

Protecting Choice & Safeguarding Inclusion

A Proposal to Regulate Physician-Assisted Suicide and Voluntary Euthanasia in Canada

Plain Language Summary and Executive Summary

Issued by:

The Canadian Association for Community Living

September 2015



Canadian Association
for Community Living

Association canadienne pour
l'intégration communautaire

Diversity includes. On se ressemble.

Plain Language Summary

The Supreme Court of Canada has decided that physician-assisted suicide and voluntary euthanasia are no longer against the law.

- “Physician-assisted suicide” is when a person kills him/herself with the help of a doctor.
- “Voluntary Euthanasia” is when a person asks a doctor to kill him or her.
- In both cases, a doctor gives drugs that will kill the person.

The Court has said that adults should be able to access a system to do this when:

- They have a medical condition that causes them to suffer all the time.
- They can make the decision all by themselves.
- They are not vulnerable to being pushed into dying by other people or their situation.
 - Being vulnerable in this way means: You are choosing to die because another person is pushing you to make this choice. Or, you are choosing to die because of other reasons – like being all alone, poor, unable to support yourself, without people who care about you, or who can assist you to live, or because you are being abused by someone.

To make sure people have a real choice, and also that vulnerable people are not pushed into dying, we have made a proposal called: *Protecting Choice & Safeguarding Inclusion*. The goal is:

To make sure people can choose physician-assisted suicide or voluntary euthanasia, but only as a real choice. This means they must not be pushed into dying by others, or because of poverty, lack of support, or abuse. Other options must always be provided. The system must safeguard inclusion of vulnerable persons in society.

Our plan is based on the UN *Convention on the Rights of Persons with Disabilities* and includes:

1. Core Values

- Autonomy – real choice
- Dignity – self-respect and self-worth
- Inclusion – having options and support to live a good life

2. Principles and Guidelines

- We have created guides for governments and doctors to create a system based on these values

3. Vulnerability Assessment and Informed Consent

- People who choose to die must first have someone else find out if they are being pushed to die or are vulnerable.

- If they are vulnerable, steps must be taken to put in place the supports a person needs to continue living in the community.
- A person must be able to make, understand and communicate the choice. They must be able to do this by themselves. A person's support network cannot make or communicate this choice for a person.

4. Advance Independent Review and Approval

- A request to die should be approved by an independent panel, which will either approve or deny the request. When the panel believes the person is too vulnerable or not able to make this decision on his or her own, it should not be approved.

5. Independent Monitoring and Public Reporting

Every year a report should be made to provincial/territorial legislatures and to Parliament about the system. The report should include the number of requests, who requested and why. It should also include any alternatives that were put in place for a person, instead of dying.

6. More Funding for Palliative Care, Disability and Community Supports

To make sure people have other options, governments must increase spending on palliative care and community supports for people with disabilities. This is the only way to make sure people have the option of inclusion in their community.

7. Governments and Community Working Together

- The basics of the system need to be in laws at both the federal level and provinces and territories. Safeguards to protect vulnerable people should be in the federal *Criminal Code* to make sure the system is the same across the country.
- Governments must work together to design the system and make sure investments are made in palliative care and disability supports in the community. Without this, many people who may want to die, won't feel like they have a real choice to continue living.
- People with disabilities, older persons, and health care providers must all be included in designing and monitoring the system, because we believe 'nothing about us without us'.

The disability community was very concerned when the Supreme Court made physician-assisted suicide and voluntary euthanasia legal. We don't want people who are already vulnerable to become even more so.

Governments must put more funding into palliative care and community supports. Without that, we are concerned that people will choose to die through assisted suicide or voluntary euthanasia because they don't have another choice. We must make sure people with disabilities have real choices to live good lives in the community, secure and safe from harm, and able to live with dignity.

We urge governments and other stakeholders to think carefully in creating a system, to prevent outcomes that none of us want. We hope the system will promote choice, dignity and inclusion for all Canadians throughout their lifetimes. We think our proposals can help do that.

Executive Summary

In *Carter v. Canada*, the Supreme Court struck down the *Criminal Code* prohibition on physician-assisted suicide and voluntary euthanasia. It directed that access must balance the right to choose with safeguarding vulnerable persons who may be induced to commit suicide.

For this purpose, we urge that the system for physician-assisted suicide and voluntary euthanasia be designed to fully account for growing vulnerability in Canadian society, including:

- Increasing prevalence and severity of disability, and multiple disadvantage
- Increasing prevalence of mental health difficulties and disability
- Lack of access to disability-related supports
- 70% gap in palliative care
- Poverty and labour force exclusion
- High rates of violence, abuse and insecurity for people with disabilities
- Barriers to health care access
- Rapid increase in cases of dementia
- High rates of depression among seniors in residential care
- Elder abuse

Our proposal, *Protecting Choice & Safeguarding Inclusion*, is guided by the United Nations *Convention on the Rights of Persons with Disabilities* and aims to ensure that:

Adults may gain access to physician-assisted suicide or voluntary euthanasia only on the basis of real and informed choice. They must be free from abuse and vulnerability to lack of support, disrespect, discrimination and devaluation. The system must respect, promote and safeguard inclusion of all persons in society, regardless of their disability or other differences.

Elements of the Proposed Plan

- Core Values
- Principles and Guidelines
- Vulnerability Assessment in Informed Consent
- Advance Independent Review and Authorization
- Monitoring and Public Reporting
- Investment in Palliative Care and Community Supports
- Federal-Provincial/Territorial Jurisdiction, Investment, Coordination and Engagement

1. Core Values

The *Carter* decision states that a system for physician-assisted suicide and euthanasia must be guided by three core values: respect for autonomy, dignity, and preservation of life.

- To respect autonomy, the system must make sure that people really *are* making self-determined choices.
- To respect dignity, the system must be grounded on the two dimensions of this value. First, dignity is harmed when a person's autonomy is restricted, as the Court stresses in

Carter. Second, dignity is harmed when a person's social group is devalued and disadvantaged on the basis of shared characteristics, which is certainly the case for people with disabilities. Harming the dignity of whole groups can undermine autonomy because members of devalued groups often become socially and economically marginalized, lose a sense of self-worth, and feel a burden on society.

- To preserve life of people who may be vulnerable to being induced to commit suicide, the system must be designed to promote their inclusion in society, recognizing:
 - that the dignity of people with disabilities and older persons is harmed by the pervasive social and economic vulnerabilities of these groups; and
 - that the experience of indignity and vulnerability can, but not necessarily does, undermine autonomy of these persons.

We strongly believe that adequate safeguards for this purpose must include inquiry into whether conditions of vulnerability are affecting a person's choice for physician-assisted suicide or voluntary euthanasia.

2. Principles and Guidelines

The system should be designed, managed and accountable according to key principles of:

- real autonomy;
- understanding of conditions of vulnerability and harm to dignity;
- protection against inducement to commit suicide;
- engagement of persons with disabilities and their organizations in design and oversight.

Specific guidelines should include:

- informed consent on the basis of legal independence;
- disability, in and of itself, is not a grievous and irremediable condition;
- clinical input from at least two physicians;
- advance authorization by an independent review panel to consider: reasons, eligibility, timeliness, decisional capacity, and assessment of alternative courses of action;
- monitoring and annual reports to Parliament and provincial/territorial legislatures;
- provision for an expedited process to ensure compassion can be exercised in situations where criteria are clearly met and death is imminent or in the near future;
- distinguishing physician-assisted suicide and voluntary euthanasia from palliative care.

3. Vulnerability Assessment in Informed Consent

A 'vulnerability lens' must be applied in all cases. Where risk of vulnerability to inducement is identified, steps must be taken to explore and provide appropriate supports for people who may request assistance to die, but who are in fact vulnerable to being induced to commit suicide because of exclusion, devaluation and abuse.

A qualified assessor is needed to undertake a full vulnerability assessment and consideration of alternative courses of action, many of which will be of a community and social support nature. This exploration is beyond the mandate and training of physicians.

4. Advance Independent Review and Authorization

Advance independent review and authorization of requests for physician-assisted suicide and voluntary euthanasia, along with an appropriate waiting period, is the only way to ensure that requests are not subject to undue influence or misapprehension. This will ensure:

- principles of autonomy, dignity and inclusion are applied in every case;
- adequate assessment of vulnerability and alternatives;
- decisions about whether to authorize or report a death are out of the hands of physicians;
- ongoing trust of family physicians by removing them from authorization of the interventions;
- an expedited process where warranted;
- protection against loosening criteria for eligibility.

5. Independent Monitoring and Public Reporting

On an annual basis, independent review bodies in each province and territory should report on requests and outcomes to their respective legislatures, and a federal authority should report to Parliament.

6. Needed Investment in Palliative Care, Disability and Community Supports

Increasing disability, entrenched poverty and a growing gap in palliative care and disability-related supports, means social vulnerability is growing. Requests for physician-assisted death and voluntary euthanasia may grow as a result. Governments must invest to close the gap in palliative care and disability supports so that Canadians have real choice and alternatives.

7. Shared Jurisdiction, Investment, Coordination and Engagement

- *Federal Criminal Code amendments* – to mandate consistent standards across the country for eligibility, informed consent, vulnerability assessments, waiting periods, and advance independent review and authorization.
- *Provincial/Territorial Regulation* – to regulate access and advance authorization, independent review boards, health professions, health care services, vulnerability assessment, informed consent, adult protection, and legal capacity.
- *Coordinated Investment Strategy* – to ensure adequate and coordinated investment for palliative care and needed disability-related supports.
- *Government-Community Engagement* – to guide development, implementation and investment – with representation from health, disability and older person communities.

The disability community has been profoundly affected by the *Carter* judgment because of the risk it poses to advancing inclusion, equality and human rights for Canadians with disabilities. We hope our proposals help build common ground for a system that protects real choice and safeguards inclusion. We urge that foresight, caution, compassion and core values guide us all in the exercise ahead so that the system will contribute to, rather than undermine, autonomy, dignity and inclusion for all Canadians throughout their lifetimes.

