

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 18 November 2015

Members

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Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

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Participating Members

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Witness

Mr Jason Franklin.

The CHAIR — I declare open the Legislative Council legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I welcome Mr Jay Franklin, who is appearing in a personal capacity. Thank you very much for appearing before us today. The committee has also read your submission and thanks you for that. Just before we get underway, I will caution 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 in the next week or so and ultimately the transcript of today's evidence will be made public and posted on the committee's website. We have allowed half an hour for our time today. I would invite you to make some opening remarks or to perhaps tell your story and thereafter the committee will have questions for you. Thank you again for your submission and for being with us today. I invite you to say whatever you wish to say.

Mr FRANKLIN — Firstly, I would just like to thank the committee for allowing me to talk on this topic of end-of-life choices. It is very important, especially for myself. Thirty-nine years ago I was born with a disease called Hirschsprung's, which is a congenital bowel disease. I was diagnosed at four days old. At 11 days old I had my first surgery to be given a colostomy bag. More surgeries followed after a number of years. At six months the diseased section of the bowel was removed, but due to many complications this led to major complications to my urinary system. Since then I have required well over 100 operations to date.

This really started to affect my life once I started high school. In year 9 I spent almost 9 months in hospital with an infection between my bowel and my bladder. This required well over nine operations. The following year I spent four months in hospital, with a large section of the bowel being removed due to it dying off because of all the antibiotics I was on. My mother Bertha, who is here today with me, has been an amazing support over my whole life and continues to be up until this day. She fully respects my decision to end my suffering after all these years and hopefully at a time and place of my own choosing.

Especially since 2000, my health has declined to a point where I have had many operations for complete bowel obstructions and for more of my bowel being removed. I had the large bowel removed and most of my small intestines. This has really affected me to the point where I have not been able to work, even part time, since 2007. I am unable to work due to my chronic pain resulting in many admissions to hospital and being prescribed heavy amounts of narcotics to at least try and assist with the pain control. Unfortunately this has provided very little relief, even from the pain clinics. Also, the reason the pain medication does not work successfully is that my body just does not absorb it because I do not have enough gut to absorb it.

On and off over the past 20 years I have required intravenous feeding. As you can see, I have got an IV line in my arm. I have now been on TPN, which is IV feeding, for well over 18 months, and this will continue for the rest of my life. I have been told that I am not a suitable candidate for an intestinal transplant due to all my abdominal adhesions or scar tissue. Because of this I would be in the same situation exactly after the transplant.

Long before I had even considered the option of voluntary euthanasia, once again I had had major surgery for another complete bowel obstruction, where they tried to remove and divide all my abdominal adhesions. This surgery lasted well over 18 hours. After that I had to be rushed back to theatre only 6 hours later due to major complications, spending two weeks in the intensive care unit and then a couple of months back on the ward trying to recover the best I could. In 2012 with the help of Dr Philip Nitschke and members of his organisation, Exit International, we started a campaign to try and raise funds to get me to Dignitas in Switzerland following my *Four Corners* story on the ABC which aired in September 2013. I have had a lot of support from family, friends and also social media.

Over the past 18 months my health has declined to a point where I am unable to travel to Zurich. I have felt I have got no other option but to make a YouTube appeal seeking help to acquire the end-of-life drug Nembutal. I know this is illegal and I am breaking the law, but I feel like I am trapped with no way out.

Even if voluntary euthanasia is legalised in Victoria, I may not qualify as this may only apply to people with a terminal illness. I would like the committee to take on board patients with uncontrollable pain and suffering, for which I have been approved in Switzerland; that is one of their criteria. I also ask the committee to strongly look at their model and see if we could adopt some of that model if there was legislation put in place.

I would like to think that if I qualify under the laws overseas, then people in my situation should be able to qualify under such laws here. Why should we not be able to do so in our own country, in our own homes if possible, where we are comfortable, cared for and loved. Please take this into serious consideration.

I would also like the committee to take into consideration the inclusion of physician-assisted dying in certain cases — for example, there are people such as myself who may not absorb the drug Nembutal and then possibly end up in a worse situation, for example, being a vegetable.

I have been trying to find out about the absorption qualities from my doctors, but yet again they are very reluctant to give out any information. Other examples that should be considered for physician-assisted dying would include people with high-level quadriplegia, end-stage motor neurone disease and lots of other illnesses whereby the patient may not be able to self-administer the drug.

I would also like to touch on the palliative care system. I feel it needs to go a lot further than just patients being terminal, especially in a situation like mine where I frequent hospital every six weeks to have IV pain relief administered, but once I go home I am back to the same problem. My pain is exactly the same; it is just totally out of control. I have had three palliative care assessments, and they have said because I am not terminal there is nothing that could help me in the home rather than having to frequent hospital or the emergency department if needed.

I would like to thank you for letting me have the chance to talk today.

The CHAIR — Mr Franklin, we thank you for the courage to be here with us today and to describe to us your situation. We appreciate it and acknowledge what you have been through, so thank you for being here.

I would like to ask a question picking up where you just left off talking about the palliative care system. Those who do not share your view and do not think euthanasia or some form of euthanasia should be legalised in Victoria would say that the problem is the palliative care system and the ability to access appropriate medical care and appropriate pain relief. What would you say to people who have that view?

Mr FRANKLIN — Like I have expressed already, oral medication I do not absorb properly. My only real answer would be to be able to access intravenous pain medication within a home setting, rather than having to sit in a hospital bed where it is obviously costing a lot of money to be in hospital when I could be cared for in my own home.

The CHAIR — Again those who do not share your view would say in addition to better palliation of your pain what is also needed is better support for people who are suffering to help alleviate that suffering. I have read of the support of your mother, and you have referred to that today as well. Can you perhaps respond to that proposition and talk about what supports you have had to help you manage?

Mr FRANKLIN — I have had a lot of support from the pain clinic at the Austin Hospital, but there is only so much they can do. I have been accused by my pain consultant in emergency one night; he said, ‘Cancer patients suffer more than you’. How would he know if he is not walking in my shoes every day? That would be my response.

Ms SPRINGLE — Thank you so much for coming in and sharing your story. It is a really important one. I am curious to know about why in particular you support the Swiss model for Australia, if we were looking to change our laws, over some of the other European models or perhaps some of the American models such as the one that has just been introduced into Canada?

Mr FRANKLIN — I know a little bit on the laws, but I suppose I know a lot about Switzerland, obviously, because I was planning to go there. They have three criteria. The first is terminal; I cannot remember what the middle one was; and then there is uncontrollable pain and suffering, and that is the one I fell under. So to answer your question, I do not feel it should be limited just to people who are terminal, and someone like myself or, as I described, people who cannot administer the drugs themselves or would need some sort of physician-assisted help, yes.

Ms PATTEN — Thank you, Jay. I must say I have heard this story many times and it always hits me. I was curious about this notion that you do not have a terminal illness.

Mr FRANKLIN — I have had the same question: when is ‘terminal’ terminal?

Ms PATTEN — Yes, that is right.

Mr FRANKLIN — The surgeons have said there is nothing further they can do for me; it is just about managing my pain.

Ms PATTEN — Yes, and if they do not feed you through an IV, then — —

Mr FRANKLIN — Then I am going to die of starvation. Who wants that? That is the worst way to go. It could linger on for months.

Ms PATTEN — That is right. So I totally understand that unrelievable pain and suffering as a criterion, and obviously if Australia is going to progress, I suspect it is not going to be in wonderful giant strides. I suspect we are going to take little steps. But I am wondering if we can also reassess what terminal illness means. And certainly for you, in palliative care, I am wondering whether, firstly, we could reassess terminal illness; and secondly, why cannot you get IV pain relief at home?

Mr FRANKLIN — I have had three assessments from palliative care, I have spoken to the head of Palliative Care Victoria. They even said that I fall between the cracks in the system, basically. They said, ‘Because you are not terminal, you cannot be administered any IV pain relief in the home’.

Ms PATTEN — That would make an extraordinary difference to your life, I would imagine?

Mr FRANKLIN — Exactly, yes. Pain is not my only issue of why I want to end my life. As I have stated, I have had well in excess of 100 operations, and it could be closer to 150. My last surgery lasted 18 hours, and then I was rushed back and in ICU for a few weeks. I do not want to go through that anymore. I have been doing it for nearly 40 years. I should have the right to say, ‘This is my body; this is my life’. I should be able to end it on my terms and not doing something violently like jumping off a train, or hanging myself in the garage where Mum might find me, or something terrible like that.

Mr MELHEM — Thank you, Jay, again, for telling us your story. It is very courageous of you to do that and I think it is important to hear from people like yourself who have been going through this for the last 39 years. The decision you are making in relation to this, is it because of pain and suffering or the burden on society and families and stuff, or both?

Mr FRANKLIN — Not a burden, definitely not. It is not only the pain, I have signed papers at the Austin Hospital stating that I do not want any more surgical intervention. If I was to get another bowel obstruction that I just want to be kept comfortable. Now to die from a complete bowel obstruction would be one of the most horrific ways to go. You are vomiting up faecal matter, you have got a tube down your nose trying to drain all the fluid out of your system, you would be in complete pain, and it would just be an awful way to go. So it is not just the pain. I do not want to have to endure that and I do not want to have to die like that.

Mr MELHEM — So on that, let us say that you are not able to get your wishes or the Parliament will not pass the legislation for assisted euthanasia, what other options do you think you have?

Mr FRANKLIN — Like I said in my presentation, I have been forced to try to obtain the drug illegally because I feel I have no other options. If there were laws in place, then maybe I would not have to seek that option. But at this time that is my only option.

Mr MELHEM — Thank you again for your bravery.

Mr FRANKLIN — That is okay. Thank you.

Ms PATTEN — Jay, when you were accepted by Dignitas, and unfortunately that was probably a long process, could you describe how it felt to have that knowledge? Was it a sense of relief?

Mr FRANKLIN — It was a huge relief. As I said in my *Four Corners* documentary, it was like I had the option sitting there in the cupboard. The physical drug was not sitting there, but I had that sitting there knowing it was an option. It gave me great piece of mind, especially after it took eight months, because I had to have a

psych review from the Austin Hospital saying that I was of sound mind. The psychiatrist was more than happy to write it, but then the legal team and the CEO of the Austin got involved, and they did not want my psychiatrist to write the letter. So it took eight months. We put in all of the information, posted up all my medical records, and sent them off to Dignitas. We had completed all the paperwork. My GP had to write a letter. Mum had to write a letter of support also. If I had had a family, so if I had a spouse and I had kids, then Dignitas looks at people differently. They will really scrutinise you a lot more. But because I do not have any siblings, sorry, any children myself, it was probably a lot easier.

But it still took eight months and all that fighting between my psychiatrist and the legal team and the CEO of the Austin to finally say, 'Okay, you can write this letter to state that Jay is of sound mind, but you have to put a clause in there stating that we cannot condone this because it is an illegal act in Victoria'. It was not happening here anyway. But yes, I finally got that, and that was sent off. Then within a couple of weeks Dignitas had virtually already given me the okay, but they were just waiting on that letter.

Ms PATTEN — Are there any specific examples of what that relief felt like?

Mr FRANKLIN — Once again, I suppose it gave me the peace of mind knowing that I had it there and I could use it when I wanted.

Ms PATTEN — How about your family?

Mr FRANKLIN — Yes, I know Mum obviously was upset. That goes without saying. But she supports my decision 110 per cent. You know that.

The CHAIR — Mr Franklin, before we conclude, is there anything else that you would like to say to us?

Mr FRANKLIN — No.

The CHAIR — Again, thanks so much for your courage and for being here and telling us your story. We really appreciate it.

Mr FRANKLIN — Thank you very much.

Witness withdrew.