Right to Die Society of Canada
NEWSLETTER

Vol. 4:3 - 9:4 (Jul. 2012 - Dec. 2017)

SOUNDBITE

"Deliberate life completion" is the phrase that author John Abraham proposes as a replacement for "rational suicide", "self-deliverance", and all the other terms that have been tried over the years.

(Abraham makes the suggestion in his 2017 book "How to Get the Death You Want", available via Amazon.com)

DATA BIT

The number: over 2000

What it is:

The number of Canadians who have received medical aid in dying (MAID) since it was legalized in June of 2016. The average age of recipients was 73 and the commonest reason for wanting MAID was cancer. In about half the cases the procedure was administered in a hospital; in the remaining cases it was administered in a home or a hospice or an institution such as a longterm-care facility.

Only five cases involved self-administration of the drugs.

When published:

October 6, 2017 on *CBC News*

Discussion:

The drugs normally used for self-medication outside Canada have hitherto not been practical for use here. For instance, pentobarbital (trade name Nembutal) has been priced at $23,000 per dose by Akorn Pharmaceuticals, the US company which holds the North American rights for it.

However, Americans too have been victims of price-gouging – this time by a Canadian company, Valeant Pharmaceuticals. It holds the North American rights for secobarbital, the traditional drug in the US (where pentobarbital is off the table because it has been used for executions). When Valeant acquired the rights for secobarbital it doubled the price, from $1500 to $3000, which many individuals could not afford and which many insurers refused to pay.

Doctors in states that allow assisted suicide have developed "cocktails" consisting of heart-slowing drugs plus opioids/sedatives, and these have been used by a substantial number of people. The cost is reasonable – about $800 – but the mixtures do not work as rapidly as barbiturates like secobarbital and pentobarbital. The people who are companioning the exiter are told to expect death in 4 hours or less, but in 20% of cases the process has taken much longer – 31 hours in one instance.

In the US, doctors are not obliged to be present during an exit. But while some Canadian provinces (such as Ontario and Saskatchewan) follow this example, at least one (BC) requires that the doctor be present and stay until death occurs. MAID-providing doctors are still quite thin on the ground, are seriously underpaid for their time, and have other patients who need their services: all these facts make slow methods very undesirable.

Fortunately, late in 2017 it was announced that an arrangement had been made to have the ingredients for secobarbital shipped to a Canadian compounding pharmacy, which would combine them into a product that could be used by exiters whose personal style inclined them towards a self-managed death. More information is available from CAMAP (Canadian Association of MAID Assessors and Providers) – camapcanada.ca.

NEWS IN CANADA

The MAID Chronicles
or ***How We Got Here from There***

Table of Contents

Public Opinion

1949 62% of Canadians were opposed to "mercy killing". [*Gallup Report*, Aug. 21 1968]
1968 Nationwide, 43% were opposed; 52% of French-speaking Canadians were opposed. [same source]
1979 Nationwide, 68% were supportive; support had risen dramatically among French speakers, to 71% [*Gallup Report*, Oct. 27 1979]

During the sixties and seventies Quebec went through what has come to be called its Quiet Revolution. The unelected upper house was abolished, the voting age was lowered from 21 to 18, women gained the right to serve on juries and to buy property without their husband's consent, a secular Ministry of Education was created, and French was made the official language.

The slogan "maîtres chez nous" ("masters in our own house") was put forward during an election campaign and caught on immediately. Quite possibly it had a micro level as well as a macro level: people desired power to shape not only their collective life but also their individual life, right up until its end.

It seems likely that the French ethos, as well as the French language, came into its own. Part of this ethos is being quite unhesitant to care strongly about the experiences you have – the age of your cheese, the temperature of your wine, and so on. Phooey on the stoicism and puritanism which often afflict the "maudits anglais". Knowing that you will likely be having experiences during the lead-up to your death, you want to be given control over those events, even being enabled to leave gracefully at a time of your choice if that strikes you as the best way to avoid experiences you don't want to have.

Gallup polled on this question every few years until the early 2000s, and Quebec continued to be the region with the highest level of support for assisted death.

Action Groups

The first social-action group came into being around the time Gallup found a huge increase in support. Additional groups followed.

1980 Dying With Dignity
1991 Right to Die Society of Canada
2007 Association québécoise pour le droit de mourir dans la dignité (Quebec Association for the Right to Die with Dignity)
2009 Collectif mourir digne et libre (Free & Dignified Death Collective)
2011 Farewell Foundation

Parliament (Federal)

In the 1990s there began to be political stirrings at the national level. Members of Parliament from several different regions put forward bills or motions proposing the legalization of aid in dying:

1991 Robert Wenman (BC), Chris Axworthy (Saskatchewan)
1992 Svend Robinson (BC)
1993 Ian Waddell (BC)
1994 Svend Robinson (BC)
1997 Svend Robinson (BC)
2005 Francine Lalonde (Quebec)
2008 Francine Lalonde (Quebec)
2009 Francine Lalonde (Quebec)

2014 Stephen Fletcher (Manitoba)

These were all private members' bills, not government bills, and they met the fate which such bills usually meet. But they received substantial media coverage, heightening public interest in the topic.

The Senate as well as the Commons took up the subject:

1994 -1995 A Special Senate Committee examined the question and published a report, *Of Life and Death*.

2000 A Senate Subcommittee checked on the implementation of the 1995 recommendations and reported that little implementation had occurred.

Individual Activism

The change in Quebec's spirit really did deserve to be called a revolution, but significant psychological change was occurring throughout the country. People had traditionally been embarrassed to reveal that they wanted death, or at least wanted the right to get it at some future time when certain circumstances had come to prevail. The popular view was that such thoughts were cowardly. But suffering or apprehensive citizens began casting aside timidity and unjustified shame. Instead of hiding they stood up (if only figuratively) and spoke out:

1991 Sue Rodriguez
1992 "Nancy B."
1993 Orval Jacques, Erwin Krickhahn, Linda Ross
1996 Austin Bastable
2010 Kay Carter, Bernice Levitz Packford
2011 Clare Endicott, Ginette Leblanc, Gloria Taylor
2012 Nagui Morcos
2013 Ruth Goodman, Susan Griffiths, John Alan Lee, Larry Librach, Donald Low
2014 Gillian Bennett, Edward Hung, Linda Jarrett, Eric McGuinness, Kim Teske
2015 Donna Delorme, Nigel Lawrence
2016 Julia Lamb, Hanne Schafer
2017 Nicole Gladu, Robyn Moro, Will Pegg, John Shields, Katherine Meany Svec, Jean Truchon, Nancy Vickers

Quebec Legislation

While Francine Lalonde was preparing for her third try in the House of Commons, a doctors' group in her province was polling its members about aid in dying.

2009 In early September the fédération des médecins spécialistes du Québec surveyed 8717 of its members concerning euthanasia, and 23% of them responded. Three-quarters of the respondents said they would be in favour of the practice as long as there were clear legal guidelines (the same percentage said Parliament should pass a law). Even more than three quarters of respondents (81%) said they had seen euthanasia practiced, though many of them were using the term to mean treatment withdrawal accompanied by continuous deep sedation. In any case, an acceptance of death and a desire to soften its edges – by one method or another – had clearly become widespread among specialists at least. Most people are in the care of a specialist – oncologist, cardiologist, pulmonologist. etc. – by the time they are close to death, so these doctors see the dying process more intimately and more frequently than family physicians. The "mainstream" doctors' group, the College of Physicians, was nevertheless developing its position on the topic and had already issued a draft report urging that euthanasia be considered appropriate in some cases.

Politicians were quick to respond. In expressing their thoughts, some of the doctors had said that euthanasia "should be part of the continuum of care." Although the writers of Canada's constitution had put criminal law in the power of the federal government, they had given power over healthcare mainly to the provinces. Quebec decided to flex its constitutional muscles. Less than two months after the doctors' dramatic statement, an all-party committee of the National Assembly was created to study aid in dying.

2010 - 2011 The committee consulted with 32 experts, received more than 300 position papers and requests for hearings, got 6600 responses to an online questionnaire, held public hearings in eight Quebec cities, and visited three European countries.

The initial assumption had been that the discussion would centre on assisted suicide. This was the only form of aid in dying allowed in the US (though official documents avoid the word "suicide" when referring to it) and Canadian media do tend to give heavy coverage to American stories.

But the committee got a surprise. Quebeckers had no interest in a do-it-yourself approach. Instead of assisted suicide they wanted euthanasia, in which they could receive service from caring experts, many of whom had just indicated their willingness to provide such service.

2012 The committee tabled a report which was examined by a Justice Department panel of 17 experts headed by lawyer Jean-Pierre Ménard.

2013 The legal panel tabled a report concluding that assistance with death should be an available option within end-of-life care. The writers noted that the word "euthanasie" had inconsistency problems, and they also faulted it for not containing the ideas of support and medical professionalism. They created the phrase "aide médicale à mourir" to include these two ideas.

(Later groups also liked the phrase, which they translated as Medical Assistance In Dying, or MAID for short. The rest is history.)

The panel recommended that legislation be drawn up, which task was given to Véronique Hivon, who was the Minister for Social Services and had been a central figure in the process right from the beginning. She produced Bill 52, "An Act Respecting End-of-Life Care", which was tabled in the National Assembly and given two months of hearings and consultations, then approved in principle.

2014 The bill was critically examined by the health-and-social-services committee of the Assembly. Fifty-seven amendments were made, the most significant being that aid in dying was restricted to people who were "at the end of life" ("en fin de vie"). Duty-to-live thinking had spread from below the 49th parallel – where the state laws all confine aid in dying to people who are within 6 months of death – to a jurisdiction above the border.

On June 5 the revised Bill 52 was passed into law, by a vote of 94 to 22.

Court Challenges

Meanwhile, back in the rest of the country, reform seekers were giving up on the federal legislative process. They turned once more to the court system.

1992 The first court challenge had been made by Sue Rodriguez, initially in the Supreme Court of BC and then in the Supreme Court of Canada. She contended that the law which denied her the right to assistance with suicide was unconstitutional because it violated sections 7, 12 and 15 of the Charter of Rights and Freedoms. The BC courts rejected her claim and ultimately the national court did the same, though the decision was close – 4 judges supported her, but 5 did not.

2011 The BC Civil Liberties Association began working with veteran human-rights lawyer Joe Arvay on a challenge to the constitutionality of the laws that criminalized aid in dying. The process began in the Supreme Court of BC.

BCCLA was a public-interest plaintiff, serving as a voice for all the unidentified people to whom the current law could cause suffering or was already causing it.

The main individual plaintiff was Lee Carter, one of Kay Carter's daughters (she is the Carter referred to in citation forms like "Carter v. Canada"). She was joined by her husband Hollis Johnson and Victoria doctor William Shoichet.

Before long an ALS patient named Gloria Taylor added herself to the group. Having heard about the challenge via media reports, she phoned BCCLA and said "You folks need somebody like me!" Lee and Hollis had accompanied Kay to the Dignitas facility in Switzerland, and were suffering anxiety about possibly being prosecuted for assisting a suicide, but Gloria was suffering anxiety about something much more frightening and much more likely: a terrifying death from respiratory failure, with her mind still crystal clear.

The Attorney General of BC and the Attorney General of Canada were "the other side" of the case, arguing that the existing laws should remain in place. The presiding judge was Lynn Smith.

The trial ran from November 14 to December 16, in Vancouver. Ten expert witnesses spoke, and responded to questions from Smith; in addition, she was given thousands of pages of written submissions.

2012 After digesting all that she had heard and read, Smith presented her 395-page ruling on June 15. She had been convinced that "the Criminal Code provisions regarding assisted suicide have a more burdensome effect on persons with physical disabilities than on others", which violated their equality rights under Section 15 of the Charter of Rights and Freedoms.

The existing laws were also seen to violate Section 7, which states that "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice". Regarding Gloria Taylor, for instance, "the legislation affects her right to life because it may shorten her life. Ms. Taylor's reduced lifespan would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted."

Smith ordered a selective suspension of the offending law, but allowed a one-year "stay of execution" so that Parliament would have time to draft suitable replacement text.

To Taylor, however, she granted an immediately-effective constitutional exemption. "She will be permitted to seek, and her physician will be permitted to proceed with, physician-assisted death under specified conditions."

Within a month the Attorney General of Canada appealed Smith’s ruling to the BC Court of Appeal.

2013 The appeal was upheld, on procedural rather than substantive grounds – 2 of the 3 judges considered that Smith had not had the authority to reconsider the question on which the SCC had ruled in the Rodriguez case.

2014 In mid-October, BCCLA made a counter-appeal to the Supreme Court of Canada.

2015 On February 6, in a unanimous decision, the Court upheld their claim – it struck down the impugned laws, to use a delightful piece of legal jargon.

Like Smith, they had been persuaded that a law which was supposed to lengthen lives could actually shorten them instead, because people who were losing abilities would exit early, while they could still manage the act without help.

Back in 1993, when the Court had considered and rejected the challenge brought by Sue Rodriguez, there was only one country – Switzerland – where laws made assisted death legal (or at least not illegal, provided that only unselfish motives were involved). The 5 judges who ruled against Sue had been concerned about the lack of evidence regarding the effects of legalization.

By 2014, abundant evidence had accumulated. Five countries and six American states had legislation or a close substitute (e.g. a court ruling).

The most impressive data came from a 2007 study by Peggy Battin and others. The researchers examined statistics from two decades in the Netherlands and almost a decade in Oregon. They found no evidence that legalizing death assistance had adversely affected "the vulnerable" (e.g. women, minors, blacks/ethnics, the undereducated, the poor, the uninsured, the elderly, the disabled, and the chronically ill). Instead they found that the people who had used the enabling laws out of proportion to their numbers in the population as a whole enjoyed "comparative social, economic, educational, professional and other privileges" (e.g. they were well-off well-educated males).

To replace the invalidated laws, the Court suggested a system involving the twin pillars of the policies in the three European countries which already had formal legislation (Belgium, Luxembourg and the Netherlands): an irremediable condition, and intolerable suffering.

Like Justice Smith in BC, they allowed a one-year suspension of the invalidation. (It later turned into a one-and-a-third-year suspension, since time had been lost because of an election campaign and a change of government.) During that time, people wanting release would be allowed to request an exemption from a superior court in their region.

Guidance for Professionals

2016 Early in the year, as the original death-date for the old laws approached and the new government had not managed to produce replacement laws, professional bodies such as colleges of physicians and surgeons drafted documents with titles like "Interim Guidance on Physician-Assisted Death" (this was how the Ontario college described its first effort, posted on January 11). The central terms in the SCC's ruling – such as "competent", "consent", "grievous" and "intolerable" – were explained and amplified to help doctors feel more confident that they would be proceeding along the lines envisaged by the Court.

Guidance from Regional Courts

2016 On January 15 the Supreme Court extended the government's grace period from February 6 to June 6. Requests for exemptions would continue to be allowed, and some superior courts decided to articulate rules concerning such requests.

Ontario's document, made public on January 29, said "the Court may require that notice of the application be served on the applicant's spouse/partner, children, parents, grandparents, siblings and any other person who will be affected by the order sought." But if the net is cast so very broadly, it will almost always contain at least one person whose first priority is to postpone their bereavement and who therefore wants to obstruct the application.

The document went on to make people responsible for bringing about their death themselves – by whatever slow or crude methods were still available to laypeople – if they were physically capable of doing so.

Rulings by Judges

2016 The first exemption application was made by Hanne Schafer, a Calgary woman who was in a very advanced stage of ALS. The Alberta Court of Queen's Bench held an expedited hearing and found that her situation was in line with the Supreme Court's thinking. They granted her request, but no Alberta doctors were willing to provide the help that had been permitted. However, two BC doctors stepped in, and Schafer died on March 1.

In mid-March a Manitoban was granted an exemption by Chief Justice Glenn Joyal.

On March 17 Justice Paul Perell of the Ontario Superior Court granted an exemption to an 81-year-old man who was in an advanced stage of lymphoma. Perell was clearly a different kind of person from the author of Ontario's January 29 document – he became visibly emotional at times, as he read out his judgment in the courtroom. The man's doctor was willing to provide euthanasia and did so very soon after the court decision, as the man strongly desired.

On April 1, BC Chief Justice Christopher Hinckson authorized a multiple-sclerosis sufferer to receive euthanasia. He also authorized two nurses to help (they had sworn affidavits in support of the applicant), and two pharmacists to dispense the necessary drugs.

The next case was very dramatic and controversial. A woman who was being referred to as E.F. had applied to the Alberta Court of Queen's Bench in April and received an exemption on May 5. She had suffered intensely for eight years from painful and disabling muscle spasms which doctors had not been able to treat effectively. Unfortunately they had also been unable to classify her condition as one of the standard neurological diseases, which meant that it had been labeled as psychiatric. (Current practice is to use "psychiatric" as the diagnosis of last resort, in much the same way as non-medical classification schemes use "Misc." or "NEC" (Not Elsewhere Classified)).

Even more unfortunately, Parliament was in the midst of considering Bill C-14, which Justice Minister Jody Wilson-Raybould had drafted to regulate the practice of medical aid in dying (MAID). This bill contained several restrictions which had not been recommended by the Supreme Court but which Wilson-Raybould wanted to include because she felt that without them Canada's policy would be too broad. She had decided that applicants whose suffering stemmed solely from a condition labeled as psychiatric should be barred from receiving MAID.

She therefore appealed the May 5 decision (wearing her Attorney General hat). The BC government also lodged an appeal, since the doctor who had agreed to help E.F. was in BC.

On May 17 the Alberta Court of Appeal denied the appeals and went on to give Wilson-Raybould a severe scolding. Government lawyers had pointed to certain passages in the SCC ruling as indicating an intention to bar psychiatric patients, but the Appeal Court said the passages had been used out of context.

The court continued by condemning, even more strongly, the government lawyers' attempts to show that the ruling suggested restricting MAID to the terminally ill. One of the plaintiffs (Gloria Taylor) had indeed been terminally ill, but the judges said that the SCC's thinking had not been confined to her situation – they were ruling on behalf of all the people who were encompassed by their summary, namely those who were suffering intolerably from an irremediable condition.

In a final rebuke the Appeal Court wrote that the SCC "did not intend [exemptions] to be an adversarial process. Can it be said to be in the public interest to have the Attorney General of Canada (Jody Wilson-Raybould) assume the role of adversary when she is not satisfied that the application meets the Carter 2015 criteria? We do not think so."

Study Panels

At several points along the road to MAID, committees of academics and other experts were set up to gather information and make recommendations.

2009 In late October (shortly after the Quebec doctors' bombshell, though the timing may have been coincidental) the Royal Society of Canada announced the commissioning of a 6-member panel on End-of-Life Decision-Making. Headed by an ethics professor from Queen's University, it included experts from Scotland and the Netherlands, along with Canadians.

Its recommendations were released in 2011. The two most noteworthy were:
(a) that Canada allow euthanasia, following the European policies instead of the American ones (which allow only self-administered death-hastening, a.k.a. assisted suicide), and
(b) that Canada refrain from denying access to people whose suffering was not likely to end naturally within 6 months, again following Europe instead of the US.

2015 In mid-July, almost halfway through the grace period which the SCC had provided for the drafting of new laws, the federal government (a Conservative one at that time) set up an External Panel on Options for a Legislative Response to Carter v. Canada. Two of the three members were vocal and long-standing opponents of aid in dying. Submissions were received and visits to the US and Europe were made, with a view to presenting recommendations "in late fall". However, on October 19 a Liberal government replaced the Conservative regime which had set up the panel. The new Justice and Health ministers extended the panel's deadline but said that only a summary of findings was now wanted, instead of recommendations.

In mid-August, another panel was set up, with strong support from Ontario but with representation from all the territories and all the other provinces except BC (which described its status as "observer"). It was called the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying. In its report, presented on November 30, it made 40 detailed and helpful recommendations. Some of them dealt with fears that doctors might be quite justified in having – e.g. #36, "Provinces and territories should prohibit any requirement by institutions that physicians refrain from the provision of physician-assisted dying external to the non-participating institution. In addition, employment conditions or privileges should not be negatively impacted in any way."

2016 As the new year began, a committee of both houses (the Commons and the Senate) began work on recommendations for new laws. The Special Joint Committee on Physician-Assisted Dying reviewed the findings of the External Panel but they also took input from a broad sample of groups and citizens. Their report, published on February 25, envisaged a very generous and compassionate system – so much so that some members of the committee stepped away and issued a dissenting report.

Federal Legislation

2016 On April 14 the Justice Minister, Jody Wilson-Raybould, introduced Bill C-14, setting out the permissions and restrictions which she and her co-writers had decided upon. The restrictions included several which had been absent from the policy suggested by the Supreme Court.

The most startling was a very retrograde limitation to applicants whose death was "reasonably foreseeable". Wilson-Raybould denied that she was adopting the terminal-illness criterion which is used in American states, but frightened doctors and the lawyers who advised them did not react with relief. They thought "We know what you mean, regardless of what you say".

Wilson-Raybould said that her "toughness" was intended partly to keep suicide from becoming normalized. But the normalization of X is a bad thing only if X itself is inherently a bad thing, and suicide can sometimes be a wise and good choice.

Another defense of her restriction involved the familiar mantra about protecting the vulnerable. But she could not have really thought about the protection process. Applicants do need protection from impulsivity and misinformation and personal or social pressure, but these protections are provided quite well by requirements which are always written into MAID laws (waiting periods etc.). Applicants are not protected by being made to suffer for six years instead of six months because they are unlucky enough to have a slow-moving disease. One is reminded of the old line "With friends like that, who needs enemies?"

True, terminal-illness policies do protect some people. They protect doctors. When doctors write prescriptions or inject drugs for a person who is at death's door, they can neutralize any psychological discomfort they might feel by telling themselves "I didn't really do anything – the person was dying anyway."

Lack of thinking inclines policy-makers towards terminal-illness requirements in another way too. Until something makes them ask questions, most people believe (or at least feel) that life is not just a right but a duty. They look down on what they regard as "leaving early" in the same way they had looked down on their schoolmates who skipped the last class of the day because they disliked the subject matter.

The Supreme Court judges were sophisticated thinkers and had broken free from the uncritical acceptance of life as an obligation. It probably never occurred to them to consider life a compulsory course. But many elected politicians are in close touch with "ordinary folks" who have not yet challenged the assumptions and attitudes that have come down to them from their ancestors. Indeed the politicians themselves may still be entangled in these mental cobwebs. So when they write or re-write laws, they do obeisance to the duty they still feel.

There were three other restrictions that had been chosen by Wilson-Raybould but had been left unaddressed by the Court or had been disagreed about by study panels. They were:

(a) the disallowing of advance requests (e.g. "give me euthanasia as soon as I deteriorate to Stage X, even if I am no longer able to see my need for it");

(b) the exclusion of all people under 18, even ones who had been judged to possess perfectly adequate decision-making capacity; and

(c) the exclusion of people whose suffering resulted solely from a condition currently labeled "mental", no matter how unlikely it was that treatment would ever succeed.

These three topics were assigned to the Council of Canadian Academies for investigation, with a report being due at the end of 2018.

Many members of the Senate found fault with the Commons version of the bill, and proposed amendments which showed an admirable clarity of thought and warmness of heart. But in the end the upper chamber deferred to the elected house.

Bill C-14 became law on June 17.

Moving On

Like many laws, the MAID law is a work in progress.

2016 The first revision attempt got started a mere 10 days after C-14 was passed. The British Columbia Civil Liberties Association, together with a 25-year-old woman who has spinal muscular atrophy, announced a challenge to the constitutionality of the law's reasonably-foreseeable-death requirement.

Julia Lamb, the individual plaintiff (BCCLA is a public-interest plaintiff, as it was in the Carter challenge), is not yet at the stage where she would prefer death to life – she has a fulfilling job as a marketing assistant for a fashion company, and a close network of friends and family. However, she experiences frequent pain from muscle contractures, she has breathing difficulties, and she suffers from falls which cause broken bones on account of her severe osteoporosis. These difficulties will increase – her disease has no cure – and she fears a time when she would have no independence at all and would not even be able to express herself. She would be greatly comforted by knowing that she herself could decide how much suffering was too much.

The case is starting in the Supreme Court of BC, like the Carter case before it. The lawyers are not charging fees but there are other costs which are unavoidable. A crowdfunding campaign to raise money for those costs met its goal of $75,000 just 10 days after the challenge was announced – clearly, C-14 is producing fear in many people besides Julia.

2017 Although rulings by judges tapered off after the passage of legislation, they did not end.

A.B., a 77-year-old Ontario woman who had suffered from intractable erosive osteoarthritis for over 30 years, had been assessed by her doctor as qualifying for MAID. But over a month went by before an additional doctor also found the woman to be qualified, and in that time the first doctor became reluctant to provide MAID. He feared that the law's requirement about reasonably foreseeable death might be interpreted in a way that would expose him to prosecution.

Lawyer Andrew Faith applied to Justice Paul Perell for clarification. On June 19 Perell ruled that A.B. did indeed meet C-14's requirements, even though her condition was not fatal and she was not terminally ill. He wrote "the language reveals that the natural death need not be connected to a particular terminal disease or condition" but rather "is connected to all of a particular person's medical circumstances", and a MAID provider "need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime."

Wilson-Raybould had actually said almost the same thing herself, responding to a question in the Commons on April 22 2016: "To be clear, the bill does not require that a person be dying from a fatal illness or disease, or be terminally ill." She said that even though spinal stenosis is not usually fatal, Kay Carter would have qualified because of her age, her general frailty, and the fact that her condition was deteriorating. C-14 itself states that reasonable foreseeability can exist "without a prognosis necessarily having been made as to the specific length of time that [the person has] remaining."

In early August A.B. received MAID, with her family gathered around.

There was some positive "fallout" from Perell's ruling. B.C. Parkinson's sufferer Robyn Moro had spoken with Dr. Ellen Wiebe in March about MAID, but initially Wiebe had been using "five years" as her rough guideline (this was what actuarial tables said about spinal stenosis, Kay Carter's condition). From actuarial tables she learned that Moro could live more than five years, so she reluctantly said No.

Perell's ruling about A.B. sent Wiebe back to the actuarial data, from which she learned that A.B. could have lived ten years. Moro's situation now looked quite different to her, and she provided MAID to Moro on August 31.

The problems are not confined to people who are disqualified (or may be thought to be disqualified) by the current version of the law. Even people who do qualify have sometimes found it difficult to access their rights.

(1) The law requires that a person's signature on a MAID application form be witnessed by two

independent witnesses. But many applicants are very isolated and have contact only with close relatives or other people who would not be "independent" according to the law. Dying With Dignity, the other Canada-wide r-t-d group, set up a system through which DWD members could visit applicants and serve as witnesses to their signature (such witnessing only involves certifying that the name was written by the person who has that name). As of Dec. 31 2017, 320 people have benefitted from this service.

(2) Doctors are not obliged to provide MAID if they have a conscientious objection to the practice, but they are supposed to refer the patient to another doctor who does not object. Initially, governments tried to facilitate this by creating a list of willing doctors and publishing a phone number which unwilling doctors could call in order to find a provider for their patient. But doctors did not call – in their eyes, referring was just as wrong as providing. In Ontario, some doctors even initiated court proceedings against the College of Physicians and Surgeons over its requirement that unwilling doctors "provide an effective referral". The next strategy, being tried by Ontario since the summer of 2017, was to allow patients themselves to call.

(3) A related problem arose when whole facilities, not just individual doctors, claimed the right to make MAID unavailable. Usually these were "faith-based" institutions such as Catholic hospitals.

2017 On May 29 the board of St. Boniface Hospital in Winnipeg approved a policy that would allow MAID in certain rare circumstances. "Rare" won't do, said the Catholic Health Corporation of Manitoba. The next day, CHCM held a special board meeting and added 10 new members to the board. A second vote, on June 12, established a no-MAID policy.

MAID assessments were permitted, but approved patients had to be transferred out of St. Boniface in order to receive the service. Such transfers cause distress and harm to the patients, some of whom die "naturally" (but not always gently) soon after being moved.

This was what had happened to Horst Saffarek of Comox BC in December 2016. The only hospital in his area, St. Joseph's, had a no-MAID policy. So when Saffarek was found to qualify for MAID, and clearly chose to receive it, St. Joseph's had him put into an ambulance and driven to a hospital in Nanaimo, an hour and a half away. He died the next day, in relative peace though without MAID, but his end-of-life experience had included substantial turbulence that should not have been necessary.

NEWS OUTSIDE CANADA

AUSTRALIA

Legislators Do It Again

The right to choice in dying has often been established via referendums or court rulings. But elected bodies have done their part too.

In 1996 the legislature of Australia's Northern Territory passed the Rights of the Terminally Ill act, in 2013 lawmakers in the American state of Vermont passed the Patient Control and Choice at the End of Life act, in 2014 Quebec's National Assembly passed "An Act Respecting End-of-Life Care", in 2015 the California legislature passed the End of Life Option act and in 2016 the city council of Washington DC passed a Death With Dignity act.

In 2017 the Australian state of Victoria became another member of the club, when its legislature passed the Voluntary Assisted Dying bill on November 22.

Dedicated and charismatic political leaders often played a large role in these events: Chief Minister Marshall Perron in the Northern Territory, Governor Peter Shumlin in Vermont, "MNA extraordinaire" Véronique Hivon in Quebec, and Premier Daniel Andrews in Victoria. Shumlin had even campaigned on a promise to work for patient-choice legislation.

California was different, as it often is: the charisma there came from a citizen, young brain-cancer victim Brittany Maynard, who had to leave her home in California and move to Oregon in order to have the end-of-life option that she wanted.

Both shamed and inspired, California politicians finally did what was needed. A bill introduced on January 21 moved with surprising speed through the Senate Health Committee, the Judiciary Committee, the Appropriations Committee, and the full Senate. Governor Jerry Brown signed it into law on October 5.

In Victoria as in Quebec, the medical community – the Royal Australian College of GPs, and palliative-care doctors – supported change: "Palliative care and voluntary assisted dying are not, and should never be, mutually exclusive. They can co-exist."

Other Australian states may be close behind Victoria. A week before Victoria's success, an assisted-dying bill failed in the New South Wales upper house by just one vote. And in Western Australia, Premier Mark McGowan is a strong supporter of VAD. Stay tuned . . .

EUROPE

Posthumous Activism

A Swiss woman named Alda Gross had concluded in 2005, at the age of 74, that her life was going downhill and would continue to do so. She was not terminally ill, or even stricken with a fatal disease, but she was being made miserable by numerous distressing indicators of bodily breakdown.

A "do-it-yourself" suicide attempt was unsuccessful. Afterwards she was given psychiatric treatment and persisted with it long enough to be declared competent, which in Switzerland is the core legal requirement "on the recipient side" of the assisted-suicide situation. (The other requirement, which is "on the provider side", is an absence of selfish motives.) Her desire to die remained strong and she approached several doctors, asking to be prescribed a lethal dose of pentobarbital, but none of the doctors complied. They were taking guidance from the Swiss Academy of Medical Sciences instead of from the law. The Academy is a private foundation without power to set real law, but its "guidelines" are influential and they include a recommendation that assistance with suicide be confined to people who are close to death.

After being turned down by many doctors she made applications for barbiturates to various authorities in 2008 and 2009 but none of her applications succeeded.

She then turned to the courts. The Administrative Court of the District of Zurich rejected her claim on November 22 2009. The federal court also ruled against her, on April 12 2010.

On November 10 2010 she turned to the European Court of Human Rights, alleging that the Swiss Confederation had breached her right to decide how and when her life should end, a right she enjoyed under Section 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms.

The application was allocated to the Second Section of the Court on January 5 2012, and given priority.

On May 14 2013 the court ruled that there had indeed been a violation of Article 8 because Swiss law did not provide sufficient clarity in its guidelines on aid in dying. The language of the ruling showed substantial compassion for Gross: "the uncertainty as to the outcome of her request in a situation concerning a particularly important aspect of her life must have caused the applicant a considerable degree of anguish".

On August 12 2013 the Swiss government requested the referral of the case to the Grand Chamber of the court and the request was granted on October 7.

On January 14 2014 the government informed the court that Gross had died on November 10 2011. She had turned to the support group Exit Deutsche Schweiz and had finally received the help she wanted.

Her lawyer told the court he had not heard about her death because he only had indirect contact with her, through a retired pastor who volunteered as a spiritual advisor with Exit and had been Gross' companion when she received assistance with suicide. Gross had told the pastor not to let the lawyer know of her death because she wanted the proceedings in her case to continue "for the benefit of other people in a similar situation."

Completed Lives

A December 2013 article in the *Journal of Medical Ethics* reported on a study in which 2000 Dutch people were asked whether aid in dying should be available to those who are physically healthy but feel that they have "finished their meal" – their life is complete, and everything evokes the response "been there, done that".

One in five respondents thought that such people should be allowed to make a graceful exit. These respondents tended to be "more highly educated, have less trust in their physicians to comply with their wishes, and more often prefer to make their own health decisions rather than allowing physicians to make them."

This opinion is not confined to the Netherlands. Two British women – one 89, and one 99 – traveled to Switzerland in 2014 to receive assistance with suicide because they could not find joy in life any more, or felt that the world was becoming the kind of place they did not want to be in.

Some people also dislike the idea of becoming a burden to their families or to the state. Usually the reaction to this is "Oh, you mustn't feel that way!" But although it is true that we shouldn't mandate altruism, forbidding it seems rather extreme. It is an important part of their self, for some people.

75-year-old Englishwoman Gill Pharaoh was such a person. A former nurse, she did not want to be "an old lady blocking beds in a hospital ward." Because assisting a suicide was still illegal in her country she also said "I have had to make my exit while I am in my right mind and capable of doing it without too much assistance, because I am afraid of compromising the people around me whom I love."

Although still healthy on the whole, she had been through a severe attack of shingles and had started to suffer from tinnitus. "I simply do not want to follow this natural deterioration through to the last stage." The Swiss organization Lifecircle, in Basel, accepted her for an AVD (Assisted Voluntary Death) and provided the service on July 21 2015. Her partner John Southall said he had put a lot of questions to her over the years about her concerns, but he agreed with her logic. "Choosing the time you die is a human right, who should deny us that?"

Greener Grass

French people do not yet have legal access to aid in dying, but as "citizens of Europe" – holders of a European-union Health Insurance Card – they have been travelling in large numbers to nearby Belgium to receive euthanasia. In 2016 Dr. Olivier Vermylen, in Brussels, told the newspaper *Sudpresse* that in his hospital French patients made up 7 out of 15 cases of assisted suicide.

UNITED STATES

Colorado

On November 8 2016, Colorado voters passed Proposition 106, the End of Life Options Act, via a ballot connected with the presidential election. Support was high – 65% to 35%, or 2 to 1. Multi-year efforts in the state legislature had been unsuccessful. Fifty-six percent of Colorado physicians support the option, according to the Colorado Medical Society.

FOOD FOR THOUGHT

(Column by Ruth von Fuchs)

At the Front of the Bus

Picture a tour bus full of people, wending its way through the countryside. Most of the passengers are sitting in the seats along the aisle, where they have a side window and can only see the place where the bus is at the moment. But some passengers are sitting close to the driver and can look through the windshield. Unlike the rest of the passengers, these people can tell where they are going.

Suppose they see that the bus is descending into a dark valley from which dense black fumes are rising. They will shout to the driver "I don't want to go to that place! Let me off the bus!"

Until a few decades ago, people on the bus of life seldom had a good idea of what lay ahead. Most riders simply continued with their customary approach to healthcare: when they didn't feel well, they went to the doctor, and did whatever they were told to do.

However, although twentieth-century advances in medical science did a good job of extending lifetimes, they also extended deathtimes. More and more people witnessed a parent or a spouse or a friend dragging themselves through a long drawn-out departure because both they and their doctors assumed that the proper thing to do was to fight death off as long as possible. A person who did otherwise would have felt like an impertinent upstart.

Those sadder and wiser witnesses did become impertinent, though. Having glimpsed where they themselves might be heading, they began to ask if they really had a duty to live. Was life like high school, where the truant officer will come after you if you don't attend, unless you have a doctor's note? Or was it like college – if a certain course or program lets you down, you can drop that course or drop out of that program?

The fabled sixties led into the seventies, and impertinence flowered. In developed countries, the right to refuse treatment was established, often through court cases. In Canada, ending your life yourself – suicide – stopped being a crime in 1972. Being able to have an expert end it for you when the time was right – euthanasia – began to strike many people as an even better idea, and they said so to Gallup pollsters.

Half a century later, Canadians are almost in the situation of not having to stay on the bus if they don't like the looks of its destination. And modern technology is helping people to see ahead more clearly than they otherwise would: American doctor Angelo Volandes has produced several short videos about treatments such as CPR (cardio-pulmonary resuscitation) which patients often misunderstand because they have only learned about them via television that was designed to entertain rather than to educate. Patients who see Volandes' videos write their advance directives differently from patients who have only seen text about the treatments (January 2013 issue of *Journal of Clinical Oncology*).

Why did I write that Canadians are "almost in the situation of not having to stay ..."? Because the first edition of our law does not let people avoid suffering, it only lets them escape it once they are in it. Usually, however, forethought and avoidance are seen as commendable behaviors. We let car-drivers do up their seatbelts before they see a car coming over the crest of a hill in their lane, and we let women use contraception in preference to abortion.

What is different about "therapeutic homicide" (to take a phrase from the editorial in the June 2012 issue of *Canadian Medical Association Journal*)?

Ending the life of another person is psychologically difficult, and it may well be even more difficult for doctors than for laypeople. One doctor with whom I was exchanging e-mails wrote "Suffering makes all the difference." So people who want to be looked after by another person may have to stay on the bus until it enters the mire and smoke of the dark valley.

But people who are willing to look after themselves could be allowed to act pre-emptively – get off the bus before it crashes. Their fellow passengers would talk with them, helping them make sure that the bus was indeed going to where they thought it was, and perhaps discussing what would be a good time to open the door. Sufferers-to-be might be quite willing to put up with a little "butting in" by kindly bureaucrats in exchange for getting access to good drugs and clear instructions, plus companionship at the critical moment if they want it.

In case lawmakers are inclined to drag their feet, questioning whether anticipatory suffering is a serious problem, here's another analogy from the transportation field:

Imagine a maiden who has been tied up by a villain and placed on railway tracks. Her eventual suffering may not last long if the villain has had the grace to position her so that the train's wheels will roll over her head. But she will suffer dreadfully in advance, from the moment she hears the train's whistle in the distance and feels the rails begin to vibrate beneath her.

WHAT WE'VE BEEN UP TO

(Report by Ruth von Fuchs)

Conferences

At the 2014 conference of the World Federation of Right to Die Societies, in Chicago, we were represented by Orillia member Marlene Caryl. She listened as a proud Canadian while Véronique Hivon outlined the path Quebec had followed in establishing the right to medical assistance with death.

She was very impressed by Australian doctor Rodney Symes' enlightening presentation on dementia. In a related session, British and European delegates led a discussion of the "old old" -- people (mostly female people) whose bodies are crumbling and who are increasingly begging their doctors for help in achieving a dignified end to their lives.

Halfway through the conference, protestors from Not Dead Yet blocked the main doors of the hotel and disabled all four elevators. This was very disruptive but it clearly showed everyone just how much fear and hurt exist "on the other side" of the death debate. Let us hope that governments will continue working towards policies that reduce the considerable anxiety now being felt by people in many different situations.

In June of 2017 I attended – at my own expense -- the first conference of CAMAP (Canadian Association of MAID Assessors and Providers), in Victoria. I was struck by the tremendous diversity in policies among the various jurisdictions and regions of Canada. I say "regions" because some areas, notably Vancouver Island, are distinct even within their province. I had lived on the island 45 years ago and clearly it is still the same quirky independent place that I remember, bless its heart.

At present all this diversity leads to what verges on injustice. But there is an awareness that policies should eventually be made more consistent, and the period during which we let a thousand flowers bloom will have been useful for helping us see which policies are "keepers".

In September (again paying my own way) I went to the other side of the country – Halifax – for the Second International Conference on End-of-Life Law, Ethics, Policy and Practice (ICEL2 for short). The "menu" was vast – concurrent sessions on dozens of topics, with a few plenary sessions involving panels of four or five speakers. I concentrated on sessions about how to improve the situation for people with mental illness, my current focus.

Submissions

At several points in the period following the Supreme Court's ruling there were opportunities for citizens to present their thoughts and concerns, and I took advantage of them. The documents I wrote are on our website, righttodie.ca. The path is:

Researchers' Buffet
  Laws / Proposals
    Canadian
      Proposals

Helping Researchers

MAID is a popular topic among scholars, and several of them contacted us asking to be put in touch with people who were trying to use MAID, or with surviving relatives of people who had used MAID. We were able to facilitate quite a few connections.

Helping Doctors

When I thought about a "conscientious objector" being replaced by a "conscientious supporter", for a given MAID recipient, it occurred to me that the replacing doctor might often have to travel quite a distance. I wondered how such doctors were being compensated.

I learned that in some places they were not being compensated at all. One doctor had made trips lasting 4 hours, 7 hours, 8 hours and 12 hours but had not been paid for any of that time, and had been told that no payment would ever be forthcoming.

RTDSC had a respectable bank balance (thanks to lower printing and postage costs, with more and more members getting e-mail and also – alas – thanks to me writing fewer and fewer newsletters) so I felt that we could and should do something. I contacted the various Colleges of Physicians and Surgeons, as well as some regional Health Authorities, saying that RTDSC stood ready to pay for time and gas (or ferry tickets or whatever) in cases where the government was refusing to pay.

In late 2016 and early 2017 we paid for 19 trips by 5 BC doctors, for a total of $11,207.82.

This fact became public knowledge on July 3 2017, when *Globe and Mail* Health Reporter Kelly Grant included it in an article about difficulties being experienced by MAID-providing doctors. The article was read by at least two people, both of whom phoned me because Grant had referred to us as a charity. They had wanted to donate, and one even had a suggestion: put a "Donate" button on our homepage. But after I explained that the reference had just been a bit of hastiness on Grant's part, the conversations came to an end.

Of course many other people would also have read the article, and awareness of this fact may have caused a little embarrassment in places where it was productive. Starting from November 15 2017, MAID-providing doctors in BC will have their travel time and costs covered ...

PRACTICALITIES

(column by Ruth von Fuchs)

This is the column in which I discuss recent developments in "self-deliverance" (the phrase is still part of the full name for Nu-Tech, which is "New Technology for Self-Deliverance"). Canadian readers may be asking "Why do we need to think about do-it-yourself suicide, now that aid in dying is legal in Canada?"

The answer is that all the constraints which currently apply to euthanasia also apply to assistance with suicide – death reasonably foreseeable, mental illness a disqualifying condition unless accompanied by a satisfactory type and degree of non-mental illness, and so on.

Philip Nitschke, who now heads Nu-Tech, has noted that a rebellious spirit is abroad in the land, particularly in the lands of Europe (he has moved to the Netherlands, though he makes frequent visits to Australia). People object to the view that good death is a privilege, a special dispensation, which they have to earn. They appreciate that their fellow citizens want to help them avoid doing something which would be a mistake, by which they mean something which they themselves would later see to be a mistake if there was a "later", but beyond that they want the power to decide for themselves when and how their life should end.

In the summer of 2017 Nitschke announced that a generous bequest had enabled Nu-Tech to offer a $5000 prize to the person who submitted the best new idea for a self-deliverance technique. There was considerable interest and the ideas were presented at a Nu-Tech conference held in Toronto on October 28 (and live-streamed all over the world).

The ideas included:

1) Life Quality Monitor (ongoing computerized analysis of various physiological variables, with heart failure being brought about when values drop below a certain point);
2) Sound-frequency testing of helium purity;
3) Easy-to-produce home-made tools for focusing compression on the carotid arteries;
4) A new method of generating carbon monoxide; and
5) Refinements to the rebreathing technique, in which one's exhaled air is cleansed of its carbon dioxide (a panic trigger) and returned as increasingly pure nitrogen.

The last two ideas shared the prize.

Nitschke also introduced a product he had developed with the help of a Dutch industrial designer. Called the Sarco (a reference to the word "sarcophagus") it is a large elongated clamshell into which a ready-to-die person would climb, then close the lid and start liquid nitrogen flowing over a heating panel that would instantly convert it to nitrogen gas to fill the chamber. The gas would be cool, probably about 5 degrees Celsius by the time it reached the person's face, but this is no worse than a late-fall day (in Toronto anyhow). Death would ensue in a matter of minutes.

To keep up to date with the Sarco and other ideas about self-scheduled death, go to

peacefulpill.com

and look for a term like "PP eHandbook" (Peaceful Pill electronic Handbook), then choose "Subscribe". For $US85 you get two years of bi-monthly online updates.

LAST WORDS

(by Ruth von Fuchs)

John Hofsess, who founded the Right to Die Society of Canada in 1991, had an AVD (Assisted Voluntary Death) at Lifecircle in Basel on February 29 2016. You can read his farewell note here:
http://www.humanistperspectives.org/issue196/hofsess.html
It formed part of *Humanist Perspectives* issue 196. A paper copy of the issue can be ordered for $6.50 from the publisher: Canadian Humanist Publications
PO Box 3769, Station C
Ottawa, ON, K1Y 4J8

As the second occupant of the director's chair, I have tried to preserve the somewhat iconoclastic spirit of the group, and above all to serve our principal goal: supporting and educating people who have been "born too soon" to have a clear path towards a good death.

I intend to go on serving this goal. The number 866-535-0690 will continue to ring in my house (evenings and weekends included) and I will check my email (ruthvonfuchs@gmail.com) every day. When I find helpful facts or important news I will add them to the website (righttodie.ca), initially under New on the Site and then in whatever section is most appropriate.

However, this will be my last newsletter. I am only 3 years younger than John, and although I still have much better health than he did I have developed an incurable neurological disease, myasthenia gravis. It is not yet very gravis, but it does reduce my energy level, and the trend line can only go in one direction.

An excellent source of news about the right to die well is Derek Humphry's message list. It was via this list that I found most of the material which I presented in the *RTDSC Newsletter* and its predecessor *Free To Go*.

To subscribe or unsubscribe via the World Wide Web, visit
http://lists.opn.org/mailman/listinfo/right-to-die_lists.opn.org
or, via email, send a message with subject or body 'help' to
right-to-die-request@lists.opn.org

Right to Die Society of Canada
NEWSLETTER

Editor: Ruth von Fuchs

Address: 145 Macdonell Ave.
Toronto, Ontario
Canada M6R 2A4

Phone: 866-535-0690 or 416-535-0690

E-mail: ruthvonfuchs@gmail.com

Website: www.righttodie.ca

ISSNs:
Print: 1927-6400
Online: 1927-6419