From: Jane Lovell

To: Special Joint Committee on Physician-Assisted Dying Parliament of Canada Ottawa, Ontario CANADA

Dear members of the Special Joint Committee on Physician-Assisted Dying,

Thank you for the opportunity to address the Committee through this brief. The brief is in four parts:

- Executive Summary
- Brief Submission
- Personal Reflection
- Summary Remarks

I hope my opinions, recommendations, and insights will help you in making your own recommendations for legislation to guide the healthcare and judicial systems as they provide and regulate services to ensure just, ethical, and compassionate end of life choices for all Canadians.

Executive Summary

In drafting recommendations for the framework of the federal response on physician-assisted dying, I encourage the Committee to consider the following:

Competent Canadians wishing assistance in dying should be granted that assistance under well-defined and monitored protocols.

- A request for assistance in dying should be made only by the person seeking assistance. The assistance cannot be sought or prevented by a family member or other party.
- Eligibility should not be restricted to a predefined list of specific medical conditions.
 Competent Canadians should be eligible for assistance in dying if they suffer from any irremediable medical condition that they consider intolerable.
- In cases where a medical condition may result in loss of competency, such as for those diagnosed with dementia, an advance request for assistance should be considered valid if the request is made while the person is competent.
- Access to assistance should be universal and be available in a variety of settings, including in the home.
- Comprehensive safeguards should be defined to ensure Canadians can make fully informed choices, free of coercion.
- Granted requests should be carried out in a timely matter.
- Individual physicians should be able to decline to participate by making a referral to another physician who is willing to assist.
- Monitoring and reporting all instances of assisted death are essential to evaluate and improve the process and outcomes.

Brief Submission

Many Canadians wish to have the option to end their lives in the manner and at the time and place of their choosing. Assistance in facilitating death should be available to competent Canadians whose irremediable medical condition is causing them intolerable suffering. Legislation concerning physician-assisted dying should address:

- eligibility to participate,
- access to service,
- safeguards to ensure ethical, fair, and compassionate delivery of service,
- and monitoring for statistics and improvement.

a) Eligibility:

Only people satisfying certtain criteria should be considered eligible for assistance in dying.

The extremely well-considered wording of the Supreme Court decision in *Carter V. Canada* sets out the criteria of eligibility as follows:

Physician assisted death should be allowed for:

"a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. "Irremediable", it should be added, does not require the patient to undertake treatments that are not acceptable to the individual."

Criteria:

<u>Intolerable Suffering</u>: Intolerable suffering is the base condition for eligibility for assisted death. Only the individual seeking assistance can judge the severity of the suffering and whether it is tolerable.

<u>Grievous and Irremediable Medical Condition</u>: Grievous is term hard to quantify. A list of qualifying medical conditions considered grievous should not be defined as it might deny access to people experiencing intolerable *irremediable suffering* as a result of any medical condition.

Competency: The consent or request for assistance in dying should only be given or made by a competent person. The person should be seeking to terminate their life, not simply allowing it. The word "consent" implies an affirmative response to a question externally posed concerning a course of action. I would prefer to see the word "request" which implies that the course of action was initiated by the person seeking assistance. In the case where the person is unable to articulate a specific request (for example, for someone who is unable to speak or write but who can communicate though other means such as blinking or some form of communication technology), acknowledgement via an affirmative indication should be considered a request.

In cases where an irremediable medical condition may result in loss of competency, such as for those diagnosed with dementia, an advance request for assistance should be considered valid if the request is made while the person is competent. Any aspect of the advance directive should be able to be revoked or changed while the person remains competent. Much careful thought must applied to defining a target condition for termination of life. Equally careful consideration should be employed in the formulation of a process by which the person's condition can be ascertained with respect to objective criteria. Ensuring that the person's wishes are respected is paramount. Providing advocacy for people without family support, and providing timely re-evaluation of the person's condition should ensure that their voice remains strong.

Age: Competency of children is hard to determine. Restricting assistance exclusively to adults assumes that adults have a certain level of base competency and ability to understand the consequence of actions that children do not. Some minors may be fully competent to understand the options before them and the consequences of their decisions. The same evaluation criteria for competency applied to adults could be applied to children, thereby giving minors the same access to assistance.

<u>Eligibility Summary</u>: Assistance in dying should be afforded to any competent person who clearly requests that their life be terminated because they have a irremediable medical condition causing suffering that is intolerable to them.

Advance requests for assistance should be valid if made by a person who, at the time of the request, was competent and had a diagnosis for a irremediable medical condition, such as dementia, that could become intolerable.

b) Access

All Canadians should have access to an assisted death, regardless of where in Canada they live. This includes easily accessible information and timely access or referral to physicians for consultation or action. Those who request assistance should also be able to elect where they wish to die, be it in a publicly funded healthcare institution or in their home

While the termination of life should be done under the supervision of a physician, the assistance should be allowed to be administered by other healthcare professionals, such as nurses or other specially trained practitioners.

The elapsed time from request to approval and from approval to the provision of service should be timely, so as to avoid undue prolonged suffering.

No physician should be obliged to participate in assisted dying beyond providing a timely referral to another physician prepared to offer assistance.

c) Safeguards

People seeking assistance in dying should be required to consult with two physicians qualified to assess eligibility and to confirm that the request is made by fully informed competent individuals, free of coercion. Other end of life options, including palliative care should also be presented. There should be no requirement for consultation with or consent from family members or any other party. A minimum elapsed time between the initial request and the granting of that request should be considered. A reasonable interval would allow the person to carefully reconsider their request, but should not be so long as to unnecessarily prolong suffering. In the case were the person is competent at the time the termination of life is to be performed, they should be asked a final time if they wish to proceed.

d) Monitoring

Monitoring and reporting all instances of assisted death are essential to ensure competent and ethical delivery. Analysis of data gathered will also highlight were improvements can be made in providing a compassionate death for those suffering intolerably, for their families, and for healthcare providers at all stages of the journey.

Personal Reflection

I very strongly believe that Canadians should be able to receive assistance in ending their lives. I ask you to include me as I take this opportunity to include some of my personal thoughts.

What may be overlooked in the discussion on procuring assistance in dying is that without reasonable access to the assistance of a physician, those wishing to end their lives must find other solutions. It is currently legal to take one's own life -- and what a lonely and frightening prospect that must be. With it illegal for anyone else to be present at a self-initiated death, and with an unsure outcome of such an unsupervised action, using perhaps fraudulently or illegally procured medication, or worse, by some other more "messy" or painful method, the taking of one's own life would be truly terrifying. To be forced to die alone, and to deny one's family the opportunity to support them in those last very vulnerable and personal moments is simply cruel. There are other legal and safe routes to end one's life -- such as travelling abroad to jurisdictions where assistance is legal and where institutions can provide a supervised death with family in attendance. However, to take advantage of these services one has to be physically and financially capable of travelling abroad. This likely means that in choosing assistance in dying, one is forced to accelerate the timing of one's death.

The lack of reasonable access to a physician-assisted death means that those without the courage or the means to take their own lives are condemned to continue their suffering, and are faced with the hopelessness and helplessness and fear of what a compromised and interminable future holds.

Surely we can do better.

Summary Remarks

A summary of my recommendations appears under Executive Summary on the first page of this brief. For brevity I will not repeat them here.

The Supreme Court decision triggering consultation with Canadians has succeeded in forcing the issue of end of life choices further into the realm of objective debate. I feel confident that such a debate will allow compassion to prevail in the Canadian legal system. Certainly I hope to benefit from progressive movement on this front: Though likely many years in the future, when the time is right, I hope I can escape my life gracefully and with dignity, with my family at my side, and at the time and place of my own choosing.

You have undertaken the very complex and fraught task in sitting on the Special Joint Committee on Physician-Assisted Dying. After careful attention to issues raised through testimony from witnesses invited to speak before the Committee, and through consideration of briefs submitted by concerned Canadians, I have every confidence that the Committee will succeed in crafting a comprehensive and well considered set of recommendations on the framework of a federal response on physician-assisted dying. You are doing extremely meaningful and important work, as individual Canadians and as Parliamentarians. I laud your efforts.

Thank you for allowing me to add my voice.

Sincerely,

Jane Lovell