

Newsletter #62

March 2006

Dear Friends:

The Euthanasia Prevention Coalition has received a good response from our supporters during the past few months enabling us to hire an assistant to the executive director. Debbie will enable me to concentrate on important projects, such as the educational video, parliamentary response and allow us to be available for the many presentations that have been requested.

Francine Lalonde, the Bloc Québécois MP who sponsored Bill C-407 in parliament last June, is intending to bring forth another bill to legalize euthanasia and/or assisted suicide. We are currently working on an effective strategy that will be announced in our next newsletter.

We continue to promote and distribute the *How Will You Say Goodbye* euthanasia paper. We have now distributed almost 180,000 copies of the paper throughout Canada. The paper features articles on palliative care, elder abuse, disability concerns, etc.

How Will You Say Goodbye is attractively designed to encourage secular Canadians to read it and be affected by its articles.

Order the Euthanasia Paper by calling: 1-877-439-3348.

- \$25 per 100 copies for orders of less than 500 copies,
- \$22 per 100 copies for more than 500 copies,
- \$20 per 100 copies for more than 1000 copies,
- \$18 per 100 copies for more than 5000 copies.

* Shipping and Handling costs are extra and will vary based on the size of the order and the location.

The parliament in the Czech Republic has rejected a proposal to lessen the penalties for euthanasia in that nation. This is good news especially since there are several proposals throughout the European Union to change the laws concerning euthanasia and assisted suicide.

Dr. Philip Nitschke may be charged in New Zealand for organizing suicide workshops in that country. The New Zealand medical council is arguing that Nitschke needs a New Zealand medical license in order to legally offer medical advice.

As you may have noticed, we have changed our newsletter style. We are hoping this new style will provide more information, cost less, and take less time for the volunteers to stuff the envelopes. Dr. deVeber recently had knee replacement surgery. The surgery went well but Barrie is temporarily less mobile.

We need your continued support.

We are preparing an effective political response to the attempt by Bloc Québécois MP, Francine Lalonde to introduce a private members bill legalizing euthanasia and/or assisted suicide. We are completing a video that will be an effective tool to change the perspective that politicians and Canadians in general have with respect to euthanasia and assisted suicide.

Finally, I continue to need a good used inexpensive car to replace my car which is nearing its end. Thank You for your continued support. Alex Schadenberg

How Will You Say Goodbye...



To Someone You Love?

Canada is moving closer to legalizing assisted suicide and euthanasia.

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Society should no longer tolerate assisted suicide. Law lets people off lightly.

By Amy Hasbrouck: Freelance writer and attorney
Montreal Gazette - February 6, 2006

On January 27, Marielle Houle was given three years' probation for assisting the 2004 suicide of her son, Charles Fariala. The maximum sentence for aiding or counselling suicide is 14 years. Media reports during and after the sentencing emphasized the emotional trauma Houle displayed at the sentencing hearing, and expressed satisfaction with the sentence "in light of the circumstances."

According to news reports, when Fariala asked his mother to help him kill himself in September 2004, he'd been under a diagnosis of multiple sclerosis for about a year and a half. His mobility was reduced and he had developed chronic pain, but he had refused offers to help and mobility aid. Fariala also had worked in a chronic-care hospital, where disabled people without other options are warehoused. He had probably developed his ideas about what life with a disability has to offer based on this experience.

Had Fariala known people with MS living in accessible homes in the community, with assisted services to enable them to maintain a regular daily schedule of work or school and social activities, with plenty of accessible public transit, he might have felt different. If he'd had hassle-free access to a full range of pain management strategies for the nerve pain that comes and goes with MS, he might have felt different. If he'd known people with disabilities who see disability not as a tragedy or curse, but as a powerful representation of the gorgeous diversity of the human species, he might have felt differently.

A barrier-free environment with in-home supports is not a reality for Quebecers with disabilities. A workable solution for independence can only be achieved by people with the strongest will and greatest persistence. As it is, public policy and the criminal-justice system continue to tolerate, even encourage people with disabilities, to kill those with disabilities.

This was demonstrated in 1997 in a study that found that of 35 homicides of disabled children by parents or guardians in North America, 43 percent of those parents received no prison time. Another 23 percent received 5 years or less. This was compared to an average sentence for child murder of 30 years.

While this trend stands in exception to the case of Robert Latimer, where the Saskatchewan farmer got a life sentence for killing his 12-year-old daughter, the public outcry against Latimer's sentence included the

same arguments used to justify assisted suicide as applied against people with disabilities.

The rationale falls into the categories of "mercy killing" and "care-giver burden." The mercy killing argument stated by parents and courts is that life with a disability is worse than death. The care-giver burden argument states that whoever is tasked to help someone with a disability, be that the state or the family, bears too great a burden.

The arguments for assisted suicide are generally made by people who, like Charles Fariala and Marielle Houle, have little experience of disabled people outside a hospital setting. Such beliefs are generally shaped and distorted by the effects of inadequate medical or other support services. Both of these arguments rest on the (usually unspoken) belief that people with disabilities have less to offer, and use more resources.

In an interdependent society, we all rely on the efficient operation of the infrastructure to get through the day. City dwellers depend on farmers, processors, truckers and retailers for food. A breakdown in the system would mean no one could function. Similarly, where the environment prevents people with disabilities from functioning, such as a workplace with stairs, or lack of home-care services, they are barred from making their contribution and demonstrating their value.

One question leaps to mind: Would the sentence have been different had Charles Fariala been an able-bodied person?

For a long time, people with disabilities were silenced or sidelined in the assisted-suicide debate. At first, the justification was that "this didn't concern 'the disabled,' just people with terminal illness."

However, persistent public education by disability groups such as Not Dead Yet and the Council of Canadians with Disabilities has shown that most assisted-suicide cases involve people with long-term, chronic disabilities like MS.

Bloc Quebecois MP Francine Lalonde has promised to reintroduce her bill to legalize assisted suicide and euthanasia. Her bill, which died the last Parliament, would have permitted assisted suicide and euthanasia for anyone with "severe physical or mental pain," even if that person refused treatment. I hope the long awaited discussion called for by the party leaders will include the people most affected by such legislation.

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The first question in that discussion should be: If assisted suicide is such a good idea, shouldn't we make it available to all Canadians, not just people with disabilities or terminal illness?

Amy Hasbrouck is an attorney and disability rights activist in Montreal and a board member of Not Dead Yet, a Chicago-based group that opposes euthanasia and assisted suicide.

Nothing Merciful About Katrina Killings

By Stephen Drake - Research director - *Not Dead Yet*
November 17, 2006

The term mercy killing is a loaded one and one that tends to generate sympathy for the killer. It's also generally used in those cases when the victim of a murder is old, ill or disabled. Young, healthy or able-bodied people tend to just become homicide victims. The mercy description is only used for a few of us. So I'm generally suspicious when I hear the term used in media reports in just about any context.

Within days of hurricane Katrina striking New Orleans, rumors surfaced of mercy killing or euthanasia at one or more hospitals in the area. Apparently, these were more than just rumors - the attorney general in Louisiana has been investigating the allegations, although little about the investigation has become public.

Until now.

On February 16, National Public Radio (NPR) aired a story on *All Things Considered* on the investigation, after reviewing secret court documents from the investigation. They make it clear that the allegations - if true - had nothing to do with compassion.

Briefly, the allegations revolve around a group of patients left on the 7th floor at Memorial Medical Center. This floor was leased to a different entity, LifeCare hospitals. According to NPR, the patients on the 7th floor were all DNR patients - they had "do not resuscitate" orders.

Life in the hospital was terrible. There was no power and no functioning plumbing. The temperature was about 100 degrees inside the hospital. There were looters hitting nearby buildings and people trying to get into the hospital itself. The staff who were required to stay with the abandoned patients wanted to get out.

Here is an excerpt from the Story:

"According to court documents reviewed by NPR, a key discussion took place on Thursday, Sept 1, during an incident-command meeting held on the hospital's emergency ramp. A nurse told LifeCare's pharmacy director that the hospital's 7th floor LifeCare's patients were critical and not expected to be evacuated with the rest of the hospital. According to statements given to an investigator in the attorney general's office, LifeCare's pharmacy director, the director of physical medicine and an assistant administrator say they were told that the evacuation plan for the 7th floor was to not leave any living patients behind, and that a lethal dose would be administered, according to their statements in court documents."

In other words, the only way the staff could evacuate was if they could report there were no more living patients to take care of. This was not about compassion or mercy. It was about throwing someone else over the side of the lifeboat in order to save yourself.

In fact, this doesn't look all that different from the abandonment of the 34 individuals in St Rita's Nursing Home in Bernard Parish. In that incident, 34 people died after being abandoned by staff. Death by drowning is easy to prove and so the owners of the nursing home care charged with 34 counts of negligent homicide. It's unclear what will happen in the case of LifeCare medical staff. It's hard to prove medication overdoses weeks after the death.

Admittedly, the hospital staff must have been exhausted and scared. We can never know how they rationalized their actions. But that doesn't make the alleged killings merciful - and one should refer to these killings using that term again. No one's calling the owners of St. Rita's merciful or caring. The same standard should apply to the LifeCare allegations.

Jean Vanier and Dr. Balfour Mount speak in Ottawa - January 31, 2006
Journey to Personal and Social Transformation

By Alex Schadenberg

On January 31, 2006; there was a once in a lifetime opportunity to watch a presentation by Jean Vanier, the founder of L'Arche and Dr Balfour Mount, the father of palliative care in Canada.

The title of the presentation was a: ***Journey to Personal & Social Transformation.***

The talk was chaired by the Hon Senator Daniel Hays, the speaker of the Senate.

Dr. Balfour Mount was the first presenter. Mount has cared for dying Canadians for more than 30 years. He stated that he is privileged to be working with the most vulnerable members of society. He described his work as being the "harrowing business of rescuing joy from heartbreak" and stated that we as human persons are truly grown-up when we "stop trying to fix people."

Mount explained that quality of life is not something to be judged based on our health but rather our wholeness. He stated that two-thirds of cancer patients assessed their quality of life as excellent and people with serious disabilities have life satisfaction ratio's that are similar to the general population.

Mount told us a story about a patient that he had named Chip. Chip had been an athlete who in general terms had everything that life could offer. Just days before Chip's death he told Mount that the last year of his life had been the best year of his life. This is astounding considering that Chip experienced great loss during that final year of his life. Chip said that during his last year he had a chance to come to know himself and the true meaning in life.

Mount stated that suffering is subjective and personal. Suffering is experienced as whole persons not simply by bodies. Suffering can present a paradox. I may have pain but no suffering or no pain but incredible suffering. Suffering is often existential or connected to spiritual pain.

Mount believes that the need to feel connected lies at the centre of the human person. Therefore how we relate to ourselves and others determines our ability to heal. Healing is not simply the healing of the physical body, but the healing of a whole person.

Mount stated that healing the whole person involves being present, accepting what is, having humility, accepting our limitations. Healing involves letting go and connecting the unity that exists between all things.

Mount concluded his talk by stating that the real teacher is experience. We learn the features of wholeness in our experiences with others. That when we learn to be healers of the whole person that this begets further healing. Our culture is in need of tremendous healing.

Jean Vanier began his talk by stating that he has lived for 41 years with people who live with rejection. These people have been put aside by society and throughout the 1960's and 70's they were institutionalized.

When parents learn of their child's disability they suffer. They fear having a child with a disability. What is the source of their fear?

People with disabilities have the ability to change us. Vanier then stated: "I am on a journey of healing and transformation."

Vanier continued by speaking about the growing gap between the rich and the poor. He asked: How is it happening that there are people who are starving?

Vanier stated that we are a society that has lost the meaning of suffering. He then argued that the greatest suffering today is the elderly who are institutionalized and ignored. They are abandoned. We have become a culture of individuality that has stopped caring about others.

Vanier said that he fears his vulnerability, that he fears his poverty, that we are all poor. But death is not a light going out but the beginning of the dawn.

He then stated that he understands the suffering of a parent who learns that their child has a disability. The reality of rejection, the fear of living, the fear of not being loved or not loveable. These parents need presence.

Living is liberating. Many people have difficulties walking, talking, etc; but simply to say , I am happy living with you. Live life, don't just submit to it.

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People are changed by a quality of presence, a quality of love. We all need to be transformed, even those who already live in community.

Vanier stated that his real value is not in power but in being fruitful. To be fruitful is to transmit life, to communicate hope.

Vanier said that his capacity to love is what is beautiful in him. We are called to be together, to love each other, to be in community. This is what makes us human.

Vanier concluded by stating that to be human is to live compassion, beauty, goodness, to become loving. We need community. Community is a place where we learn to love. The opposite of community is loneliness. Loneliness is more painful than living with others' difficulties. Our world needs us to become a community, where we are together.

We must reject individualism.

The evening was concluded with remarks by the retired Senator Al Graham, the national patron of L'Arche Canada.

Disabled activists oppose California assisted suicide bill

By Clea Benson - February 8, 2006
Sacramento Bee - Sacramento California

Lilibeth Navarro, a community activist in Los Angeles who became disabled after surviving polio as a child, remembers visiting her doctor after a near-fatal bout with pneumonia.

The physician, she recalls, urged her to sign a do-not-resuscitate order so that it could be on file the next time she was admitted to the hospital. To Navarro, 50, the doctor's attitude appeared markedly different than the manner medical professionals seemed to display toward family members such as her 93-year-old grandmother.

Doctors presumed, she said, that her fully mobile grandmother would want them to use all medical technology at their disposal to extend her life.

"What's the difference?" said Navarro, who uses a motorized wheelchair. "I wasn't walking and she was walking. It's scary. It's very scary."

Experiences such as Navarro's are at the heart of the reason why many disability rights activists have opposed efforts to legalize assisted suicide in the past year, joining religious and conservative groups at protests outside the U.S. Supreme Court and the California Capitol.

The advocates say societal bias combined with an emphasis on cost-cutting in the health-care industry may pressure people with disabilities to request lethal prescriptions - and their doctors to provide them - when what they really need is more support for living.

The matter is heating up in California, where Assembly members Patty Berg, D-Eureka, and Lloyd Levine, D-Van Nuys, say they will hold hearings next month on

Assembly Bill 651, a measure that would permit doctors to prescribe lethal drugs to terminally ill patients.

Berg and Levine tried unsuccessfully last year to pass another aid-in-dying measure, Assembly Bill 654. But they are more optimistic about their chances in the wake of a U.S. Supreme Court decision last month clearing the way for states to make their own laws on assisted suicide.

Meanwhile, the issue has become a flashpoint in a broader struggle for the civil rights of the disabled that is taking hold across the United States.

Some advocates say people who live a rich, full life of the mind are often consigned to nursing homes or other institutions because they cannot care for themselves physically.

Until society provides more support that allows people with disabilities to live independently in their communities, they say, people with potentially terminal diseases might choose suicide simply because they don't believe they have other options or don't want to be a burden to their families.

Activists also say health-care institutions have a bias against spending money on expensive care, and that bias may lead doctors to be more likely to prescribe lethal drugs to disabled patients.

"We get reports from around the country that individuals with disabilities go into hospitals for some kind of treatment and hospital staff pressure them to sign (do not resuscitate) orders," said Paul Longmore, a history professor at San Francisco State University and an expert on disability studies. "That's really serious discrimination."

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Supporters of assisted suicide say there is no link between their cause and the civil rights issues that people with disabilities face. Assembly Bill 651 even includes language condemning discrimination against the disabled in response to concerns raised by activists. It also specifies that lethal prescriptions can't be issued solely because of a patient's disability or advanced age.

"I certainly agree that the disability community has not always been treated fairly, and I have great respect for that," Berg said. "However, there is a real difference between chronic illness and terminal illness."

But others believe that bias against the disabled is so insidious that the two issues can't be separated.

"There are the folks who see it as a right-to-life issue, and there are the folks who see it as a right-to-death issue," said Teresa Favuzzi, director of the California Federation of Independent Living Centers, which opposes the bill. "And for the disability community, it's

about the right to live, to be seen as valuable."

Disability Activists Condemn Assisted Suicide as Distraction from Important Issues **Media Release - Olympia Washington**

February 3, 2006

The Washington chapter of Not Dead Yet, a national disability rights group, spoke out today against the introduction of a bill that would legalize assisted suicide in Washington State.

"Some will have you believe that this bill is an effort to offer a pain management strategy of last resort, or a step to support individual choice. Those frameworks are red herrings," says Joelle Brouner, disability activist, who notes that "fear of being a burden" and "loss of autonomy" are two of the most common reasons given by people seeking legally assisted suicide in Oregon.

The central issues are credibility, power (state, institutional, and individual), and class. I don't know how often a perfect stranger has said, I don't know if I'd want to live if I were in a situation like yours. When I explain that I have a great life they appear perplexed. In a culture dominated by narrow understandings of "quality of life" and "independence" disability is perceived to be worse than death.

Longmore pointed to attempts by hospitals and government agencies to cut health-care costs and

suggested that economics could play a role in some of the support for assisted suicide.

"People with disabilities are much more familiar than other Americans with how the health-care system works and for that reason, I think we can speak with authority on this subject," he said. "We know that patients are denied the kind of care they have a right to, particularly with regard to things like pain management... We understand the horrible experiences people have that can lead them to support assisted suicide."

Disability rights activists opposing assisted suicide also say it can be hard to draw the line between a chronic disease and a terminal illness, regardless of whether safeguards are written into the law.

"It is the experience of disability that a lot of us have defied medical science," Navarro said.

When she was diagnosed with polio at five months old, Navarro said, "my parents were told I might die in two weeks. Boy, that's the longest two weeks of my life."

Activist and organizer Duane French says "people forget that medicine is big business. People with chronic illnesses require expensive care. When a person's desire to live, and to pursue every treatment threatens the bottom line, too many already believe the cost outweighs the benefit. The individual who is, sick, tired, and vulnerable is already fighting an uphill battle. When you consider adding the power of state policy to the considerable power of doctors, you are creating an incentive for promoting death. It's a prescription for abuse, and injustice."

Activists consider it particularly repugnant for the Senate Health and Long-Term Care Committee to consider hearing SB 6843. The same committee that is supposed to support the health and well-being of people in long-term care is instead advocating a policy of abandonment. Good public policy isn't based on fear or the worst case scenario.

With all the very real problems confronting the poor, seniors and people with disabilities in this country, it's unconscionable that we are wasting time and energy on this sideshow distraction.

German Nurse on trial over 29 deaths

Associated Press - Kempten, Germany

A nurse facing murder and manslaughter charges has gone on trial over the deaths of 29 patients in what has been described as the biggest series of killings in Germany since the end of World War II.

Stephan Letter, 27, faces a possible life in prison if the Bavarian state court in Kempten convicts him on 16 counts of murder, 12 of manslaughter and one of mercy killing.

Though he maintained when he was arrested in July 2004 that he was trying to spare the 17 women and 12 men needless suffering, prosecutor Peter Koch said Letter was "exercising power over life and death."

The patients were aged between 40 and 94, though most were older than 75. They included two gravely ill women, aged 40 and 47, but not all were seriously sick, authorities have said.

He "killed arrogantly ... making decisions according to his own standards," Koch told the court.

The deaths at the hospital in nearby Sonthofen, in the Bavarian Alps, began in February 2003, less than a month after the nurse started working there. The last suspicious death occurred in July 2004.

The nurse also is charged with two counts of attempted manslaughter.

'Medicine found at flat'

In one case, Letter allegedly gave an injection to a 22-year-old German soldier hospitalized after she was lightly injured in a fall. She recovered and was able to leave the hospital after briefly losing consciousness.

Letter avoided arrest at the time only because the doctor did not believe the soldier's story, Koch said.

When he was finally arrested in July 2004, the nurse admitted to some of the killings, and that he could not remember others, prosecutors have said.

Letter is alleged to have used a mixture of the sedative midazolam, the anesthetic etomidate and the muscle relaxant lystenon to kill the patients.

Police tracked down the nurse as they investigated reports that the drugs were missing and compared the times when patients died to the hours he worked. Investigators said they found unsealed vials of the medicines at his apartment.

Investigators checked into 83 patient deaths that occurred during the nurse's tenure, and exhumed 43 bodies. Many could not be exhumed, however, because they had been cremated.

Some 280 witnesses were also questioned in what Kempten criminal police chief Albert Mueller described last year as "the biggest series of killings in postwar Germany."

Some 22 days are scheduled for the trial to hear 87 witnesses and three witnesses. It is expected to conclude in May.



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