JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS REGARDING THEIR OWN END OF LIFE CHOICES



TRANSCRIPT OF EVIDENCE TAKEN AT PERTH TUESDAY, 1 MAY 2018

SESSION TEN

Members

Ms A. Sanderson, MLA (Chair)
Hon Colin Holt, MLC (Deputy Chair)
Hon Robin Chapple, MLC
Hon Nick Goiran, MLC
Mr J.E. McGrath, MLA
Mr S.A. Millman, MLA
Hon Dr Sally Talbot, MLC
Mr R.R. Whitby, MLA

Hearing commenced at 5.12 pm

Mr ANDREW VERMEULEN Private Citizen, examined:

Mrs Hendrikje Vander SCHAAF Private Citizen, examined:

The CHAIR: On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am the Chair of the joint select committee. We have Mr Simon Millman, Hon Dr Sally Talbot will join us shortly, Mr John McGrath, Dr Jeannine Purdy, Hon Colin Holt, Hon Nick Goiran and Hon Robin Chapple.

The purpose of this hearing is to examine the adequacy of the existing laws and resources for endof-life choices from your perspective as a member of our community willing to share your personal experience. It is important you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege. This does not apply to anything you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet and the audio visual recording will be available on the committee's website following the hearing.

Do you have any questions about your appearance today?

Mr VERMEULEN: No, not at all. A little bit nerve-racking but.

The CHAIR: Do not be nervous. Do you want to make a statement for the committee?

Mr VERMEULEN: I guess I can. I am assuming you have all had a lot of statements or submissions to read, so you are probably lost somewhere in the paperwork. First of all, I want to thank you for the opportunity to allow us to speak to you. We thank you for the opportunity. We do have a personal story. As I say in the submission, my father-in-law had dementia for many, many years. The last eight years of his life he was unable to communicate at all. He pretty much lost control of all his body functions. It was a very difficult time, but we still believe that his life had purpose and his life had meaning. I want to say right up-front that we have a particular bias. I will not shy away from that. We are Christians and do believe in God. That does flavour our beliefs very much. We believe that we are created as humans as a special act of creation. We believe that we are above animal and plant life.

Therefore, we believe strongly that life death is beyond our authority and beyond what we should be doing. Having said that, as I said up-front, it does colour our thinking, when we looked at our father-in-law, Hennie's husband, we knew that his life had purpose and I think in a social setting there was definitely a purpose in his life. Even if you are not a Christian, I contend that to go down the line of euthanasia is not going to be good for society. In our submission, in my submission, I indicated four ways in which I believe our father's life had purpose even though there were times when we questioned the purpose of his life. I do know whether you have the submission there, but my mother-in-law would go and visit her husband every single day and help him, feed him, where possible. I think from our perspective, our children, so Bill's grandchildren, they could see the commitment that Mum showed Dad and that taught us something about the commitment of marriage and of love. I think that is a powerful message. That was one. The second one was that we were living in Albany and they were in Perth, so it was a bit of a drive for us to see our father and

grandfather, but when we did, our children also were taught that at times life can be hard and we should not shy away from the fact that life can be difficult at times. But our children got to see that we also had to show love to our father and they could also see Hennie's love towards Bill, so that was a powerful message also for our children, the next generation.

We had a number of times at Fair Haven in Armadale, the retirement village and hostel where the staff would say to us, "He is such a lovely old man." Personally, as someone who came a number of times a year—every few months—I had no communication with my father-in-law and my wife had no communication with her dad, and the carers still said he was such a lovely old man. There was something about his character that still came out that we who were less frequent visitors did not see. So, there was still a person there, even though he had dementia.

The fourth reason that we think euthanasia is not good for society is that the experience that we went through for 12 years, especially the past eight years, means that we can now empathise with others who are going through this journey and we can now encourage others and be a blessing to others, which, if we go down the line of euthanasia, is something that will not happen. Although, we state right from the offset our particular bias we do believe in God and we do believe that human life is special and [inaudible] life, even with that there are four reasons I have mentioned why from a perspective that may not be in line with Christian principles, we still say that it is not a good way to go for society. Thank you.

The CHAIR: Mr Vermeulen, your father-in-law, Bill, spent his final years in—would it be an aged-care facility?

Mr VERMEULEN: Correct.

The CHAIR: Did he have access to palliative care in the aged-care facility?

Mr VERMEULEN: Yes, he did.

The CHAIR: Did that involve managing his pain levels well? Were you comfortable that his pain was managed well at the end?

Mr VERMEULEN: Yes. There were times when there were infections. My mother-in-law, Hennie, can speak more about that, but there were a few times he ended up in hospital, but his pain levels were definitely managed and monitored carefully.

The CHAIR: So, it was around 12 years from his diagnosis to when he finally passed away; is that correct?

Mr VERMEULEN: Yes, maybe a little bit less.

Mrs van der SCHAAF: From the diagnosis. As a family we already knew that he had this, but from the doctor's diagnosis it was 12 years.

The CHAIR: How much of that time did he spend in the aged-care facility?

Mrs van der SCHAAF: He spent nine years.

Mr J.E. McGRATH: For those of us who are not familiar with dementia, what typically happens with a person who develops dementia, and as it progresses, what impact does it have on their body and their mind, and what sort of pain can they go through?

Mr VERMEULEN: I am not sure that there is a typical answer, because I hear from other people whose families go through this situation they do vary in the types of dementia. I think in the early years when my father-in-law had dementia, it was very difficult for Mum, because they were still at home and there were times when he would wander off, but not every dementia patient wanders off. My father-in-law used to wander off, he used to look for his house or he did not know he was

in his house. He got lost from time to time, so that was a very difficult time. There were good days, but there were also bad days and as time went by the darker days, the worse days, increased. There was no pain from the dementia itself, but it was more the other health issues that came up, which from time to time caused pain. When he shifted to the aged-care facility, he was at the point where he could still walk and control his functions, but his recognition of his family was going downhill most the time. He did not recognise people. Have I answered your question?

Mr J.E. McGRATH: Was that condition brought on by the dementia or just the ageing process?

Mr VERMEULEN: Just the ageing process. He had some heart issues early on in the piece or just before this happened, actually, so he had a pacemaker. He was once in hospital with pneumonia, was it?

Mrs van der SCHAAF: No, bladder problems.

Mr VERMEULEN: Bladder problems, so that created an issue which he was not able to express his pain, but the carers were able to recognise, Mum was able to recognise, that he was in pain, he was given pain relief and they just left it at levels where he was comfortable. We could see that he was comfortable and the carers could see that he was comfortable.

Mr J.E. McGRATH: One final question: was he able to recognise family members right up until the finish or not?

Mr VERMEULEN: No. When he first shifted to the aged-care facility, there were times he could, but I reckon probably the last eight years of his life he could not.

Mr J.E. McGRATH: So, he could not recognise any members of the family, not even his wife?

Mr VERMEULEN: No, he could not recognise anyone, but there were times when the touch from Mum calmed him down, so he recognised something there, even though he could not express it. Even on his deathbed we sang a song that he may have known from his childhood, which seemed to calm him down a little bit, so there was still something there, but to say Mum's name or anyone else's name, he could not do that, no.

The CHAIR: Mr Vermeulen, I just want to ask you to turn the volume down slightly at your end. We have got a little reverberation and I think that may help, thank you.

Did your father-in-law have an advance health directive?

Mr VERMEULEN: We are not aware of that. Maybe he did, but I am not sure what that is.

The CHAIR: It is a legal document where you outline what care you will or will not accept if you end up in hospital.

Mr VERMEULEN: Okay, yes, that was the case, because I think one time that he was in hospital, mum was asked whether he could be put on life support if—Mum, do you remember that?

Mrs van der SCHAAF: Yes.

Mr VERMEULEN: So, probably the answer to your question is yes, but the details of it I am not sure.

Mrs van der SCHAAF: I do not know the details either.

The CHAIR: So it is hard for you to assess whether that advance health directive was complied with or not by the facility?

Mr VERMEULEN: It was, because he never went down the line where he needed to go on life support, so the decision did not have to be made whether to turn his life support off or not.

Hon NICK GOIRAN: Mr Vermeulen, just in respect to this question on the advance health care directive, I understand that your father-in-law would not have had capacity to make a decision, so I

think you were indicating there that your mother-in-law was being asked for what decisions she wanted made in the event of life support.

Mr VERMEULEN: Correct.

Hon NICK GOIRAN: I think that lends itself to it being the case that there would have been no advance health care directive, because only the person themselves can make that choice.

Mr VERMEULEN: Okay, so in that case there was no advance health care directive.

Hon ROBIN CHAPPLE: Again, not understanding particularly well the condition, at the very end of life, did your husband, your father, just slowly pass away or was there a trauma associated with the end of life?

Mrs van der SCHAAF: No, there was a slow going down, but then all of a sudden he could not eat or swallow anymore and then it took three days and he quietly just stopped breathing.

Hon ROBIN CHAPPLE: Thank you. I know that might have been a bit personal, but that actually helps build a better picture for us.

The CHAIR: Is there anything else you would like the committee to know?

Mr VERMEULEN: No, I think we have shared what we wanted to share, thank you.

The CHAIR: Thank you both very much for your evidence this evening. It is very, very helpful for us to hear from people with direct experience with their loved ones and themselves, so we really appreciate you sharing that with us.

I am going to read the closing statement just a close of the hearing. A transcript of this hearing will be forwarded to you for correction of transcribing errors only. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information, or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript. Again, thank you very much for taking the time to give evidence to us today.

Hearing concluded at 5.27 pm
