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Brief to the Quebec National Assembly's Select Committee on the issue of Dying with Dignity

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Executive Summary

Offering assisted suicide and/or euthanasia to some who want it would create a burden of proof for many other chronically or terminally ill individuals to prove that their lives are worth continuing. When some parts of society see the availability of euthanasia and or assisted suicide as a much cheaper and faster solution, it becomes more expedient to use it. This is also a question of how we want future generations to die: do we want to live in a culture that promotes death as medical treatment, or one that respects life and does not prolong it beyond its natural length, as current laws allow? To allow euthanasia and/or assisted suicide would also permanently damage the doctor/patient relationship for many patients who opt for life while their doctor offers death as their recommended treatment option.

Research shows that individuals who ask for assisted suicide or euthanasia rarely do so for physical reasons. The primary reasons are psychological and emotional, and these conditions are readily treatable today.

Canadians already have many rights at the end of their life. Under current law, they have the legal right to:

- refuse treatment
- withdraw treatment
- create a living will
- create a do not resuscitate order

These same laws already allow a certain level of autonomy and control. Euthanasia and assisted suicide are unnecessary legal entanglements. They foster concerns over individual's rights at the end of life, as if those rights listed above did not exist.

Finally, the international examples show us that no law surrounding these issues currently operating anywhere in the world can legislate against future abuses of that law. Switzerland and the Netherlands are examples of this.

Since many of the reasons why people ask for assisted suicide or euthanasia are themselves treatable, should we not make every effort to help people recover hope, so that they can die at peace with themselves and their families, when their natural last day arrives.



I. Why are assisted suicide and euthanasia not only issues of individual rights?

If assisted suicide and/or euthanasia are made legal for the very few people who request it, the majority of patients who don't want to die a hastened death will face pressure to do so. The case of Barbara Wagner in Oregon, where assisted suicide is legal, is instructive. Her health plan refused to pay for expensive cancer treatment at her request, instead offering to pay for the drugs she could take to die. [1]

This sends the message to those currently living with chronic or terminal illnesses that their lives are not worth living, such that they will have to justify expenses incurred to keep them alive when the cheaper alternative of a hastened death is available. As Baroness Campbell of Surbiton, a prominent disability rights campaigner, has stated: "Disabled people are fearful that when it becomes an option, it will gain a credibility that will erode the resolve of many people experiencing personal difficulties. "Not only will it enter our heads, it will also enter the heads of our families and friends, those who provide us with health and social care support and, ultimately, those holding the purse strings." [2]

Dr. Margaret Cottle, a palliative care physician and a clinical instructor at the University of British Columbia offers this observation which is pertinent to the committee's considerations of assisted suicide and euthanasia:

"Euthanasia kills the patient twice.' The first time is when you look at the patient's life and say, 'Yeah, you're right. Your life really isn't worth living.' And the second time is when you actually do it." [3]

This is the opposite of compassion and choice.

Another question to answer is this: given that a change in the law will affect future generations, how do we want our grandchildren and great grandchildren to die? If assisted suicide and/or euthanasia are made legal, a cancer patient who wants to begin or continue treatment may feel or be challenged as to why they are costing the medical system so much when they could just take pills and die. Our elders, with life savings hanging in the balance, could be pressured by family members or caregivers to die early so that the inheritance will not be depleted. The medical community, with cost pressures already present today, may itself put its weight behind assisted suicide and/or euthanasia and, even by offering that option, add pressure to people who are chronically or terminally ill. If the choice is expensive treatments that may or may not extend your life or a quick death, the cost of staying alive may itself be a burden to patients, pushing them to die early.



Ultimately, the medical system in Quebec and every other region of Canada is based on a relationship of trust between doctors and patients. Patients need to trust that their doctor is working in the best interests of their health. A study of cancer patients in Oregon and Washington found that "Patients with depression and psychological distress were significantly more likely to feel that discussions that included explicit mention of euthanasia or physician-assisted suicide would increase trust in their physician whereas patients with pain believed such discussions would not increase trust." [4]

II. Why Do People Ask for Assisted Suicide?

Psychological and Emotional Needs

Current research shows that those people who say that they would choose euthanasia or assisted suicide are most often suffering from other non-life threatening afflictions. In fact, when these issues are correctly diagnosed and treated, the patient no-longer wants to die. The most common issues are:

<u>Depression</u>: Multiple studies show that individuals are more likely to ask for assisted suicide or euthanasia when they are depressed. [5] A Dutch study found that almost 25 per cent of terminal cancer patients were suffering from depression. [6] This same study found that "the risk of a request for euthanasia by patients with depressed mood was 4.1 times higher than that of patients without depressed mood" when the study began. [7] A 1995 Canadian study found that "[t]he prevalence of diagnosed depressive syndromes was 58.8 per cent among patients with a desire to die and 7.7 per cent among patients without such a desire." [8]

Another study found that "while oncology patients experiencing pain are unlikely to desire these interventions [euthanasia and assisted suicide] patients with depression are more likely to request assistance in committing suicide." [9] Depression is treatable.

<u>Sense of Burden</u>: It is very common for individuals at the end of life to feel that they are a burden on others. [10]

In one study of patients with Amytrophic Lateral Schlerosis (ALS or Lou Gehrig's Disease) in Oregon and Washington, "patients who discussed wanting assisted suicide were reported by their family caregivers to have... greater distress at being a burden in comparison to ALS patients who did not discuss wanting assisted suicide." [11]



Whether they feel a burden to their loved ones

- emotionally (because they see the pain their deterioration is causing their loved ones). or
- physically (because of the physical burdens of caregiving) or
- they feel a burden to the hospital financially (due to the costs incurred in end of life care),

assisted suicide or euthanasia is seen as a way to stop the pain.

<u>Loss of Control</u>: A person diagnosed with a terminal illness loses almost all sense of control over their lives as they are unable to do anything to stop its progress. "Oregon physicians report that the most common reason patients request PAS (physical assisted suicide) is not pain or depression but a need for control. This need is usually related to patients' fears of the future and presents the physician with an opportunity to address their specific concerns and to develop interventions that will relieve the anxiety of most patients." [12]

<u>Hopelessness</u>: faced with no hope of recovery, individuals may lose any sense of meaning or purpose to their lives, and therefore desire to end it. One study found that "in the terminally ill, as with other populations, hopelessness is associated with suicidal ideation more strongly than is depression." [13]

But hopefulness is recoverable, hopes for the future can be encouraged in even the terminally ill. [14]

<u>Loss of Dignity</u>: Something as basic as requiring help to use the bathroom and shower can cause a profound loss of dignity. But dignity lost is able to be recovered through therapeutic help. Dr. Harvey Chochinov, an internationally recognized palliative care specialist and professor at the University of Manitoba, has developed *Dignity-conserving care*:

To decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose and dignity, patients are offered the opportunity to address issues that matter most to them or speak to things they would most want remembered as death draws near. An edited transcript of these sessions is returned to the patient for them to share with individuals of their choosing. [15]

Chochinov tested this therapy with terminally-ill patients and found that

Ninety-one per cent of participants were satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported a heightened sense of



meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. [16]

Death is not the solution to these real issues. Treatment is available for all these symptoms through palliative care teams. Death removes the option of healing in these important areas, even for patients who are terminally ill, and means that their lives end in real existential suffering, not in relief.

What rights do Quebecers and other Canadians currently have at the end of life?

As in the rest of Canada, patients or their legal representatives in Quebec already have the right to:

- Refuse treatment. In Quebec, as in the rest of Canada, patients can say "no" to treatment. Whether a cancer patient refuses chemotherapy or a patient with Lou Gehrig's Disease refuses to go on a respirator to allow them to breathe, such a decision is affirmed within provincial and federal law as legal
- Withdraw treatment. Patients can also withdraw treatment. A cancer patient can stop chemotherapy treatments. A person paralyzed from the neck down can have the respirator removed, or refuse food and drink
- Create a "mandate in anticipation of incapacity" which makes clear the patient's desires as regards treatment. These documents describe the patient's desire for treatment options: they may ask that everything possible be done to keep them alive, or they may ask that nothing be done. Yet again, these documents can describe desires for care for specific situations
- Create a do not resuscitate order. This document clearly states that a patient does not want medical personnel to engage in any form of Cardiopulmonary Resuscitation

These legal rights already allow a person to refuse drawn-out, painful treatment. As palliative care treatments become more widely available, individuals can control their treatment options, and move toward death in relative comfort due to advances in whole-person care.

For the most part, the main beneficiaries of a change in the law regarding euthanasia and/or assisted suicide are doctors, who would then be free from legal prosecution if they engaged in either of these activities.

Assisted suicide and euthanasia are not needed, as though Quebecers were without any rights at the end of their life. We have so many already, that these additions wouldallow one more option to a few individuals but would take away choice at the end of life for a vast number of individuals now and in the future (see above).



Canadian federal and provincial law does not force individuals to live beyond their natural course of death.

Further Abuses

The international community gives ample evidence that no law legalizing euthanasia or assisted suicide can protect citizens of its country from further abuses unforeseen by the original law. Recently, an investigation by a Swiss newspaper suggests that Ludwig Minelli, the founder of Dignitas, has been made rich by Dignitas' operations. "Minelli declared that he had no taxable personal fortune in 1998, when he established Dignitas. Ten years la(t)er, he has an annual income of about US\$150,000 and a personal fortune of \$1.8 million. How did he become so wealthy"? [17] Recent news articles have also suggested a link between Dignitas and hundreds of urns filled with human ashes found at the bottom of a lake near the clinic. [18]

And in the Netherlands, a law which originally allowed euthanasia and/or assisted suicide only for competent, terminally ill adults with less than six months to live now allows doctors to kill newborns, with their parents' consent. Eligible newborns are those who have either:

- "no chance of survival. This group consists of infants who will die soon after birth, despite optimal care with the most current methods available locally." Instead of keeping the child comfortable until death arrives, doctors actively kill them. [19]
- "a very poor prognosis and are dependent on intensive care. These patients may survive after a period of intensive treatment, but expectations regarding their future condition are very grim."[20] If the intensive treatment won't give a high return in terms of future health, the baby can be killed.
 - or
- "a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering." [21] Once doctors judge that a child is experiencing "unbearable suffering", they can approach the parents for permission to kill them.

And a petition has been presented to the Dutch parliament by senior citizens attempt to make it legal for senior citizens who are simply tired of life to have assisted suicide when they want to die, regardless of the state of their health.

The gradual and continuing broadening of those eligible for assisted suicide or euthanasia in the Netherlands clearly shows both the ethical and legal difficulties of containing these practices once they are made legal.

In short, the example of Dignitas, operating where assisted suicide cannot be offered for profit, and of the Netherlands, show us that no law can be crafted which will not be widened in the future to include more vulnerable people.



Ultimately, the question before all of us is this: since research shows that depression, hopelessness, lack of control and dignity as well as a sense of burden contribute to the desire for assisted suicide, should we not make every effort to restore or remove these things, as opposed to creating a nation where people are helped to die when they are most down and out?

Recommendations

- That the committee recommend that euthanasia and assisted suicide remain illegal in the province of Quebec, and that the punishments laid out in the law be enforced in courts of law.
- That doctors be further trained to recognize and treat the suffering of patients for what it is (ie: depression, sense of burden, loss of control, hopelessness, loss of dignity) or refer patients for treatment, rather than offering death as the solution to their treatable problems
- That patients requesting assisted suicide or euthanasia be screened and treated for the aforementioned contributing factors so that they can continue life with renewed hope rather than dying in despair



Endnotes

[1] James, S.D. (2008, August 6). Death Drugs Cause Uproar in Oregon: Terminally III Denied Drugs for Life, But Can Opt for Suicide. *ABC News*. Retrieved online July 12, 2010 from

http://abcnews.go.com/Health/story?id=5517492&page=1

[2] Campbell, J. (2010, June 3). Disabled people need help to live, not die. *guardian.co.uk*. Retrieved July 13, 2010 from <u>http://www.guardian.co.uk/commentisfree/2010/jun/03/disabled-people-assisted-suicide</u>

[3] Stirk, F. (2006). A Natural Death: An Interview with Dr. Margaret Cottle. *IMFC Review*, Spring/Summer 2006. Retrieved online July 12, 2010 from <u>http://www.imfcanada.org/article_files/A_natural_death.pdf</u>

[4] Emmanuel, E.J., Fairclough, D.L., Daniels, E.R., et al. (1996). Euthanasia and physician-assisted suicide:

attitudes and experience of oncology patients, oncologists, and the public. *Lancet* Vol. 347, Issue 9018, pp. 1805–1810.

[5] Chochinov, H.M., Wilson, K.G., Enns, M., and Lander, S. (1998). Depression, Hopelessness, and Suicidal Ideation in the Terminally Ill. Psychosomatics, Vol. 39, pp. 366–370.

[6] van der Lee, M., et al. (2005). Euthanasia and Depression: A Prospective Cohort Study Among Terminally III Cancer Patients. *Journal of Clinical Oncology*, Vol. 23 pp. 6607-6612. Retrieved July 14, 2010 from http://jco.ascopubs.org/cgi/reprint/23/27/6607

[7] *Ibid*.

[8] Chochinov, H.M. Kristjanson, L. J, Hack, T. F., Hassard, T., McClement, S., and Harlos, M. (1995). Desire for Death in Terminally III Patients. *American Journal of Psychiatry*, Vol. 152, pp. 1185-1191.
[9] Emmanuel, E.J et al. (1996).

[10] Chochinov, H.M. et al. (2007). Burden to Others and the Terminally Ill. *Journal of Pain and Symptom Management*, Vol. 34, pp. 463-471.

[11] Ganzini L, Silveira M.J., Johnston, W.S. (2002). Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain and Symptom Management*. Vol. 24, pp. 312-317.

[12] Hendin, H., Foley, K. (2008). Physician assisted suicide in Oregon. *Michigan Law Review*, Vol. 106, pp. 1613-1640. Retrieved July 9, 2010 from <u>http://www.spiorg.org/publications/HendinFoley_MichiganLawReview.pdf</u>

[13] Chochinov, H.M. et al. (1998). Depression, Hopelessness, and Suicidal Ideation in the Terminally III.

[14] Hudson, P.L. et al. (2006). Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. *Palliative Medicine*, Vol. 20, pp. 693-701.

[15] Chochinov, H.M., Hack, T., Hassard, T., Kristjanson, L.J., McClement, S., Harlon, M. (2005) Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Psychology*, Vol. 23, pp. 5520-5525.

[16] *Ibid*.

[17] Cook, M. (July 3, 2010). Has assisted suicide made the founder of Dignitas a millionaire? *Bioedge.org*. Retrieved July 8, 2010 from <u>http://www.bioedge.org/index.php/bioethics/bioethics_article/9088/</u>

[18] Boyes, R. (April 28, 2010). Ashes dumped in Lake Zurich put Dignitas back in the spotlight. London: The Times. Retrieved July 8, 2010 from <u>http://www.timesonline.co.uk/tol/news/world/europe/article7109939.ece</u>

[19] Verhagen, E., Sauer, P. (2005). The Groningen Protocol — Euthanasia in Severely III Newborns. *New England Journal of Medicine*, Vol. 352, pp. 959-962. Retrieved July 12, 2010 from

http://content.nejm.org/cgi/content/full/352/10/959/T2

[20] *Ibid*.

[21] *Ibid*.