

April 29, 2016

Standing Committee on Justice and Human Rights
Sixth Floor, 131 Queen Street
House of Commons
Ottawa, ON K1A 0A6

Dear Committee Members,

Re: Subject Matter of Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)

We respectfully request that there must be an allowance for advanced consent to medical assistance in dying, especially in the case of a victim of Alzheimer's Disease.

Alzheimer's clearly fits the Bill's definitions of: *"grievous and irremediable" medical condition as a serious and incurable illness, disease or disability, in an "advanced state of irreversible decline," and "natural death has become reasonably foreseeable."* Death is guaranteed. The only thing missing is the recognition of the disease's unavoidable creation of the inability to be able to trigger the assisted dying process at the moment of decision, given the Bill's current restrictions.

The Government's suggestion that this omission from the Special Joint Committee on Physician-Assisted Dying report's recommendations 'may be considered' after 'further study' is no comfort. Things like that almost never see the light of day, particularly later in a mandate.

I am very concerned that the political, religious and certain medical folks hold that the criteria for "life" is solely based on the presence of heartbeat and that everything must be done to keep it beating.

My own view, from personal experience, is that life actually ends when the cognitive brain functions cease to exist, as with Alzheimer's. I am only my brain. It's my personality, my life. My body is just the house for my brain. The body will cease to be me if I could not recognize my wife and children. I will be dead, regardless of a heartbeat. My body would be no use to anyone without it...other than satisfying those who would claim to be fulfilling their oath by "preserving" a life while wastefully keeping a bed occupied instead of allowing the space for someone who really needs it.

My father "lived" for almost seven years after he ceased to recognize my mother, sister, me or anything else. The last memory I have of him talking was his thinking I was also one of his grandchildren when I'd taken my two kids to see him and then, back at the "care home", introducing my mother to the staff as his mother and me as his brother, Bill (he had no brother). He had been a VP of Bell when he retired but in trying to make conversation with him about developments he'd been predicting for years before they became a reality, there was nothing but a blank look. Then followed seven years of nothing.

Of equal concern is that there is no consideration that this long period also seriously affects others, forcing a cruel and continuously long grieving period. It effectively ruined my mother's life by destroying her outgoing personality with unfounded guilt about his condition and feeling the requirement to withdraw from her friendships to spend hours with him, in the "home", every

day, without his recognition. It left me guilty, feeling that I had to make a long, at least bi-weekly, trip to their town to see him, help deal with mother's life and their matters and introduced stresses for my sister because she lived on the other side of the country and felt left out. It taxed my then young children's memories of their grandfather and changed their relationship with their grandmother from joyous to compassionate. It cost the province's health care system and depleted his financial resources for the cost of the questionable term, "palliative care", in the nursing home.

There was nothing positive resulting from this seven year period.

My aunt (dad's sister) also died of Alzheimer's around the same time frame. Although it wasn't called that back when their mother, my grandmother, died, I suspect, from anecdotal descriptions, that she also had it.

My odds of contracting this disease are, therefore, better than average.

If it comes to that, I don't want to have my wife, children and grandchildren to have to go through this tragic type of experience all over again. I don't want my body to spend time vegetating in the type of "home" that my dad experienced, incurring the health system's costs and the redirection of what estate I may have from my family to the "system" for no good reason.

There are even a few activists who argue that the brain may still function even though communication is impossible. I don't believe that from my experience but, if that were the case, I would be in a cruel mental anguish about the effect I would be having on those close to me without the recourse to communicate the suffering.

Hopefully not, but if I do find myself in this situation, I plead with your committee to include a provision to recognize a legal document expressing my wishes, executed when I am still of "sound mind and body", to allow my wishes to be followed whenever my cognitive brain "dies" and not in a restrictive medical brainwave sense, but in the real life sense that I describe, above.

My Dad would have wanted that.

Thank you for your understanding. I hope that a recognition of advanced consent in the case of Alzheimer's victims will be included in the Government's regulations.

Yours sincerely,

James G. Leworthy