Special Joint Committee on Physician Assisted Dying
Testimony submitted by:
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Toujours Vivant-Not Dead Yet is a non-religious organization by and for disabled people. Our goal is to inform, unify and give voice to the disability rights opposition to assisted suicide, euthanasia, and other life-ending practices that have a discriminatory impact on disabled people. TVNDY was founded in Québec in 2013 and is affiliated with the Council of Canadians with Disabilities. I am also writing in my capacity as a board member of Not Dead Yet, a U.S. disability rights organization founded in 1996 to oppose the legalization of assisted suicide and euthanasia.

Every major disability rights organization in North America opposes assisted suicide and euthanasia because virtually every person who receives physician aid in dying has a disability, whether or not they also have a terminal illness. The United Nations defines disability as "long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others."[1] Thus even people with cancer and heart disease find themselves confronted with disabilities as the disease progresses.

However few people who have disabilities want to identify as disabled, not wanting to join the most marginalized and despised group in our society. In fact, many people state they'd rather be dead than disabled. Hence the popularity of assisted suicide and euthanasia.

It is disability, and not pain or fear of death, that underlies the most common reasons for requests for assisted suicide. The 2014 report on the Oregon Death with Dignity program notes, "the three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%).[2]

The loss of autonomy and decreasing ability to participate in activities are largely due to barriers in the environment and public policy that forces people who need help with activities of daily living into institutional settings. These are not problems endemic to the disabling condition itself, but to societal choices on how long-term care funds are spent. In addition, the perception that needing help with personal care somehow diminishes one's dignity is an artefact of a set of beliefs that values "rugged individualism" over the natural interdependence we all share. In short, the problems that lead to requests for assisted suicide and euthanasia arise from attitudes and lack of choices caused by discrimination.

Most assisted suicide laws do not address these most important reasons for assisted suicide requests. In addition, such laws confounds the urgent need to relieve pain and

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[1] http://www.un.org/esa/socdev/enable/faqs.htm#definition, retrieved 21/1/16

[2] https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf retrieved 21/1/16

emotional distress with the desire for death. Therefore, any law passed by parliament should be, first and foremost, a palliative care program, to ensure that every Canadian receives adequate pain relief and emotional support as s/he faces death, disease or disability. Death should be a disfavoured last resort after a specific sequence of steps are followed to ensure that the reasons for the death request have been thoroughly addressed.

The Supreme Court agreed with the lower court's finding that carefully crafted safeguards could minimize the risks inherent in assisted suicide.[3] Yet most proposals set forth so far have essentially the same as the laws currently in effect in other jurisdictions. The problem with these laws is that protections and safeguards are mostly reactive rather than proactive, in that they apply after the life-ending act has occurred. Instead of preventing people from being wrongly killed, they give lip service to identifying and punishing negligence and bad actors after the fact.

Assisted suicide laws are also focused more on protecting health care professionals from liability than on protecting people from coercion, manipulation, and social pressure to request euthanasia or assisted suicide.

By satisfying the terms of the United Nations convention on the Rights of Persons with Disabilities, Canada can begin to improve the circumstances in which people who become disabled find themselves. Combined with an individualized approach that provides effective palliative care and home based services, a comprehensive end-of-life policy can address the most common reasons behind requests for assisted suicide and euthanasia..

If Canada wants to become a world leader in this field, it should pass a law that identifies and protects vulnerable persons from inducement to commit suicide, and provides the palliative care and community supports necessary to afford them resilience in the face of death, disease and disability. We must break with other jurisdictions and have judicial and administrative review to determine eligibility, competency, voluntariness of the request, and ensure that the person is not in a vulnerable circumstance.

Canada has rejected the death penalty in order to ensure that no innocent person may be wrongfully put to death. Imposing a few procedural steps before the fact exacts but a small price to prevent ineligible or vulnerable persons from being killed through negligence, coercion, or medical error.

In addition, we must keep detailed records of the assisted suicide program, and perform analyses not just on the program records, but track all life-ending acts to ensure that illegal and coercive practices do not continue on the back wards of long-term care and other medical facilities. Finally, penalties for violation of the terms of the law must pose an effective and meaningful deterrent to non-compliance and bad actions by all who are involved in assisted suicides.

I. Goals of EOL legislation:

A. To provide the full range of choice and control at the end of life;

B. To relieve physical pain and symptoms, as well as emotional and existential distress;

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[3] http://www.canlii.org/en/bc/bcsc/doc/2012/2012bcsc886/2012bcsc886.html# at para 883, and https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do at para 105, retrieved 21/1/16.

C. To protect vulnerable persons from being induced to commit suicide in times of weakness;

D. To prevent the serious public health problem of suicide;

E. To prevent life-ending acts that fall outside the scope of the law, as well as intentional killing of ill and disabled persons under the guise of "mercy";

F. To protect the medical profession's integrity, ethics and physicians' role as healers and advocates;

G. To avoid sending a message that the lives of old, ill and disabled people are less valued in our society; and

H. To create a law which resists the shift toward enlarging eligibility criteria, and increased tolerance for violations of the stated eligibility criteria.

II. Definition of terms

A. Adult

An adult is a person who is 18 years of age or older.

B. Assisted suicide

An act, undertaken by a person with the advice, knowledge, means and/or assistance of a physician or medical professional, to end his/her life.

C. Assisted Suicide Commission

A five-member panel which administers and supervises all activities of the assisted suicide program.

The ASC shall consist of three persons appointed by the minister of health (including at least one physician and one palliative care specialist), a person appointed by the attorney general, and one person appointed by the coroner's office.

Commission members may serve no more than two five-year terms consecutively.

D. Assisted suicide Technician

An Assisted Suicide Technician, employed and assigned by the Assisted suicide Commission, will oversee the administration of each assisted suicide. This person will have emergency medical certification and additional specialized training.

E. Case coordinator

A person employed by the Assisted Suicide Commission to provide information and guide those who request assisted suicide through the process. The case coordinator's duties include obtaining disability accommodations, collecting and maintaining records, ensuring compliance with the law, and supervising and recording the assisted suicide itself.

F. Eligibility Determination Panel

An expert panel appointed by the minister of health consisting of a physician, a palliative care professional, a social worker, a mental health professional and a disabled activist. Its function is to determine whether a person making a request is eligible under the law.

G. Grievous and irremediable medical condition

Any medical condition which:

- Represents a substantial dysfunction of one or more major body system(s);
- Is not amenable to, or is beyond mitigation or treatment;
- Is permanent and/or is likely to cause death within six months;
- Causes significant pain or other persistent physical symptoms such as vomiting, diarrhea, choking, coughing, seizures, difficulty breathing;
- Renders the person unable to commit suicide unaided.

H. Intolerable and enduring suffering

- Intolerable means physical and psychological / existential suffering that arises from the medical condition and which, regardless of mitigating measures, renders a person unable to carry out activities of daily living.
- The persistence of suffering is determined based on the nature of the grievous and irremediable medical condition:
    - Where the medical condition amounts to a chronic illness or permanent disability, persistence of suffering will be adjudged after an adjustment period of one year;
    - Where the medical condition is likely to cause death within six months, persistence of suffering will be measured over a period of two weeks;
- Psycho-social causes of suffering are addressed during a vulnerability assessment, and those circumstances remedied before a request for assisted suicide may be considered.

I. In the circumstances

The person's circumstances are directly linked to the supports available:

- whether effective palliative care is available;
- Whether accessible housing and help with activities with daily living are available in the community or the person must be institutionalized to have daily needs met;
- whether income supports and respite care are available for family caregivers or whether the person feels like a burden in her/his own home.

J. Vulnerable to inducement to commit suicide

A person is vulnerable when natural resilience and buffers are removed or compromised by poverty, isolation, discrimination and devaluation (based on gender, age, race, and disability) and lack of needed supports. A person is vulnerable who does not have access to medical treatment, palliative care, or needed auxiliary aids and services.

K. Witnesses

Witnesses shall be competent adults who are not:

- A relative of the person by blood, marriage or adoption;

- An owner, operator or employee of a health care facility where the person is receiving medical treatment or is a resident; or
- Implicated in the affairs of or entitled to any portion of the estate of the person making the request under any will or by operation of law.

III. General provisions

A. Accessibility

All activities under this law will be carried out in a manner accessible to and usable by people with disabilities. This includes access to facilities and equipment, and removing communication barriers.

Each province will be responsible for providing all information and forms in both official languages and in accessible formats. In addition, qualified interpreters, scribes and assistive technology shall be made available to enable people with communication disabilities to effectively relate and understand all information about the assisted suicide process.

B. Assisted suicide

Assisted suicide, rather than euthanasia, shall be the method of medically-assisted death.

C. No Advance directives

Advance directives may not be used as a means to consent to assisted suicide when the person becomes incompetent.

D. Exemption

Hospices and palliative care facilities shall not be required to administer assisted suicide. They must inform people upon admission as to their policy vis-à-vis assisted suicide.

IV. Eligibility Criteria

A. In general

A person is eligible for assisted suicide if s/he is a competent adult resident of the province who has a grievous and irremediable medical condition that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition, and is not vulnerable to inducement to commit suicide.

No person shall qualify for Assisted Suicide solely because of age or disability.

B. Mitigating measures

People requesting assistance to die are asking society to grant an exception to its policy of suicide prevention. In return, these people must be willing to accept some burdens to ensure that society can safeguard its most vulnerable from potential coercion, exploitation and abuse under such policies. Thus it seems reasonable to ask those requesting suicide assistance to at least try reasonable palliative measures before declaring that their pain and suffering are so severe as to warrant state-sponsored killing.

C. Capacity to consent

Assisted suicide is not medical care and is not designed to improve the person's physical condition, but only to kill. Therefore we believe a traditional "medical decision making" capacity assessment is not appropriate.

We recommend the development of a unique legal standard/test for determining competency to choose to end one's life that reflects:

- a suicide prevention standard that identifies risk for suicidality (including vulnerability, major depressive disorder and demoralization syndrome as risk factors);
- the ability to appreciate the life-and-death nature of the judgment;
- the suicide of a disabled or terminally-ill person is as "irrational" as that of a non-disabled person; and
- the understanding that a desire for self-destruction runs contrary to human instinct, and shows potential vulnerability as a lack of personal resilience and robust mental health.

D. Voluntariness

We recommend that, as part of the eligibility determination, there be a detailed psycho-social evaluation to assess, *inter alia*, the voluntariness of the request. This evaluation would look for internal and external factors that may interfere with a free and informed choice for assisted death.

V. The application

A. Request must come from the person

We believe it is imperative that the impetus for assisted suicide or euthanasia come from the individual, and not a physician licensed and paid by the government. There are well-funded advocacy groups which will ensure that public knowledge of this option is widespread. For a doctor to suggest assisted suicide puts the imprimatur of authority behind the suggestion, thus applying a subtle pressure on the patient.

B. Form of the request

The request must be written according to a single application form that is used throughout the provinces and territories in order for information gathered to be uniform.

The Case Coordinator will assist the individual to:

- fill out the application form, (including obtaining materials in accessible formats or arranging for interpreters or alternative communication methods);
- Obtain signatures from two disinterested witnesses that the person appears lucid and the request appears informed and voluntary at the time it is made;
- Arrange for a consultation with a second physician specializing in the person's irremediable medical condition(s);
- Arrange for a psycho-social evaluation;
- Arrange for a palliative care consultation;

- Arrange for peer counselling or rehabilitation services, as necessary;
- Ensure that the person has been informed of all treatment options, and arrange any additional consultations that may be necessary; and
- Ensure that the person is aware of home modifications and home-based care options and assist the person to obtain these services, as necessary.

The results of these consultations along with the medical reports of two physicians, will be part of the application packet that is forwarded to the eligibility determination panel.

C. Witnesses to the request

The signature of the completed request form shall be witnessed by two persons who attest, to the best of their knowledge, that the person is competent to make the request and is doing so in a free, informed and voluntary manner.

D. Role of the family

The physician, case coordinator, and the person shall discuss whether there is a compelling reason not to inform the person's family (such as a history of abuse or a danger to the person). Absent a compelling reason, the person's family will be contacted as part of the psycho-social evaluation.

E. Revocation of request

A request for assisted suicide may be revoked at any time, by any means (orally or in writing).

VI. Medical and other assessments

A. Medical assessments

The person will receive a thorough physical examination (with appropriate tests) by a primary care physician who has a pre-existing relationship with the person of at least two months, and a second physician who specializes in the irremediable medical condition(s) that cause the suffering which have led to the request for assisted suicide. Each physician will offer a detailed case history, including diagnosis, prognosis, treatment history and results, further recommended treatments and palliative measures, etc.

Each physician will also answer eligibility determination questions.

- Does the person have an grievous and irremediable medical condition?
- Does that medical condition cause enduring suffering?
- Is that suffering intolerable to the individual?
- Are there reasonable measures the person can try that could ease his/her suffering?
- Are there aspects of the person's circumstance that could be modified to improve his/her quality of life?

The physician will include his/her recommendation along with the case history, which will be forwarded to the eligibility determination panel.

B. Other assessments

- A detailed Psycho-social assessment will be carried out to determine:
    - Vulnerability – Establish the person's resiliency, the available resources, and the physical, economic, psychological and other threats to that resiliency;
    - Psychological health / competence – assess for competence using modified standard outlined under the section eligibility criteria – capacity/competence. (See above)
- Palliative care consultation;
- Informed consent Worksheet – With assistance from the case coordinator, the person will complete a worksheet summarizing information about the medical condition, alternatives to assisted suicide (rehabilitation, palliative care, home-based services), what to expect from assisted suicide, and the pros and cons of assisted suicide.

C. Waiting period

- Where the medical condition amounts to a chronic condition or permanent disability, a waiting period of one year is required to allow for a period of grief and adjustment.
- Where the medical condition is likely to cause death within six months, a waiting period of two weeks, or the time to complete the assessment (whichever is longer) is required.
- The person must reiterate the wish to die on multiple occasions during the waiting period.
- The person can withdraw the request at any time, by any means.

VII. Eligibility and approval

A. Determination of eligibility

The Eligibility Determination Panel will examine each record to make a recommendation as to whether the person eligible within the definition of the law.

If the panel determines the person does not meet these eligibility criteria, the application is rejected and a report is included in the dossier explaining:

- The reasons for the determination of non-eligibility;
- recommendations for medical, rehabilitation, palliative, psychological or social service interventions to improve the quality of life of the person making the request.

The person then has 10 days to submit new information demonstrating his/her eligibility.

If the person's circumstances change, s/he can re-apply after 30 days.

If the panel finds the person meets the eligibility criteria, the file will go to a judge for approval.

B. Approval

A Superior court judge will convene a hearing of all parties to determine:

- Whether the person is vulnerable;
- If the request is voluntary;

- If the person has given informed consent;
- If the person's death will inflict undue suffering on (an)other person(s);
- If allowing assisted is likely to:
    - subvert the public policy of suicide prevention;
    - violate charter right to life or provisions against discrimination on the basis of age, race, gender or disability or other protected status;
    - Send the message that the lives of people with disabilities have less value than those of non-disabled people;

VIII. The Assisted Suicide

A. Administration of assisted suicide

Administration of assisted suicide will take place in the setting of the person's choice. The person will have the choice to:

- Swallow a liquid or capsules;
- Self-administer an intravenous injection;[4]

B. Role of the Medical technician

The medical technician will be present to set up the assisted suicide, oversee the progress, deal with any complications, and if the person changes his/her mind, to administer an antidote to the lethal drug.

C. After the assisted suicide

- The cause of death on the death certificate shall be listed as "assisted suicide."
- An autopsy will be performed in all cases of assisted suicide. Information about the underlying medical condition, any likely prognosis, or other relevant details will be included in the person's dossier.

IX. Compliance and Oversight

A. Powers and responsibilities of the Assisted Suicide Commission

The ASC's responsibilities and powers include:

- Ensuring compliance with all aspects of the assisted suicide law;
- Receiving and investigating all complaints related to assisted suicide and other ending-of-life practices:
    - In addition, the ASC will perform periodic studies, retrospective examination of all deaths in a given institution (selected at random) to determine whether euthanasia, non-voluntary withdrawal of medical care, and other illegal ending-of-life practices are occurring.
    - The ASC will be empowered to investigate any anomalous results of these studies.

[4] An IV line established ahead of time, is set to release the lethal dose upon the action of the person

- Pursuant to its investigations, the ASC and their staff will have access to medical and personnel records, policies and procedures, site visits and any other records or information necessary to a thorough inquiry.
- The ASC will have the power to suspend personnel and policies, remove and rehouse persons-at-risk, and impose sanctions on institutions where illegal and abusive practices are found.
- The ASC will provide expertise to the attorney general in prosecuting illegal ending-of-life practices.
- The ASC will collect and retain all records related to the program and file annual reports regarding the functioning of the assisted suicide law.

B. Data Collection & Preservation

- Data to be collected:
    - Detailed demographic information;
    - Reasons for request for assisted suicide;
    - Medical condition giving rise to request for assisted suicide;
    - (Where eligibility is denied) reason for refusal;
    - Information regarding use of palliative care, community supports, or barriers to these services;
    - Additional information to be determined.
- Data shall be retained for 50 years.

C. Penalties

- A person commits an offence if he willfully falsifies or forges a declaration made under this Act with the intent or effect of causing the person's death. A person guilty of such an offence shall be liable, on conviction, to imprisonment for a term not exceeding twenty-five years.
- A person commits an offence if he encourages, coerces or unduly influences a Patient to choose Assisted Suicide. A person guilty of such an offence shall be liable, on conviction, to imprisonment for a term not exceeding twenty-five years.
- A Witness commits an offence if he willfully puts his name to a statement he knows to be false. A person guilty of such an offence shall be liable on conviction to imprisonment for a term not exceeding five years.
- A person commits an offence if he willfully conceals or destroys a declaration or revocation made under this Act. A person guilty of such an offence shall be liable on conviction to imprisonment for a term not exceeding five years.
- A Physician with responsibilities related to an Application commits an offence if he or she willfully fails to submit the required information. A person guilty of such an offence shall be liable on conviction to imprisonment for a term not exceeding five years.