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Euthanasia Prevention Coalition response to the Special Joint Committee on Physician Assisted Dying

The Euthanasia Prevention Coalition (EPC) was founded in 1998 to work in coalition with groups and individuals to build an effective social barrier to euthanasia and assisted suicide.

For the purpose of this report we will use the term "assisted death" to reference euthanasia and assisted suicide. We do not consider the term assisted death to be an accurate term because it does not define the term "assisted" nonetheless it is the term that was used by the Supreme Court of Canada.

EPC does not believe that assisted death should ever be permitted, because it gives doctors the right in law to kill their patients. We do not believe that laws permitting assisted death can effectively safeguard people from assisted death when they are living through the most vulnerable time of their life. Nonetheless, the Supreme Court of Canada has decided to impose assisted death on Canada.

Many people are convinced by the theory that legalizing assisted death promotes individual autonomy and the relief of suffering. EPC is convinced that the practice of assisted death, when examined, leads to real human concerns, abuse and abandonment. EPC does not consider assisted death as necessary for relieving suffering and we question that autonomy is always present.

The purpose of this document is to provide direction on preventing the abuses that occur with assisted death in the jurisdictions where it is legal, with the intention of preventing similar abuses in Canada.

The questions EPC will focus on are: **How does the law work in other jurisdictions? What abuses are happening in those jurisdictions? What must be done to not repeat the abuses that are evident in the practice of assisted death in these jurisdictions**?

Since the Supreme Court has imposed assisted death upon Canada, our primary concern is with the oversight of the law. Oversight is a primary concern since assisted death concerns the life and the death of people. Recognition that there was an error in the decision making process or in a person's judgment concerning assisted death, or a recognition that the person was not competent to make such a decision, cannot return the person to life once they are dead.

In jurisdictions where assisted death is legal, the law outlines a set of procedures or conditions that physicians must follow before the assisted death can be done. When examining the laws in jurisdictions where assisted death is legal, it may appear that these laws are designed to provide assisted death as a "last resort" for people who are living with unbearable physical or psychological suffering, but this is often not the case.[1]

The case of Emily, a 24-year-old healthy woman in Belgium who lives with suicidal ideation and was approved for euthanasia, shows us that euthanasia, even for psychological suffering, is not based on a "last resort." In June 2015, Dr Lieve Thienpont, who works with the Belgian euthanasia clinic, approved the euthanasia death of "Laura," (the name that was used for Emily) based on her assessment that Emily was living with unremittent psychological suffering.[2] Later that year, Emily, who was being featured in a video documentary by the Economist Magazine, changed her mind and decided to live.[18] We are happy that Emily changed her mind, but clearly euthanasia was not based on a "last resort."

Belgian law requires that the person who requests an assisted death must be competent and conscious at the moment of making the request.[1] Research from Belgium indicates that this is not always the case.

A study published in the NEJM entitled: ***Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium*** (March 19, 2015) found that 4.6% of all deaths in the first six months of 2013, in the Flanders region of Belgium, were by assisted death and 1.7% of all deaths were assisted deaths without explicit request representing more than 1000 assisted deaths without explicit request in 2013.[3]

The supplemental appendix in the study informs us how the researchers classified the data. It states:

"*If in the latter case the drugs had been administered at the patient's explicit request, the act was classified as euthanasia or assisted suicide depending on whether the patient self-administered the drugs. If drugs were used with the same explicit intention to hasten death but without the patient's explicit request, the act was classified as hastening death without explicit patient request. This can include cases where a patient request was not judged as explicit by the physician, where the request came from the family or where the physician acted out of compassion.*"[4]

This research study confirms that many intentional hastened deaths are occurring without the explicit request of the patient which contravenes the Belgian assisted death law and medical ethics.

Belgian law also requires physicians who are considering assisting the death of a patient to consult another physician about the serious and incurable character of the disorder and inform him/her about the reasons for the consultation.[1]

The supplemental appendix from the study *Recent Trends in Euthanasia and Other End-of-Life Practices* states that a second physician was consulted only 92.6% of the time.[4]

This study indicates that there is significant under-reporting of assisted death in the Flanders region of Belgium. The data from the study indicated that 4.6% of all deaths in the Flanders region of Belgium in the first six months of 2013 were by assisted death.[3] Since there were 61,621 deaths in the Flanders Region of Belgium in 2013, based on the data (4.6%), there would have been approximately 2834 assisted deaths in the Flanders region of Belgium in 2013. But according to the official Belgian euthanasia statistics, there were 1454 reported assisted deaths in 2013.[5] **Therefore as many as 1380 assisted deaths may not have been reported to the Euthanasia Control and Evaluation commission in 2013.**

The 2015 assisted death data from Belgium indicates that there were 2021 reported assisted deaths in Belgium in 2015.[19] Media reports state that Professor Wim Distelmans, the chair of the Belgium Euthanasia Control and Evaluation Commission stated: "*Remember, there could be some euthanasia cases carried out but which are not declared*."[19]

For the first time, the Belgium Euthanasia Control and Evaluation Commission have admitted that they do not know how many euthanasia deaths actually occur.

In January 2014 the bioethics news service, *Mercatornet*, reported that Dr. Marc Cosyns stated in an interview in the Belgian *De Standaard* news that he does not report his euthanasia deaths to the Euthanasia Control and Evaluation Commission.[15]

This indicates that some physicians do not follow the basic requirements of the law, meaning that they do not report an assisted death, they may not have obtained a second opinion, and they often hasten death without an explicit request. Physicians who do not fulfill the requirements of the law are not being brought before the Belgium Association of Medical Unions or the Euthanasia Control and Evaluation Commission to answer to their actions.

Questions arise, such as: Why are there significant numbers of under-reported assisted deaths? Why are there significant numbers of assisted deaths without explicit request? Why are there assisted deaths whereby the physicians did not follow the required procedure of the law? Why have the reasons for assisted death expanded to allow a 24-year-old healthy woman, who lives with suicidal ideation, to be approved for assisted death?[2]

The reason is that the Belgian euthanasia law does not provide effective oversight of the law. The same problems that exist within the design of the Belgian law also exist in the design of the Netherlands law, the Oregon law, the Washington State law, and the Québec assisted dying law. Each of these assisted death laws have similar design flaws leading to a lack of effective oversight. These laws are not designed to provide effective oversight for patients, but rather these laws are designed to ensure that the doctors are protected from potential prosecution.

How does the law work in jurisdictions where assisted death is legal?

1. A person must request the assisted death. There are several requirements within these laws that may differ, such as a written request, an oral request, a statement within a Living Will or Power of Attorney, a request from the Power of Attorney, nonetheless, each of the laws require that an explicit request be made.
2. A doctor must examine the patient to ensure that the patient's condition meets the requirements of the law. Requirements vary based on the jurisdiction.
3. The doctor must explain that alternatives to assisted death are available. This also varies based on the jurisdiction.
4. A second doctor must either examine the medical file or examine the patient to ensure that the decision of the first physician is correct or at least following the accepted protocol.
5. In the case of a person who is requesting an assisted death based on psychological suffering, one of the physicians approving the assisted death must be a psychiatrist. In Belgium, for instance, the psychiatrist is the third physician to approve the assisted death. In Oregon and Washington State, if the doctor suspects that the patient is requesting an assisted death based on depression or issues related to mental illness, the physician is expected, but not required, to send the patient for a psychiatric or psychological assessment.
6. If the assisted death is approved, the doctor who carries out the "assisted death" is required, in all jurisdictions, to report the death to the government agency.

The problems with the framework of these laws are self-evident. These laws require physicians to decide who will die by assisted death and then the law requires the physician who assists the death to self-report the death to a government agency. This provides no effective oversight of the law because doctors do not self-report abuse of the law. Consider the following:

1. *An explicit request must be made to the physician*. What if an explicit request is not made to the physician, but a family member urges that an assisted death be done? What if the person is not capable of making a explicit request, such as a person who is living with dementia?

None of the laws provide third party oversight to ensure that an explicit request has been freely made. The physicians are responsible to ensure that an explicit request has been made. The data from Belgium indicates that 1.7% of all deaths are hastened without explicit request.[3] Most of these deaths are not reported as an assisted death. Even when a suspicious death is reported as an assisted death, the reporting procedure is based on a self-reporting system by the physician who assists the death. Doctors do not self-report abuse of the law.

2. *What if the doctor examines the patient and provides a wrong diagnosis or influences the patient with an overly negative prognosis*?

Wrong diagnoses have resulted in people dying by assisted death. Pietro D'Amico died at an assisted suicide clinic in Switzerland in April 2013. After his death, his autopsy revealed that he did not have a life-threatening condition. You cannot return from an assisted death.[6]

It is a human reality that many people will react to a poor prognosis by becoming depressed or experiencing "feelings of hopelessness." A study from the Netherlands found that patients with a depressed mood were 4.1 times more likely to request euthanasia.[7] A similar study from Oregon found that 15 of 58 (26%) of people, who had asked for assisted suicide were depressed or experiencing "feelings of hopelessness."[8]

Since none of the assisted death laws require that a psychiatric assessment be done to ensure that the patient is competent and not depressed or that the person is not reacting to an overly negative prognosis by a physician, a physician assessment does not ensure effective oversight of the law.

3. *No jurisdiction requires that effective treatment must be tried before assisted death can be done*. A physician explaining the alternatives to assisted death may or may not be a protection for patients, especially a patient who is depressed. Many people who request an assisted death are in fear of future suffering rather than current suffering, therefore, without a required palliative care or psychiatric consultation, it is impossible to know whether patients actually know that they have an alternative to assisted death.

We know of one case of a depressed Belgian woman who died by assisted death without ever receiving treatment for depression.[9]

Jeannette Hall, who lives in Oregon, was diagnosed with cancer in 2000 and given six months to one year to live. She did not want medical treatment, she wanted an assisted death. Her doctor encouraged her to try medical treatment, and after counseling, she changed her mind. She received treatment and went into remission. Jeannette is now happy to be alive, but if she had a different physician she would have died by assisted death.[10]

It is important to question that if a doctor negatively assesses the future prognosis of a patient, in such a manner that the patient experiences feelings of hopelessness, would the patient actually be freely choosing an assisted death?

4. *The requirement of a second doctor approving the assisted death* does not necessarily provide greater oversight for the patient. The second doctor may properly assess the patient but often the second doctor has a professional relationship with the first doctor and is simply carrying out the formal duty of approving the assisted death.

It is very important to state that when the second doctor does not agree with the assessment or decision of the first doctor, the first doctor simply needs to ask another doctor. No jurisdiction requires that when a second doctor disagrees with the assisted death, based on a clinical evaluation, that the assisted death will not occur. For instance, Belgian law only requires that a second doctor be consulted. As already stated, Belgian research indicates that sometimes a second doctor is not even consulted.[4]

Dr. Charles Bentz, an Oregon doctor, had a depressed patient who died by assisted death. According to Dr. Bentz, he referred his patient for treatment for melanoma. The cancer specialist contacted Dr. Bentz asking him to be the second physician to approve the assisted death of the patient. Dr. Bentz, who had recently examined the patient, explained that the patient did not qualify for assisted death in Oregon because he was depressed. The oncologist simply called another doctor for a second opinion.[11] Even though Dr. Bentz was the primary physician and refused to approve the assisted death based on depression, he could not protect his depressed patient from assisted death.

Even when a physician abuses the safeguard of requiring a second opinion, it simply doesn't matter because the law requires the doctor who assists the death to be the doctor who sends in the official report of the assisted death to the government agency. As previously stated, doctors do not self-report abuses of the law.

5. *In the Netherlands, Belgium, and Québec, people can die by assisted death based on psychological suffering*. There are several concerning stories about people who have died by assisted death based on psychological suffering.

A study was published in British Medical Journal (July 27, 2015) by psychiatrist Dr. Lieve Thienpont, entitled, ***Euthanasia requests, procedures, and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study*** contains concerning data. Dr. Thienpont works with the Belgian euthanasia clinic.[12]

A close analysis of the data shows that of the 100 requests for assisted death for psychiatric reasons, only 57 people followed through with the process. Of these 57 requests for an assisted death for psychiatric reasons, 48 were approved for assisted death and 35 died by assisted death. It is distressing that 26 out of 35 who died by an assisted death were women.[12]

It was Dr. Thienpont who introduced the world to "Laura" (Emily) the 24 year-old physically healthy woman who was living with suicidal ideation, as an example of why euthanasia for psychiatric reasons was necessary.[2]

Dr. Wim Distelmans who operates the Belgian euthanasia clinic and the chair of the Belgian Euthanasia Control and Evaluation Commission stated that 50 – 60 people with psychiatric conditions die every year by assisted death.[13]

The 2014 Netherlands euthanasia report stated that there were 41 assisted deaths for people with psychiatric conditions and 81 assisted deaths for people with dementia.[14]

In the Netherlands, euthanasia for the reason of psychological suffering, was approved for an otherwise healthy blind woman,[20] an autistic man who was lonely and depressed after retiring from his life-long work.[21] and an otherwise healthy woman who was living with tinnitus.[22]

The Euthanasia Prevention Coalition does not question that people who live with psychiatric conditions are suffering. We question whether it is possible to define, based on objective criteria, when assisted death for psychiatric reasons should be done. These decisions are based on subjective criteria, whereby a person is lethally injected because the person deems that their psychological suffering is too intense.

If assisted death is going to be imposed upon Canadians, then it should be based on objective criteria, not subjective criteria. **Assisted death for psychological suffering should not be permitted.**

6. *Laws permitting assisted death require the doctor who assists the death must fulfill the reporting requirements of the law.* This system provides no effective oversight of the law. The report is submitted to the government commission after the patient has died. If an inappropriate decision was made, the decision cannot be reversed as the patient cannot return from death. These reports do not provide effective oversight because doctors do not self-report abuses of the law, they will not self-report questionable actions and often they do not report at all.

The recent Belgian study[3] (referred to earlier) indicates that nearly half of the assisted deaths are not being reported. The Belgian studies[3, 16] are important because they examine every death, not just the deaths that are found in the official euthanasia reports. The data in these studies have been extensively

analyzed enabling us to conclude that the Belgian euthanasia law is not always followed and in many cases it is ignored.

If you think that these concerns only apply to Belgium and possibly the Netherlands, the 2014 *Washington State Death With Dignity report* states that 176 people were prescribed a lethal dose, 119 people reportedly died by ingesting the lethal dose and 27 people who obtained a lethal dose and died, that their status is unknown.[17] What kind of oversight enables a person to obtain a lethal dose, but the status of whether or not the lethal dose was ingested is simply unknown? Is it safe to have a lethal dose sitting around the house?

If assisted death is to be imposed on Canada, we must not employ the same flawed system of oversight. Every jurisdiction that has legalized some form of assisted death does not provide effective oversight of the law, even though assisted death is a life and death act.

People on death row are provided a system of checks and balances and the ability to appeal a decision, whereas with assisted death, every jurisdiction where it is legal relies on physicians to self-police and self-report their actions.

EPC recognizes that everyone experiences, at some time in their life, what can be defined as a vulnerable time. People who request an assisted death are not necessarily seeking to die, but rather they may be seeking help in a very difficult circumstance.

We do not view the lethal injection of people experiencing vulnerable circumstances to be a form of autonomy, but rather as a form of abandonment.

We will never accept the concept that lethal injections or lethal prescriptions can be defined as a form of healthcare or as a type of medical treatment. We will always call it what it is, killing people or assisting in their suicide.

Nonetheless, assisted death is being imposed by the Supreme Court of Canada upon Canadians, therefore we are providing some clear guidelines to avoid similar abuses of assisted death occurring in Canada.

Summary:

Since the Supreme Court of Canada has imposed assisted death upon Canada, there must be effective oversight for the law to provide "safeguards" that actually protect people at a vulnerable time of their life.

1. A "before the death" approval system and a third party reporting system must be created to ensure that there is effective oversight of the law and to ensure that the law is followed. Physicians who assist the death of their patients, must not be the ones who also report the death.
2. The most effective "before the death" approval system to ensure that an assisted death is following the law, is to empower the courts to approve the assisted death. Only the court has the ability to ensure that the requirements of the law have been met
3. Psychological suffering cannot be a reason for a person to be approved for an assisted death. There are too many variables and no objective criteria when considering an assisted death for the reason of psychological suffering.
4. Physicians who do not participate in assisted death due to their conscience or personal beliefs, must not be forced to participate in any way, including referral. In early January 2016, the Dutch Medical Federation (KNMG) upheld the right of doctors to refuse to participate and their spokesperson stated that: "*Euthanasia should not be something that can be forced on doctors*.[23]

End Notes:

1. http://www.ethical-perspectives.be/viewpic.php?TABLE=EP&ID=59
2. http://www.demorgen.be/nieuws/laura-is-24-jaar-en-fysiek-gezond-ze-krijgt-deze-zomer-euthanasie-b3d9c64f/1NGENU/
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19. http://www.news24.com/World/News/belgian-euthanasia-cases-hit-record-high-20160127
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21. http://www.nrc.nl/nieuws/2014/01/11/negen-keer-euthanasie-op-patient-psychiatrie
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23. http://www.dutchnews.nl/news/archives/2016/01/doctors-should-have-the-right-to-refuse-euthanasia-requests-knmg/