[redacted]

[redacted]

From: sandra morris [redacted]
Sent: Tuesday, 10 May 2016 11:46 AM
To: Margaret Fitzherbert
Subject:

Dear Margaret – Thank you for giving me time yesterday to tell a little of my, and more importantly my partner Albert's story. It would mean a great deal for me, and for Albert's legacy, for the Vic Gov Committee enquiring into end of life options to include in your deliberations the information I can offer in relation to Albert's voluntary assisted death.

To that end I have attached a letter to the Committee, also a direct link to Andrew Denton's podcast about Albert's story (2 interviews in that podcast). I also have a 5 minute recording of Albert's views about the imperative need for a legislative framework to cater for end of life choices, spontaneously expressed just 1.5 hours before he died. This is an extremely moving piece for me, and one which I could pass over if the committee wishes, in which case I would need to supply a transcript with it since Albert's voice is weak and faltering. I would be fine about doing that, but would not wish it to become publicly available without discussion with me. I have attached a snap of bert and I taken 9 months before he died, and another taken three weeks before he died.

It is my birthday to-day (the first one in 45 years that I have not celebrated with Albert), and I choose not to celebrate it this year. Can't think of anything to celebrate. However, I have to say that the most meaningful gift would be to know that what I am handing you can be a relevant inclusion in your committee's work. Albert would wish this. I was regretfully unaware of this committee's work and would most certainly have met deadlines for submission had I known. Should you wish to interview me of course I would be there like a shot.

With very best wishes to all,

Sandra Morris-Leonzini
[redacted]

To: The Victorian Government's Enquiry into End of Life Choices

Re: My husband's journey and decision on a voluntary assisted death

Date: 10/5/2016

On June 22nd 2015 my beloved partner Albert Gabriel Leonzini chose to end his life to avoid the awfulness of a motor neurone disease death. Albert was supported in his choice by myself, his brother, and by a respected medical practitioner. Albert's story is presented in Episode 3 of the Andrew Denton's podcast series 'Better Off Dead', which includes a 10 minute interview Andrew conducted with Albert and I, as well as a 40 minute interview two months after Albert's death.

Everything to do with Albert's decision and his ultimate action in ending his life (because of the suffering with motor neurone disease), and the support he received, is publicly available through that podcast. I suggest to the committee the value in hearing the two interviews. It will become clear to you that Albert's decision was consistent with his long-held views about the necessity for Australia to provide a wider range of end of life choices to people with unbearable pain or intolerable suffering, and to those wishing to avoid that. He supported voluntary assisted dying, but believed that euthanasia was relevant for those who were unable to take the voluntary steps themselves because of incapacitation (such as loss of swallow, severely impaired breathing, physical inability to make it happen, or the stress of doing it).

One and a half hours before Albert took his final action, I recorded a spontaneous and brief conversation we had in which he expressed his frustration at the lack of relevant legislation in this country, forcing people to take matters in their own hands; and also that most people did not have the opportunity that he had – to have a voluntary assisted death. He was bothered by the inequity of this; that they did not have the opportunity that he had.

I very much want to represent to your committee the fervour of Albert's feeling and thinking about this, for inclusion in the formulation of the committee's thinking and recommendations. For me to represent his views and actions in this way enables his contribution to the development of a humanitarian legislative policy and strategy. This contribution would also constitute a profoundly meaningful legacy of Albert's, and an implicit acknowledgement of the courage it took for him to take his own life and end the motor neurone disease taking over his body – 'a dumb waiter for the disease", at a time when the quality of his life was heading into a stage he was adament to avoid.

Support of Medical Practitioner

No-one influenced Albert's decision about whether to live or die. Albert knew his own mind and what he wanted, which was to avoid a bad death, in his perception, which is the only one that ultimately matters. The medical practitioner supporting Albert understood Albert's preferences from what Albert told him in clear and certain terms. His compassion, care and regard were the obvious motivators for his support of Albert's wishes; it was abundantly clear that his only motivators were altruistic and humanitarian.

Albert and I experienced his duty of care through his responsive and responsible action in supporting Albert's considered preferences about how to die, where the alternative was an appalling quality of end of life. That 'considered preference' was for Albert to be able to have the choice to end his life himself when the quality of life became intolerable.

Albert experienced the ethics of the medical practitioner's duty of care through the regard and respect he showed for Albert's thinking, through his recognition of Albert's determination to avoid an awful end, and through his compassion in realising Albert's obvious deterioration to motor neurone disease.

Respect, recognition and compassion were his responsiveness to Albert (in listening to and hearing his patient's fears and aspirations); but he showed courage in supporting Albert's access to Nembutal to achieve his goal of choosing the time to die, **should he decide to exercise that choice.**

Albert and I saw this as entirely responsible by the medical practitioner – to provide opportunity for Albert to take control to avoid a bad death. After all – he'd lived well, so if he had the chance, should he not be able to die well also (on his own terms)?

The quality of Albert's last 6 months of life was as good as it could be, largely because he had no more worry (nor did I) about his dying badly. This enormous relief freed us both to take the most out of life – to make the rest of Albert's life as good as it could be.

The medical practitioner provided information and the means for Albert to continue life without the stress of worrying about being forced to endure an intolerable death, by his own definition, not by anybody else's. He did this by responding to Albert's direct request of him to support him in a solution that would allow him to have control over how long he would live; he also did this by being available to support Albert when/if needed.

Postscript

It was not clear until 5 days before Albert died that he would in fact act to end his life; it was clear however for the preceding 6 months, that he had the choice about whether to do so, and that empowered him to live quite well and quite positively for as long as he did. He died by his own hand to end intolerable suffering, with his most loved ones right with him in love, and a deeply caring and responsible practitioner.

In Conclusion

I am aware there have been derogatory statements and inferences made about medical practitioners who support voluntary assisted dying or euthanasia. Drawing on my own experience I can comment as follows:

- Their motivations are explicit – they would rather counsel people for life, and strive to keep people alive; at the same time they respect peoples' right to request and choose the time to die if faced with unbearable suffering and untreatable pain, and they will assist but not undertake. They understand that what is bearable to one is unbearable to another, and the definition of ''unbearability" is a suffering person's call.

- They have expanded the definition of 'duty of care' to include the emotional intelligence of acknowledging that people have intuitions and perceptions of what is tolerable to them in the face of unbearable suffering and untreatable pain. As such, the duty of care demonstrates a methodology and a philosophy which allows that there is no single way of showing compassion or ministering to a seriously unwell person.

- They do not kill, and the use of this language upsets me. It is insensitive to families who hold the deepest gratitude for these medical practitioners' intentions and supportive actions. It is provocative in the debate about euthanasia or voluntary assisted dying because it pushes people into emotionally charged views as opposed to rational thinking about a viable way forward in a complex terrain. Extremist language sets up prejudicial thinking – the very opposite of what is required for this country to collaborate on enquiry into and advocacy for a contemporary solution that provides responsible choice.

It appears to me that some people miss entirely the intent, the mettle, and the heart of these practitioners – I can only speak from experience, and that I do.

Sandra Morris-Leonzini

From: [redacted]
Sent: Saturday, 13 February 2016 9:21 AM
To: [redacted]
Subject: Albert's Story
Attachments: EP 3.docx; ATT00004.htm

Sandra,

Attached is the script for episode 3, and here is the link to the webpage.http://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/3-the-80-year-old-outlaw

When we've finished the final polishes on the ep I will send a copy through to you. Most likely that will be tomorrow.

I can confirm that this episode will be released on Tuesday. I hope you like it.

Best,

Andrew

STOKKE