

Private Brief submitted to the Standing Committee on Justice and Human Rights

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My thoughts, concerns and suggestions about Bill C-7.

Getting to where we are today

It took decades in the courts and tremendous effort, deadlines were extended before Canadians were finally able to have medical assistance in dying (MAiD) if they met the criteria and wanted it. As of June 17, 2016, Bill C-14, legalizing medically assisted dying became law.

During the time leading up to getting Bill C-14 passed into law, we were told safeguards were needed to protect the vulnerable. Bill C-14 had many safeguards and Bill C-7 removes some but adds others.

Bill C-14 had to be a compromise, a careful balance between what was required to meet the Supreme Court of Canada decision in *Carter v. Canada* and what was needed to protect the vulnerable.

But C-14 didn't meet the *Carter* decision.

It fell short and the government chose not to remedy these issues at the outset in 2016 nor since. Rather they waited. They waited for the courts to, in effect, decide what changes were needed. Bill C-14 was itself a response to the *Carter* decision.

One most contentious aspect of C-14 was the criterion that to be eligible for MAiD, the person's natural death had to be "reasonably foreseeable." (RF) But *Carter v. Canada* never mentioned this. In fact, Kay Carter herself was elderly but not near death. Her prognosis was maybe 5 years. So her natural death was not reasonably foreseeable. So we thought.

However, when questioned soon after Bill C-14 became law, Justice Minister and Attorney General Jody Wilson-Raybould said that, of course Kay Carter would have qualified.

What that seemed to mean was "reasonably foreseeable" meant a person's natural death might be expected in maybe 5 years or so.

It didn't take 5 years to challenge this aspect of C-14.

To that end, 10 days after C-14 became law, BCCLA filed suit on JUNE 27, 2016. The goal was to effectively get rid of the RF criterion. Their plaintiff was Julia Lamb, a 25-year-old suffering a non-terminal disease. Court cases can take a long time. In fact the court date to hear this case would have been this month, NOV 2020, 4½ years later. (The case was stayed) The decision could have been rendered maybe another year from now. Then there might be appeals which could go on for many more years. The *Carter* case took from APR 2011 to FEB 2015 to go through the court system. It resulted in Bill C-14 becoming law on June 17 2016-5 years later.

In a stroke of good fortune, I hesitate to call it that, there was the case of Jean Truchon and Nicole Gladu in Quebec Superior Court. These two were suffering terribly and physically deteriorating over the course of decades. They suffered from chronic conditions but neither was about to die in the foreseeable

future. They wanted MAiD but were not approved. They won their case when Judge Christine Baudouin rendered her decision on SEPT 11 2019. The decision gave Quebec 6 months to correct the law or the requirement would be suspended. 6 months would mean March 11, 2020.

Minister of Justice and Attorney General of Canada, David Lametti decided not to appeal the decision. He asked for and was granted two extensions. Therefore, we have C-7 which should come into effect by DEC 18 2020 if it is to meet the latest deadline.

But, I fear, history is repeating itself.

Just as C-14 did not meet the Carter decision, so too Bill C-7 does not meet the Truchon-Gladu decision.

I will deal with a simple most explicit example right here.

The wording of Bill C-7 is clear.: "persons whose sole underlying medical condition is a mental illness are not eligible for medical assistance in dying."

So anyone suffering from mental illness as the sole diagnosis would not be eligible for MAiD.

Singling out a specific illness, disease or condition goes contrary to the very Quebec Superior Court decision that Bill C-7 was supposed to address. This is the same as what happened with Bill C-14. It was supposed to comply with the Carter judgment and it did not from the start.

Here is the statement by Judge Baudouin, ***"What the plaintiffs are really looking for is that the law recognizes equally the suffering, the dignity and, ultimately, the autonomy of people who, like them, are affected by serious and irremediable health problems, without any hierarchy, whether death is near or not,"*** Baudouin said.

I am not a lawyer but it seems to me singling out mental illness is an error. I feel mental illness is too often seen as a weakness, maybe a personal thing and not comparable to physical illnesses like cancer.

This is wrong.

Safeguard: Waiting period

C-14 imposed a 10-day waiting period. When a person completed their written request for MAiD signed in the presence of 2 independent witnesses, they had to wait 10 days before they could die with MAiD, provided they met the criteria, were assessed and approved. This period could be shortened if the assessors believed the person might lose capacity or die before the 10 days had elapsed.

C-7 removes this 10-day waiting period ***but only*** if the person's natural death ***is*** reasonably foreseeable. So determining if the person's natural death is reasonably foreseeable remains in Bill C-7.

So there is no 10-day waiting period if the person's natural death ***is*** reasonably foreseeable. Under Bill C-7, when assessed and approved, such a person can have MAiD on a day and at a time they decide. No 10-day waiting period. MAiD could be as soon as the earliest day that can be arranged, if they want MAiD on that day. It could be scheduled on a specific day in a few days or weeks. Or the decision can be pushed into the future. There is no requirement for a person to choose a definite date for MAiD once they are approved. It could be months later or never, ever.

So basically, there is no waiting period when a person's request is assessed and approved **only** if their natural death is reasonably foreseeable. So that determination of natural death being reasonably foreseeable or not must still be made by the assessors.

However if the person's **natural death is not reasonably foreseeable**, we get a new, arbitrary 90-day waiting period. Where did this come from?

To be clear, it seems the 90-day waiting period in C-7 would apply to people like Jean Truchon or Nicole Gladu, the two plaintiffs in the Quebec Superior Court case. After years of suffering, they finally make a request for MAiD, get assessed and approved and then would be expected to wait 90 days from the date of their request, in case they change their mind.

I just can't imagine the need for adding 90 days of suffering in the case of Jean Truchon or Nicole Gladu. In cases like theirs, there should be no waiting period once they are approved for MAiD. The choice of the day should be theirs, alone.

I respectfully suggest all reference to natural death being reasonably foreseeable or not be removed from Bill C-7.

Waiting period for Special Cases

I would suggest there might be a need for a waiting period in some special cases but not for people who have been suffering for a year or more.

I can envision special cases where a waiting period might be in the interests of the person, not for people suffering from an illness, disease or condition for years but in the case of a person who had a catastrophic event, for example. Imagine someone who just had a car crash, a health event or surgery that left them incapacitated and the incapacity is deemed to be permanent and irreversible. In the weeks following, they may feel life as they knew it is over and they want MAiD, the sooner the better. Perhaps these people might be required to wait for a time to maybe adjust to their new life. They may find the life they have may be quite alright, meaningful, maybe enjoyable and worth living.

So in these cases it might be in the best interest of the person to delay MAiD for a period. Maybe 90 days. Maybe more or less.

Waiving final consent: C-14 requires the person be capable of providing final consent to MAiD moments before MAiD is provided. With Bill C-7, this final consent immediately before MAiD is provided can be waived **if** the person has a written agreement with the MAiD providing clinician to schedule MAiD on a specific day. If the person has lost capacity on that day the clinician can provide MAiD on or before that day.

This is a welcome revision.

It is often referred to as Audrey's Amendment after the Halifax resident who would have liked one more Christmas with family but chose to have MAiD months earlier because she feared losing capacity for final consent.

Of course, when the day for MAiD arrives, if the person **has** capacity, they must still provide final consent.

NOTE: No time limit is specified. Would the waiver of final consent apply if the date agreed for MAiD was, for example, two months later on January 15. After Christmas.

Also Bill C-7 is unclear if waiving final consent would apply to a person whose natural death is not reasonably foreseeable. e.g. a person with dementia who is approved and sets the date before losing capacity.

What is missing in Bill C-7

No mention of MAiD being possible for people suffering from dementia

At present under C-14 and with changes proposed by Bill C-7, people suffering from dementia who have lost capacity are not eligible for MAiD. If they cannot provide final consent, they cannot access MAiD.

There is no waiver of final consent for people with dementia.

I feel this is cruel. According to the QC Superior Court decision in Truchon cited above, dementia like mental illness must not be treated differently from other illnesses, diseases or conditions.

For people suffering from **dementia who have been assessed and approved but at some future date can no longer provide final consent**, I suggest the final consent before MAiD could be delegated to the substitute decision maker (SDM) just as other health care decisions are routinely delegated to that person at the present time.

How could MAiD be provided to patients with later stage dementia with reasonable safeguards?

The substitute decision maker would be named in the person's advance request document along with a clear statement from the person that they would want the SDM to decide for MAiD or not at some future date under certain conditions. This would be done while the person is still capable. The advance request would authorize the specific SDM to request MAiD for the person when they (SDM) believed the time was right. The decision would be left up to the SDM, alone. They would be under no undue duress to decide one way or the other. They would make the decision to ask for MAiD or not.

To further minimize any doubt as to the person with dementia to still would want MAiD, the advance request should be executed after diagnosis of dementia and perhaps revisited periodically as long as the person was still capable. I believe that is the case in Denmark.

The Netherlands is one jurisdiction that permits euthanasia in the case of persons suffering from late stage dementia. It is based on an advance request stating assisted death be provided at some future date when certain conditions have been met and the person can no longer provide consent. In these cases the onus is on the treating clinician to confirm the person, among other conditions, is suffering unbearably. This is difficult especially if the person is unconscious in a coma. So in practice, assisted death is very rarely provided to people suffering from late stage dementia: 0.03% of euthanasia deaths in 2019. (There were 2 cases in 2018, 2019 and 3 cases in 2017)

One GP from the Netherlands told me these cases are very difficult. Currently, the Netherlands does not allow the substitute decision maker to decide and request euthanasia for a person with late stage dementia. As a result many more people with dementia choose to ask for euthanasia before they have lost capacity. This means they choose to die sooner than they might have if the SDM could act on their

behalf at some future date. In the Netherlands, about 2.5% of euthanasia deaths or 160 per year are for people with early stage dementia. BTW, the population of the Netherlands is 17.3 million.

Bear in mind that in Canada, the substitute decision maker already is generally allowed to decide to make all manner of healthcare decisions for the patient. This includes such as when to stop treatment, withdraw life support, nutrition, hydration (VSED) or personal care. The SDM is already allowed to make health care decisions when the person has dementia or any other illness, disease or condition.

But today with C-14 and with what is proposed in Bill C-7, under no circumstance would the substitute decision maker be allowed to request MAiD for the person who named them as SDM.

I would suggest for Canada, that the substitute decision maker be allowed to follow their written agreement with the person and that would include allowing the substitute decision maker to decide to ask for MAiD when they felt the time is right. Or the SDM could decide not to follow the advance request and not ask for MAiD, ever. They would be able to change their mind about ordering MAiD or not. They are responsible for the decision.

This would be a most serious responsibility assumed by the substitute decision maker. But they would know and understand how serious it could be when they agree to be substitute decision maker. They would enter into the agreement in good faith with the promise to do their best. Perhaps, to be perfectly clear, this should be spelled out in the advance request and the advance request should also be signed by the substitute decision maker. Of course like other decisions made by the substitute decision maker, this decision would be made at the discretion of the SDM independently, without duress, outside pressure or consequence to not honour the request when the time came if that is what they wanted.

In conclusion, I am grateful to have this opportunity to submit this personal brief as a private citizen. At your request, I am prepared to present this brief orally and to answer questions.

Submitted respectfully by,

Jeffrey H Brooks

Disclaimer: The views expressed in this document are mine and are provided 'for information only'. They are not intended as medical or legal opinions or advice. At present, I have no affiliations to any organization. In retirement, I was trained as a palliative care pet therapist and worked as a volunteer in palliative care for 7 years. Until Covid-19, I was volunteering in extended care and ran a Men's Group for men with dementia. I was co-organizer of the Victoria Chapter of a national right-to-choose organization (2015) but left that role more than 18 months ago. I was first to identify that finding the two independent witnesses for the patient request for MAiD was a major issue for many people contemplating MAiD. In response to this, I prepared a training program and we trained a local team of competent and confident witnesses. They did roll out this program across Canada. I also prepared **Assisted Dying 101: The basics** and presented it to any group around Victoria who invited us. Finally, I took over preparing a monthly report about MAiD in BC in 2017 and expanded it to include other provinces. At the present time I prepare and issue **MAiD in Canada** quarterly.