

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Shepparton — 13 August 2015

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Mr Ronald Henney.

The CHAIR — Mr Henney, thank you very much for joining us this afternoon. I just 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 within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for our discussion this afternoon. We have received your submission. I invite you to make some opening remarks, and thereafter the committee may have questions for you.

Mr HENNEY — Thank you very much for having me. I would just like to say a little bit about myself, the situation I find myself in and the way ahead and maybe to the end. I am 61 years old, and I have a debilitating disease called inclusion body myositis. Over the next few years, realistically by the age of 65, I could require high permanent care. This condition, they say, will not kill me. Therefore I could live to 80 or 90 years of age. I also have ruptured discs in my lower back. I am in constant discomfort, which would be high rates of pain if not for medication. My knees are being destroyed by the way I walk, and there are swallowing side effects with IBM which mean I can choke on food. Eighteen months ago I walked unaided 4 kilometres up the Doncaster Hill to Westfield. Today, 1 kilometre on flat ground would see me laid up for at least a day. I still work full-time, although I am not there every day. There is no treatment or cure for this disease.

This is exactly how I feel: I will not be a brain in a useless body for the rest of my life, which could be 25 years. This brings me to the choices I am left with. If I knew I could choose when to die, I could live until things had gone far enough and die with dignity with loved ones who choose to be there. I do not have that luxury, so I have to weigh up options — and they would be much sooner so that I still have the strength and ability to end my own life. I know people who have not taken this option and wished they had. Being preoccupied with researching one's demise is not quality of living.

Then I realise there are the innocent people who would be involved — their grief counselling, guilt trips, search parties and who knows what else, which could be ongoing for years, depending on the circumstances. I realise this is a very complex issue and will take a lot of fine tuning. I do not believe religion should be involved in the end result as it is voluntary. I am not the type of person who would like to involve any innocent parties in my demise, as I have lived for 50 years knowing what it is like to take someone's life. This is who I am today, and I am not desperate. My life is just that: mine. I have lived a good, productive life, always worked, paid taxes and been involved. I feel very strongly that I should have the right to die as I have lived.

The CHAIR — Thank you, Mr Henney, for making this submission and having the courage to tell your story to the committee.

Ms PATTEN — Thank you, Mr Henney. I think it is always really poignant for us to hear such a personal story, and I cannot imagine what it is like constantly thinking about this and researching this. Have you spoken to your family? Have you got family support on board with you for this?

Mr HENNEY — Yes. My brother is a big support. I am married but my wife does not get it, and I can understand that. If it was not for the fact of Facebook, a place I was never, ever going to go to — the best support going is there because you deal with people around the world; 24 hours a day you can contact someone if you are not doing that good or if they are not doing that good — to have like-minded people, people in the same situation, actually makes it better, because on bad days knowing there are people worse off does not help but on good days, when you can help them, well, it does help. I found that by accident.

Basically when you are disabled there is no guide, there is nothing that you get handed to you to say, 'These are the things you can get, this is what you can access, these are the forms you fill out'. There is nothing. You are in the dark totally and pretty much stumbling around until your own research turns a light on, and then from there you sort of find a way and a bit of a web happens then and you can start doing some research. You can basically research what you have got, but that is from a medical point of view and it is from a science point of view, it is not from a personal point of view. A personal point of view is totally, totally different.

I am a person who is very resourceful. I have really never had to ask for help to do anything. I have always been able to sort any situation out, whatever. I applied for a scooter through SWEP, which I got a letter back to say

that, 'When funding becomes available blah blah blah, and then if there is no-one who is more disabled — well, eventually we will get there'. I stated on it that I work full-time and this could actually mean that I could work longer. I might as well have told my dog that because he would have gone, 'Yes, I get it'.

The era I grew up in, our brains are tuned not to complain. We put up with a hell of a lot. The next lot is going to be totally different; good luck to them. Probably with a couple of drinks and in a group you could talk for two days on the pros and cons, the whys, wherefores, the lack ofs. It is never-ending. But for me to have an out, because I am a realist, and I know that when I go, 'Enough is enough', that means that I could live a good quality life and even productively longer, for the simple reason I know that I can say, 'It is time to say goodbye'. Like I said, that is not there, and I do not want to pick out a car.

I have already looked things up. It is not negative, it gives me peace of mind to know. I saw my grandfather suffer. My father-in-law, every time I saw him he would say, 'Shoot me. For God's sake, shoot me!'. I saw my brother-in-law die, and I know for a fact — he had cancer, and they say three months is quick; it is not when you spend three months with someone with cancer — I know exactly what he would have done if he was well aware of where he was headed. He would have stopped it a lot sooner, because they say you are not in pain, but when you get shifted — and I know how tough this bloke was and his face was screwed up like you would not believe — there was something going on. He was not doing it just for the sake of doing it.

With our house, it requires either ramps or whatever eventually, or we move. To move is probably a better option, but with the pressures you have already got, you have got the hassles of selling your house, the hassles of buying another place — giving it to them. We thought about a lifestyle place because that sort of covers all options. Realistically I am not too concerned about myself. I am concerned about my wife and how she is going to be at the end.

Even with the scooter, it ended up that I bought my own wheelchair — I do not need it yet but I am practising — because if I did not, I cannot wait 12 or 18 months, because right now if I fell over at home, I am there until someone picks me up.

I have started photography. I used to do it, but I have taken it up again because it is something I can still do and I like to achieve. I go out to the bush. The reason I wanted the scooter was the fact that if I broke down and I had no mobile service, I can actually get somewhere where I can do it. If I broke down without anything there, I would just sit down and wait because I cannot walk, and if I fall over, that is where I stay. That in itself, again, is not going to stop me from doing what I do, because I am not curling up in the corner over there and saying, 'This is crap. I've had enough'. I have not had enough, but I would like to be able to say when I have.

Ms SPRINGLE — I think we have probably all got an idea of perhaps what your answer will be, but are you able to articulate what you would like to happen to make your situation more in line with your end-of-life choices?

Mr HENNEY — Again, as far as being concerned for myself, I really do not have a lot of concern. The way I die I certainly have concern about, because I am not a masochist and I suffer enough pain as it is, but I would like to be able to see that we can move without too many difficulties. I would certainly like to see the department — I spoke to the girl at SWEP. She was fantastic. I could not have asked for a nicer person, but she does not control the way things are done. She would like to help everybody there and then, but it is just not possible. Truly, I do not know how you guys do it because there are so many people who want stuff, and you have to find out who should and who should not and all that sort of thing.

I would like for me to die knowing that my wife is in a comfortable situation, where the grandkids can come and visit and stuff like that, and that we did not have to waste a whole lot of money putting stuff in our house and then making it unsaleable because who wants to buy a house that is got all this crap in it for a disabled person. It has to be removed, and it is more money spent. It is like everything to do with disabilities; it is ridiculously priced to start with and with nothing at the end.

I bought a \$30 000 wheelchair for \$1000 for the simple reason that they are everywhere, but a lot of people do not realise this or do not research. That is where I am from. If I can save myself a bob, I will by doing a little bit of research. As far as the end goes, I have basically put a peg in the ground, and when I get to the peg, that is when I will make the decision. Hopefully, I am quite a few years off that peg, but that could change. I have had three falls so far. I know I have another one coming; it is inevitable that it will happen. They are excruciatingly

painful. My dog loves them; he wants to give me mouth-to-mouth if it is outside — he thinks it is a game. But at the moment I can still pick myself up. I actually did it a month ago to see if I could still get myself off the ground but I had not fallen over, so if I had had a fall, I do not actually know. That is always there.

My wife plays golf. She likes to go away and do it, and I like to encourage her to do it because the day is going to come when it is going to be more and more difficult for her to do it. I should not impede on her life completely — it is just not right, it is not fair. If something went wrong while she was away, I could possibly die where I lay. I would hate to think how she would deal with it and the guilt trip she would be on. And if we were in a different house, different situation, with less trip hazards and less things to worry about, then, yes, life could be a lot easier.

That is the plan, whether it comes to fruition or not is another thing. But I just find having to pay stamp duty to sell your home to buy another home — it is all about your survival. It is not because, ‘Gee, this is what I want to do’, yet you still have to pay all these ridiculous fees because that is the way it is. The family home is something really.

When I was speaking to my OT, I said about the ramps. By the time you get them engineered, which you have to do — it has to be all done in a certain way — you would not get a ramp built. Just about everybody I have spoken to who has done it has said they made the inquiries and then found out someone who is a welder and turned around and paid for it themselves. It worked out that they got it when they wanted it and they got it done how they wanted it. It is just sad that that is the way it is. Unfortunately I have no answers for that; that is where smarter people than me have to deal with it.

Ms PATTEN — I just have one quick question, Mr Henney. We have been hearing a lot about the advances in palliative care and the advances in end-of-life care or in disability care, and I think there have been some remarkable progressions. Certainly in Shepparton we have been hearing some brilliant stories about the successes here. Many people will say to us that there is no need for voluntary euthanasia if we have good palliative care. Could you tell me what you would say to that?

Mr HENNEY — I do not believe that is right. The simple reason is, and again I think that is just the era I was born in, I basically — the peg in the sand for me is no-one is wiping my bum.

Ms PATTEN — Yes.

Mr HENNEY — I do not want to be there. That to me is degrading, embarrassing, all of that, and I just do not want to be there. There are plenty of people who would deal with that and not even bat an eyelid.

Ms PATTEN — You are not one of them.

Mr HENNEY — No. And my wife and I have spoken about it. It is fairly difficult to talk to her, but it is getting easier. But it is not something that I dwell on. It is not something that every day I wake up and go, ‘I better find out if there are any new ways of doing it’. It is just there, and I know one day down the track — it does not bother me. As far as death goes, when you are young death is a frightening thing; when you are older, it is getting closer. I am way more than halfway there, and it is certainly not scary, just the way that it might be. I do not go near water because if I fell in the water, I would not get out, and I really do not want to drown. Even to walk from there to here I have to make decisions that I never, ever had to make. It is just how I have got to do it, and again, I can live with it. They are not my issues. Out there, there is a time and a place it is going to happen, and I believe that we should be allowed to choose that time and place.

Mrs PEULICH — You said your wife would not have a bar of it. Why?

Mr HENNEY — Sorry?

Mrs PEULICH — You said your wife has a different view.

Mr HENNEY — No, she is fine with what I say, or she accepts what I say, because she saw her mum die, she saw her stepdad die, the way he died, and things like that. She knows me and she knows that I am just not going to be there. I think she accepts it. What she has problems with is actually accepting where I am now and how I am progressing. It must be tough for anybody to watch someone who could pretty much do anything go to pretty much cannot do anything. There are a lot of stresses and strains in the household because of it.

Mrs PEULICH — You mentioned the use of social media, Facebook. You mentioned that it is a source of support, because you have got presumably an international network of like-minded individuals. In addition to the support, is the social media serving any other purpose? Or perhaps IT. You said you have researched certain things. So it is a source of information of, what, how to commit suicide?

Mr HENNEY — Yes, absolutely. Anybody who researches anything, they put it up on the website for us to peruse over. I have got inclusion body myositis. There is dermatomyositis, there is polymyositis, there is JDM. So a lot of the stuff does not interest me, but there is a lot of stuff that does. There are things that cross over.

Mrs PEULICH — So the information that you have been seeking out is predominantly about your own physical illness?

Mr HENNEY — Yes.

Mrs PEULICH — Not any other purpose?

Mr HENNEY — I also offer ways of doing things. Someone every day has come up with a problem: they are having trouble getting out of bed or they are having trouble tying their shoes or things like that. A lot of times there are very, very easy fixes for it that they just have not — —

Mrs PEULICH — So it is not another, sinister purpose?

Mr HENNEY — No, no sinister purposes at all. It is totally support.

The CHAIR — Mr Henney, thank you so much for your submission and for, as I say, having the courage to tell your personal story to us as a committee. We really appreciate it.

Mr HENNEY — Thank you very much for having me. It has been a delight.

Witness withdrew.