

Brief to the  
HOUSE OF COMMONS STANDING COMMITTEE ON JUSTICE AND HUMAN  
RIGHTS  
regarding  
**Bill C-14 on Medical Assistance in Dying**

Penny Mills

May 1 2016

I have a slow moving form of ALS. We gradually lose all voluntary muscle control. Our minds don't degenerate. Our hearts continue to pump. We are aware of everything happening to and around us, but become unable to do the simplest things for ourselves. We can't predict our life span. *For these reasons the requirement in C14 that natural death must be in the reasonably foreseeable future, and the denial of advance directive means that people like me, Gloria Taylor and Sue Rodrigues can not qualify for medical assistance in dying.*

*At this time. although I am not even close to wishing to die, I can barely sign my name and my speech is impaired.* In C14 we have been inexplicably lumped in with those with mental deterioration. This is illogical and unfair. Some become "locked in", without even their eyes to communicate. How could such a person make their wishes known as per C14?

When the Carter Decision came out in 2015, I felt safe. A strange idea, I know, feeling safe upon hearing that I would have the Right to Die at my choosing, with my family around me. It meant I didn't have to choose to die before I wanted or needed to, while still capable of doing so. It took me many years to conclude I wanted the choice of ending my life. Now that option and feeling of safety and comfort has been taken away from me.

For me, C14 makes a mockery of the SCC Carter decision.

Carter vs Canada was about two mentally competent female adults with progressive *physical* degeneration. Yet conversations with MPs on TV re: Advance Directive default to only *mental* degeneration. C14 fails to take into account the differences. I fail to understand how C14 became totally about

mental degeneration and discriminatory against people like those women who went to Court for relief from unbearable life.

After hearing my Town Hall presentation, delivered by a friend because of my impaired speech, MP Rob Oliphant put my name forward to the Standing Committee on Justice and Human Rights to be a witness, but I was not selected. Unless the Committee has invited someone else to speak re: physical degeneration, we'll continue to be ignored and invisible at the Committee's hearings.

I hope this brief will make us visible and ensure full consideration of the following changes:

Amendments to C14 to allow people with ALS and other purely physical degeneration access to medical assistance in dying.

Remove the requirement for natural death time to be foreseeable and allow advance directive.

Alternatively, C14 should be referred to the Supreme Court for an Opinion.

Sadly, MPs will all see ALS play out its cruel relentless, incremental degeneration in MP Maurile Belanger. I pray his MP friends will stay in touch with him if he isn't able to continue in the House. ALS can be lonely. He is fortunate in that he will be more able than many to financially access the technology available.

ALS is the most expensive condition to have. Even with subsidies, the patient cost is enormous for all the necessary equipment. Example: power wheelchairs for us cost approximately \$25,000. Even with Ontario paying 75%, 25% must be born by the patient and family. Not easy if you can't work, are retired or on Disability benefits. Without a wheelchair modified van, one becomes housebound.

The inexorable end, assuming natural death doesn't intervene, will be the same for all of us with ALS. At worst we end up totally paralyzed, without speech, needing others to in effect, be our bodies 24 hours a day. Without 24/7 homecare, which most cannot afford, our families bear the brunt of this burden for months or years. This skewing of family dynamics can cause dysfunction in

families.

Palliative Care is also big on the TV talk show circuit. Hospice is not an option because according to Rick Firth, president and CEO of Hospice Palliative Care Ontario, ventilators and bi pap (breathing assist) machines are considered devices that prolong life, making them inconsistent with the tenets of end-of-life care, which focuses on pain control as life comes to a close.

There are a few beds in Toronto East General Hospital for those who choose to live paralyzed, on a ventilator. Other than that there is no suitable palliative care I'm aware of. Imagine lying in a nursing home, without being able to scratch an itch or pick your nose and unable to use a buzzer or call out to passing staff for help.

So, no palliative care, no 24/7 homecare and no choice for assisted death.

At best we may die in a fatal fall, car accident, or choke to death. Yes, we do talk about such things as preferable and joke about being hit by a bus on our way home from ALS support group.

Respectfully submitted

Penny Mills