CSSS – 058M C.P. – P.L. 52 Loi concernant les soins de fin de vie



## Euthanasia Prevention Coalition

## Bill 52: "An Act Respecting End-of-Life Care"

## Submission to the Quebec Committee on Health and Social Services Committee

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Euthanasia Prevention Coalition Box 25033 London ON N6C 6A8 1-877-439-3348, <u>info@epcc.ca</u>, <u>www.epcc.ca</u> Proposed changes to the law, through Bill 52, which have the effect of legalizing euthanasia in Quebec represent a serious risk to people at the most vulnerable time of their life. The proposed changes reflect a fundamental transformation in the doctor patient relationship which runs contrary to the established ethic and values of the medical profession throughout Quebec, Canada and around the world.

Virtually every medical association in Canada and around the world have upheld the principle, to "Do No Harm" by opposing euthanasia and assisted suicide as being contrary to basic medical ethics.

Euthanasia and assisted suicide is legal in seven small jurisdictions throughout the world. Continued prohibition of euthanasia remains the norm in virtually every country, state, and international convention.

It is a mistake that will have tragic consequences if Quebec legalize euthanasia because they will also be placing members of society at risk of subtle pressure for euthanasia or having it inflicted upon them without request.

#### The Euthanasia Prevention Coalition (EPC)

EPC is a not-for-profit organization which represents a broad cross-section of the Canadian population, including people with disabilities, seniors, healthcare practitioners and members of different cultural and religious backgrounds.

Our mandate is to preserve and enforce social, legal and medical safeguards prohibiting assisted death and to promote compassionate healthcare respectful of the lives, dignity and autonomy of vulnerable people.

EPC was granted intervener standing by the Quebec Superior Court in the case of Leblanc c. Canada (Procureur général). This case involved a constitutional challenge to s.241(1)(b) of the Criminal Code in an attempt to strike down laws against assisted suicide in Canada.

EPC was granted intervener standing by the BC Supreme Court and by the BC Court of Appeal in Carter v. Attorney General. This case involved a constitutional challenge to

s.241(1)(b) of the Criminal Code and related provisions in an attempt to strike down the laws against assisted suicide and euthanasia in Canada.

EPC was granted intervener standing before the Supreme Court of Canada and the Ontario Court of Appeal in the case of Rasouli v. Cuthbertson (2011) ONCA 482. This case involves the interpretation of Ontario's Health Care Consent Act and particularly the definition of treatment as including the requirement of consent to implement a plan of treatment which includes the withdrawal of mechanical ventilation and implementation of palliative care where such a plan is anticipated to result in the death of the patient despite objections raised by the applicant's substitute decision-maker.

EPC was granted intervener standing in the Appeal court of Ontario case of Scardoni v. Hawryluck (2004), 69 O.R. (3d) 700. This case involved the interpretation of prior expressed wishes under the Health Care Consent Act in Ontario and the proper application of the best interests test set out under Section 21 (1) of that Act, along with argument as to the appropriate means by which to interpret relevant provisions of the Act in a manner consistent with the terms and values set out in the Charter of Rights and Freedoms and particularly sections 7 and 15.

#### **Euthanasia Prevention Coalition's Position:**

The question of legalizing euthanasia is profound. This question cannot be treated lightly and it must be decided based on the common good of every member of society.

The Euthanasia Prevention Coalition opposes all forms of euthanasia and assisted suicide. We are convinced that it is never acceptable to provide a means, in law, for one person to have the right in law, to cause the death of another person. We recognize that prohibitions on causing the death of another human being are designed to equally protect every citizen in society.

We understand that situations occur, whereby people seek to end their lives, but we are convinced that these situations become very different when the law allows someone else to actually cause the other person's death. The stakes are high in the euthanasia debate. The euthanasia debate concerns personal and societal decisions to intentionally cause the death of people.

#### **Definitions:**

Euthanasia is to knowingly and intentionally perform an act that is explicitly intended to end another person's life <sup>1</sup> whereby the death is caused by the act. The specific conditions for euthanasia will vary based on laws, rules, and social acceptance.

Assisted suicide means to knowingly and intentionally provide a person with the knowledge or means or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.<sup>1</sup>

Bill 52: "An Act Respecting End-of-Life Care" avoids using the terms euthanasia or assisted suicide in the debate, but rather uses the term "medical aid in dying" as part of "end-of-life care."<sup>2</sup> The term "medical aid in dying" can have a wider application and lacks the precise definitions of euthanasia and assisted suicide.

It is assumed that the Quebec government intends through Bill 52 to regulate the acts of "medical aid in dying." In his critique of Bill 52, Alex Schadenberg, our executive director, points out that Bill 52 employs ambiguous language.<sup>3</sup>

EPC published a critique of Bill 52 on June 18<sup>th</sup> stating:

Bill 52: "An Act respecting end-of-life care" defines "end-of-life care" to mean: palliative care provided to persons at the end of their lives, including terminal palliative sedation, and medical aid in dying.

The bill states that doctors would administer "medical aid in dying." Euthanasia is to directly and intentionally cause the death of another person, usually by administering a lethal injection.

"Medical aid in dying" is therefore a euphemism for euthanasia in Bill 52.

Since the definition of palliative care includes: *terminal palliative sedation and medical aid in dying,* therefore the definition of palliative care includes euthanasia.

Bill 52 states that it creates a "right to receive palliative care." A right to receive palliative care would be good, except that the definition of palliative care includes medical aid in dying (euthanasia). Therefore Bill 52 also creating a right to receive euthanasia.

The definition of "terminal palliative sedation" in Bill 52 is unclear. Sedation for the purposes of palliation is good, but due to the vague definition, EPC is concerned that the abuse of terminal palliative sedation will result in euthanasia without request being done "under the radar" and being reported as terminal palliative sedation.<sup>3</sup>

Due to the vague, ambiguous and unclear definitions that Bill 52 uses, the EPC sends out a warning that if passed, Bill 52 is likely to be significantly abused in a similar manner to the Belgian euthanasia law.

#### **Critique of Paragraph 26**

The definitions in Bill 52 are very similar to the Belgian euthanasia law. This is important because we expect that Bill 52 will be interpreted in a similar manner to the Belgian euthanasia law. Chapter IV paragraph 26 defines who would qualify for "medical aid in dying" which is a euphemism for euthanasia.

26. Only a patient who meets the following criteria may obtain medical aid in dying:

- be of full age, be capable of giving consent to care and be an insured person within the meaning of the Health Insurance Act (chapter A-29);
- (2) suffer from an incurable serious illness;
- (3) suffer from an advanced state of irreversible decline in capacity; and
- (4) suffer from constant and unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable.

26 (1) This will not limit Canadians from going to Quebec as "euthanasia tourists." Canadians will be able to arrive in Quebec and qualify to die by euthanasia within a short period of time, based on the Health Insurance Act (chapter A-29).

26 (2) This definition is not limited to people who are terminally ill. Many people who live with an incurable serious illness are not terminally ill. This definition will allow a person with a chronic condition, such as being an insulin dependent diabetic, to qualify.

26 (3) Many people who live with an advanced state of irreversible decline in capacity are often people who are living with long-term disabilities. These people will often require social supports to live their life with full equality but Bill 52 qualifies them to die by euthanasia, whether the social supports exist for them or not.

Many people with disabilities fear that decriminalizing euthanasia will further extend the social and cultural discrimination that they experience. To think that someone is "better off dead," or that there are people, or newborns, whose "lives are not worth living" leads to furthering the cultural discrimination for people with disabilities who are living with an advanced state of irreversible decline in capacity.

26 (4) Many people live with constant and unbearable physical or psychological pain which cannot be relieved in a manner that the person deems tolerable. There are no effective definitions and objective measures for determining whether or not a person will deem effective treatments for pain and symptom management that is oriented to a person's physical or psychological pain.

Since the bill defines the criteria for euthanasia as having: physical or psychological pain which cannot be relieved in a manner the person deems tolerable, therefore, people who live with chronic depression or mental illness would qualify for euthanasia, even if they reject effective treatment that they deem intolerable.

#### Euthanasia in Belgium.

We have decided to focus on the experience of euthanasia in Belgium. Bill 52 appears to be based on the Belgian euthanasia law. We can predict what will happen in Quebec by examining what has happened in Belgium.

Euthanasia was legalized in Belgium in 2002. The Belgian model essentially defines euthanasia as a form of medical treatment and regulates it as a medical act, in a similar manner to Bill 52.

Several recent studies have been done on the practice of euthanasia in Belgium; and recently, there have been several shocking cases of euthanasia in Belgium. We will suggest that these cases directly flow from the definitions in the Belgian euthanasia law. We believe that similar shocking cases will occur in Quebec based on the definitions used in Bill 52.

The first study we will examine is: *Physician-Assisted Deaths Under the Euthanasia Law in Belgium: A Population-Based Survey* (Canadian Medical Association Journal – CMAJ June 15, 2010).<sup>4</sup>

This study is based on data obtained from questionnaires sent to physicians related to deaths in the Flanders region of Belgium. Based on responses from 3623 questionnaires, the researchers identified 137 euthanasia deaths, 5 assisted suicide deaths and 66 assisted deaths without explicit request. Therefore, there were 208 assisted deaths with 66 (32%) of the assisted deaths being done without explicit request. (p. 895)

It is significant that the data uncovered 66 assisted deaths without explicit request since the Belgian euthanasia law and Bill 52, require that assisted death be only done with explicit request. The study indicated that most of the people who died by assisted death without explicit request were not competent. The study stated:

"Where the decision had not been discussed with the patient, the physician specified as reason(s) that the patient was comatose (70.1% of the cases) or had dementia (21.1% of the cases); in 40.4% of the cases, the physician indicated that the patient had previously expressed a wish for ending life (not equivalent to an explicit request for euthanasia)." (p. 896)

The study found that assisted death with request was most often done to alleviate pain or to fulfill a wish to end life; whereas assisted death without explicit request was most often done to reduce the burden on the family or because they did not want to prolong the life of the patient. (p. 897)

The researchers found that the demographic group of persons who died by assisted death with request in comparison to assisted death without explicit request was different. The study states:

"Our finding that euthanasia and assisted suicide were typically performed in younger patients, patients with cancer and patients dying at home is consistent with findings from other studies. Our finding that the use of life-ending drugs without explicit patient request occurred predominantly in hospital and among patients 80 years or older who were mostly in coma or had dementia fits the description of "vulnerable" patient groups at risk of life-ending without request." (p. 899)

In their conclusion, the authors of the study stated:

"Our study showed that physician-assisted death with an explicit request from the patient (euthanasia and assisted suicide) and use of life-ending drugs without an explicit request were different types of end-of-life decisions that occurred in different patient groups and under different circumstances. Unlike euthanasia and assisted suicide, the use of life-

ending drugs without an explicit patient request often involved patients with diseases other than cancer, which have an unpredictable end-of-life trajectory." (p. 899)

This study found that euthanasia without request represented a different demographic group from those who died by euthanasia with an explicit request. The study stated that for euthanasia deaths without an explicit request the demographic group:

# "fits the description of "vulnerable" patient groups at risk of life-ending without request."

This study proves that at least one vulnerable patient group is negatively effected by the legalization of euthanasia in Belgium.

The second study we will examine is the: *Reporting of Euthanasia in Medical Practice in Flanders Belgium: Cross Sectional Analysis of Reported and Unreported Cases* (British Medical Journal – BMJ November 2010)<sup>5</sup>

This study is based on the same data as the previous study obtained from the responses to questionnaires linked to the deaths of people who died in the Flanders region of Belgium. Based on the responses from the 3623 questionnaires, the study concluded 52.8% of the assisted deaths in the Flanders region of Belgium were reported, while 47.2% of the assisted deaths were unreported. (p. 5174)

Similar to the Belgian study that determined that 32% of euthanasia deaths were without explicit request, <sup>4</sup> the unreported assisted deaths represented a different demographic group than the reported assisted deaths. The study stated:

"However, in a bivariate analysis there was a significant relation between reporting of euthanasia and the patient's age, with deaths of patients aged 80 years or older reported significantly less often than deaths of younger patients. Cases were also reported less often when the time by which life was shortened was less than one week compared with when the life shortening effect was greater." (p. 5178)

This study found that when the assisted death was reported, usually the safeguards or due care criteria were followed, but when the assisted death was not reported the "rules" were usually not followed. The study stated:

"A verbal as well as a written request for euthanasia was present in 73.1% of all reported cases, whereas a legally required written request was absent in the majority (87.7%) of the unreported cases. In reported cases, the decision was always discussed with others, which was not always the case (85.2%) in unreported cases. Other physicians and care givers specialised in palliative care were consulted (97.5%) more often in reported cases than in unreported cases (54.6%). ... In reported cases of euthanasia the drugs were almost always administered by a physician (97.7%); in unreported cases, the drugs were often administered by a nurse alone (41.3%)." (p. 5178)

The following reasons were offered by the doctors for not reporting the assisted death:

"For 76.7% of the cases, physicians answered that they did not perceive their act as euthanasia, whereas for 17.9% they gave the reason that reporting is too much of an administrative burden, 11.9% that the legal due requirement had possibly not all been met, and 8.7% that euthanasia is a private matter between the physician and patient. A small proportion (2.3%) did not report the case because of possible legal consequences." (p. 5178)

It is significant to note that a number of assisted deaths were not reported out of fear that the legal due requirement had not been met or reporting would lead to possible legal consequences. Therefore, the reporting system did not ensure that the legal requirements were being met.

Concerning the "safeguard" of the requirement to consult another physician, the study found:

"Consultation occurred in almost all reported cases, whereas it occurred in only half of all unreported cases. This association was also found in the Netherlands, where the most important reason for not consulting was that the physician did not intend to report the case. Physicians who intend to report a case seem to consult another physician and comply with the other requirements of the law, whereas physicians who do not intend to report a case appear to consult a physician only when they felt the need for the opinion of a colleague." (p. 5183)

The researchers pointed out that since most of the unreported euthanasia deaths were done on people who appeared to be closer to death, the physician either felt under pressure to end the life of the patient or the physician felt that there was not enough time to go through the legal process. (p. 5183)

"The physician may ... prefer to use opioids or sedatives because these drugs are more readily available and there is less control over their distribution than with neuromuscular relaxants. By disguising euthanasia as pain alleviation, physicians can proceed with the euthanasia process without having to comply with the stringent, and in their perception time consuming, procedures of the euthanasia law." (p. 5183)

To disguise assisted death as palliative care or palliative sedation relieves the physician of the requirement of reporting the death, but it also forgoes the safeguards that were intentionally built into the law.

Since Bill 52 defines palliative care to include terminal palliative sedation and "medical aid in dying" and because Bill 52 does not define terminal palliative sedation, the issue of disguising assisted death as palliative care will likely be a serious problem.

The study concludes:

"As such legislation alone does not seem sufficient to reach the goal of transparency ("total" or a 100% transparency seems to be a rather utopian ideal) and to guarantee the careful practice of euthanasia." (p. 5183)

The study "*Legal Euthanasia in Belgium: Characteristics of All Reported Euthanasia Cases*" indicated that no physicians have faced prosecution for causing a death outside the parameters of the law in Belgium.<sup>6</sup>

This study shows that vulnerable people die by euthanasia in Belgium and these deaths are not being reported, making it an invisible crime. (p. 5178)

The final study that we will analyze is: *The role of nurses in physician-assisted deaths in Belgium.* (CMAJ June 2010).<sup>7</sup>

This study is based on the data collected from 1265 questionnaires that were received from nurses in Belgium. (p. 906)

The data from the questionnaire determined that 248 nurses reported that the last patient in their care died by euthanasia. Almost half (120 nurses) reported that the last patient in their care died by euthanasia without explicit request. (p. 906)

This study also found that people who died by euthanasia with request were more likely to be under the age of 80, to have cancer and to die at home. In contrast, people who died by euthanasia without explicit request were more likely to be over the age of 80, were less likely to have had cancer and were more likely to die in a hospital. (p. 907)

The lethal dose was injected by the nurse 12% of the time, even though this is illegal in Belgium. The study stated:

"The drugs were administered by the nurse in 14 (12%) of the cases of euthanasia. The physician was not co-administrator in 12 of the 14 cases, but the drug was always given on his or her orders. The nurse administered neuromuscular relaxant in four cases, a barbiturate in one case and opioids in nine cases. In nine cases the physician was not present during the administration of drugs." (p. 907)

The study stated that factors that were significantly associated with the nurse administering life-ending drugs were:

"the absence of an explicit request from the patient, the patient being more than 80 years old and the nurse having had a recent experience with life-shortening end-of-life decisions." (p. 907)

The study found that nurses are acting outside of the law. The study concluded:

"It seems that the current law (which does not allow nurses to administer the life-ending drugs) and a control system do not prevent nurses from administering life-ending drugs." (p. 909)

"By administering life-ending drugs at the physician's request in some cases of euthanasia, and even more so in cases without an explicit request from the patient, the nurses in our study operated beyond the legal margins of their profession." (p. 910)

EPC focused on studies from Belgium because Bill 52 is similar to the Belgian euthanasia law. The data from these studies proves that:

- 1. As many as 32% of all assisted deaths are done without explicit request.
- 2. As many as 47% of all assisted deaths are not reported.
- 3. The law restricts assisted deaths to physicians. Nurses are doing euthanasia, even though the law does not permit it.
- 4. Assisted deaths that are done, outside of the parameters of the law, are rarely reported turning them into a "silent crime."

- 5. There have been no attempted prosecutions of euthanasia abuses.
- 6. At least one vulnerable patient group is at risk of death without explicit request. The studies all found that assisted deaths which are done without request, or that are done by nurses, or that are not reported are more likely to be done to people who are over the age of 80, incompetent to make decisions for themselves, and living in a hospital. This demographic group: "*fits the description of "vulnerable" patient groups at risk of life-ending without request.*"

There is more. A study that was published in the Journal of Pain and Symptom Management (November 2011) entitled: *Process and Outcomes of Euthanasia requests Under the Belgian Act on Euthanasia: A Nationwide Survey*<sup>8</sup> found that only 5% of all requests for euthanasia in Belgium are refused.

Recent news stories concerning euthanasia in Belgium include: a botched sex change victim dying by euthanasia in Belgium; <sup>9</sup> a Belgian woman with Anorexia Nervosa, who was allegedly sexually abused by psychiatrist, died by euthanasia; <sup>10</sup> Belgian twins, Marc & Eddy Verbessen died by euthanasia out-of-fear of blindness; <sup>11</sup> and a mentally ill, chronically depressed woman died by euthanasia in Belgium. <sup>12</sup>

To suggest that there is no indication that vulnerable groups are dying by euthanasia in jurisdictions where assisted death is legal are wrong. Data that is provided by the reporting procedures in the Netherlands, Belgium, Oregon and Washington State are limited. There are clear indications that vulnerable patient groups are at risk when assisted death is done without request and those deaths are rarely reported.

In April 2013, the World Medical Association (WMA) reiterated its opposition to euthanasia. The WMA resolution <sup>13</sup> on euthanasia stated:

"Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness."

The Supreme Court of Canada, in Rodriguez, found that there is way no half way measure that meets parliament's objective to protect societies most vulnerable people from the risk of serious abuse and death in the event of the legalization of euthanasia.

The EPC is convinced that if Bill 52 is passed and becomes law, that over time, these same abuses will occur in Quebec.

Members of the EPC oppose recognize that euthanasia cannot be effectively controlled and threatens our lives when we are vulnerable.

The EPC recognizes that once euthanasia becomes legal it incrementally extents to other groups of people, who were originally.

The experience of other jurisdictions, such as Belgium, that have legalized euthanasia and re-affirm the conclusion of the Supreme Court of Canada in Rodriguez.

Bill 52, is based on the Belgian euthanasia law. Bill 52 employs vague, ambiguous and unclear language. Bill 52 will not enable physicians to effectively prevent the abuse of euthanasia in Quebec as has occurred in Belgium.

The EPC urges the Quebec National Assembly to reject the decriminalization of euthanasia in favour of a regime that provides greater equality and access to end-of-life care for all of every Quebec citizen without resorting to giving its doctors the right to cause the death of their patients.

Maintaining a prohibition on euthanasia is based on concern for patient safety and the equal protection of every Quebec citizen, especially when they are at the most vulnerable time of their life.

#### **Endnotes:**

- 1. Canadian Medical Association: Euthanasia and Assisted Suicide (Update 2007) http://policybase.cma.ca/dbtw-wpd/Policypdf/PD07-01.pdf.
- 2. Bill 52: An Act respecting end-of-life care, Chapter 1: Paragraph 3:3.
- Quebec euthanasia Bill 52: a very dangerous bill. June 18, 2013. http://alexschadenberg.blogspot.ca/2013/06/quebec-euthanasia-bill-52-very.html.
- Physician-Assisted Deaths Under the Euthanasia Law in Belgium: A Population-Based Survey (CMAJ June 15, 2010). http://www.cmaj.ca/content/early/2010/05/17/cmaj.091876.full.pdf+html
- Reporting of Euthanasia in Medical Practice in Flanders Belgium: Cross Sectional Analysis of Reported and Unreported Cases (BMJ November 2010). <u>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2950259/pdf/bmj.c5174.pdf</u>
- Legal Euthanasia in Belgium: Characteristics of All Reported Cases (Journal of Medical Care February 2010). <u>http://www.worldrtd.net/sites/default/files/u22/Smets\_reported%20euthanasia%20cases\_Med%20Care.pdf</u>.
- 7. The role of nurses in physician-assisted deaths in Belgium. (CMAJ June 2010). http://www.cmaj.ca/content/182/9/905.full.
- Process and Outcomes of Euthanasia requests Under the Belgian Act on Euthanasia: A Nationwide Survey (Journal of Pain and Symptom Management - November 2011) http://www.ncbi.nlm.nih.gov/pubmed/21570807.
- Nathan krijgt euthanasie na mislukte geslachtsoperatie, (HNL.BE Oct 1, 2013) <u>http://www.hln.be/hln/nl/957/Binnenland/article/detail/1714448/2013/10/01/Nathan-krijgt-euthanasie-na-mislukte-geslachtsoperatie.dhtml</u>.
- 10. Another speed bump for Belgian euthanasia (bioedge.org February 8, 2013) http://www.bioedge.org/index.php/bioethics/bioethics\_article/10388#comments.
- Brothers use right for euthanasia in Belgium (Reuters January 16, 2013) <u>http://www.hurriyetdailynews.com/brothers-use-right-for-euthanasia-in-</u> belgium.aspx?pageID=238&nID=39124&NewsCatID=351.
- 12. How my mother died. (mercatornet February 4, 2013) http://www.mercatornet.com/articles/view/how\_my\_mother\_died
- World Medical Association Resolution on Euthanasia (revised by the 194<sup>th</sup> WMA council session April 2013) <u>http://www.wma.net/en/30publications/10policies/e13b/</u>