

From: Sue Frizzell
Sent: Saturday, February 13, 2016 10:10 AM
To: ~Physician-Assisted Dying Committee Comité Aide médicale à mourir
Subject: PHYSICIAN ASSISTED DYING (PAD)

I am very appreciative that a **SPECIAL JOINT COMMITTEE ON PHYSICIAN ASSISTED DYING** has been set up to formulate and propose legislation to be brought before parliament by the end of February. I am also appreciative that it has been mandated to give the Canadian public (the true stakeholders in this matter!) the opportunity to share their views.

In this regard I herewith respectfully submit my opinion on this most important of issues. I truly hope that this process will result in legislation that will give all Canadians the democratic right to die with dignity according to their own choice of timing, manner and location and with the assistance of a medical professional. This indeed will prove to be a milestone in Canada's human rights history. Those who disagree with physician-assisted-dying have every right to express their views but in a democracy they do not (at least in my opinion) have the right to negate this option for everyone else.

Critical will be the role of medical professionals (or perhaps, in time death specialists?) without whom the 'dignity' part of the equation would be impossible, as it is the medical professional who prescribes (and even in some cases administers) the medication necessary for us to die peacefully and without suffering. I have no argument that a medical specialist is essential in this process; after all we are talking about the premature end of our lives and most certainly, from my point of view, an MD's empathetic and knowledgeable advise on end-of-life options is an absolutely necessary part of the process.

In the forthcoming legislation, I fear that the committee will only include those with terminal illnesses having a predictable or even specific time period while excluding a very critical segment of the population who suffer horribly from the ravages of progressive and irreversible cognitive impairment such as dementia or serious brain damage due to stroke or accident. These illnesses although also terminal do not have predictable time periods. For those who suffer from irreversible cognitive impairment especially those who have gone beyond the stage of being able to have a meaningful consultation with their doctor on their end-of-life options, physician-assisted-suicide is much more problematic but no less compelling.

I, and many, many others have witnessed loved ones left to linger and suffer in a vegetative state as bodily functions slowly deteriorate ...a fate they never would have tolerated for their pets let alone if given the choice for themselves. The media is replete with heart-rending stories of this relentless, ravaging disease and the despair of their loved ones who are left helpless in its wake. At this point, I would like to insert a quote from a recent newspaper article which caught my attention;-

"For those who hold press conferences denouncing assisted-dying legislation ..I'd have the same message as for disability activists who think it threatens their own lives, the same message for those who confuse apples and oranges mistakenly mixing up right-to-die with the undeniable need for more and better palliative care services. What I'd really like to do is present all of them with a single image of Sheila's (sister) final year; loss of all movement, inability to eat or drink, loss of speech, compromised

breathing,..all this while receiving palliative care - wrapped in relentless deterioration and the certain knowledge that the only relief will be death...telling me more than once no one should have to die this way." (Ottawa Citizen Dec 19th 2015)

In anticipation that the forthcoming legislation will include provisions for those suffering from irreversible cognitive impairment and for those of us who do not want to suffer interminably, I have gone ahead and requested a a consultation with my family doctor of 25 years as to how I could best ensure not only none medical intervention but more importantly assistance in obtaining lethal medication in a timely manner (and also if necessary the administration of a lethal dose by injection in the case of sudden serious cognitive damage).

This meeting along with and much reading on the subject (especially the article in the NYT Magazine May 17 2015 about Sandy Bem, a Cornell psychology professor, who having been diagnosed with early onset dementia set in motion a step-by-step plan based on her descriptive suicide window and which according to her plan culminated in her suicide by a lethal dose and with her loved ones in attendance) has helped me formulate my own plan of action.

This plan is not set in stone and will be reviewed from time to time. However, contingent on it working will be parliament passing the necessary legalization legislation which needless to say I am very much counting on. Also, part of the key to this working will be the awareness of my family doctor, and my 'Power of Attorney for Personal Care' that the following documents are up-to-date and in their possession.

THE FOLLOWING 3 DOCUMENTS MAKE UP MY ADVANCE DIRECTIVE FOR IRREVERSIBLE COGNITIVE IMPAIRMENT

DOCUMENT #1 COVERING LETTER TO MY DOCTOR

December 31, 2015

I wish to thank you for spending so much of your time in September discussing with me the very important topic relating to physician-assisted-dying and some of the implications for doctors and patients with respect to the impending implementation of legalization in February 2016. Although I can't put myself in your shoes, I can understand that this must be a deeply troubling issue for you. It is unfortunate that we need to call on doctors to assist us in this regard – much better would be a new profession of death practitioners specialized in end-of-life (EOL) options.

In my initial tackling of this very thorny subject I decided to exclude situations where I am diagnosed with a short-term terminal illness (i.e. with a predictable time limit) but cognitively competent and therefore able to discuss my EOL options. My problem is with irreversible cognitive impairment with no predictable terminal time limit. The attached document (Advance Directive) is only intended to deal with this. Being able to arrange and set in motion the method, time and place of my death is very important to me.

In the case of progressive dementia, I will need help ;-

- a) identifying the 'specific markers' which characterize my cognitive decline and measuring their advancement
- b) identifying my 'self-suicide' window so that I do not miss the boat so to speak!

c) obtaining the lethal drug (with instructions) in a timely manner so that it is available at the time I need it.

Even more problematic is when irreversible cognitive impairment is due to stroke or accident. This may necessitate emergency practitioners and/or physicians to assist in my death (euthanasia) especially if I have passed my identifiable markers and my self-suicide window? In this case, it will be critically important for paramedics to be able to assess the severity of the damage and to be alerted to the existence of this Advance Directive and take appropriate action (eg no life-saving intervention in the case of severe damage). In this regard, and as you so wisely advised, I will carry a MEDIC ALERT CARD (sample attached) in my wallet and a copy on my fridge which will provide contact details.... probably wishful thinking that these dots between emergency personnel, hospital staff, and your clinic will connect; but hopefully at some point I will be able to count on physician-assisted dying so that I do not linger in some kind of semi-comatose state.

Also critical in making this Advance Directive workable will be periodic cognitive testing. I did have a MOCA TEST a few years ago at your clinic which quite possibly could be used as a base for comparison. It was suggested at the time that I should update the assessment every year or so. And then there's the question concerning the reliability and comprehensiveness of cognitive tests and their ability to assess and predict brain impairment and its effect on behaviour.

At this stage, achieving clarity about my end-of-life options seems beyond reach but at the same time I feel compelled to get my thoughts/wishes in writing before my mental capacity takes a downturn for whatever reason. It is such a densely complex subject and yet so personal. The NY times magazine article (May 17 2015) about Sandy Bem's experience and other testimonials have been very helpful. Any suggestions will be very much appreciated. Once this Advance Directive is settled (ie fine-tuned) and added to my medical file at your clinic, I am assuming it can be put to rest except perhaps for an occasional review until such time it is needed.

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DOCUMENT #2 MY ADVANCE DIRECTIVE ON FILE WITH MY DOCTOR

December 31,2015

THIS ADVANCE DIRECTIVE APPLIES ONLY TO IRREVERSIBLE COGNITIVE IMPAIRMENT/FAILURE FOR SUSAN GAIL FRIZZELL

THIS ADVANCE DIRECTIVE FOR ME SUSAN GAIL FRIZZELL is to be on file at my doctor's clinic along with my more general advance directives , (THAT IS, THE

ORIGINAL ADVANCE DIRECTIVE Copied from the Jewish General Website and THE ADVANCE CARE DIRECTIVE KIT extracted from the Ontario Dying with Dignity website). These documents are also on file with my Power of Attorney for Personal Care (POAPC)

MY PRIMARY CONCERN IN THIS ADVANCE DIRECTIVE IS TO ESTABLISH THE TIMING, METHOD AND LOCATION OF MY DEATH IN THE CASE OF SERIOUS 'COGNITIVE IMPAIRMENT' WHICH IS DIAGNOSED AS IRREVERSIBLE.

(However, I do recognize that there may be brain treatments available at the time when I am afflicted with cognitive impairment which might be able to reverse my condition and be worth trying and perhaps even obviate the need for this document; however, until such remedies exist the following directive represents my wishes.)

1) IN THE CASE OF BEING DIAGNOSED WITH DEMENTIA

(A) TIMING:

Typically cognitive failure due to dementia progresses at a predictable trajectory but the rate of this progression can vary widely which makes it necessary for me **now** whilst mentally competent to establish identifiable 'markers' which will alert me (and those close to me who are able to assess me) to the appropriate timing of my own demise by my own hand.

Once early stage dementia has been diagnosed, I will need a detailed roadmap of signs to watch for so that I do not miss the critical time period in which I am able to commit suicide. **While necessarily a subjective exercise, I will need guidance here to help me establish and fine tune medically-understood markers.**

BEHAVIOURAL MARKERS AS A RESULT OF COGNITIVE FAILURE THAT I WOULD FIND INTOLERABLE WOULD INCLUDE *INABILITY TO-*

- a) engage in conversation in a meaningful way
- b) recognize people I should and by the next day unable to recall their visit or any conversations.
- c) comprehend what I am reading or what someone else might be reading to me
- d) co-ordinate movements that are required to give me a certain degree of autonomy and quality of life (such as an ability to eat on my own, incontinence, dress myself, tend to my personal care at least at a minimum level... all due to cognitive failure as opposed to a failure of motor ability)

THE ABOVE BEHAVIOURAL MARKERS WILL BE A QUESTION OF DEGREE; BUT *WHAT WILL BE OF PARAMOUNT IMPORTANCE WILL BE MY ABILITY TO TAKE MY OWN LIFE IN THE CASE OF ADVANCING DEMENTIA.*

Once dementia has been diagnosed, regularly scheduled MOCA-type tests and other relevant medical assessments will assist in determining the degree of impairment and in establishing the timing of end-of-life action.

MEDICAL ASSESSMENTS

Some years ago, after I took a MOCA test at my family doctor's clinic, it was suggested to me that I schedule this test every 3 years or so. Once early stage dementia is diagnosed the timing of these tests will need to be stepped up. In addition, it will be important to have a broad range of medical assessments that take into account a variety of expert opinion in order to obtain a comprehensive picture.

(B) METHOD :

With regard to **METHOD**, I am assuming that if I have been diagnosed with irreversible 'moderate'/advanced dementia and I am fast approaching some of the markers listed above; and also, and more importantly getting to the point of no return of competency in being able to self-suicide I will need to take appropriate measures. At this point, **I am assuming that once physician-assisted-suicide is legalized in February 2016 I will be able to get a prescription for a lethal dose of appropriate drugs.** At this time, I can only use guidelines from published literature. Presently, I favour the method in the book "The Peaceful Pill Handbook " by Philip Nitschke who suggests pentobarbital in combination with an anti-nausea drug which provides a 'gentle' way to die.

This means that I will need to obtain a lethal dose in a timely fashion from a medical practitioner and it assumes that obtaining such a drug will be legalized by the time I require it.

(C) LOCATION:

At the time of writing this I have a preference for my home but this could easily be subject to change; and, as I have donated my body to Queen's Dept. of Anatomy perhaps somewhere close to Queens would make sense?

2) IN THE CASE OF IRREVERSIBLE BRAIN DAMAGE DUE TO AN ACCIDENT OR STROKE CAUSING COGNITIVE FAILURE;

A) TIMING

If I am only moderately cognitively affected then this document will not likely be required at this stage;

However, in the event that I have cognitively passed my 'markers' and unable to commit suicide, it will be critical for emergency paramedics (or other emergency medical practitioners) to be aware of the existence of this **ADVANCE DIRECTIVE** so that they know not to implement life- saving intervention. In this regard I will carry a **MEDICAL ALERT** notification card in my wallet providing my Physician's and my POAPC contact telephone numbers.

B) METHOD

In the case of irreversible brain damage and/or stroke, self-suicide is not likely to be an option but if it is, I wish to follow the same pattern as above.

However, if self-suicide is not an option, I will have to rely on a medical practitioner (in conjunction with my POA for Personal Care for the implementation of physician-assisted suicide (euthanasia). My not being able to self-suicide should provide sufficient evidence in its own right to implement physician assisted-suicide, please do not delay!!

C) LOCATION

Under the circumstances it won't matter! but again somewhere close to Queens University might be the best spot as body transfer to Queen's Department of Anatomy will work more smoothly.

DOCUMENT #3 MEDIC ALERT CARD TO BE IN WALLET AND FRIDGE

MEDIC ALERT FOR SUSAN FRIZZELL

**IF DEAD,OR IRREVERSIBLE
DISABLING BRAIN DAMAGE
DUE TO ACCIDENT OR
STROKE DO NOT MEDICALLY
INTERVENE UNTIL YOU
HAVE CONTACTED MY
DOCTOR OFFICE 1-613....
AND/OR MY POAPC 1-613-..**

REVERSE

MEDIC ALERT FOR SUSAN FRIZZELL

**BOTH HAVE COPIES OF MY
ADVANCE DIRECTIVE
REGARDING COGNITIVE
IMPAIRMENT DUE
TO ACCIDENT OR STROKE**

Sent from my iPad