

## PROPOSED RECOMMENDATION FOR CHANGES TO BILL C-14

Bill C-14 should be amended to include provisions for advanced directives and consent for persons diagnosed with dementia. Section 241.2(1) (e) should specify that informed consent may be given in advance, at the time of the original diagnosis. Section 241.2 (2)(d) which speaks of “reasonably foreseeable death” should be deleted in its entirety.

## REASONS FOR CHANGES

Anticipation and fear of suffering can be as devastating as the disease itself. For those diagnosed with dementia, the greater fear is not of death itself, but of the suffering, humiliation and loss of dignity which will precede death. For family members, the knowledge of what the future holds is equally painful.

Anyone who has visited a nursing home will know what lies ahead for those with advanced dementia. The quality of life, or lack thereof, is readily evident - complete lack of independence, inability to communicate, inability to recognize family members, inability to carry out even basic functions such as feeding oneself or looking after any aspect of one's hygiene.

Having the right to give an advance directive and consent would greatly alleviate the fear of future suffering, both for the patient and for family members and caregivers. It would allow the patient to live life to the greatest extent possible for as long as possible.

People with advanced dementia may live many years. If death is not “reasonably foreseeable”, then they are forced to continue living, notwithstanding that they have a “grievous and irremediable medical condition”

## PERSONAL STORY

My father had Alzheimers. At the end, he spent 7 long years in a vegetative state. Unable to communicate in anyway, unable to move independently, not showing any signs of recognizing family members, he lay in bed, 24 hours per day, staring at the ceiling. I called him “the living dead”.

My husband was diagnosed with dementia 3 years ago. He is still able to live at home, with my assistance. His biggest concern is the future. As long as he has what he calls “quality of life” he cherishes every day and gets what enjoyment he can. However, each day has a shadow over it - the thought that he may be confined to a nursing home and be forced to live in a manner which terrifies him. He worries about the tremendous burden he may place on his family. He does not want others to be “victims of his process of death”.

We have discussed physician assisted death. He is Dutch, and is familiar with the laws in the Netherlands. We even saw a dutch movie called “The Good Death” which dealt with a man going through with “assisted death”.

If my husband and I knew that physician assisted death would be possible for his case, it would alleviate a lot of the fear and stress. To know that he could die in dignity, at a time of his own choosing, would remove a large burden. My husband is very clear about when he wants to end his

life. It is not difficult to formulate the conditions – they are based on reason and common sense. My husband is an otherwise healthy 72 year old man. His parents lived to their mid nineties. His biggest concern is that he will live a long life, but that those last years will be spent in a nursing home. Those years would not be considered “living” by my husband. He would consider them a maximum mandatory life sentence of suffering and degradation.

We are considering going to a foreign country for a physician assisted death – but that entails great expense, the trauma of travelling, and ending one's life in a strange place, without all family members. Our five children would not be able to attend. More importantly, it would force my husband to end his life earlier than necessary.

## CONCLUSION

As our population ages, there will be a growing number of people with dementia. This problem will not go away, it will only increase and must therefore be dealt with now.

People suffering from dementia are not offered any relief by Bill C-14. Dementia is a “grievous and irremediable medical condition:” It progresses at different rates for different people. However, the end result, advanced dementia, is the same for all – it robs them of the ability to give an informed consent. Bill C-14 denies people with dementia the right to avail themselves of “medical assistance in dying” merely because of the manner in which the disease manifests itself.