



Right to Die Society of Canada

NEWSLETTER

Vol. 4 No. 1-2 (Jan. 2012 - Jun. 2012)

SOUNDBITE

"Life needs an ESC (Escape) key."

(Newsletter editor Ruth von Fuchs, and probably many others as well)

DATA BIT

The number: 4%

What it is:

60% minus 56%. In a survey of 1669 California adults, 60% of respondents said it was "extremely important" to make sure their families weren't burdened by tough decisions about their care, but 56% had not expressed their wishes to the person who would be making those decisions.

Discussion:

The person with the wishes may not be solely responsible for the disconnect. Spouses or offspring or other potential proxies may have deflected attempts to start a just-so-you-know conversation, in a misguided effort to spare the "worrier". The situation often calls for persistence or even a bit of craftiness.

When published:

February 14, 2012 (Valentine's Day!) in *San Francisco Chronicle*

NEWS IN CANADA

Report of Quebec Committee

The all-party committee which had been holding

hearings throughout Quebec since late 2010 released its report on March 22. The recommendations are notable for their compassion and courage. They also show a practical turn of mind, and awareness about the ways of the world.

Of primary interest for the right-to-die community is the recommendation that medical aid in dying be recognized as appropriate end-of-life care, provided certain conditions are met. Rather than imposing do-it-yourself responsibilities on people who are weak and tired (as in places where assisted suicide is allowed but euthanasia is not), the Quebec thinkers propose that people should be able to receive service, from members of the profession that has served them all their lives.

With respect to qualifying conditions, the recommendations move bravely and humanely outside the mainstream by including people who have constant and unbearable psychological suffering that cannot be relieved by any method they could tolerate.

The committee's "practical turn of mind" shows in several parts of the recommendations about advance directives:

- Such directives should appear in patients' medical files and be recorded in a register
- Doctors should be required to look for patients' directives
- Directives should be allowed to include an instruction that medical aid in dying is to be provided if certain circumstances prevail
- Facilities' quality-and-complaints personnel should regularly check that advance directives for medical aid in dying are being honoured
- An expert committee should be created to look at the possibility that someone who has developed a dementing condition such as Alzheimer's disease

could express a desire to receive medical aid in dying (presumably at a fairly-distant future time, when the person's decline has reached a specified stage).

Practicality is also evident where the committee notes changes that should be made to prosecutorial guidelines and to the ethics codes of medical-professionals' associations. And in the ultimate touch of realism, the committee sets a deadline for the tabling of a bill in the National Assembly: "no later than June 2013".

Wise Decision in BC

After listening to ten expert witnesses, and pondering thousands of pages of written submissions, Judge Lynn Smith announced her ruling in the Carter case, on June 15.

She had been quite persuaded by the arguments of the plaintiffs (who included Lee Carter, ALS sufferer Gloria Taylor, and the British Columbia Civil Liberties Association). They asserted that Section 241(b) of the Criminal Code of Canada, which makes it an offence to assist with a suicide, is unconstitutional because it violates two sections of the Charter of Rights and Freedoms: Section 7, establishing the right to "life, liberty and security of the person", and Section 15, prohibiting discrimination on the basis of disability.

In Sections 1324 - 1329 of her decision, Smith presents a deeply-thought account of how the current law harms people, especially people like Taylor:

"First, they experience a shortened lifespan if they take steps to end their lives sooner than they would feel it necessary to do if they were able to receive assistance.

Second, they are denied the opportunity to make a choice that may be very important to their sense of dignity and personal integrity, that is consistent with their lifelong values and that reflects their life's experience. Further, their ability to discuss and receive support in this choice from their physicians is impaired.

Third, for persons who are physically disabled, they are deprived of a measure of self-worth in that they are denied the same degree of autonomy as that afforded to others.

Fourth, while palliative care including palliative

sedation may relieve the suffering of many, for some persons it may be unavailable (due to the nature of their illness) or unacceptable to them (because they value maintaining consciousness and the ability to communicate, feel that death while under palliative sedation will be difficult for their families to observe, worry that they will in fact maintain consciousness, or for other reasons). Thus, they may be required to undergo physical pain or psychological suffering or both, possibly exacerbated by terrible fear about what is yet to come.

Fifth, they are required to undergo stress. The non-availability of physician-assisted death means that patients cannot obtain an "insurance policy" that they may never use but that gives them some peace of mind and relieves their fear."

Smith wrote "I find the conclusion inescapable that the Criminal Code provisions regarding assisted suicide have a more burdensome effect on persons with physical disabilities than on others." This violates their equality rights as established by Section 15 of the Charter.

Overall, Smith concluded that "the benefits of the impugned laws are not worth the rights limitations they create." She agreed with the plaintiffs' claim that the blanket prohibition on assisted suicide is overbroad and has effects which are grossly disproportional to its objectives.

New laws could achieve the desired objectives by setting out conditions under which exceptions would be made, along the lines of the policies in places such as Belgium and Holland and Oregon. Several expert witnesses had described the experience of those jurisdictions and Smith was convinced that effective safeguards can be designed and enforced.

In Section 1393 of her decision she indirectly presents her sketch of what a new law might say: "(the impugned provisions) are of no force and effect to the extent that they prohibit physician-assisted suicide by a medical practitioner in the context of a physician-patient relationship, where the assistance is provided to a fully-informed, non-ambivalent competent adult patient who : (a) is free from coercion and undue influence, is not clinically depressed and who personally (not through a substituted decision-

maker) requests physician-assisted death; and (b) has been diagnosed by a medical practitioner as having a serious illness, disease or disability (including disability arising from traumatic injury), is in a state of advanced weakening capacities with no chance of improvement, has an illness that is without remedy as determined by reference to treatment options acceptable to the person, and has an illness causing enduring physical or psychological suffering that is intolerable to that person and cannot be alleviated by any medical treatment acceptable to that person.” To protect people like Taylor, by ensuring that Section 15 would be respected, physical disability (present or impending) should be seen as an important additional indicator.

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

To Taylor, however, Smith 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.”

NEWS OUTSIDE CANADA

GERMANY

A Step in the Right Direction

Berlin doctor Uwe-Christian Arnold believes that a patient who is approaching death should be able to choose when and how to meet it. Over the last 15 years he has supported about 200 patients by providing them with drugs which they could use to end their life when they felt the time had come.

The German Medical Society objected to this practice, stating that if Arnold did not abandon it he would forfeit his medical licence and be fined \$60,000.

Arnold lodged an appeal with Berlin’s Administrative Court. On April 2 the court announced it had decided in his favour, saying that to ban doctors from helping the terminally ill would be “against freedom of conscience”, and ruling that the Society’s threat was invalid because the organization had no legal standing.

Indeed, the national society has had less-than-national jurisdiction for quite some time; many of the regional medical societies have declared themselves not bound by its dicta.

NETHERLANDS

Inequities Eased

Theoretically, Dutch citizens have access to medical aid in dying if they meet the legal requirements. But in practice, qualified applicants have often been rejected, because doctors are the gatekeepers of the service.

For instance, one of the requirements is unbearable suffering, but a doctor who is reluctant (perhaps on personal ideological grounds) may decide that the suffering cannot be considered unbearable, regardless of what the patient feels and says. As another example, the doctor may be uncertain about how to interpret the law with respect to a given case, and decide to err on the side of caution.

People in the Dutch right-to-die movement have long deplored this situation, in which innocent people suffer merely because of having Doctor X instead of Doctor Y.

For some patients, a right-to-die group can solve the problem by connecting the person with a different doctor, one who would know and respect the law. But this approach does not work for patients who live in a rural area where the obstructive doctor is “the only game in town”.

Finally one of the groups, the one called NVVE for short, decided that something more had to be done. They set up six teams, each composed of a doctor and a nurse, that could go wherever a needy patient happened to be. March 1 was the start date of the service.

In their initial contact with a patient, the team will begin a process of getting thoroughly informed about the patient’s history and prognosis. They may also connect with the patient’s original doctor, in case a bit of “continuing education” might lead to a change of mind. Team members themselves will have access to an independent consultant (the Netherlands has a service called SCEN that gives doctors guidance

regarding euthanasia cases).

Eventually, if it is verified that the patient does indeed meet the requirements, the team will make a final visit and will administer life-ending treatment according to the normal procedure, usually in the patient's home and with family members gathered around.

UNITED KINGDOM

Report of Falconer Commission

After a year of investigation and deliberation, Britain's Commission on Assisted Dying presented its report to Parliament. The 415-page report was made available on January 4.

It proposes that assisted suicide (but not euthanasia) be made legally available, in cases meeting certain requirements:

- 1) The person is within a year of dying from their disease;
- 2) Two independent doctors are satisfied with the diagnosis;
- 3) The person has been made aware of all their alternatives (in the way of social and medical help);
- 4) The person has not been pressured or been made to feel that they are a burden;
- 5) The person's illness is a physical one, not one that is currently classified as "mental"; and
- 6) The person can self-administer the necessary drugs.

There are obvious similarities to laws that exist in other jurisdictions, such as Oregon. But Lord Falconer, who chaired the Commission, seemed clearer on what he did not recommend than on what he did. Writing in the *Daily Telegraph* on January 2 he said "Commissioners visited the (Dignitas) clinic and spoke to the people who ran it. They did not like much of what they saw . . . But should the UK adopt the model used in Holland? . . . We doubt it . . . And would we want a system that required the ingestion of around 90 capsules of medication in a short period of time, often without the supervision or support of a doctor, as is the case in Oregon?"

UNITED STATES

Good News for Final Exit Network

A February 6 ruling of the Georgia Supreme Court meant that the four Final Exit Network volunteers who were arrested in 2009 (in connection with the suicide of John Celmer) will not have to stand trial. The charges against them will be dismissed.

Georgia does not criminalize assistance with suicide. What it did try to criminalize, in a 1994 law aimed at preventing a Kevorkian-style atmosphere, is making a public advertisement or offer to assist. But the Supreme Court judges unanimously struck down that law, saying it violated freedom-of-speech rights established by both the Georgia Constitution and the US Constitution.

Doctor Uses Law He Helped Create

(Article based on a tribute written by Derek Humphry)

British-born Peter Goodwin began his medical career in South Africa, then emigrated to the US in 1962. In his work with patients he was struck by how powerless they were. In 1990 he joined the Hemlock Society, then in 1992 became chair of the Oregon Right to Die Committee.

The laws proposed during earlier US campaigns, in California and in Washington State, had included euthanasia (e.g. lethal injection) as well as assisted suicide (e.g. prescribing a fatal dose of a drug). Goodwin's understanding of his fellow physicians led him to recommend that Oregon try for a law confined to assistance with suicide. Doctors recoiled from the idea of giving an injection, and would be more likely to accept a law in which they played a remote role – prescribing the lethal overdose but not being present – because in that situation the responsibility lay with the patient.

At an annual meeting of the Oregon Medical Society, Goodwin tried to get the Society's support for the proposed law. He did not achieve that objective but the Society did agree to not oppose the law.

Voters approved the law in 1994 and again in 1997. Since 1998, about 600 citizens have used the Death With Dignity Act. On March 11, surrounded by his family, the 83-year-old Goodwin used it himself. In

2006 he had been diagnosed with corticobasal ganglionic degeneration, a rare disease with no cure and very few therapies to relieve symptoms. Thanks in part to his own efforts two decades earlier, he had the power to choose the time and the manner of his death, once his doctors had confirmed that his disease had progressed to the point where he was likely to die from it within six months.

WORLD

Biennial Conference Held in Zurich

(Overview by Ruth von Fuchs)

The 17th conference of the World Federation of Right to Die Societies ran from June 13 to June 18, with Federation business occupying the first day and the beginning of the second.

Thursday June 14 saw four new societies being inducted into the Federation, bringing the total number of member societies to 48 (from 26 countries). One of the new groups was the Canadian organization Farewell Foundation, based in Vancouver (604-521-1110 or www.farewellfoundation.ca). The other three were Society for Old Age Rational Suicide (Britain), Lifecircle (Switzerland), and Ultime Liberté (France). Lifecircle will accept people from outside Switzerland, as Dignitas has done for many years. Ultime Liberté shares with Farewell Foundation the view that aid in dying can be provided safely and competently by non-doctors who have received the relevant training and acquired the necessary experience.

Thursday also featured speakers from Japan, USA, and the Netherlands, as well as a multi-national panel.

Friday June 15 was Public Day. Several of the speakers were eminent or controversial or both.

Lawyer Roger Kusch, of Sterbehilfe Deutschland (Death-Help Germany), described "Cases of Assisted Suicide in Germany".

Andreas Brunner, Attorney General of the Canton of Zurich, outlined his views on "How the State Should Handle Assisted Suicide". Brunner and Dignitas have often had differences of opinion, it could be said.

Ludwig Minelli of Dignitas made the case that

tragic suicides (and equally tragic failed attempts) are made less likely when society no longer has a blanket prohibition on providing exit assistance. Able to openly seek information and support, people become less isolated and desperate. Quite often they gain enough peace of mind to go on living.

Other speakers included Philip Nitschke ("Real End-of-Life Choice") and Swiss Justice Minister Simonetta Sommaruga ("What Degree of Self-Determination at Life's End?")

For all the presentations just mentioned (and for several others), the full text is available via the website of the World Federation, www.worldrtd.net. In the column that runs along the left side of the homepage, click "Conferences"; on the page which then appears, choose "Zurich". A link to the public-day speeches is given first, and then come quite a few other links that you may want to follow.

Much of the full-text content is in German but Nitschke's speech and Faye Girsh's reports are in English. To find an English version of Minelli's paper, search "referat-wf-kongress" in google.com/ncr and ignore the warning message you receive, or try <http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-wf-kongress-suizidversuche-e-15062012.pdf>

While you are on the site you may very well want to sign up for monthly news-messages from the Federation. Back at the homepage, go once again to the column that runs along the left side, but now click "News". On the page which then appears, use the second block at the right-hand side of the page to give the address you want the messages sent to (you can leave the "Filter" block as it is).

The left column of the homepage also helps you subscribe to the Federation's twice-a-year newsletter (edited by Faye Girsh) and to the almost-daily ERGO message list (prepared by Derek Humphry).

Early on Saturday, news of Judge Smith's enlightened decision (see pages 2-3) reached the participants in the conference. Much rejoicing and congratulating ensued!

The happiness continued through the morning, when Dignitas hosted a tour of its new facility "the blue house" and offered refreshments in the sunny garden. Tour participants were also taken to the Dignitas office and met many of the 15 part-time

employees who keep Dignitas functioning.

Saturday afternoon was devoted to Nu-Tech, the informal “think tank” that connects people in many countries who are working to find new self-deliverance techniques and improve existing ones. Some information from the session is presented in the “PRACTICALITIES” section further on in this issue.

The conference closed with a banquet celebrating the 30th birthday of Exit Deutsche Schweiz, the host group for the conference. As usual, several awards were presented. The Tenrei Ohta Award, for the person who has had the most influence on the global r-t-d movement, was given to Ludwig Minelli of Dignitas. The Canadian honor, the Marilynne Seguin Award, went to Russel Ogden of Farewell Foundation.

FOOD FOR THOUGHT

(Column by Ruth von Fuchs)

In Other Words

“Assisting” suicide is the terminology used by the Criminal Code of Canada, in the section where it describes an offence for which the penalty can be as much as 14 years of prison. The same word is used in the laws of many other jurisdictions.

Unfortunately there are many different notions about what constitutes, or does not constitute, “assisting”.

The most extreme interpretation I have come across involved a man with Parkinson’s who called me to learn about ways in which he could exercise some control over his dying. One step I suggested was that he buy and use a living-will book which was then available – “Let Me Decide”, by Dr. William Molloy. He wanted to write down the details but his hand was shaking so much that he could not manage. He asked his son, who was in the room, to write down the information for him. The son refused, out of fear that he could be accused of assisting with a suicide.

At a less extreme level, the forbidden action is translated as “allowing”. An Ontario ALS sufferer who chose to end his life before enduring the final stages of his disease was fully supported by his family, who notified the authorities after he had exited. The young

police officer who soon arrived was aghast when told that the man had suicided – he cried “And you didn’t stop him?”

A much more common translation is “accompanying”. Many exiters act while their family members are away at work, or they tell their relatives to leave the house for a while and create an alibi by going to a place where they are known to staff and fellow patrons, enabling any investigators to confirm that the exiter did not have companionship and moral support from a loved one.

“Facilitating” is a translation popular with doctors.

When people are trying to end their life by refusing food and fluids, they often have trouble getting a good night’s sleep during the week or so before they lose consciousness. But when they ask their doctor for a sedative (and some useful drugs can be dissolved under the tongue with just one ice chip) the doctor may think “If I do this I will be assisting my patient’s suicide by making the process more bearable.”

Similarly, at least one doctors’ association has forbidden its members to provide patients with their medical records if there is a possibility that the records are wanted for sending to Dignitas.

All these creative translations flourish in the climate of fear created by the current law. People anxious to shield themselves let their imaginations run wild, and recoil in every way they can think of.

But it is futile to try making sense of a prohibition on assisting with a self-administered death. The law itself is nonsense.

Ending your life yourself is a legal act, and by the time you are in a state which makes you consider that act, you may very well need help with it. We are a social species and helping our fellows is one of our most characteristic activities. Under “Humane” my dictionary says “Human; having the feelings and dispositions proper to man; kind; benevolent; tender; merciful”. Humane support in situations of hopelessness and helplessness should be encouraged by our laws, not discouraged.

PRACTICALITIES

(Column by Ruth von Fuchs)

NuTech at the World Conference

“NuTech” is the nickname adopted by a group of informally linked right-to-die workers (myself among them) who are trying to develop “new technology” for self-deliverance, and to refine existing technologies. It has become traditional for the group to meet at the same time and place as the World Federation conference, though usually there is a printed disclaimer making it clear that the NuTech meeting is not actually part of the conference. At the 2012 meeting there was standing room only, in a space that could seat 50. Highlights follow.

A very useful DVD has been produced by Dr. Boudewijn Chabot in the Netherlands. The English version is entitled “Dying at Home with Helium”. It shows one method (the “hem” method) for making a suitable bag/hood, and it also covers how to prepare and use all the other materials (low-pressure helium tank, vinyl tubing, etc.). If you search < dying-at-home-with-helium > in google.com/ncr you will get to a website which can be used for ordering the DVD and for reading some valuable extra information about the method. (The site also lets you order a Dutch or German version, if you prefer – click the appropriate bar near the top of the screen.)

Ordering via the website requires using a bank to transfer the funds (22.50 Euros, which is about US\$30). An alternative is take advantage of a “bulk purchase” made by Faye Girsh. Canadian-dollar cheques will be accepted but the amount should be \$35 to allow for a fee which her bank will probably charge. The cheque should be made payable to Faye Girsh and mailed to her at

#108 - 7811 Eads Ave.
La Jolla CA
USA 92037.

Write “Helium DVD” in the “Memo” area of the cheque. Print your address somewhere too, if it is not imprinted on your cheques.

The disc is designed to be played via a computer, in the CD/DVD drive or via an external disc reader.

Special offer! Faye also has copies of Chabot’s

book “A Hastened Death by Self-Denial of Food and Drink”, which is now out of print. If you make your cheque for \$45 instead of \$35 she will send you the book as well as the DVD. Even if you think you would not want or need to use this method, it doesn’t hurt to be prepared for surprises such as a non-fatal stroke or a change in the attitudes of relatives.

Neal Nicol, from the USA, showed a device he has developed for compressing the carotid arteries to cut off the blood supply to the front part of the brain. Loss of consciousness occurs quickly and will be followed eventually by death if one is not getting oxygen, e.g. if one has enclosed one’s head in an elasticized bag. Some people have died without using a bag but the brain also gets oxygenated blood via arteries that come up from the spinal column and cannot be compressed because they are protected by bone.

Nicol’s device is very high-tech and many people would have trouble getting the necessary parts, which include pediatric sphygmomanometer bulbs. It is also very distinctive-looking, which means that after the third time it was used by an institutionalized person an image of it would be circulated on message lists used by hospitals and nursing homes, with the likely result that the luggage of incoming patients/residents would be searched and the device would be confiscated if it was found.

Carotid compression can also be accomplished via everyday items such as a strong toothbrush and a length of inch-wide sturdy cloth tape, of the kind intended for stiffening the tops of curtains. These items are not likely to be confiscated if they are found during a search conducted in the Admitting Department.

Many of the participants in the workshops given by Chris Docker (in Scotland and England) have made sure that their take-with-me-to-hospital bag contains what they would need in order to end their life by the compression method, if their prospects became very grim and they were unlikely to be able to go home. (Theoretically the method is not restricted to an institutional setting, but practically speaking it is usually seen as a last-resort option.) The latest edition of Docker’s book *Five Last Acts* can be purchased via <amazon.com> for about \$50 US.

Tijn Hagens, of the Dutch group “de Einder” (The Horizon), works with people who qualify according to the spirit of the law, or according to the future law, but perhaps not according to the current letter of the law – e.g. people who feel they have completed their life, or those whose misery stems from an intractable condition which is considered to be “mental”. (Other Dutch groups, and some groups outside the Netherlands, also have expressed concern about such people.) These born-too-soon citizens are informed about exit methods they can implement themselves, such as helium or chloroquine.

Chloroquine is an anti-malaria drug which is available without prescription in several places outside North America, including some European countries which are close to Holland. (The desirability of being able to obtain the drug without a prescription stems from the fact that a doctor is unlikely to prescribe the necessary quantity to anyone who does not seem healthy enough to be planning a six-month stay in Central America or some other place where the malaria parasite has not yet become resistant to chloroquine. But people who are that healthy may not be equipping themselves for an exit, saying “I’ll cross that bridge when I come to it.”)

Since chloroquine may cause convulsions before it causes death, people need special sedatives in addition to it, and of course they also need a strong anti-vomiting drug such as metoclopramide. (The book *Five Last Acts*, mentioned above, gives details about chloroquine use.)

BOOKS

In Search of Gentle Death

(Review by Faye Girsh, June 12)

I am on my way to Zurich and have been travelling around the UK with Richard Côté’s astonishing new book on my iPad. I have gotten through almost all 480 pages and am constantly amazed and impressed with the writing, the organization, the research, and the inclusiveness of this work.

It will certainly be an encyclopedia for our movement for a long time, though it reads like a novel.

It is a testament not only to Dick but to the differences in approach to this question of self-determined, dignified death.

I am proud of him for including all these avenues thoroughly and without the negative implications that we sometimes apply to other people’s work when it is not our own approach. It also more than justifies the existence of the World Federation since there is such a vast, international striving to achieve the same end.

Ordering:

www.corinthianbooks.com or 843-881-6080

Price: \$29.95 US plus shipping

Peaceful Pill Handbook, 2nd Edition

Philip Nitschke, co-author of this book, uses the phrase “peaceful pill” as shorthand for “tolerably reliable and comfortable exit techniques available to laypeople”. Wide-ranging and detailed, like the first edition, this new version covers recent developments.

For a hot-off-the-press level of recency, people can subscribe to the digital version or “e-Handbook”, which will send regular notifications to their e-mail address, telling them which content has been updated since the last notification and allowing them to read whatever new material is of interest to them.

On www.peacefulpill.com people can order the print version or subscribe to the digital version. The print version costs \$40 US and the digital version costs \$85 US for 2 years.

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: ruth@righttodie.ca

Website: www.righttodie.ca

ISSNs:

Print: 1927-6400

Online: 1927-6419