Submission to the Victorian Parliamentary Committees Inquiry into End of Life Choices

…the tintinnabulation that so musically wells
From the bells, bells, bells, bells,
Bells, bells, bells -
From the jingling and the tinkling of the bells.
- Edgar Allan Poe ‘The Bells’ (c.1848)

I have tinnitus, or as I prefer to think of it, tintinnabulation. The word was invented by Edgar Allan Poe to describe the lingering sounds a bell makes after being struck. It makes it sound more poetic and less like a disease, or a condition, but it is not an accurate description of what I hear, and it doesn’t fade like tintinnabulation.

Many people suffer from tinnitus but in my own case I don’t say ‘suffer’ because it is more discomfort than suffering and, whilst certainly unpleasant, it’s not unbearable, at least not at this stage. Do I wish it would stop? Yes of course. The realisation that it is unlikely to ever stop makes me feel quite claustrophobic. It varies in intensity and frequency. Sometimes it’s less loud and not as insistent. And when I’m listening to the ocean it almost disappears, it is as if it neutralises it. Some tinnitus sufferers wear a device that constantly produces a noise which more or less successfully neutralises the sound.

A Dutch woman Gaby Olthuis did suffer unbearably from tinnitus. As she lived in The Netherlands where euthanasia is available for people who are suffering unbearably but who are not not terminally ill. But Gaby did not just have tinnitus, she subsequently developed hyperacusis, a condition where you become
so hypersensitive to sound that it causes unbearable pain. I am also sensitive to certain sounds and I hope I don’t end up with hyperacusis. Is it possible for me to imagine it getting so bad that I would not want to be alive anymore? Absolutely.

Gaby successfully requested and received euthanasia in The Netherlands in 2014 aged 47. Many people were ready to condemn her, especially because she was young and she had children. The Levenseindekliniek (end of life clinic) was reprimanded by the authorities for acceding to her request. But who could deny that her suffering is unbearable after watching this heartbreaking interview with her, recorded three weeks before her death?

https://goo.gl/dfMxe2 [link to mp4 file]

And if Gaby had been unsuccessful in getting medical help, she would have ended her own life. She had obtained the means to do so peacefully at a time of her choosing. People are ending their own lives every day because they are suffering unbearably. Making it legal for them to do so under medical supervision, gives them peace of mind. It makes it easier but doesn’t make it more likely. It certainly makes it less traumatic for the people that care about them. Not only can they can end their lives with their loved ones present if they wish, the presence of a medically qualified person means that if something goes wrong help is available.

I urge the Victorian Parliament to legalise medical assistance for people who are suffering unbearably, however I would propose that the decision whether the person applying for assistance is suffering unbearably be made not by a doctor but by a panel of citizens from the community similar to a jury system. The panel would have the power to hear evidence from experts including the treating doctor and people who suffer from the same disease or condition as the applicant. If the application was successful the panel would accede the request and a doctor would then be able to assist in the death of the applicant.

Thank you for your time.

Dr. Johannes Klabbers
Melbourne.

cc
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My postal address is [redacted]