TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 16 September 2015

Members

Mr Edward O'Donohue — Chair	Mr Daniel Mulino
Ms Nina Springle — Deputy Chair	Ms Fiona Patten
Ms Margaret Fitzherbert	Mrs Inga Peulich
Mr Cesar Melhem	Ms Jaclyn Symes

Participating Members

Mr Gordon Rich-Phillips

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Witness

Ms Suzanne Jensen.

The CHAIR — I would like to welcome Ms Suzanne Jensen to the committee. Thank you very much for being here this evening.

I will just caution before we start that all evidence taken at this hearing is protected by parliamentary privilege, as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today’s evidence is being recorded. You will be provided with a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee’s website.

Ms Jensen, the committee has received your submission, and we thank you for that. I invite you to make some opening comments, and thereafter the committee will have questions.

Ms JENSEN — Thank you for your invitation to address the hearing today. I want to start by saying that I have looked at all the submissions that are on the committee’s website. There are 700 of them, and they are from a lot of highly educated people — medical people, ethicists, lawyers, religious people, laypeople — but for reasons that I do not know, there are 28, including myself, who have actually disclosed that they are sick. What can I say? I do not know why. Similarly, from the transcripts that have appeared on the website from these hearings, I do not know how many there are, but aside from myself, there was one gentleman who appeared last week or the week before, so we are the only two people that are sick. I suppose I could say that I am like the elephant in the room here: I am the person this discussion is about — and the choices that I want to make in relation to how my life will end and that it will end with some sort of dignity with the least amount of suffering for my family. But it is like all this discussion is going on around me, not with me, which concerns me a little.

Just a little bit of my history: I come from a very fit, healthy family — nobody has had anything wrong with them. In 2009 I was diagnosed with oesophageal cancer. I underwent a procedure called an Ivor Lewis Oesophagectomy. I had most of my oesophagus removed, part of my stomach, lymph nodes — who knows what else. I was 8½ hours in surgery. I was a week in intensive care. I was three weeks in hospital. I underwent chemotherapy.

Three years later, I recovered. I still did not go back to the same standard of health and life that I had; however, I got on with it with the unwavering support of my fantastic husband, who is here tonight, my kids and my workplace. We have just got on with it. I went backwards and forwards for tests and treatments and all the rest of it, and after five years of scans, medical procedures, blood tests and all the rest of it I was officially medically divorced from my oncologist, which was very exciting. That was in November last year.

In September last year I had whooping cough, which used to be called 100-day cough. That was okay. We did what needed to be done there, but it just would not go, so I went back to the doctors after lots of different medications I was provided to try to get my breathing happening. I was diagnosed with lung cancer. While that caused me and my family quite a bit of distress, to be honest I really was not that surprised when that was the diagnosis. I was probably more surprised with the cancer diagnosis in 2009 than I was with the lung cancer.

I have undergone chemotherapy — intravenous chemotherapy — and I am currently on oral tablet chemotherapy. That has some side-effects, but you just get on with it; that is fine. I am a glass-is-half-full type of person. I am not dwelling on anything. I am just dealing with what is going on as well as I possibly can. I have great support, as I said, from home but also in my workplace.

It intrigues me that I can make a decision about legally availing myself of an abortion if that is what I choose. I can lawfully choose to turn off medical equipment that might be sustaining an unsustainable life. I can refuse medical treatment for my current cancer. I can say, ‘I don’t want any chemical treatments; I just want to go for an organic dietary-based treatment’, if I choose, and that is all okay. I can also choose on religious grounds to refuse to have a blood transfusion, and that is okay. But all of a sudden it is not okay for me to decide for myself, because I am not going to be informed or considered enough to do that, but I can make those decisions about somebody else. I do not quite get that. I have had this discussion with my family; they know where I sit with this.

The other thing I would say too is that this never leaves you; it is there 24/7. I do not think about it 24/7, but it is always there. It is always in the back of my mind. You see ads on TV about smoking, the issues that come with smoking and articles in newspapers and magazines about people who have survived cancer or whatever other ailment that they have had or illness that they have had.

I do voluntary work with the Cancer Council, and I speak to people with a new diagnosis of cancer about their fears and the concerns they have around their workplace. I work in a great workplace, so that has really taken a lot of pressure off in terms of my job, but I know there are a lot of employees out there — with the three years that it took me to recover from my surgery in the first place, I know that if I had not have been with the employer that I am with, I just would not have a job. It is that simple. That is the reality of it. You are constantly going and seeing doctors and nurses and having tests, and people ask you how you are. That is all great, but like I said, it is there 24/7. To think that you can just put all these wonderful things in place — then people go away, and I am still left with the thoughts and whatever else.

We all have things that we keep to ourselves, that we do not disclose to those who are nearest and dearest. There are things that I think about — my life and how it might end — that I do not disclose to anybody. We all have those sorts of secrets. I just find it really difficult that people can make this decision around me. It is disappointing, and I think there should be more input from people like myself who are unwell — and there are lots of people with illnesses, not just with cancer, who can be considered here.

In closing, I just want to say that Australia and Victoria have world's best practice medical staff, doctors, nurses, medical facilities, and to suggest that they would be somehow coerced or ill informed about a decision that I might make about what I want to happen to me at the end I think is misinformed. It is almost insulting to their intelligence that you would think that they would not take my thoughts into consideration. I could go on and on and on.

The CHAIR — Thank you, Ms Jensen, for what you had to say, but also for your preparedness and courage to share your personal story. We very much appreciate it.

Ms PATTEN — Yes, thank you for your frankness.

Ms JENSEN — That is all right. That is what it needs!

Ms PATTEN — Indeed. You have obviously given this quite a bit of thought. As you say, you are the person that we possibly are talking about. In saying that, what would be the perfect scenario for you that would keep you with that glass half full? If you could write our recommendation, would you know what it is?

Ms JENSEN — I just want to have a choice about what I can do for myself, not just, 'Well, we'll put you in palliative care. We'll look after you there, and that's all okay'. That is fine; I have no issue with that. It is not necessarily what I want to do, and at the moment my treatment is going well. It is difficult to say what I might decide if my health deteriorates. I do not know. That is further down the track. I am just getting on with it as best I can. But I feel that I should have a choice about what I can access and what I can do for me that is best for me and best for my family.

Ms PATTEN — Is that about saying that, yes, you can withdraw from treatment? As you say, you could say, 'Absolutely no more chemical treatment. I'm only going to eat apples now', or take a different tack. We heard from the first witness, Mr Mackenzie, who spoke about the Oregon model, which was knowing that when you felt that you were ready — if things go pear shaped, go the other way — that you would know there was a time that you just wanted to say — —

Ms JENSEN — Goodbye.

Ms PATTEN — Yes. Is that what you are saying? That you just want to be able to say, 'I want to be able to say goodbye when I want to say goodbye.'?

Ms JENSEN — And I should have the options about how I go about that, and it should be my decision. I am quite confident. I am informed. I can make a considered decision about this now, and I have made that decision in consultation with my family so that then if it goes pear shaped and I get to the other end, nobody can say, 'Oh well, she is just too distressed to know what's going on', because we have already had this discussion. We do not talk about it all the time or any of that sort of thing, but we have had the discussion, yes.

Ms PATTEN — As you would. Thank you.

Mr MULINO — Thank you very much for sharing your views and your experience. Notwithstanding the numbers of submissions, I think everybody in this committee very much values the perspective of people who are experiencing serious illness. It is going to be very much front and centre in terms of things that we consider. Clearly you would like choice. I am wondering: do you have views on what kinds of protections might be appropriate; should that kind of choice only be available for terminally ill people, for example? This is one of the issues that is often flagged when implementing this kind of regime is talked about.

Ms JENSEN — Probably. Yes, I think there needs to be some sort of safeguards, I suppose, if you want to call them that. I have looked at Dignitas, I think in Switzerland, and the way they go about things. You have to send them your medical records. They have three different doctors look at them, and then they determine whether you can even go onto their program. Assuming that that is the case, then you go and see them, they go through the process and you see a psychiatrist. I think there is a lot to be said for expert analysis around your illness. I also saw the program last night on *Dateline*, which was very interesting. So, yes, I think there should be some safeguards around that so it is restricted to people who have a terminal illness.

The CHAIR — Ms Jensen, thank you very much for your evidence.

Ms JENSEN — No worries. Thank you.

Witness withdrew.