**Newsletter September, 2013**

**Online discussion of end-of-life issues**

It’s time for people with disabilities to talk openly about aid in dying. The conversation is going on around us and about us, but without us!

What does it mean that only people with serious illness or disabilities are eligible for aid in dying? Is it really a choice to die when we have so few choices in how to live? Why do non-disabled people get suicide prevention services while we get help to die? What about the services and access we need to live as equals in our communities?

Join us every Friday to talk about what’s at stake for people with disabilities in the end-of-life debate, and how we can turn the talk from “dying with dignity” to “living with dignity.”

The French session will begin at 1 p.m. on Friday, ET, the English chat will begin 2 hours later at 3 p.m. Join us for one or both sessions.

When the session is in progress, click on the link below to enter. You can send questions or comments by text in the chat window. Or if you are subscribed to google+, send an email to [tigrlily61@gmail.com](mailto:tigrlily61@gmail.com) and ask for an invitation to participate by video/voice.

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**Hearings on Bill 52**

The schedule and list of invitees for hearings on Québec's euthanasia proposal (Bill 52) came out on August 23rd. No indication that they will accept testimony from others who were not invited, have hearings outside of the National Assembly in Québec city, or allow the general public to be heard on the matter. The hearings will happen between September 17 and October 10. I have written to request that Toujours Vivant-Not Dead Yet be invited to speak.

Now that a bill has been proposed, you would think the public should have a say. Of course the National Assembly would argue the public was supposed to have its say three years ago, before the Commission on the Question of Dying with Dignity. But three years ago, they weren't proposing to change the definition of medical care to include killing people whether or not they had a terminal illness, and they weren't proposing euthanasia without even a psychiatric evaluation, or letting heirs fill out the forms, or any number of other problems with this bill.

Also, there's no evidence that the people whose lives are on the line -- people with "incurable conditions" (disabilities) will have particular access to this process any more than they had three years ago. If you don't have reliable public transportation, or can't get out of your unadapted house, or don't have personal assistance services to enable you to go out for any reason other than medical appointments, how are you supposed to participate in the political process? Writing a letter does not have the same impact as rolling into a hearing room with 15 or 20 of your closest wheelchair-using friends.

So instead of direct democracy, the views and needs of people with disabilities are supposed to be represented by coalitions of non-profit, government-funded service organizations; never mind that their interests are sometimes at odds with those of their disabled clientele.

An informed citizenry can take action to affect the process. Visit tvndy.ca for information on contacting your MNA.

**17 Sep. 2013 –** Collège des médecins du Québec • Fédération des médecins omnipraticiens du Québec • Fédération des médecins spécialistes du Québec • Association médicale du Québec • Ordre des pharmaciens du Québec • Ordre des infirmiers et infirmières du Québec

**18 Sep. 2013 –** Ordre des travailleurs sociaux et thérapeutes conjugaux et familiaux du Québec • Association Québécois des établissements de santé et de services sociaux

**19 Sep. 2013 –** Ordres de psychologues du Québec • Association des conseils des médecins, dentistes et pharmaciens • Barreau du Québec • Chambre de notaires du Québec • Association de Barreau Canadien, Division Québec

**24 Sep. 2013 –** Commission des droits de la personne et des droits de la jeunesse • Protecteur du citoyen • Curateur publique • Collectif des médecins contre l’euthanasie. Refus médical de l’euthanasie • Coalition des médecins pour la justice sociale • Rassemblement québécois contre l’euthanasie

**25 Sep. 2013 –** Vivre dans la dignité • Association québécoise du droit de mourir dans la dignité • Collectif mourir digne et libre • Regroupement provincial des comités des usagers

**26 Sep. 2013 –** Conseil pour la protection des malades • Fédération interprofessionnelle de la santé du Québec

**1 Oct. 2013 –** Alliance des maisons de soins palliatifs • Maison Michel-Sarrazin • Association des gestionnaires d’établissements de santé et de services sociaux du Québec • Réseau des soins palliatifs du Québec • Société canadienne du cancer – division Québec • Société de soins palliatifs du Grand Montréal

**2 Oct. 2013 –** NOVA Montréal • Office des personnes handicapées du Québec • Association du Québec pour l’intégration sociale • Confédération des organismes des personnes handicapées du Québec

**3 Oct. 2013 –** Fédération des Mouvements Personne d’Abord • Association québécoise de gérontologie

**4 Oct. 2013 –** Carpe Diem • Centre de recherche sur le vieillissement • Comité national d’éthique sur le vieillissement et les changements démographiques du Conseil des Aînés

**8 Oct. 2013 –** Association québécoise de prévention du suicide • Centre de recherche et d’intervention sur le suicide et l’euthanasie • FADOQ • Association québécoise de défense des droits des personnes retraitées et préretraitées • Association québécoise des retraité(e)s des secteurs public et parapublic • Association des retraités en éducation et autres services publics du Québec • Me Danielle Chalifoux

**9 Oct. 2013 –** Mme Margaret Somerville • Me Delphine Roigt • Mme Jocelyn Downey • Dre Annie Tremblay

**10 Oct. 2013 –** Dr Howard Bergman et Dr Marcel Arcand • Fédération des sociétés Alzheimer du Québec • M. Jean-Pierre Béland • M. Hubert Doucet • Me Jean-Pierre Ménard, Me Jean-Claude Hébert et Me Michelle Giroux (Comité d’experts juristes)

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**News briefs**

**New website:**

Toujours Vivant-Not Dead Yet’s website has been revamped and updated. You will find a library, re-posting of updates from our facebook page, and a link to our weekly online discussions. Visit us at tvndy.ca.



**Bentley Case:**

Margaret Bentley is an 82-year-old woman living at a British Columbia nursing home. In 1991, Ms. Bentley wrote a “statement of wishes” saying she would not want to be fed if she became cognitively impaired.

In 1999 she developed Alzheimer’s disease and due to the progression of her illness, Ms. Bentley is now being spoon fed by the nursing home staff. Her husband and daughter brought a lawsuit in August against the nursing home and the BC government to stop the feeding and comply with the 20-year-old statement of wishes. However the nursing home and government say that giving food by mouth must continue, to meet the legal mandate to provide sustenance.

Anti-euthanasia activists believe that Ms. Bentley’s choice to eat shows her wish to continue living. They say people have a right to change their mind and retract an advance directive, and without another means of communication, eating is her best way of stating her current wishes.



**Hate mail**

In August, a Newcastle, Ontario woman received an anonymous letter from someone claiming to be a neighbour, complaining about noise made by her autistic grandson and saying the boy should be euthanized. Public reaction against the letter was strong, but prosecutors elected not to investigate the letter as a hate crime. While the letter was full of insults and exclamation points, it also brings to mind the case of Annette Corriveau, who received widespread support last year following her appearances on the Dr. Phil show in the U.S., and the 16:9 program in Canada. Ms. Corriveau is seeking permission to kill her two adult disabled children.



**Hate page**

Also in August, a French facebook page appeared advocating that disabled people should be euthanized to save money. Québec disability activists mobilized quickly and many people sent requests to facebook administrators to have the page taken down. The page disappeared within a few hours, but it’s unknown whether it was facebook who removed it.



**Message from Living with Dignity**

It is a great pleasure to announce the appointment of Mr. Nicolas Steenhout as director general of the Living with Dignity network (LWD).

Mr. Steenhout is originally from Montreal. He has extensive experience in advocacy and media relations for the needs of people with disabilities, in Canada, the U.S. and New Zealand. He directed Centres for Independent Living in two U.S. states. He comes to VDD from Massey University, Palmerston North, New Zealand, where he is responsible for examination accessibility for students with disabilities.

I am especially happy that, thanks to his international experience in fighting for the rights of vulnerable people, Mr. Steenhout will support Living with Dignity in its mission, which is to promote the access of all citizens to care that is truly human throughout life until its natural end. He joins us at a critical moment in the history of Quebec, to join in the fight to prevent the introduction of medical euthanasia (Bill 52) in Quebec’s health care system. Together we will continue to defend the inherent dignity of every person. Welcome Nicolas!

*Marc Beauchamp, President of the Board of Directors, Vivre dans la Dignité - Living with Dignity*

**MCHQ demonstrates in Montréal**

On September 1, more than 100 people with disabilities demonstrated in Montreal to demand equal access and supports to improve our quality of life. The event was organized by Mouvement Citoyen Handicap Québec.

