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The Devil is in the Details: Thoughts on Medical Aid in Dying for Persons with Mental Illness

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One day many years ago, my buddy's phone rang a 6:00 A.M. Her friend, the newly minted and very agitated minister of health, was on the other end of the line.

"He lied to me", the Minister shouted.

"Who lied to you?", my buddy asked.

"The Premier", the minister responded. "He promised me that I was going to be in charge of the health care system."

"But you are", my friend answered, somewhat confused.

"I am not," the minister shouted. "There is no system."

And the line went dead.

I thought of that exchange as I contemplated today's topic.

As you will hear, I'm committed to a world where those with mental illness are entitled to the same rights and services as everyone else and further entitled to whatever accommodation is necessary to make that a reality. And I believe that this must include access to medically assisted dying in the right set of circumstances.

My problem is whether much seemingly irremediable suffering in the case of those with mental illness is caused by our disjointed and underfunded system as well as a society that is persistently hostile to this population. We have a country full of committed and highly skilled mental health professionals. We have some great institutions and organizations and stellar services like ACT but we are letting those with mental illness down in so many ways.

The system is catastrophically underfunded and disjointed. The right hand often doesn't know what the left hand is doing. Continuity of care is often absent. Access to care is nearly impossible for many and many more wait endlessly for help. Access to care and the type of care that one can expect is highly inconsistent across the great expanses of our country.

It was my privilege more than a decade ago, now, to collaborate on a report to government on Community Treatments Orders under the Ontario Mental Health Act. After two years of

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study, we reached the conclusion that the community treatment order programme was a great success. We also concluded, however, that this success had little to do with the control that community treatment orders gave physicians over their patients. We discovered that the success of the programme was largely attributable to the extra resources allocated for things like housing and other services and the fact that community treatment orders forced physicians and other health and helping professionals to construct a detailed care plan for each individual and then to work together across disciplines and in and outside of institutions to provide holistically for the needs of that specific individual. We also found that this holistic care was otherwise lacking for most needy individuals in the province and that people were floundering and suffering as a result.

Although there have been small signs of improvement, prejudice and hostility towards those with mental health challenges is deeply ingrained in our social fabric.

Let me put this another way. Many years ago, the provincial government commissioned a major study on the way forward for mental health care. Like many other reports, it is somewhere on a shelf gathering dust. More the shame because that study suggested that our mental health care system could never address the true needs of its clients without meeting their three primary needs which the author defined as a home, a job and a friend.

Given these realities, a very strong argument can be made that we have no business even talking about medically assisted dying for those experiencing irremediable suffering as the result of mental illness until we address the access issues and come to grips with the question of whether a good part of the suffering is rooted in societal attitudes and responses to those with mental health challenges rather than something wholly within the individual her or himself. As someone wiser than me recently said, "How can we talk about dying with dignity without properly addressing the issue of living with dignity?" It is critical that medically assisted death should never be an escape valve for non-existent or under-resourced services and supports.

Assisted dying also worries me because we have a history in Ontario of implementing things meant to empower patients only to see them ultimately used for the benefit of governments and institutions. I speak for example of the ubiquitous practice of long-term care facilities strong-arming their residents to sign powers of attorney for personal care and property, not for the benefit of the resident but because a consultant wandered the province some years ago and convinced them that they could save millions by doing so. And, frighteningly, there has been no shortage of speculation on how much our health care system could save from assisted dying.

I am tempted to say that we should adjourn today's session until all these issues are properly addressed. After much thought, however, I am convinced that the issues that I have just described mean that we have to proceed with great care and trepidation, but proceed we must, down the road of medically assisted dying for those with mental illness.

At this point, I want to address some red herrings that I don't think belong in the debate.

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I think that it is important to be careful that we don't use our topic as a cover to deal with other agendas. What I am thinking of particularly, is allowing our session to serve as a cover for a discussion of the morality and wisdom of medically assisted dying in general. The debate over whether we should legalize and regulate assisted dying may be ongoing in the United States but it's yesterday's debate in Canada. The Supreme Court's decision in Carter makes that clear. You are entitled to believe that the court was wrong but today is not the place for that. You are entitled to oppose physician assisted dying in spite of Carter but please don't inject that debate into today's topic. In other words, we should be discussing where we go from here. This is not the time and place to argue that we should be turning back the clock.

The other issue, in my mind at least, that does not belong in today's discussion is the impact that assisted dying may have on the sensibilities of physicians or their views on their proper role, or lack of a role. We need to remind ourselves that the health care system in general, and the assisted dying debate, is not about the professionals. Docs and nurses and even has-been lawyers like me are not at the centre of the universe. The health system and the delivery of health care is not about us; it's about the people that we serve. We just work here. That doesn't mean that individuals should not be able to opt out as conscientious objectors as long as they properly inform and refer, or that physicians emotionally impacted by their work do not deserve compassion and care, but the debate should not be physician-centric 'cause it's not about you. Those days are over. We fought too long and too hard to put patients at the centre of the health system to give any of that ground back.

So why do I believe that access to medically assisted dying should be extended to the mentally ill? I do so because the supreme court's reasoning, the Charter and the moral justification for medically assisted dying clearly applies to those who suffer from grievous and irremediable medical conditions whether caused by a physical ailment or a mental one. And the basic human right to autonomy, self-determination and control over one's own body and one's own fate is just as important and central to those dealing with mental illness as all others, assuming such a dichotomy even exists. It's particularly interesting that Reid and Ghallager and several other cases cited by the court in Carter and central to its reasoning, are mental health cases; cases dealing with the autonomy and humanity of folks who are mentally ill.

David Lepofsky, the famous human Canadian human rights lawyer and renowned disability advocate, maintains that the chief constitutional justification for medical assistance in dying is found in section 15 of the charter. That's the section that confirms equality without discrimination based on a number of factors including mental and physical disability. I won't go into Lepofsky's reasoning except to say that it would be odd, indeed, to discriminate on the basis of mental illness in the application of a law mandated by the Supreme Court as an affirmation of autonomy, self-determination and control over one's own body. In furtherance of this argument, I note that the International Convention on the Rights of the Disabled, to which Canada subscribes, forbids the denial of rights on the basis of mental illness. We are bound to accommodate, to make it work, and not to exclude based on disability because it is expedient to do so.

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Anyone who would deny that the suffering caused by mental illness is sometimes just as horrid as the worst suffering caused by a physical ailment just hasn't been around long enough. The pain, the depression, the fear and the suffering rooted in some delusional disorders, the agony and suffering caused by some psychotic illnesses can be just as real and just as horrible as any physical ailment that you can imagine.

I am not saying, however, that inclusion of those with mental illness will not be without its serious hurdles. The most obvious hurdle is the fact that the legislation, as currently drafted, appears only to be available to those whose death is approaching. Obviously this would have to change.

Next is the reality of episodic illnesses. Many mental illnesses, as we all know, fall into this category. Some folks can be into a full blown, depressive episode in January and completely well in June. For others, these variations can be more subtle. Some of the variations are related to treatment, some are spontaneous. The episodic nature of some mental illnesses is one of the reasons that I believe that a one year waiting period in the case of mental illness should be considered. There could be some flexibility to this but I think that a lengthy waiting period is advisable.

I also think that the issue of remediability presents special problems in the case of mental illness. The Supreme Court in Carter made it very clear that a condition is to be considered irremediable even if a theoretical treatment option exists but the patient rejects it. I don't know how this should work in the case of mental illness. I do, however, know a few things.

Firstly, no one should be forced to remain on, or return to, a medication that they find worse than the disease. I am reminded of a comment related to the Reid and Fleming case referred to in Carter. That case involved the treatment of a chronically psychotic gentleman with medications that he found intolerable and had rejected while capable. The court said his human right to autonomy and self-determination dictated that treatment could not be ordered even though the treatment was demonstrably effective for him. His lawyer, the late, legendary, Carla McGague was later quoted in the Globe and Mail saying that the case stood for the proposition that everyone, even psychiatric patients, get to choose their own hell. So, I think that it would be wrong to make assisted death contingent on acceptance of treatment that a capable mental health patient has tried previously but found intolerable, even if the doctors thought it effective.

Should we, however, require that the person accept other proposed treatments during the waiting period? I honestly don't know. On the one hand, this would address the objection from some quarters that assisted dying should not be available to this population because there is always another treatment that we could try. On the other hand, it violates the spirit of Carter and puts a burden on those living with mental illness that does not apply to others. I also know that it is laughable to argue that no one should ever be able to seek assisted dying on the basis of mental illness because there are endless treatment possibilities and the patient should be required to try every one of them.

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Then we have the issue of capacity. Now, the government completely ignored everything we have learned about capacity when it enacted the current law. It says that the patient must be capable but doesn't define the term. It requires physicians to apply what is really a legal rather than a medical construct. In my many years of experience, I have seen oodles of docs who really get capacity but I have also seen many who just don't get it at all, or who just use it as just another tool to achieve what they view as the best interest of the patient. If we are to extend the right to medically assisted dying to those with mental illness, these omissions will require addressing.

We will need some degree of oversight. I discuss this below. We will also need a clear definition of capacity. I think that the Ontario definition, which has really become the global gold standard is a good starting point but not sufficient. That test, set out in the famous Weisstub report, requires that the person be able to understand the information relevant to making the decision in question and be able to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

This test is a good starting point but would need to be further refined. For example, what about the effect of depression? On the one hand, you can argue that depression is inherent in the current test because a person with severe depression may not be able to see potential good outcomes and is, therefore, incapable of seeing the potential good of seeking treatment or continued life rather than an assisted death. On the other hand, you can argue that the question of depression is so front and centre in this issue that it needs to be better spelled out.

But it goes beyond that. I have reached the point where I question whether the Ontario test is missing something, particularly in the case of a vulnerable person facing a decision on assisted dying. I am not yet sure how to frame that question but it has something to do with independence of thought. Capacity is about the ability of an individual to make his or her own decisions. So how do we determine if the person in a vulnerable state is so overwhelmed by the pressure exerted, intentionally or not, by a family members, carers, etc. that he or she is incapable of an independent decision?

I don't know. And this issue is further complicated by the fact that the model we use of individual decision-making is not reality-based and, to the extent that it is, is completely Euro-centric. Even in European-Canadian culture, decisions are made to a certain extent by some or all of the family group. But, in some of the cultures that make up the Canadian mosaic, group decision-making for family members is more deeply entrenched. How much of that is too much? When is the line crossed such that we should not accept the patient's decision as having been made capably?

Add to all of this the looming issue of conflict of interest on the part of those with influence over the patient. An American comedian whose name I long ago forgot used to tell the following story:

An old man is in hospital dying when his son rushes in. "Dad", he asks breathlessly, "is there

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anything I can do for you, anything at all?" To which the man replies, "Just one thing and then I will be at peace. Bring me a piece of mother's apple strudel." The son rushes out and returns a few moments later and tells the old man that his wife has refused the request. "Why not?" the old man asks, "I'm dying anyway." The son says, "That's just the point. Mother says the strudel is for after the funeral."

Now, I'm not a clinician but I will tell you that my thirteen years on the Consent and Capacity Board and its predecessor brought me face to face with lots of strudel cases; cases where it was clear as can be that family had an agenda other than the best interest of the patient, often an agenda that involved getting the ill family member off their back or ensuring that there would be enough money left over when all was said and done to buy that F150 pickup truck. And what makes this worse is that, in my experience, attending physicians sometimes spotted this but sometimes they didn't.

I used to see lots of professional conflict of interest as well. I would see social workers acting as hospital discharge planners making placement capacity decisions with one eye on getting the bed blocker out of the hospital. It is inevitable that health professionals, probably unconsciously most or all of the time, will influence patients considering assisting dying in a way that is likely to free up scarce but much needed resources like beds.

Let me come back to the oversight issue. I firmly believe that, in the case of mental illness we need not only a waiting period but an independent multi-disciplinary review.

I am a bit biased, but I would use the Consent and Capacity Board model with an added twist. I would want to Board to have an independent report not that unlike the pre-sentencing reports that judges get before sentencing in criminal court. An independent person, probably a social worker, would look at the file and interview people as required and make a report to the board. The worker would also report on whether enhanced services, social, medical or otherwise, of some sort, might ameliorate the applicant's problems. The board would then hold a hearing to consider whether or not to approve the patient's request for a physician assisted death. And the Board would also have the authority to abridge the waiting period.

So there you have it. I am in favour of making assisted dying available to capable folks with mental illness. In fact, I believe that it is immoral and probably illegal not to offer it.

But I have all sorts of concerns that I would like to be addressed before we move ahead.

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