

**AN ARGUMENT FOR THE SAFEGUARD OF PRIOR
MULTIDISCIPLINARY REVIEW FOR ALL CASES OF
PHYSICIAN-HASTENED DEATH**

**Brief to the Special Joint Committee
on Physician-Assisted Dying**

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I get why you don't get it ...

I get that you don't get what presenters¹ are trying to say about vulnerability.

For you, there's never been cause to doubt your doctor's wisdom;
There's never been cause to doubt that your doctor has your best interests at heart.
There's never been reason to think that maybe your doctor doesn't think your life is worth living.

You *have* a doctor that you like and trust.

You've never lived in a nursing home or a psychiatric facility, or any other institution in which doctors and nurses make the rules, enforce those rules, and administer punitive "treatments" as consequences when those rules are bent or broken.

You've never had reason to doubt the goodwill of your doctor.

But disabled people have had reason. Disabled people are not valued as equal members of society, especially the ones who are unable to speak, unable to use the toilet independently, unable to move or breathe without assistance. People who lurch, or drool, or utter loud noises at inappropriate moments; people who require a lot of expensive equipment to get around, to manage, to get educated, to get employed, to stay healthy, to steer clear of doctors.

They never assume that doctors are their friends. Some are, but some are not.

The Supreme Court has put disabled lives in doctors' hands as if they are all noble, ethically superior human beings. But they are members of society, and they share the preconceptions and prejudices of their society. They are fallible and they are corruptible.

You appear to assume that all people have a family doc with whom they have a close, trusting relationship. This strikes me as a fantasy based on TV versions of doctors like Marcus Welby. The reality is that many people don't have a family doctor, or have no choice about which family doctor they see in a clinic practice. They may rarely see the same doctor twice. They may not like or trust the doctor they are assigned to when the old one retires. They may avoid or delay medical attention in order to avoid exposing themselves to unpleasant interactions with their doctor.

Furthermore, when they end up in hospital for emergency care, usually they do not see and have no access to their family doctor, even if they do have a good relationship. While in hospital, they are evaluated and treated by staff doctors or specialists who don't know them at all. There would be no reason to assume that these doctors know anything more than what is spelled out on the chart — blood, pulse, respiration test results. Encounters with such doctors often leave a patient wondering if they noticed the person at all, or just the chart.

You have not heard from many people with disabilities, and many of the ones you have heard from are members of small ad-hoc affiliates of Dying with Dignity. They support physician-assisted death for all, with no rules or restrictions. They are entitled to their view.

But you have not appeared to listen to voices on the other side, and I'm wondering why.

Why are you able to hear Steven Fletcher as he tells his heart-wrenching story about the three months he spent clinging to his living hell of a life, being intubated and suctioned and immobilized, and how the first thing he did as soon as he could talk, was talk to his lawyer and have it written down that he must never again be subjected to this "well-intentioned torture" (at the hands of doctors, mind you!) but be allowed to die instead? The story is moving, to be sure, but had he died, he would not be here to tell it, or to make his plea for us to accept that he should have died, and that others should be assisted to die. And yet he speaks. And yet he accuses those of us who oppose his "solution" of lacking empathy and compassion! Hardly. I do have empathy and I do feel compassion for him in his confusion and ambivalence towards life. I'm glad he didn't die.

Why can you hear his arguments and not those of my friends? I'm just guessing, but it may have to do with the fact that he lived his first 23 years in a strong and able body, much like yours, your son's, your daughter's. Likewise the articulate Linda Jarrett from Dying with Dignity, who lived the first 50 years of her life in a body much like your own. (I feel for her too, by the way.) You are able to hear her. You understand her. You get that, when normal life hits an enormous obstacle, you want to die. I get that. Now the Court has said it's a person's right to check out, as long as they're an adult (some are saying "almost an adult" will do), their suffering is enduring (how enduring?) irremediable (like so many of my disabled friends) and intolerable (in a purely subjective way). You want to die? You don't even have to do it yourself anymore, you can overcome your ambivalent clinging to life by convincing a doctor to do it for you. To you.

You *must* go ahead and make your new law.

But take great care — greater care than you appear to be inclined to take, from the questions and postures revealed in your Committee hearings — take great care to build real safeguards for persons who have lived with disabilities all their lives, have gone to segregated schools, faced discrimination in employment, in leisure, in transportation, in social situations — even, yes, in health care. Their fight is for equality, for support so that they can live their lives and have a few choices about the basics: where to live, and with whom; how to organize their days; where to work and hang out; whether or not to raise children. Their fight is to live, and live well. And of course, to die well — supported, pain-controlled, surrounded by those they love and who love them, not rushed, not hastened or hurried out of the way.

Maybe some of them will choose the needle or cocktail of death. But all of them want to be reassured that they will never be pressured in any way to do so. Not by economic necessity; not by subtle devaluation of their personhood; not by over-burdened care-givers; not by scarcity of pain-control options; not by lack of social support; not by shame or fear or sadness or grief or loneliness.

You may think a right to choice in this matter doesn't impact on them at all. But many of them feel differently. They feel that choice for some will endanger others.

How?

Consider:

If you think all doctors are going to wait for all patients to "mention it first" before mentioning death as one of their "health-care options", then you are dreaming. If you think such a suggestion is just a neutral matter of fact, then you have no conception of the tornado of emotion that can whirl inside the mind of a devalued person.

If you think that "willing" doctors — enthusiasts — won't want to practice their new skills or advance their ideology, you're not in touch with reality.²

If you think all doctors are good, ethical people who only have their patients' best interests at heart, you are naive. You need to do some reading.³

If you think pressure on the health-care system due to the baby-boomer bulge won't lead doctors and hospital boards to consider "promoting" assisted death, your head is in the clouds. And the easiest beds to clear are those containing very sick disabled people, some without active family involvement, who can't muster the anger and entitlement to advocate for themselves — to resist and insist on real palliative treatment, not an easy fix.

Let's be honest. Some disabled people do succumb to despair. They do struggle, and they do suffer. And sometimes their suffering is intolerable and they consider suicide, and some of them carry it out. No matter how disabled they are, they can figure out ways to do it. That's a sad and tragic fact. In our community, in the indigenous communities, even in the tony neighbourhoods of the wealthy and well-educated, suicide is a sad and tragic fact.

Our Supreme Court, however, has decided that suicide by the desperately ill is not tragic and sad, but rather understandable, supportable and even a constitutional right, deserving of medical assistance. Some of our doctors say they are ready to fill the role of suicide assistant, a role that will remain illegal for all other human beings — at least for now. Some will be thrilled with the power vested in them. A small number may abuse that power. There might be enthusiasts like Dr. John MacEachran among them. During his forty-five years on the Alberta Eugenics Board, MacEachran and his cohorts approved over two thousand individuals for medically unnecessary sterilization surgery. A recent case in Belgium brought to light a doctor who has euthanized "hundreds" of his patients. ⁴

Most of us probably won't be unlucky enough to end up with an enthusiastic cowboy doctor who revels in his new role, but you can't tell us not to worry.

But honestly? Nobody's even telling us not to worry — they're just scoffing at our fear and dismissing our concerns. Not even listening.

You may do the same, but I wrote this on the off chance that one or two of you might actually hear. If you are that one or two, thank you for reading.

Thank you for speaking up on behalf of a rigorous, compassionate process that kicks in immediately when a patient requests assistance to die.

Thank you for recognizing the wisdom of involving a team of people, not only physicians, in the discussion and exploration of options open to a person who makes such a request. Thank you for recognizing a role for a social worker, a pastor or spiritual advisor, a friend or concerned family member.

Thank you for standing against the notion that careful consideration constitutes obstruction.

Thank you for recognizing that while doctors might be experts in physical medicine, they are not experts in spiritual well-being or existential anguish — and that includes psychiatrists and psychologists, who nevertheless might have some tools that could and should be employed in the service of reduction of suffering.

Thank you for ensuring that, when such a request is made, the response is not a mechanical ticking off of boxes on an eligibility chart, but rather a response of real compassion and caring for the person dealing with such deep anguish.

Thank you for your attention to my thoughts on this matter.

Respectfully submitted,

Patricia Seeley

¹NB: I am not a disabled person, but have lived with one for thirty years and have made many, many friends in the disability *rights* community — in organizations representing thousands of people with disabilities and their families, notably CCD and CACL, but also DAWN, PUSH, ARCH and others. Their fight is my fight too, but these are my words alone.

² In an actual incident from my own life, my disabled partner, having come through an acute pneumonia, was sleeping peacefully in a Toronto hospital, with me installed in a lounge chair at the foot of her bed, also sleeping. In came two doctors, one of them an intern. When I awoke and asked why they had a tube down her throat, the doctor replied that the patient, my partner, needed to be suctioned, and they were following protocol. But she didn't need suction just then, sleeping peacefully with her respiration stable and supported. No, he needed to give his intern an opportunity to practice on a living patient. My partner and I were too shocked and traumatized to object in the moment. The incident went unreported. A hospital ward is not a safe place to make enemies.

³ Right up into the '70's, people like Leilani Muir and others were subjected to surgical mutilation and are, today, still living with their physician-administered scars. Remember that good people who thought of themselves as social progressives enthusiastically supported these eugenic atrocities.

www.eugenicsarchives.ca

www.movingimages.ca

And understand that calling something “medical” does not automatically make it *ethical*:

<http://www.theverge.com/2014/12/12/7382821/torture-cia-report-doctors-nurses-psychologists-enabled>

<http://doctorswhotorture.com>

'Among all criminals and murderers, the most dangerous type is the criminal physician' - Miklos Nyiszli, prisoner and pathologist to Dr. Josef Mengele at Auschwitz.

<http://www.auschwitz.dk/doctors.htm>

⁴ <http://www.sbs.com.au/news/dateline/article/2015/10/29/belgian-euthanasia-doctor-could-face-criminal-charges>