

Brief from Ellen Agger
to Special Joint Committee on Physician-Assisted Dying
February 1, 2016

Dear Special Joint Committee on Physician-Assisted Dying,

Thank you for the opportunity to voice my recommendations, as a Canadian citizen, on physician-assisted dying (PAD) that is now the focus of your hearings in Ottawa.

Executive Summary

I offer my recommendations – and reasons for them – as you make your own recommendations to Parliament, which is in a position to draft laws on PAD that will protect and ensure access to PAD to all Canadians.

My recommendations include:

- respecting the Carter decision’s clear legal definition of access to PAD for Canadians who have a “grievous and irremediable” medical condition that causes suffering intolerable to them;
- protecting patients as well as physicians who conscientiously object to providing PAD themselves; and
- ensuring equitable access to PAD across Canada.

I want to address three areas of concern: who is eligible for PAD, how to protect patients and how to ensure access.

Eligibility:

1. Definitions:

Dr. Jocelyn Downie, in her excellent presentation during Meeting 6, made it very clear from a legal standpoint that the definition of “grievous” is quite clear: “very severe or serious illness.” I urge you not to start down the slippery slope of trying to list medical conditions that would be eligible for a person to receive PAD. Some will always be left out. As well, it’s not the federal government’s job to assign eligible medical conditions to legislation; that’s a medical decision that only a patient and their doctor can assess. Federal legislation must protect the autonomy of grievously ill adult Canadians who define what is, and what is not, tolerable suffering to them. That autonomy is what the Carter decision is about.

2. Advance consent:

I heard quite a lot of confusion in the presentation and answers by the Alzheimer Society of Canada in Meeting 8 on Feb. 1. Advance directives are already legal documents in many provinces; they are, for example, called Personal Directives in Nova Scotia and Advance Directives in British Columbia. Advance consent or advance declarations are documents that a person who has received a diagnosis of a grievous and irremediable condition, including dementia, can prepare when still competent. This is critical and I urge you to include this consent in your recommendations for federal legislation.

Let me elaborate by sharing my personal experience on this. I was the primary caregiver for my mother who developed a rapidly progressive dementia, which we later learned upon autopsy of her brain to be fronto-temporal dementia. She had a gentle death due to dementia, which caused her to aspirate food and develop pneumonia. My father, in contrast, developed Alzheimer's disease but suffocated to death, with great suffering, from lung cancer. I wonder often what I would want if I were to develop any of these conditions.

I learned in 2014 of the very sad case of Gillian Bennett of BC, a woman with dementia, who took her own life possibly much earlier than she would have otherwise if she had been able to make an advance consent document for PAD when she reached a certain stage in her disease process. I never want to be in that position.

Another case I learned about from my former MP, who told me about a constituent in his riding, where I lived until recently, who had ALS. This gentleman had no choice to access PAD at a future date (or at all at that time), when he was no longer able to communicate his end-of-life wishes to his physician. His family heard a loud bang one day and went out to the field to find this man dead. He had chosen to end his life early, while he was still able to, by shooting himself on the family property. Imagine the suffering this man faced and the horror of his family who then will always have to remember this terrible scene.

Yesterday, I learned that a friend has a rare and aggressive form of uterine cancer. She is now facing a grim, and likely short, future. The SCC decided in its Carter decision that my friend has the charter right to have access to PAD, should she choose it. What if she has a stroke or another condition that makes it impossible for her to give competent consent as she is dying? She should have the right to decide in advance if and when she wants to access PAD to relieve her suffering. She is competent to make that decision now.

I share with you one more personal story: I suddenly, unexpectedly and shockingly developed unstable angina one year ago. I was out of Canada at the time, but I had a diagnostic angiogram to discover that I had an 80% blocked coronary artery. The cardiologist informed me that there was a 1% chance of a stroke when he inserted a stent to keep the blood flowing through that artery, a procedure I consented to. However, if I had had a debilitating stroke (and if I was in Canada at the time), I would very much have wanted to have a voice in my choice to give advance consent to PAD, should that happen.

These are just a few scenarios that highlight the importance of including advance consent for those Canadians who want to define what they consider to be unacceptable suffering if they should not be competent in future.

On a final note, I worked for 10 years as webmaster for the Alzheimer Society of Canada and met many people with different kinds and at different stages of dementia, as well as watching my own parents go through this frightening disease. I personally feel strongly that I should, as a competent adult, have the human right to decide my own death, in

advance, when conditions that I set out are reached in the development of any grievous and irremediable medical condition, including dementia, should I be so unfortunate as to be diagnosed with that.

I realize this is a more difficult – and contentious – aspect of legislative recommendations by your committee, but I urge you to consider these examples and to give Canadians a true voice over their own dying. By including the right to advance consent to PAD for people who have been diagnosed with a grievous and irremediable medical condition – be that dementia, ALS, cancer or another condition – the SCC Carter decision to recognize our autonomy for decisions over our own deaths will be honoured.

Protecting patients:

1. Who can approve PAD?

On the question of how many health practitioners are required to approve a request for PAD, I suggest that two physicians are adequate (or appointed, appropriate practitioners, such as nurses or nurse practitioners, especially important in rural and northern areas where physicians may not be available).

Last week, a man with ALS in Victoria contacted a friend of mine, asking how he can access PAD, during this period when the SCC gave the federal government a 4-month extension until June 6, offering access during that time through a province or territory's superior court. This man is dying and he quickly rejected the burden and indignity, as a competent adult, of having to apply to a court for permission to receive PAD. He said he did not want to pursue that. I can only imagine how stressful his life is at this stage when he is losing everything about his life as he knew it and is ready to die; how can we demand that a person such as this man have to ask a court for permission to a charter right, as one hearing presenter called for at today's hearings? I can say the same for requiring that a dying person apply to a review panel or wait during an extended period, a "cooling off period," as some call it. Physicians, as has been stated already by many of the presenters, including organizations representing physicians, deal with many end-of-life decisions now. They are fully competent – and are already charged with the responsibility – to assess a patient's competency in making such decisions for themselves. I believe that two physicians can make good assessments of competency, as well as making the important assessment on whether a patient has been pressured into making the request for PAD.

2. Collecting data:

As in other countries where PAD is available, data should be collected so we understand the picture of who is requesting PAD. This information should be available to the public.

Ensuring access to PAD:

1. Equitable access for all Canadians:

I am greatly concerned that equal access to PAD be available across the country. I now live in BC, where our provincial government has made it clear that it is not ready to create systems to ensure appropriate access to PAD, even tabling its own appointed, bi-partisan committee's report that provided recommendations on this. I urge the Joint Committee to ensure that access is equitable across the country, even as health care is a provincial responsibility. We do not want to face the situation like that of abortion, where it is still not available in PEI, for example, and women who choose to have an abortion must travel out of their home province to access this service. This is unacceptable.

2. Physician conscientious objection and referral:

There has been much discussion about conscientious objection by physicians who do not feel they can provide PAD to their patients. I fear a loss of focus on the patient in this discussion and urge you to include in your recommendations that these physicians must refer their patient to another doctor or third-party referral agency that can provide access to PAD when the patient is eligible to receive it. Physicians must not be allowed to abandon their patients in perhaps their greatest time of need by refusing to refer them, if the physician himself or herself is not willing to provide PAD. That would certainly contradict the value and practice of "physician do no harm" that is accepted in our society.

3. Facility access to PAD:

Publicly funded hospitals, long-term care facilities, hospices and similar institutions must also be required to allow access of a physician who is willing to provide PAD, even if the institution's own doctors will not. An ill and dying patient, like the man with ALS who contacted my friend, is in no position to spend their final days "doctor shopping" or "hospital shopping." This could also prove impossible in small and rural communities, like the one I lived in for the last 15 years.

Every time I discuss these issues with people I meet, I hear stories such as mine. Everyone knows someone who has faced a difficult death. Not once have I heard anyone say we should not have good access to PAD.

In summary, I urge the Joint Committee to respect the Carter decision's definition of access to PAD for Canadians who have a "grievous and irremediable" medical condition that causes suffering intolerable to them; to protect patients as well as physicians who conscientiously object to providing PAD themselves; and to ensure equitable access to PAD across Canada.

I thank you for your consideration and laud you for the very difficult job ahead of creating your recommendations for federal laws on physician-assisted dying in Canada.

Yours sincerely,

Ellen Agger

