

Right to Die Society of Canada (Ruth von Fuchs, President)

- 1) What are the objectives (including for whom and for when)?**
 - 2) What are the obstacles?**
 - 3) What are some ways of dealing with the obstacles?**
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1) What are the objectives?

For whom?

The "owner" of a life usually wants it to continue as long as it is mainly pleasant, but stop when the pleasantness ends. Relatives and friends tend to feel the same, though they are less well equipped to make judgments about pleasantness. Management personnel in care facilities have a financial interest in residents' longevity, and they may have a lower standard about pleasantness, contenting themselves with an absence of obvious displeasure, even if that absence depends largely on drugs.

For when?

In an advance directive, writers are concerned with future pleasantness or unpleasantness. They may list particular types of unpleasantness known to be common in advanced dementia (such as sorrow, bewilderment, fear, and guilt). They may consider unpleasantness for their loved ones as well as for themselves, e.g. by stipulating that their life should not extend into a time when they can no longer recognize family members.

In addition to future miseries, however, people can suffer in the present because of a possible future situation which may or may not involve distress at that time. They may worry about a situation in which they are different but in ways that do not necessarily indicate suffering.

One of my uncles was a brilliant university professor and a gentle person whose hobby was painting landscapes, but he developed dementia and became subject to rages so extreme that he had to be institutionalized. In one of these rages he tried to push a little old lady through a plate glass window. (Presumably his sedation level was immediately adjusted upwards.) His son, a cousin with whom I was quite close when I was a child, is having his prime-of-life years blighted by the fear of being similarly betrayed by his nervous system. Many other Canadians, with or without a genetic connection to a dementia victim, are equally anxious.

2) What are the obstacles?

Anxiety on this subject is fuelled largely by our country's present demand that all life-ending actions be performed or requested by the owner of the life, and at a time when that person is fully competent.

Regarding action by the owner of the life: it is sometimes claimed that there is no need to permit advance requests for MAID because if we get diagnosed with dementia we can always end our life ourselves. After all, the condition does develop slowly, and it usually does not strike until we

have had at least five or six decades of good life, so maybe we should not be greedy. There are people who would not mind having a do-it-yourself death (I am one such person, and Gillian Bennett was another). But many difficulties currently stand in the way.

The fastest and most graceful method, a powerful anti-emetic followed by the drinking of a pentobarbital solution, is problematical in many ways. The smallest danger is losing several hundred dollars, if the supplier you try turns out to be a scammer; the worst danger is having police break down your door and ransack your house in a "wellness check", having been alerted by an international police agency that found your e-mail order. There are several non-pentobarbital methods (see the books listed under **Resources** on righttodie.ca) but many people find them rather taxing and/or deficient in gracefulness.

Regarding action by a doctor or a nurse practitioner: these people appreciate the reassurance they receive when a person states that MAID is still wanted. They do regret that the present law occasionally leads someone to forego pain-relieving drugs in order to keep their mind clear enough to provide the required confirmation on D-day, but most professionals are likely still content with the power to shorten the required waiting period in cases where the person is at risk for losing competence. I suspect that almost all of them would draw back from ending the life of an unconscious person, or – worse yet – a conscious person who appeared happy.

Apart from the obstacle created by the current-and-competent affirmation requirement, there can be psychological obstacles (within someone's relatives, for instance) and what might be called systemic obstacles (within institutions and the incentive structures that govern them).

A young woman who phoned me told this story: her grandmother had always been a very proud and meticulous person. After she went grey she dyed her hair black, and she always wore heels when she went outside the house. Following a major but non-fatal stroke she was reduced to lying on her back in hospital and seemed to most observers to be very unhappy. When her daughter and grand-daughter came to visit she would fix her eyes on them and weep copiously. The grand-daughter was sure she was pleading to be released but the daughter said "They're tears of joy".

As has already been mentioned, the continuing life of an institution resident is a matter of financial stability for that institution. Probably no employee or shareholder of the institution consciously thinks of things this way, but their actions (and inactions) are shaped by the situation.

3) What are some ways of dealing with the obstacles?

The problems with self-deliverance may take time to resolve. Pentobarbital is effectively unavailable through legitimate channels, having been priced at \$23,000 per dose. Some people have suggested that we could get a compounding pharmacy to produce pentobarbital for use by those who meet the requirements of the MAID law, but this may not be as simple as it sounds.

In the meantime, perhaps approved candidates could be given a prescription for DDMP (diazepam, digoxin, morphine and propranolol), the second secobarbital substitute to be developed in the USA. (Secobarbital's price was raised to \$3000, enough to make the drug unacceptable to many insurers and unaffordable to most patients.)

The problems with life-ending actions/inactions by outsiders have been tackled by some people in their Living Will. My own directive has the following post-script:

"The above characterizations [*personal traits which caregivers and substitute decision-makers should be mindful of, such as my being a proud person and a public-spirited person*] refer to "the real

me". If I am somehow overtaken by dementia before I can escape, and I begin to look happy being someone quite different from the real me (e.g. slovenly, or selfish), you are to consider that this new person is an impostor and has no credibility. Do not let her betray the real me. Withhold or withdraw all life-support from her, but protect her from suffering while she dies, through continuous deep sedation if necessary."

American legal scholar Norman L. Cantor recently revised his Living Will to include these passages:

"I wish to die upon reaching a degree of permanent mental dysfunction that I deem to be intolerably demeaning. For me, this means mental deterioration to a point when I can no longer read and understand written material such as a newspaper or financial records such as a checkbook . . . it is critical to shape the post-mortem recollections of my loved ones and to preserve the lifetime image as a vital, critically thinking individual that I have strived to cultivate. In addition, it is important to me to avoid being an emotional, physical or financial burden on my family and friends, even if they would willingly assume such burdens. I fully understand that my determination to avoid prolonged, progressive debilitation could prompt my demise even though I might appear content in my debilitated condition."

[*Changing the Paradigm of Advance Directives to Avoid Prolonged ...*

blogs.harvard.edu/billofhealth/2017/.../changing-the-paradigm-of-advance-directives/

Posted on April 20, 2017 by Norman Cantor]

These two efforts address the apparent-happiness situation, which is more problematic than the obvious-distress situation. But even with that situation, medical personnel may say "If the person does not ask for death, then I am doing what a veterinarian does." I respond "Is that so bad?" Personally, I would be happy to have my relatives and caregivers look after a dog-like or cat-like me with the same empathy and concern I have finally learned to practise with my pets. We fear abuses, but they are rare, and we should not let our policies be distorted by excessive cynicism.

Hesitation about providing MAID to a demented person could perhaps be reduced by including a video component in one's advance directive. The prospective provider could then see the face of the real/former self, alert and passionately pleading for the power to drain the glass of life, instead of the current face, which might be contorted or drug-glazed.

It would be wise for people to use a standardized form, or at least receive editorial guidance (e.g. from a specialist social worker or from a right-to-die consultant). A Dutch dementia patient who was at the centre of a troubling case in January 2017 had written in her directive that she would like euthanasia "when I myself find it the right time . Since she was almost certainly never going to find any such thing, once her dementia had progressed, her unfortunate wording damaged the credibility of the whole document. Medical staff in her facility had to determine "the right time" on her behalf, from her mood and her behaviour (she became angry and fearful, and wandered the corridors at night).

The person's relatives could help too, if we amended the law to allow MAID requests from substitute decision-makers. (See my comment about excessive cynicism, above.)