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Brief to Special Joint Committee on Physician-Assisted Dying

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Over the past 5 years, I met and talked to over 1000 patients and more caregivers and persons visiting dying patients. I had longer conversations with possibly 5% of these. This was on the palliative care unit in a hospital environment. I am a palliative care volunteer, pet therapist and palliative caregiver coach.

I see physician or medical-assisted death as part of the continuum of palliative care. You don't abandon the patient or leave him/her to fend on their own, ever.

This brief will touch on my personal experience as a devoted son, as a palliative care volunteer and as a senior. I see volunteers playing an essential important role in support of palliative care in home, hospital and hospice situations. I believe it is unethical to rely on volunteers to perform tasks that fall under the role of paid personnel. But there are many other roles we can/do play in palliative care.

As a senior, my vast experience as a volunteer makes me aware and reminded of what lies ahead for me. No, I am too old to die young but watching people in their 30s die of cancer is horrible. There is nothing fair about being dealt that card. I am a senior and know I might want and need a way out if I ever get to the point where suffering makes my life no longer worth living.

My Parents' Deaths

I was present at the time of death for both parents. My father died of natural causes after 6 years in an institution. He had a form of dementia. He was 'happy' and, although 100% dependent on care for every physical need, he seemed able to enjoy life to a certain point, life in the moment. His life, in its own evolving way was probably still worth living. We would never know that for certain as he could not have told us. He was not completely aware of his condition. In my humble opinion as his advocate, I would have had no reason to hasten his death. It was illegal at the time but even in today's environment, I would see no reason to prolong his life or hasten his death.

My mother died from cancer, about three years after diagnosis. We were able to support her death in palliative care in her home. We had an appropriate level of support from various government agencies, Victorian Order of Nurses and the palliative care outpatient physician from her hospital. Three days before she died, her palliative care physician made an impromptu visit to visit her patient at home. She just showed up to see how her patient was doing and to also assess how we were doing. I assume the doctor would have arranged transport to the hospital palliative care unit if she was not 100% convinced her patient was comfortable, her care was not compromised in any way and the set up was safe for the patient, my mother. She asked mother if she had any questions. My mother asked, "How long will I have to wait?" She had decided not to eat or drink anything a week earlier. The doctor responded, "You won't last the weekend." That meant three days maximum. My mother responded "That long?" My mother also asked when we should start giving her morphine. The doctor said to give her morphine when she was in pain. She was not in pain.

So my mother was ready to 'go' and the thought of waiting three days was, for her, cruel. That was 2001. Of course, I did not offer to hasten her death. All I could do, all we could do was to be there for her, to wait and watch. It was cruel on the family too. Today, it is 2016 and physician-assisted dying should be law in the coming months, I would probably mention this as a possible option to my mother if the subject came up.

I was touched by those experiences. I was profoundly affected and decided, 10 years later, to be trained as a palliative care volunteer. I have been doing this ever since.

Televised Proceedings: Special Joint Committee on Physician-Assisted Dying as of FEB 1, 2016.

I do admit I am addicted to watching these hearings. They are for the most part so interesting.

When I listen to the presentations of some groups, it all seems so clear, almost simple. What's left to discuss? Examples of this are the BC Civil Liberties Association and Dying with Dignity Canada.

Other presenters too often mention how the subject is so complex, very complex. Their presentations are hard to follow, not clear. It seems they don't have a clear vision as to what is needed to meet the needs and wishes of patients and The Carter Decision. The presentation of the Canadian Cancer Society and the Alzheimer Society of Canada are examples of organizations that did make presentations but did not have a clear position on how our society would or should deliver physician-assisted dying. Their presentations left your committee wondering. It was bizarre to watch. They showed up but had nothing to offer.

My Position on End-of-Life care including Physician-Assisted Dying

"Everything should be made as simple as possible, but no simpler" is attributed to Einstein.

As mentioned, I was present for the death of both parents. I met more than 1000 patients who died, on average, two weeks after I met them. I was a caregiver coach.

Based on my experience, I suggest it can be simple.

I support the notion that no physician should be forced against his beliefs or conscience to administer physician-assisted dying. That is his/her right. But in those cases, I support the position of BCCLA that recommends such physicians immediately, without waiting, make their refusal known to their professional organization, the institution administration or some other body. This would not amount to a referral which might be against the conscience of the physician (or other health care provider) but would assure timely, unencumbered access for the patient requesting physician-assisted dying.

Palliative care is already a right of every citizen of Quebec. It should/must be a right of every Canadian.

Most patients would prefer to die at home. We are told dying at home is far less costly than dying in an acute care hospital or hospice or dying in the palliative care unit of an acute care hospital.

Moreover, palliative care in a hospital is defined as being for patients who will die within two weeks of admission on average. That means that even with palliative care in a hospital someone needs to care for the palliative patient for the whole period between, “There is nothing more we can do for you” and final admission to hospice or a palliative care unit.

I suspect when presenters are talking about palliative care they are referring to hospice, hospital palliative care and less palliative home care. That is not in the best interest of the patient wanting to die at home.

So if most patients would prefer to die at home and it is less expensive to die at home, why are most Canadians dying in hospital? Why is there not more support for dying at home?

Why does dying at home cost the patient and family money while dying in hospital is ‘free’ to patients? I suggest there could be some level of budget redistribution to provide and improve palliative home care services and reduce dependency on costly hospital stays. Palliative care at home should not cost the patient more than the same services in a hospice or hospital unit.

So there is a definite need for excellent outpatient palliative home-care. That should be the right of every Canadian who needs it.

I was part of a research project in Montreal in 2013-2014 whereby experienced palliative care volunteers were trained as palliative care caregiver coaches. We coached family caregivers, one on one in a home setting so they were competent and confident in the journey with their loved one. The whole point was to keep the patient out of hospital as much as possible while not sacrificing patient care, comfort, dignity, safety. The project was successful beyond expectations. We need that.

Volunteers play an essential role in end of life support. This includes in-home support as a caregiver coach. It also includes volunteering in a Palliative Care Unit of an acute care hospital or hospice. Having a robust volunteer programme with appropriate training and ongoing support is essential for the efficient, cost-effective palliative care programmes. Being a PC volunteer has enhanced my understanding of the dying process and greatly increased my appreciation of the whole process. I am often the ‘go-to’ person when a friend needs some guidance.

When someone asks me what I do as a volunteer, I say “nothing.” No, I don’t turn the patient, I don’t change diapers. Yes, I will feed them if that is permitted. But my main role as a volunteer is to be there in the moment. We often talk about stuff the patient cannot or would never talk about with anyone else: spouse, family, doctor. The subjects are those often most important to the patient.

The Last Hours of life

The cars we all drive must by law have functioning airbags. Yet the vast majority of us has never used an airbag and probably never will. Yet, we do derive some degree of comfort and solace in the knowledge that ‘if all hell breaks loose’, the airbag is there for us.

I propose it should be the same for physician-assisted dying. Knowing we could depend on the medical team to end our suffering, if/when we so decide, provides comfort and solace to a patient nearing the end of his/her life. Palliative care is actually physician-assisted dying. So what we are really talking about is physician-assisted death. In effect, we are asking for medical support for the whole journey, up to and including the last breath.

Similarly, having airbags in your car didn't just happen moments before a crash. They were there when you bought the car. Your wishes and plan should be in place long before the last hours of life. That is obvious when you are diagnosed with cancer. It is more obvious when you have a relapse and are going for a second round of chemo or radiation. That is when you should be introduced to palliative care and your options.

You just don't want to wait. As Wanda Morris, CEO of Dying with Dignity Canada, stated when you have a diagnosis, that is the time to have a single purpose document stating as the disease progresses then, if, if, if ever, then I would no longer wish to live and I hereby request physician-assisted dying. That would be simple and would apply to a terminal illness like cancer and maybe heart disease.

What if you don't have a diagnosis? I am 66 and seem to be healthy. But my experience tells me I could become an incompetent invalid any day now or in the future. Sure 30% of us will die of cancer. That is predictable. But 70% won't. So for people like me, I would want an advance declaration or some other document to define what I would want and under what conditions, I would want to die. It would be too late to sign anything if I waited in the case of certain illnesses.

Advance declarations should be followed, just as wills are followed. "If I am unable to get out of bed for x months, if I don't recognize my spouse. A list of all those 'ifs' that would make my suffering unbearable. This would apply to such things as stroke, dementia.

There should be no need to go before a judge or committee to approve anything. The Supreme Court has already decided.

My physician or health care worker could consult just as they would at present if they needed confirmation of a treatment or diagnosis. In some cases, those few cases that are actually complex, yes, maybe two physicians should concur before allowing physician-assisted dying.

Yes, it is as simple and as complex as "My life; my choice". I think it should be a right as defined by Carter v. Canada that Canadians be able to decide if they wish to 'go' a few hours, days or weeks before they would die without intervention to hasten death.

Legislation

I left maybe the most important item to last. I live in BC. BC is the province where all of the physician-assisted dying cases originated and were fought. Sue Rodriguez: "Whose life is it?" and Gloria Taylor, Lee Carter. Yet the government of BC is not leading. Quebec did lead the way with their Bill 52 which will have to be broadened to comply with Carter v. Canada.

I submit that your committee follows the recommendation of Jocelyn Downie where a federal commission comprised of representatives of the Government of Canada, and every province and territory, would manage the dossier. This would effectively get around the overlap of jurisdictions between the federal and provincial/territorial governments. It would also ensure common standards across all provinces and territories which is not the case for medicare today.

Respectfully submitted by:
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