



# Right to Die Society of Canada

# NEWSLETTER

Vol. 3 No. 4 (Oct. 2011 - Dec. 2011)

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## SOUNDBITE

"I don't think people are particularly bothered about death, it's **the life before death** that worries us."

*(British author Sir Terry Pratchett, speaking to the BBC. Pratchett has been diagnosed with early-onset Alzheimer's disease.)*

## DATA BIT

**The number: 0%**

### What it is:

The degree of reduction in the quality and availability of palliative care, in places where aid in dying has been legalized.

Figures from Belgium, Switzerland and the Netherlands were compared with figures from France, Germany and Spain.

### Discussion:

The researchers found that no deterioration in palliative care had followed upon the establishment of formal policies permitting euthanasia and/or assisted suicide.

In some countries, notably Belgium, palliative care and assisted dying are quite closely linked. "In Belgium all palliative-care options must be disclosed to the patient, many institutions demand a palliative-care consultation when euthanasia is requested, and the highest prevalence of euthanasia or assisted suicide is found in palliative-care units."

### When published:

October 24, 2011 in *British Medical Journal*

## NEWS IN CANADA

### BC Legal Challenge

"The Carter Trial", as it has come to be called, ran from November 14 to December 16 in Vancouver.

The name refers to Lee Carter, one of the original plaintiffs. She and her siblings had accompanied their mother, Kay Carter, to the Dignitas facility in Zurich so that Kay could have a dignified death at the time of her choosing. Kay had been a longtime supporter of the right to die and she managed to find both the strength and the money for her last determined act (she tapped her life's savings and sold most of her belongings).

In honour of Kay, and for the sake of the many future Canadians who would be in a similar situation and would need help to implement their last choice, Lee joined with several other people and groups in mounting a challenge to Canada's law on support with suicide.

The other individual plaintiffs were Lee's husband Hollis Johnson (who had travelled to Zurich along with his wife and who shared her anxiety about being prosecuted), Victoria physician William Shoichet, and ALS victim Gloria Taylor. The BC Civil Liberties Association 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 Attorney General of BC and the Attorney General of Canada argued against changing the law.

In the lead-up to the trial, several additional organizations were granted intervenor status. In the "pro-change" camp were Farewell Foundation for the Right to Die, Canadian Unitarian Council, and the Ad-Hoc Coalition for Persons With Disabilities. In the "anti-change" camp were the Christian Legal Fellowship and the Euthanasia Prevention Coalition.

Because Gloria Taylor's condition was quite serious (she had already lived six months longer than her doctors expected), the pro-change lawyers asked that the trial be fast-tracked. The BC Attorney General wanted it to be held off until March of 2012 but Judge Lynn Smith agreed that Taylor's situation justified a speedy hearing, in 2011.

Initially, the BC Attorney General also sought a court order mandating the creation of a list containing the names of all Canadians who were likely to have knowledge about cases of assisted suicide, a list which might well have included many members of choice-in-dying groups such as RTDSC and DWD. People on the list could be required to testify. However, he did not persist with his request.

Although the case took the form of a summary trial – saving time by relying mainly on affidavits instead of witness testimony – both "sides" called several expert witnesses.

Pro-change experts included Dr. Linda Ganzini (an Oregon psychiatrist), Dr. Marcia Angell (former editor of the *New England Journal of Medicine*), Dr. Helene Starks (a bioethics professor at the University of Washington), and Prof. Margaret Battin (a philosophy professor at the University of Utah). Three of the women had conducted research on aid-in-dying practice and Dr. Angell had reviewed many relevant studies during her two decades as NEJM editor. Professor Luc Deliens, a medical sociologist working at the Free University of Amsterdam and the Free University of Brussels, gave evidence via video conference from a Canadian embassy in Europe.

Anti-change experts included Dr. Douglas McGregor (an advocate of palliative sedation as a substitute for aid in dying), Prof. John Keown (Chair of Christian Ethics at Georgetown University), Dr. Jose Pereira (a palliative-care professor at the University of Ottawa), Dr. Herbert Hendin (a psychiatrist with Suicide Prevention International), and Dr. Harvey Chochinov (a psychiatry professor at the University of Manitoba).

You can read detailed and revealing day-by-day accounts of the trial on the website of Farewell Foundation, [www.farewellfoundation.ca](http://www.farewellfoundation.ca).

[On the homepage, choose FAREWELL BLOGSPOT in the coloured square at the top right corner. On the page that then appears, go to the

calendar at the top of the righthand column and click on the double backwards-facing arrow preceding the abbreviated month-name at the bottom of the calendar. Continue going backwards one month at a time until you see the calendar for November. The reports for Days 1 to 10 are there. To get to December, for Days 11 to 21, click the double forwards-facing arrow at the bottom of the calendar.]

## Report of Royal Society Commission

On November 15 the Expert Panel on End-of-Life Decision-Making released its report. The panel's general conclusion was that "Assisted suicide and voluntary euthanasia should be legally permitted for competent individuals who make a free and informed choice that their life is no longer worth living. Canada should have a permissive yet carefully regulated and monitored system with respect to assisted death."

At least two aspects of the panel's thinking are noteworthy:

1) The experts recommended that euthanasia be allowed, in addition to assisted suicide (with euthanasia, people who have become helpless can still obtain release).

The laws that finally passed in Oregon and in Washington State allow only assisted suicide, because strategists suspected that the inclusion of euthanasia was what had doomed several earlier American initiatives. Interestingly, however, it may well be that most Oregonians thought they were voting for both euthanasia and assisted suicide. A 2000 survey of Oregon residents found that only 32% were aware that lethal injection was still prohibited. This study was prompted by a case in which a dying man was suffering unrelievably and his son asked the doctor "Why don't you just give him a shot?" It was reported in the November 15 2000 issue of *JAMA* [*Journal of the American Medical Association*].

2) The panel also disagreed with the Oregon / Washington policy of restricting to the terminally ill. This limitation had been put into the US laws for the same reason that euthanasia had been taken out: increased palatability. For the many people who believe we have a duty to live, it seems wrong to let

anyone leave the field before they are absolutely beaten to the ground. Also, when aid is provided to someone who is very close to death, the providers can comfort themselves by saying "I didn't really do anything, because the person was dying anyway." Finally, as with Point 1 above, the US voters may not have been completely clear on what they were voting for. The laws use "terminally ill" to mean "virtually certain to die within six months", but many laypeople think the phrase is just a useful synonym for "fatally ill" or "incurably ill". It is not uncommon for people who contact RTDSC to say they have been terminally ill with X for Y years.

The full text of the report (117 pages) is available at:

[http://www.rsc.ca/documents/RSCEndofLifeReport2011\\_EN\\_Formatted\\_FINAL.pdf](http://www.rsc.ca/documents/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf)

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## **NEWS OUTSIDE CANADA**

### ***NETHERLANDS***

#### **Release from Dementia**

The Volkskrant news service reported in early November that euthanasia had been provided to a 64-year-old woman who was suffering from "severe senile dementia". She was a longtime supporter of assisted dying and had written down her wishes while she was still competent, though at the time of her death she was no longer able to express herself properly.

25 patients in the early stages of Alzheimer's and other dementias received euthanasia in 2010. The Dutch law confines assistance to people who are suffering severely, but it does not overlook mental suffering. Psychiatric patients who have no prospect of being cured, and people who face virtually certain mental deterioration, can apply for aid in dying.

Many Dutch doctors feel that unrelievable "situational suffering" should also be considered. In a recent online poll conducted by KNMG (the country's medical association), over 68% of respondents agreed with the statement that doctors should be allowed to factor in "vulnerability, loss of function, confinement to bed, loneliness, humiliation and loss of dignity".

## **WHAT WE'VE BEEN UP TO**

### **Not Gone Yet**

(Report by Ruth von Fuchs)

RTDSC members received several letters, from me and from Dying With Dignity, in the first part of 2011. Somewhere in some of this mail there was evidently a passage which suggested to at least a few readers that I was resigning or retiring or otherwise becoming unavailable for consultation.

It isn't so! Although political advocacy is indeed RTDSC's primary "reason for being", the occasions on which we could fruitfully engage in it are likely to be few and far between. In the meantime, member education and support will continue to have a strong call upon my time and energy.

### **What About Annual Dues?**

(Report by Ruth von Fuchs)

With the previous newsletter issue, the one which broke the long silence from me, I did not say anything about anyone being "overdue" – I was too conscious of being overdue myself! And even in this issue I am only going to do a bit of explaining and previewing.

I have bought a new computer, a laptop on which one of our kind members has installed Microsoft Office. Our membership database is currently stored in a non-Microsoft program and has to be translated before addressed envelopes can be printed easily. I plan to transfer the records to the new computer, taking advantage of the occasion to re-arrange the information in ways that will make it faster for me to generate lists of the members who live in a certain area, or whose renewal dates fall within a certain quarter.

To make things even simpler, I plan to use only quarterly dates: January 1, April 1, July 1, and October 1. Formerly, your renewal date was the date of your first payment to the Society (usually the date on your cheque). Now it will be the start date of the quarter that follows the quarter in which you joined. For example, a recent new member sent a cheque dated April 18; his renewal date is July 1.

I want to close this message by saying a warm "Thank you!" to all the kind and patient members who sent me cheques without being asked and without knowing what had caused my tardiness. I was touched and fortified by your support.

### *As we went to press (April 2012):*

#### **Son of EuthaNEWSia**

(Proposal from Don Martin)

I have volunteered to restart EuthaNEWSia, focusing on Canadian news and opinion about end-of-life issues. But because such material does not come along regularly, messages will not be regular either.

However, we could generate some content. From time to time we could send a questionnaire to all MPs and print the results in this newsletter. RTDSC does not have charitable status and is therefore allowed to "name names" where politicians are concerned – who did not return a completed questionnaire, who seems to be anti-choice, who seems to be pro-choice, and who is "on the fence" (where MPs often are).

If you want to comment on my proposal, or make suggestions about questionnaire content, send me an e-mail via [info@righttodie.ca](mailto:info@righttodie.ca) or post a letter to the address at the bottom of page 6.

#### **FOOD FOR THOUGHT**

(Column by Ruth von Fuchs)

#### **Important(?) Distinctions**

Withdrawing treatment vs. withholding treatment, intending death vs. foreseeing death, killing vs. letting die – distinctions like these have generated many pages in the end-of-life literature.

We have tended to simply accept that such distinctions are important, and perhaps enter the debate ourselves. But an interesting fact reveals itself if we ask "To whom are these distinctions important, and why?"

Are incurable patients fretting about them as they lie helpless in their beds? No. It is doctors who

care so passionately about them, because they affect the psychological comfort of medical practitioners.

A professional who disconnects a ventilator, or injects a euthanatic into a vein, cannot avoid feeling responsible for having ended a life. We find this feeling uncomfortable, thanks to "instincts" that have been bred into us over millions of years (and have been more helpful than harmful on the whole).

When doctors order continuous deep sedation for patients who are not receiving nutrition and hydration, similar mental discomfort occurs if the doctors acknowledge that death is the intended result of their actions.

Of course, doctors are not the only people who try to avoid psychological discomfort. But medicine is a service profession. The ideal is that practitioners will give priority to their patients' comfort, not to their own. Fortunately, doctors who are strong enough to do this are becoming more common. The future may be selfless and honest . . .

#### **PRACTICALITIES**

##### **Advance Directives**

(Tutorial by Ruth von Fuchs)

There are two ways of directing your care in advance: by a proxy directive, and/or by an instruction directive.

1) Proxy directives have legal force, but the laws in question are provincial or territorial laws, so the situation depends on where you live. The terminology also is place-dependent.

"Power of Attorney for Personal Care" is used by New Brunswick and Ontario; "Representation Agreement" is used by BC and Yukon; "Health Care Directive" is used by Manitoba, PEI, and Saskatchewan; "Advance Healthcare Directive" is used by Newfoundland; "Personal Directive" is used by Alberta and Northwest Territories; "Authorization to Give Medical Consent" is used by Nova Scotia; and "Mandate Given in Anticipation of Incapacity" is used by Quebec.

As the Quebec name suggests, these documents come into effect when you cannot speak for yourself. The person you designate (who does not have to be a relative but should be someone who knows you well) has full authority to instruct your caregivers on your behalf.

You can of course specify more than one person, but it is wise to list the potential proxies in descending order of trustworthiness, and to specify that they are to act "severally" rather than jointly. If there is a committee containing an even number of members, the vote may be tied (e.g. your daughter understands that you would not want your life prolonged in the given circumstances, but your son disagrees). In such a situation the medical team will almost certainly follow the instructions of the more conservative advocate(s).

On the back of your RTDSC membership card there is space to print the names and phone numbers of your first-choice and second-choice proxies. You should also post the information on your refrigerator (a common place for ambulance personnel to check) and in the address book of your mobile phone, if you have one, under I.C.E. (In Case of Emergency).

The first item in the "Resources" section of [www.righttodie.ca](http://www.righttodie.ca) is headed "Power-of-Attorney Documents and Help". It provides a starting point for research, in every province/territory.

### **Note to readers in BC:**

The law on Representation Agreements was revised on September 1. On [www.nidus.ca](http://www.nidus.ca) you can find what you need to know if your Agreement was made before that date. You can also phone 877-267-5552 or send an e-mail to [info@nidus.ca](mailto:info@nidus.ca).

2) Instruction directives are commonly called "living wills". They do not have quite as much legal force as proxy directives (some studies have shown that they are disregarded rather frequently), but most doctors appreciate knowing what a patient wants and doesn't want.

A good approach is to create a draft document, either by writing something out in your own words or by filling in the blanks of a form. Then you can start with the person you are thinking of naming as your first-

choice proxy, and go over the document. The ensuing conversations will help your potential proxy understand how you think, and you will be helped to spot any unclear wordings. You may even find that the person should be your second-choice proxy instead of first-choice.

Once you are comfortable with your document and with your proxy choice(s), give a copy of the document to each potential proxy. It will serve as a refresher course, if/when someone needs to be your voice.

Living-will forms are available from many sources. One recent and very useful example is entitled "Your Life, Your Choices" (type that into your browser, quotes included). It is more than a form – it is a workbook providing a great deal of helpful medical and tactical information. You will need to put about half an inch of paper into your printer!

Much of it is structured in terms of diagnoses and therapies ("If I have X, do Y but not Z"), as has traditionally been the style with living wills, and the section that constitutes the LW form (pages 37 - 43) is like this.

But the document also contains valuable facts and advice about the processes involved in advance care planning. There are sections entitled "Common questions about choosing a spokesperson", "Asking someone to be your spokesperson", and "Starting the discussion".

Besides thinking in terms of diagnoses, however, laypeople often find it helpful to think in terms of symptoms or situations. Doctors can work with this information too.

One approach is to make two lists, headed "States Whose Ongoing Presence Would Make Me Prefer Death to Life" and "Powers Whose Ongoing Absence Would Make Me Prefer Death to Life".

The word "ongoing" is important. For instance, there might be some powers you could stand being deprived of for a short time, as part of "getting over a hump".

In case you want some ideas, here are the lists created by one person – myself -- but they are offered only as examples. Your personal fears and values may be quite different from mine.

"States Whose Ongoing Presence . . ."

- severe & intractable pain
- severe & intractable nausea
- severe & intractable shortness of breath
- severe & intractable dizziness
- severe & intractable itchiness
- severe & intractable "stinkiness" (being the source of foul smells)
- severe & intractable weakness
- severe & intractable dementia
- blindness
- total & unremitting incontinence

"Powers Whose Ongoing Absence . . ."

- ability to communicate (to receive and to transmit)
- ability to move at least some parts of my body
- ability to change the location of my body, if only by using a wheelchair
- ability to take nourishment in a way that lets me enjoy sensations of taste

Regarding your transition from life to death (given that at least one of the above conditions applies), some special factors may need to be mentioned.

If you have a pacemaker or an implanted defibrillator, you may wish to explicitly say that deactivating it should be part of the comfort care which you receive during your transition. Getting this done may be quite a feat for you or for your proxy, and "having it in writing" could help.

If you want to be an organ donor, you can add a sentence to the effect that you are willing to be kept on life support for a brief time in order that your organs may be properly harvested.

Besides giving copies of your document to your potential proxies, or if you have no one who is able and willing to speak as you would speak, you should carry a copy with you and/or store one in a prominent place in your home. If it is very bulky you can carry just a note telling people where they can find the full text (e.g. "on the highest shelf of the bookcase").

To maintain the credibility of your directive, review it once a year (on your birthday, for instance). Write the date on each page and initial it. Small changes can be handled as margin notes but for major changes you should produce a new document.

## Hood-Making Instructions

Now that pre-elasticized plastic bags can no longer be ordered from GLADD in California, people wanting to be prepared for self-deliverance via helium are back to creating home-made items. Fortunately, modifying a store-bought turkey-roasting bag is not difficult.

Instructions for one method are already available for downloading but there are two alternative methods which are easier. Both produce a very reliable product and can be managed by anyone with normal dexterity. No sewing machine is required.

One method was developed by three members of RTDSC and is now being taught (as of press time, April 2012) by Jim Chastain from Final Exit Network of Florida. The other method was probably developed simultaneously in several places – USA, Scotland, Australia – by creative members of r-t-d groups.

Illustrated instructions for both methods of elasticizing the mouth of the bag, plus ideas about where to buy the materials for the project, are available from RTDSC. They cannot be e-mailed but they will be sent by post at no charge. To order, write to us at 145 Macdonell Ave., Toronto ON, Canada, M6R 2A4. Enclose proof that you belong to a right-to-die or choice-in-dying organization.

The instructions do not cover how to use the bag. For that you need books such as *Final Exit*, *Five Last Acts*, or *Peaceful Pill Handbook*.

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