Guidance for My Proxy Decision-Makers and My Care Providers

(Anonymous Female) (May 24, 1941 –)

(I start with quick-reference material, then I provide background & legalities.)

Examples of Situations to be Evaluated on My Behalf

(A) States Whose Ongoing Presence Would Make Me Prefer Death to Life:

- severe and intractable pain
- severe and intractable nausea
- severe and intractable shortness of breath or difficulty with breathing (e.g. because of a nasogastric tube)
- severe and intractable dizziness
- severe and intractable fatigue/weakness
- severe and intractable dementia
- severe and intractable "stinkiness" (being the source of foul smells)
- severe and intractable itching
- blindness
- total and unremitting incontinence

(B) Powers Whose Ongoing Absence Would Make Me Prefer Death to Life:

- ability to communicate (to receive and to transmit)
- ability to move at least some parts of my body
- ability to change the location of my body, if only by using a wheelchair
- ability to take nourishment in a way that lets me enjoy sensations of taste

Decision-Making Factors

As I understand things, medical professionals commonly decide in terms of outcomes and probabilities – e.g. a 1 in 5 chance that procedure X would improve or restore my health. I am comfortable with this approach but I have some points to make.

1) Outcomes:

The philosophers who were known as "the American pragmatists" (e.g. Peirce, Dewey and James) recommended focusing on **actions and their effects**, as a way to clarify one's thinking. I like this approach and I want my proxy and my doctor(s) to use it.

For instance, if someone suggests that although I might object to tube feeding (because it is "artificial") I would not object to spoon feeding (because it is "natural"), I want the response to be along these lines (here presented as being my words):

"What matters is not my caregivers' view of a given action. What matters is the effect of the action on me. If an action will prolong my life when I would not want it prolonged, that action should not be performed, no matter how innocent it is in the eyes of its perpetrators."

2) Probabilities:

Since I am not desperate for "one more day of any kind at any price", I would only want interventions with **very good odds** on improvement or restoration – e.g. 4 in 5 rather than 1 in 5.

3) Burdens:

As was suggested by the words "at any price", medical people also consider the burdens of treatment. Here again, my lack of desperation indicates a demanding approach: if the burdens of a possible procedure are **significant**, I would not want that procedure.

Additional Help with Decision-Making ("Philosophical")

Regarding life-extension as a possible objective, these facts are relevant:

1) I do not view life as a good in itself.

I value it as a necessary condition (but not a sufficient condition) for the having of pleasant experiences. If it permits mostly unpleasant experiences, or no experiences at all, you are to consider that I have put my hand up and asked to leave the room.

2) I am not infinitely greedy for more and more life.

I am writing this at the age of 66 and already I am content with what I have been given by Fate:

- I have made contributions to a field of endeavour (online information retrieval) and a social movement (right to die)
- I have been mostly fortunate in my relatives, spouses, friends and colleagues
- One of my wisterias has bloomed
- I have learned and performed a Baroque choreography set to one of Mozart's German dances, fulfilling a dream that had been with me ever since I first heard his music.

Regarding how I would think in a given situation, these facts are relevant:

1) I am a "**fussy**" person. Smells and tastes that most people would not mind may be minded quite intensely by me. The same goes for sights and sounds and feels.

2) I am a **proud** person. If I could not be sure that my hair and skin and clothes looked reasonably good (according to my standards at the time I am writing this) I would not want to be seen by other people, which would probably mean that my life could not be extended.

3) I am **easily bored**. If all I had "to keep my mind alive" was mainstream radio or television or the conversation of demented room-mates, I would prefer that my whole body be no longer alive.

4) I am a **public-spirited** person. If I think that tax dollars may someday be spent on prolonging my life after it has become a curse rather than a blessing, I know that these dollars will have been stolen from people who could have benefited from more sensible spending policies, and I will be distressed in advance by the fear of being made to die as a thief.

5) I like to be **useful**. If any of my **organs** may be acceptable for transplanting, I request and authorize my proxy to take whatever steps are necessary in order for my organs to be harvested properly. This can include transferring me to a hospital if I am not already in one, and maintaining my body with life-support technology for the interval required. However, I wish to

avoid suffering during this process, and I therefore ask that I be kept unconscious (via anaesthetics but no neuromuscular blockade) while it is going on.

If my organs are not usable or not needed, I want my intact **cadaver** donated to the School of Anatomy at the University of Toronto (or to the nearest medical school, if I happen to be very far away from Toronto when I die). At the time I was writing this document, MacKinnon and Bowes (**416-465-7508** or 1-800-268-6736) was the official cadaver-pickup agency for the U of T medical school.

Post-Script:

The above characterizations 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.

Legalities (concerning my Power of Attorney for Personal Care, attached)

This power of attorney is intended to be valid in any jurisdiction in which it is presented.

Photocopies of this document may be relied upon as though they were the originals.

My proxies (initial proxy and all substitute proxies) have consented to act in my place. Their signatures are below:

1st) _____ (_____ ___, 20___)
2nd) _____ (_____ ___, 20___)
3rd) _____ (_____ ___, 20___)
4th) _____ (_____ ___, 20___)

My proxy has the authority to withhold or stop any form of care or treatment for me (including nutrition and hydration, supplied by any method), even if such withholding or stopping will bring about my death.

My proxy has the authority to request euthanasia for me, if it is legal in my jurisdiction of residence at the time I need it.

My proxy has the same rights I would have with respect to my medical records (e.g. may see them, may obtain copies of them, may consent to disclosure of them).

My proxy has the authority to engage in the following activities with respect to healthcare and personal-care professionals or institutions:

- requisitioning information
- signing contracts, waivers and other empowering documents
- hiring and firing (of professionals)
- admitting and discharging (to/from institutions)
- pursuing any legal action in my name, and at the expense of my estate, to force compliance with my wishes as determined by my proxy or to seek actual or punitive damages for failure to comply

"Confirmation" signings, after 20___:

_____ (_____,20___)
_____ (_____,20___)
_____ (_____,20___)
_____ (_____,20___)
_____ (_____,20___)
_____ (_____,20___)

(Continue on back of sheet, if necessary)