that I should have done that.”

Toews couldn’t write for about two years after her sister’s death. During that time, she thought and read “a lot about the philosophical and theoretical” issues surrounding suicide, and eventually she began turning her thoughts and her experience into fiction for the same reason all writers confront the blank page or computer screen: to try to make sense of it.

She knew that once there is a suicide in the family, the “door has been opened” and the choice is there. Now she realizes that her sister must have known that being run over by a train “was an option since their father “had done it successfully, but she didn’t want to exercise it because it was so horrible.” That’s why Marjorie wanted Toews to take her to Switzerland, “where she could take drugs and just fall asleep.”

In retrospect, the futility of trying to keep Marjorie alive seems clear. The people who loved her were trying to do the impossible by thwarting her suicide attempts. Death was inevitable; how she died was something else. By failing to recognize Marjorie’s desperation, did Toews condemn her beloved sister to a terrible and lonely death? That is the question that haunts Toews and fuels her novel.

Before we said goodbye, Toews told me that the question she is asked most frequently at readings and book signings is about the state of her own psyche. Most readers want to know if it was therapeutic writing *All My Puny Sorrows*. In other words, does she feel better now? As I walked away, I realized that is the wrong question. What readers should be asking is, Did the novel make *me* think more deeply about the thorny ethical issues surrounding physician-assisted death, and about who has the right to have help ending a life that is unbearable? That is the tortuous debate dividing many psychiatrists and bioethicists, as we shall see. Patients should be part of this discussion, and allowed after several failed therapies, to make their wishes known. They should be able to demonstrate to a prescribed number of doctors that, despite their depression, they are competent to make their own

choices and to take responsibility for them.

While I was researching this book, Quebec exercised its jurisdictional muscle over health care and passed a medical-aid-in-dying bill in June 2014. The law calls for enhanced palliative care and physician-assisted death for the terminally ill, under strict conditions. But before the law, which was influenced by a European rather than an American model, came into effect, the Supreme Court of Canada changed the national legal landscape.

More than twenty years after Sue Rodriguez narrowly lost her constitutional challenge, the Supreme Court agreed to hear the Carter challenge—again on appeal from British Columbia. The case involved five plaintiffs: Lee Carter and Hollis Johnson (a married couple who had taken Lee's mother Kay Carter, to Dignitas in Switzerland to have an assisted death); William Shoichet, a doctor willing to help suffering patients die if physician-assisted dying were legalized; the British Columbia Civil Liberties Association; and Gloria Taylor, who, like Rodriguez, was suffering from ALS. In February 2015, the court reversed its earlier decision and ruled that two sections of the Criminal Code violated the Charter of Rights and Freedoms with respect to physician-assisted death for grievously suffering patients.

The decision didn't come soon enough for Kim Teske, an Ontario woman who had inherited the gene for Huntington's disease. A simple blood test can determine if you are a carrier of the hereditary defect whose symptoms combine elements of Parkinson's, Alzheimer's, and schizophrenia, but few people who are at risk want to find out because there is no cure and no treatment.

Nobody knew, back in the early 1970s when Teske's father, Larry, died of testicular cancer at forty-two, that he carried the gene. He may have died before the movement, cognitive, and psychological deficits of the disease had manifested themselves, or his cancer may have camouflaged his symptoms. His widow, Gwen, was thirty-nine and had six children to raise. The eldest, Brian, was sixteen, the youngest, Deanna, was nine and Kim, eleven, was in the middle. All three of them inherited Huntington's.

Brian was the first to show symptoms—erratic behaviour, belligerence, repetitive movements. Even then he was a married father of two children. He wanted to end his life, but he waited too long and became so incapacitated by the disease that he had to be institutionalized in the autumn of 2012. Kim, a slight, lean woman with short dark hair and a vivacious personality, was diagnosed in 2008. She didn't want to end up like her brother in a nursing home, waiting either for a feeding tube to be inserted or to choke to death. "I love life and I love me, but I don't want to live like that," she told me repeatedly. "And I have a plan."

With the help of her younger sister Marlene, Kim found Dying with Dignity on the Internet and made an appointment with client advisor Nino Sekopet. Dying with Dignity won't help clients die, but it will listen to them—a rare occurrence in my experience of summary dismissals from doctors who refuse to discuss death wishes by insisting that it's a societal problem, not a medical one. By taking her seriously and offering her information about the various legal ways a person can die in Canada, Sekopet was raised almost to sainthood by Kim. For the rest of her life, she called him "my angel."

Sekopet discussed the ins and out of going to Switzerland, the problems of acquiring and consuming lethal drugs, the dangers of incriminating others in her suicide, and the legal option of denying herself food and nutrition until she died. Like so many, Kim wanted to leave a political message: the law should be changed to allow people facing a hideous death sentence a way out. That's why she told me her story, which I wrote about in the *Globe and Mail* in July 2014.

A couple of weeks before her fifty-third birthday, she stopped eating and drinking, a terrible choice, but one that her family supported. It took Kim twelve days to die, a process that filled me with

horror and left me with admiration for her courage and determination. On the first anniversary of her death, I visited her brother Brian in his nursing home.

A handsome man with sparkling hazel eyes and a shock of dark hair with a few specks of grey, he seemed to comprehend everything, swivelling his head to follow conversations, but he could no longer walk, talk fluently, or feed, dress, and bathe himself—never mind “wipe his own bum,” a phrase I heard repeatedly from the Teskes. Like Kim, he was surrounded by family, who visited him every day and fed him dinner. I asked Brian what he thought about his sister’s choice and he blurted, “Mad as hell.” Was he angry because she had escaped the fate that likely awaited him—choking to death or, if he were lucky, pneumonia after a chunk of aspirated food causes an infection in his lungs? Such philosophical niceties were beyond his ability to articulate.

He had already refused to have a feeding tube inserted when he could no longer eat even pureed food. Would he choke to death or follow his sister Kim’s lead and starve to death? Nobody knew for sure, probably not even Brian, but his devoted wife said that it would “be his decision,” although “anything would be better than watching his face turn grey and his lips blue while he struggles to catch a breath.” She’d seen him almost choke to death a few times.

Luckily for Brian and his family, he was spared that horrific decision because he died in his sleep in September 2015, four months after my visit. That leaves only the youngest Teske carrier, Deanna, a sunny vivacious woman with pronounced involuntary movements, or chorea. She says she won’t mind ending her days in an institution. The nightmare of Huntington’s likely won’t stop with her generation because one of her two daughters has already tested positive—Brian’s son doesn’t want to know if he will be stepping into his father’s shoes someday soon.

How can you write about such depressing stuff? friends ask. Yes, death can be heartbreaking, frustrating, even infuriating. However, it is also heartwarming and animating to discover the grace and resilience with which individuals deal with pain and suffering, observe the many ways their loved ones support them in their illnesses, and accept and understand their desire to welcome death to their deliverer. Their stories have the power to change minds. That is why writing about assisted death is so inspiring.

For every supporter of a change in the law, there are many more people who are complacent, or simply uninformed about choices and responsibilities when it comes to dying. Let me begin this book by stating unequivocally that assisted death cannot replace the need for more and better palliative care. Curing is the ultimate goal in health care, but we need to get over the notion that it is always achievable. It isn’t. Caring is something else. An intrinsic part of patient-centred care, caring can be overridden by the fear of telling people the truth about their illnesses or by an arrogant belief that there is always another treatment, another operation, another intervention that is worth inflicting on suffering patients. Caring existed long before curing was based on anything more than luck, hope, and prayers. We must never forget that.

Let me also dispel three common myths about assisted death.

Myth Number One: The struggle for dying with dignity is over. *Now that the Supreme Court has ruled that physician-assisted death is legal, everything is settled.*

Not by a long shot. The court declared sections 241(b) and 14 of the Criminal Code “void” because they infringe on an individual’s section 7 Charter rights to life, liberty, and security of the person. The court can’t order Parliament to make new laws. Its job is to interpret existing laws and decide if they uphold or violate entrenched Canadian rights and freedoms. As the court wrote in its unanimous judgment: “It is for Parliament and the provincial legislatures to respond, should they so choose, by enacting legislation consistent with the constitutional parameters set out in these reasons.” To give

Parliament time to act, the Supreme Court declared that its ruling was suspended for twelve months until February 6, 2016.

The Harper government failed to initiate any legislation, leaving Canadians to face the prospect of unequal access to physician-assisted death in different parts of the country, with some provinces, such as Quebec, offering medical services that are unavailable elsewhere. Could that result in legal challenges to the Supreme Court arguing that patients in other provinces and territories are being discriminated against because of residency requirements? Or, following Brittany Maynard's example of moving from California to Oregon, would Canadian patients living in a province that has not legislated physician-assisted death travel to Quebec and try to qualify as residents in order to ask for help under that province's medical-aid-in-dying legislation? At best, we were likely to have a patchwork of services, because health care is provincially regulated and delivered.

Stephen Harper's Conservative government was defeated in the general election in October 2015 and replaced by the Liberals under Justin Trudeau. He recalled Parliament on December 4, 2015. Within just over two months, including the Christmas recess, until the Supreme Court decision comes into force, the Liberals asked for a six-month extension to give the government time to draft, introduce, and try to pass legislation.

In a split decision, the Supreme Court ruled in the middle of January 2016 that the federal government could have a four-month reprieve to get its legislative regime in place. The extension was two months short of the government's request, but equal to the amount of time Parliament had been suspended because of the election. Quebec, which had implemented its own medical-aid-in-dying legislation in December 2015, was allowed to continue offering end-of-life services that were unavailable elsewhere. The judges acknowledged that giving Quebec an exemption "raises concerns about fairness and equality across the country," so they compensated by allowing grievously suffering individuals, who meet the criteria set out in *Carter*, to apply for a court-ordered exemption. That should work, assuming they can find willing doctors to help them die. That's not my notion of a peaceful death process.

That still leaves suffering Canadians in limbo. We will have the court's definition of who is eligible for physician-assisted death, but unless the federal government passes legislation there will be no national standards, no national regulatory body, no comprehensive statistics and record keeping, and no way of knowing if abuses occur or if deserving patients are denied the help they need and want. Many Canadians will continue to die in the shadows or, if they can afford it, travel to Zurich to a clinic offering assisted suicide to foreigners.

That's the choice Susan Griffiths of Winnipeg made in 2013 at the age of seventy-two. Diagnosed two years earlier with multiple system atrophy, an incurable and treatment-resistant neurodegenerative disease, she knew life was going to get much worse before blindness, an inability to walk, and a painful, lingering death finally released her from a life that was becoming intolerable. The mother of three (and grandmother of six) made the decision to become what many call a death tourist after her balance and fine motor skills deteriorated. She was losing more and more independence and requiring increasing doses of pain and other medications. Dignitas accepted her after determining that she sincerely wanted to die and was competent to make the decision to end her life.

The price she had to pay was more than financial; she also had to die while she was still physically capable of travelling to Dignitas in Zurich. In Switzerland she had to meet separately over three days with two local physicians, who were charged with determining the sincerity of her motives and her competence to make the decision.

As part of her end-of-life preparations, she wrote to more than three hundred Canadian MPs asking

them (futilely, as it turned out) to raise and debate assisted suicide in the House of Commons. She also spent a few days enjoying a final gathering with family from Europe and Canada. “We want the law to change,” she told the *Winnipeg Free Press* before ingesting a fatal drug dose on April 25, 2013. “We want there to be a choice at the end of your life. We need a law to say we can choose our own death.”

The Supreme Court has ruled that physician-assisted death is legal, but it didn’t design a regulatory framework and it can’t rewrite the Criminal Code.

Myth Number Two: My living will means I have nothing to fear. *If I get dementia, my substitute decision maker will follow my instructions and I will have the early but dignified death that I have spelled out in my advance care directive.*

Pulling the plug is not as simple as it sounds, even after the Supreme Court ruling. In its judgment, the court allowed physician-assisted death for “a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including a terminal illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.”

The key word in terms of dementia is “competent.” Being competent when you make the decision about what you want to happen if you should become mentally incapacitated is the first step. The crucial question, however, is whether you must also be competent when you make the request for physician-assisted death. And that of course is unlikely, since the reason you made out the advance care directive in the first place is that you wanted to end your life if you became mentally incapacitated. This sounds contradictory, but if you aren’t competent to make the request, how is your substitute decision maker and, more significantly, the doctor (or doctors) who must decide if you are to be given a lethal injection know whether you still want to end your life? People change their minds all the time about what makes life intolerable. It is part of the resiliency of the human condition that we adapt to new and seemingly alarming situations. On the other hand, doctors frequently accept Do Not Resuscitate orders and other treatment refusals in advance care directives from incompetent patients. Is asking for physician-assisted death different?

The Supreme Court was silent on advance care directives, so lawmakers and regulatory bodies still have to determine their validity for patients suffering from dementia and other cognitive impairment. Several doctors have told me, the patient with dementia often isn’t suffering; it is her family and caregivers who are distressed by Granny’s inability to recognize them. And yet it is hard to believe that some patients aren’t suffering, especially those whose frustration and impairment require them to be sedated and institutionalized on locked wards.

Even the most carefully wrought plans run afoul of the law and the liability fears of long-term care facilities. The case of Margaret (Margot) Bentley is a cautionary tale. A former nurse who had cared for patients with advanced dementia, the British Columbia resident didn’t want her life prolonged when she developed the same devastating disease. She even put her wishes on paper (although there is some confusion about the date and signatures on her directives), stating that she did not wish to be kept alive by artificial or heroic means if she had deteriorated beyond any possibility of recovery. The directives included no “electrical or mechanical resuscitation” and no “nourishment or liquids.” As well, she appointed her husband and, failing him, one of her daughters “as proxy for the purpose of making medical decisions” if she became incapacitated.

It sounds as though Bentley knew what she wanted and how to ensure it would happen. That isn’t how it worked out, however. Bentley was diagnosed with Alzheimer’s disease in 1999 and a decade later was moved into Maplewood House in Abbotsford. Now in her eighties, she can no longer speak or recognize her grown children or her husband. Her muscles have grown rigid, and she often sits with

her eyes closed and her hands fixed in a claw-like position; when her caregivers put her to bed, her body usually curls into a fetal position.

Her family has been fighting Fraser Health, the regional integrated health care authority, over Bentley's care since 2011. They want caregivers in the long-term care home to stop feeding her so that she can die. When the home refused to stop spoon-feeding Bentley, arguing it had a duty of care, the family tried to remove her to a palliative care facility elsewhere in the system. When that request was denied, the Bentleys went to court in 2013 to ask for an injunction ordering the home to stop feeding her.

Justice Bruce Greyell of the B.C. Supreme Court refused, arguing that spoon-feeding was "personal care" not health care. By opening her mouth to receive nourishment, Bentley was not simply responding to the pressure of a spoon against her lip, she was "communicating her consent." The Bentleys were shocked by the ruling. So was criminologist Robert Gordon of Simon Fraser University, the co-author of B.C.'s legislation on living wills. Arguing that the Bentley ruling sets a much higher bar for how such documents will be scrutinized in future, Gordon issued a blanket piece of advice in an interview with the *Vancouver Sun* in February 2014: take your living will to a lawyer or redraft it. Other experts have added this shouldn't be just any lawyer—choose one who is well versed in advanced care directives.

Myth Number Three: I can die my way. *I'm not worrying about what judges, doctors, and politicians decide about physician-assisted death because I have a secret stockpile of drugs. Someday when I feel the time is right, I will simply put on some soft music, mix myself a potion, and drift off into an eternal sleep.*

Some people, such as the poet and essayist Richard Outram, do succeed in ending their lives when living becomes intolerable. A stagehand by day and a cerebral poet by night, his collections include *Benedict Abroad* and *Turns and Other Poems*. He was married to Barbara Howard, a painter. Their lives were a collaboration of his words and her images. After her death at seventy-six in 2000, however, everything that made his life joyful was extinguished. "The two of them fed each other beautifully and with enormous intensity," the writer Barry Callaghan recalled for an obituary of Outram that I wrote in the *Globe and Mail*. "They were the closing of the couplet. So, what are you going to do with a one-line couplet? He really was his work and his love for her."

Outram struggled alone for nearly three years and then, on one of the coldest nights of 2005, he consumed a goodly quantity of pills and drink. Then, in a grand Blakean gesture, he sat on the sidewalk porch of his house, illuminated only by the stars in the night sky, contemplated the universe, and quietly allowed himself to die of hypothermia. He was seventy-five.

Not many of us have that kind of resolve. Not many of us are so adept at calculating the correct combination of drugs and orchestrating the appropriate circumstances to ensure that our wishes won't be thwarted. Remember the film *Still Alice*, based on the bestseller by Lisa Genova, in which the character played by Julianne Moore persuades her doctor to write a prescription for powerful sedatives? Alice, who is suffering from early-onset dementia, hides the pills and then leaves explicit suicide instructions on her computer desktop, hoping she will be able to both find and follow them in the gap between realizing her life has become intolerably circumscribed and the moment when the disease will have eroded her ability to act. Inevitably, she is foiled by a combination of her own confusion and memory loss and the inconvenient arrival of a caregiver.

Still Alice is fiction, but there are plenty of real-life examples of botched suicide attempts. Linda Jean McNall and her mother, Shirley Vann, drove with their dogs from their home in Arizona to Alberta for a final vacation near Jasper National Park before they planned to carry out a bizarre

suicide pact. Both women were ill, impoverished, confronting escalating medical bills, divorced, and despondent. McNall, fifty-three, was a diabetic who suffered from hepatitis C and depression. She couldn't imagine living without her mother, who had been treated for colon cancer and kidney failure and was in constant pain.

In May 2013, they pitched a tent at Rock Lake, about 350 kilometres west of Edmonton, injecting themselves and their dogs with insulin, swallowed some sleeping pills, and opened a propane tank to let the gas escape. Vann and the dogs died, but McNall survived, presumably because she required a larger dose of lethal drugs than her mother, who was twenty-five years older and half her size. McNall was charged, incarcerated in a psychiatric institution for several months, and eventually put on trial. She was convicted of aiding a suicide and sentenced to time served before being deported to the United States in January 2014.

One of the worst cases of botching a double suicide continues to reverberate within a family that will call Hutcheson. (They told me the story on the condition that I change their names.) James and Mabel Hutcheson were British immigrants who had settled on the prairies in the 1960s. He was a doctor, she was a teacher. By the time they reached their early eighties, they had two grown sons and several grandchildren. She was suffering from a series of complex complaints and was in constant pain. James was more robust, but he too suffered from chronic afflictions and was determined not to end his days in a nursing home, either on his own or with his increasingly disabled wife.

A "take-charge" sort of man, James had a "clinical view of life and death," his elder son Joshua explained in an interview. Realizing that his wife would soon require more care than he could provide, James was determined to "do a self-checkout" for them both with a lethal cocktail of painkillers and sedatives. Being forced to leave the home in which they had lived for decades and move into a long-term care facility was anathema to him, and possibly her.

"Some Thursday you will get a call from our cleaner," he frequently told Joshua, explaining that the unsuspecting woman would arrive on her usual day and discover the couple dead with a suicide note by their sides. For at least two years, Joshua, a prominent professional who lived and worked halfway across the country, dreaded Thursdays for fear of receiving an ominous phone call from his parents' house.

In fact, his father talked so openly and so often about the final exit plan that it developed an air of gallows humour. Joshua remembers even begging his father to avoid a particular Thursday in 2011 because he was launching a huge initiative that week at work. Sure enough, that is precisely when the phone call came from the emergency department of a hospital in his parents' town. Joshua and his wife had to rush to his childhood home to take care of his parents.

The cleaner had arrived that morning to find a long handwritten suicide note, three ravenous cats prowling the house, and her employers breathing but in distress. James, despite his medical training, hadn't stockpiled sufficient drugs to kill either of them, especially Mabel, who had been taking opiates for chronic pain for years. She was clinically addicted and therefore had a massive tolerance for his drug of choice.

James was in a coma, but Mabel had nothing more serious than a gash on her head from falling out of bed. Their younger son, who hadn't appreciated the seriousness of the suicide pact, was in shock and disbelief. A week went by before he finally agreed with Joshua that they should disconnect the machinery and allow their comatose father to expire. Their mother lived in misery and deepening depression in a series of institutions for another two years before she too finally died.

"Everything my father tried to avoid came to pass," Joshua said, shaking his head woefully. "The doctor tried to spare us, but they screwed it up. If I ever take that route, I'm going to be damn sure I don't."

leave a mess behind for my children.”

Neither James nor Mabel was terminally ill or suffering intractably from an irremediable disease or illness. They were simply old, worn out, and in continual pain. It is hard to imagine a circumstance in which they would be eligible for physician-assisted death in Canada, assuming the federal government enacts a law and regulatory regimes are established. Couples like the Hutchesons will likely be on their own in the “self-checkout” line, although their numbers, as we shall see, will spike as the baby boom enters its eighth and ninth decades.

For people like them who can't face long-term care facilities and really want a guaranteed exit, violence or starvation and dehydration are still the most reliable means of ending your life. As mentioned earlier, Marjorie Toews made several suicide attempts before she hiked out to the train tracks on the edge of town. Tony Nicklinson, a British civil engineer and former rugby player and skydiver, had suffered from locked-in syndrome for seven years, since suffering a catastrophic stroke in 2005. Paralyzed from the neck down, unable to speak, feed himself, or attend to any of his physical needs, he stopped eating and drinking after his appeal to the U.K. High Court for assistance in ending what he called his “living nightmare” was denied in August 2012. He died of pneumonia six days later, after turning his face to the wall and refusing nutrition and hydration.

Britain still doesn't allow assisted death, despite many attempts to pass legislation over the decades. Switzerland has become an increasingly attractive destination for affluent Britons who want to end their lives by assisted suicide.

Coping with increasing health problems frequently inspires thoughts of suicide pacts, especially devoted couples who can't imagine living on alone after one member dies or is institutionalized. Vladimir Fiser and Marika Ferber, for example, couldn't find a peaceful solution to her chronic pain and increasing infirmity. Although Fiser was still relatively hale, he didn't want to live without his wheelchair-bound wife.

Fiser had fled Croatia as a teenager, after his lawyer father and other family members were executed by invading German forces. He became a refugee in the Italian-occupied part of Croatia, and was smuggled to Switzerland after the Germans invaded Italy in 1943. After the war he returned to Yugoslavia, earned an economics degree from the University of Zagreb, and subsequently moved to Israel. That's where he reunited with Ferber, whom he had known when they were children in the Jewish community of Osijek, a small town in Croatia, in the 1920s.

Both of them were married to others by then. When his wife and her husband both died of cancer, the two childhood friends became romantically involved. They married and immigrated to Canada, where he earned a social work degree from the University of Toronto and found a job at the Lakeshore Psychiatric Hospital.

The couple settled in Etobicoke on the western edge of Toronto, living for two decades in an apartment on the eighteenth floor of a high-rise. Police found their suicide note in the apartment early one morning in late October 2013 after the couple managed to climb over a three-foot concrete barrier and jump to their deaths. Both in their late eighties, they didn't want to be separated in death, as they hadn't been in life once they had found each other again. “I am not sad that you left this world, after all it was your choice,” read one of memorial notes left at the base of the apartment building, according to an article in the *Hamilton Spectator*. “I am sad because society let you down and could not help you die with dignity. I pray that you are now in God's comfort, free from sickness and enjoying your afterlife together as you wanted.”

Then there is the curious case of Jacques Delisle, a prominent Quebec jurist who is serving a life sentence in a maximum security prison for murdering his wife. One month after the Supreme Court

decision in the Carter case, Delisle, the only Canadian judge ever convicted of first-degree murder, launched a jailhouse appeal to have his murder conviction reopened, arguing that he didn't kill his disabled wife, Nicole Rainville; he merely assisted in her suicide.

Rainville, a vivacious, intelligent, and engaged wife and grandmother, had suffered a stroke on her sixty-ninth birthday. She was paralyzed on the right side of her body and had diminished capacity. "The light had gone out," her daughter later told the CBC. Rainville's health continued to deteriorate and her husband retired a year early from the Quebec Court of Appeal to care for her. In the summer of 2009, Rainville fell and fractured a hip, which kept her hospitalized for a long time and left her despondent and suicidal, according to her sister's testimony at Delisle's trial. Meanwhile her husband, a devoted caregiver and husband, according to their son, was secretly having an affair with his long-time secretary.

There is no doubt that Rainville died from a bullet wound to the head from a .22 calibre pistol in November 2009. The question is who pulled the trigger. Delisle called the police, saying he had returned home from running some errands and found his wife covered in blood on a chesterfield in the living room. He told them she had found the loaded gun in his study. Now he admits that he had retrieved the gun at her request and left it on a table beside her before he left their condo that morning. He lied to the police, he said later to CBC journalists from *The Fifth Estate*, because he was worried about how his family and his peers would react if he admitted he had helped his wife commit suicide. Clearly he was thinking emotionally, like a scared human being with something to hide, rather than a judge steeped in the law.

During his murder trial he told his grown children the truth about his role in their mother's death. They were shocked, which perhaps explains their bizarre entreaty that he shouldn't take the stand on his own defence because of the effect the disclosure would have on his grandchildren. He succumbed to their wishes, declined to testify at the last minute, and was subsequently convicted and sentenced to life in prison without the possibility of parole for twenty-five years.

He appealed his conviction to the Quebec Court of Appeal and the Supreme Court of Canada, but neither court agreed to hear the case. *The Fifth Estate* and Radio-Canada broadcast the results of a joint investigation into the ballistic evidence in March 2015, arguing persuasively that the only person who could have wielded the gun, given Rainville's injuries and the residue smudge on her left hand, was the victim herself. Lawyer James Lockyer, founder of the Ontario-based Association in Defence of the Wrongfully Convicted, called a press conference to announce that he had taken on the case. Federal justice minister Peter MacKay subsequently said he would examine the request for a new trial.

What would Rainville have done if she had had better medical care and support services at home and legal access to physician-assisted death? We will never know. One thing is certain: a judge who spent his career serving the law and passing judgment on others now finds himself pleading for mercy in the case of his own disabled wife's violent death.

The struggle to ease the way the suffering die is far from over. Despite overwhelming public support, there is no new federal law. Provincial and territorial ministries of health, colleges of physicians and surgeons, and other organizations including the Canadian Medical Association are struggling to update legislation and establish a regulatory framework reconciling what the Supreme Court defined as the Charter rights of patients and physicians.

The former federal government's inaction has left doctors and medical associations in a regulatory limbo as they struggle to accommodate the conscientious objections of some doctors and to anticipate and respond to imminent changes in the Criminal Code.

Fortunately, plenty of people are eager to help the government initiate the necessary national

conversation about how to improve options and define responsibilities for patients and doctors. Many of them talked to me while I was writing this book. They include philosophers, ethicists, lawyers, doctors, patients, families, and legislators such as former Conservative MP Steven Fletcher. He drafted two private member's bills that have been introduced into the Senate, which correspond quite closely with the Supreme Court's conclusions. Fletcher, the survivor of a catastrophic collision between the car he was driving and a moose, knows better than most of us the meaning of vulnerability, autonomy, and the sanctity of life. Life is the first choice, he said to me, but it is not the only choice.

Along with choice comes the responsibility to make our wishes known, to ensure that our doctors, politicians, and lawyers are offering us the ease and the options we need at the end of life. The way we lead our lives, both personally and publicly, can have an impact on how peacefully we leave them. Now is the time to speak out and join the debate. Your own death could depend on it.

CHAPTER TWO

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