

Right to Die Society of Canada

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Special Joint Committee on Physician-Assisted Dying
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First off, I should make it clear that although I am writing this on RTDSC letterhead -- hoping to catch your eye -- I have not polled our members and I am not claiming to speak for all of them (though I do happen to know that many of them think in much the same ways as I do). I am speaking only as myself. However, during the last 30 of my 74 years I have acquired considerable expertise and understanding about death, not only through reading but also through many conversations and consultations with people who were thinking about their own dying or about a dying they witnessed.

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1) "Consent"

I strongly advise you to refrain from using the word "consent" in any legislation you produce.

In choosing to write "consents to the termination of life" the Supreme Court judges were probably thinking of consent to treatment. Here the typical scenario is that the doctor suggests a procedure – "I think you would benefit from a midlothian defrangellation" – and the patient consents – "Well, if substantial improvement is very likely, go ahead".

With assisted dying, however, the suggestion should come from the patient (directly and currently, in the ideal situation, but there is room for discussion of requests via formally authorized proxies, and/or via standardized and detailed written or videotaped advance directives). It may be more than a suggestion; it could be a request, or a plea, or a demand, depending on the condition and the personality of the patient.

Most frequently, however, the patient will be making a selection. When matters have reached a certain stage, the doctor will present the patient with a list of possible next steps, one of them being assisted dying. After outlining the advantages and disadvantages of each option, he or she will give the patient some time to think, and perhaps to consult with significant others. Ultimately there will be a situation of patient's orders and doctor compliance (or doctor refusal and patient referral, if assisted dying is chosen and the doctor is unwilling to provide it).

The term "consent" would feed the fears of those who believe that soon we will see bureaucrats scanning databases of patient records and deciding that certain lines should be removed from the spreadsheet.

Moving from the negative (what not to say) to the positive, I offer these possible re-wordings of the judges' phrase "clearly consents to the termination of life": "clearly desires death" or "clearly wants to stop being alive".

2) A Hierarchy of Hoops?

In their presentations to Justice Smith in BC, and possibly also in their presentations to the Supreme Court (I have not read a review of the arguments), the advocates of doctor-aided dying often pointed out that we already have robust safeguard structures in place to protect patients who choose life-ending courses of action other than euthanasia or assisted suicide – discontinuing dialysis, having their ventilator disconnected, etc. We assess their capacity to make such a momentous decision, we look for signs that they are being pressured, we ensure that the information provided to them was complete and current, we give them time to reflect, and so on.

Nevertheless, there has been a tendency to suggest that patients must jump through quite a few more hoops for euthanasia or assisted suicide (EAS) than for dialysis discontinuation, ventilator disconnection, refusal of food and fluids, etc.

One idea which some might advance, to justify the difference, is that non-EAS methods are reversible (up until a certain point), unlike EAS. But although this is true for dialysis discontinuation and for refusal of food and fluids, it is not usually true for ventilator disconnection.

The main difference does appear to be this: with the non-EAS methods, doctors can distance themselves quite substantially from the procedures and the patient, but with EAS they cannot. Their hands must write the prescriptions or inject the drugs.

Of course, doctors too deserve comfort care, but I think most of them would acknowledge that patients' needs for comfort – including the comfort of oblivion – should come first. When you (drafters of EAS legislation) find yourselves assuming that such-and-such a hurdle must be put in place, ask yourselves "Are we adding this requirement mainly to reduce the frequency with which doctors are called upon to perform actions that may cause them some psychological discomfort?" If the answer is "Probably yes", reconsider. Or, when you continue to feel that the extra safeguard is needed, take this as a sign that it should be added to the list of hoops for non-EAS exitings. All life-or-death decisions should be treated equally, regardless of how intensively their implementation involves a doctor.

3) The Role of Suffering

The Supreme Court judges wrote that medical aid in dying should not be available to a person unless/until "enduring suffering" is present.

They were likely thinking about euthanasia more than about assisted suicide. Human beings (except for psychopaths) have an instinctive revulsion from the act of ending another person's life. Perhaps doctors feel it even more keenly than laypeople. A perception of suffering may be necessary before they can overcome their revulsion and do what is in the best interests of the sufferer. For practical reasons, therefore, it probably makes sense to include current suffering among the requirements for access to euthanasia.

It makes much less sense to include current suffering among the requirements for access to assistance with suicide. Some people who are headed for decline and misery do not want to get too close to the fire. Especially if they are content with what they have been given by Fate, they want to quit while they're ahead, die with a good taste in their mouth, etc. In jurisdictions which permit only assisted suicide (e.g. Oregon and Switzerland), pre-emptive exiting is allowed. Brittany Maynard did not have to wait until her brain tumour had made her life unbearable, and Dignitas accepts Huntington's patients before their personality changes have turned them into sociopaths who probably could not even negotiate a plane trip to Zurich.

With assisted suicide, our main concern in drafting laws should be to minimize the chances that the person would be making a mistake (by which we mean performing an act that would be considered a mistake even by its enactor, upon reflection). If people are willing to take responsibility for carrying out the procedure themselves, they deserve a reward for putting up with a little butting in by kindly strangers.

That reward will be to have their euthanatic provided to them legally, so that they need not risk prosecution or financial loss when a Customs department confiscates the barbiturates for which they paid several hundred dollars.

4) Dementia

Some people who are given a diagnosis of irreversible dementia (vascular, Alzheimer's, etc.) will deal with the situation by applying to receive suicide assistance as soon as they have put their affairs in order. These will likely be people who are content with what life has already given them, and do not want to chase that with experiences of decline and loss. Gillian Bennett was such a person, though she was born too soon to get assistance with her suicide, and had to manage it by herself.

Other people, however, may not yet be ready to leave. They may know that in the first stages of dementia they could be happy more often than not. Their relatives and friends would probably find them cute, and not greatly mind the small extra trouble of caring for them.

But the other thing such people may know is that if they do not exit during the very early phase of their disease, when they are still having lucid intervals adequate to satisfy standard competence requirements for assisted dying, they will eventually descend into uninterrupted incompetence, whereupon they and those who love them will be trapped unless we see fit to let euthanasia be ordered in advance.

These people want the law to "remember" their former or real self, and respect it. They want the possibility of being released from a terrible situation which they dreaded when it was still their future and which is now their present. They want their present to receive a postcard from their past – a legally-binding directive created by their real self, decreeing that their life should be painlessly ended when certain conditions have come to prevail.

Can we make such postcards work?

The people who do the ending of the life will often have to act without any signs of gratitude or appreciation from the owner of the life. They may even know that the person would be cursing and resisting, if he or she had not been given the usual dose of sedative or anti-psychotic or whatever.

Their task will be easier if the person's directive has a video component, so that the present face – perhaps blank or contorted – can be offset by the past face, alert and animated and passionately pleading for the ability to enjoy life a little longer, secure in the confidence that the life will stop when the enjoyment stops.

In some cases, reassurance will also be available from still-competent people who knew the person well and who could understand a desire to "drain the glass of life". They agreed to serve as official proxies, who would be called upon to confirm the person's values when the time came.

Margot Bentley had not been diagnosed with dementia at the time she wrote her advance directive, as far as I know, but she was certainly aware of how possible it was – in her work as a nurse, she had often cared for dementia patients. It could be said that she wanted to drain the glass, or at least she thought it was safe to do so once she had documented her wishes about the conditions under which she would want her life to end, and made her feelings clear to her husband and her daughter. But she also was born too soon, plus the whole family had an innocent and unjustified faith in the compassion and respectfulness of the system.

As a salute to her, let us try to create a compassionate and respectful system.

Ruth von Fuchs
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