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 SEVEN

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

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Hearing commenced at 2.32 pm

Mr WILLIAM PHILIP
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 and I am the Chair of the joint select committee. We have Mr Simon Millman, Hon Dr Sally Talbot, Mr John McGrath, Dr Jeannine Purdy, Hon Colin Holt, Hon Nick Goiran, Mr Reece Whitby, and Hon Robin Chapple. The purpose of this hearing is to examine the adequacy of the existing laws and resources for end-of-life choices from your perspective as an individual member of our community who is 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; however, it does not apply to anything you say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast within Parliament House and via the internet. The audiovisual recording will be available on the committee's website following the hearing. Do you have any questions about your appearance today?

Mr PHILIP: No. I am pleased to have the opportunity to appear, I do appreciate that. Forgive my voice, it tends to get a bit crackly, but if you do not understand me, please tell me.

The CHAIR: Absolutely. Did you want to make a statement for the committee before we ask questions?

Mr PHILIP: I would assume that the committee has available to it the submission that I made and I would like to expand a little bit on that.

The CHAIR: Yes, please do.

Mr PHILIP: Basically, I have more or less in precis form given you the last three years of my wife's life. She received a diagnosis in 2014 of an inoperable non-metastasising cancer of the stomach. If she had been 40 years younger she would have had perhaps a 20 per cent survival chance with a very major operation. At the age of 78 there was no chance of anything being done surgically or medically to improve the situation. My wife occupied extremely senior positions in nursing including director of nursing at the biggest nursing home in the state for about 10 years; as second in charge at Shenton Park Annexe, when Sir George Bedbrook was in charge of it; charge sister at Royal Perth Hospital; and we ran our own nursing home also for many years in the 1970s, 80s, 90s and up to the beginning of 2000. My experience with aged care, both directly working in it and as a husband and confidant of somebody who was extremely good at it—it has been pretty good. My wife was always convinced that the end of life was something that should be dignified and comfortable if it possibly could. When she received the diagnosis of this adenoma, she thought that she was probably going to die of something like a ruptured bowel, a ruptured stomach or some complication thereof, and she was terrified. She had been, for quite some years before that, on various opiate drugs for a serious back injury which resulted from 50 years of hard lifting in nursing and she had accumulated quite a large supply of those which she took all at once. I was fully aware that she intended to do that. I was in the room when she took them. I did not assist her in any way, but I did not try to stop her and I promised that I would not call doctors or take her to hospital. I understood her intention to die. She was fully in her right mind and she was not going to go any further than she had to. She did not. She survived for four days at home with me keeping an eye on her and trying to make sure that she did not have any nasty complications if she did survive. Eventually it became obvious that

firstly, the opiates had worn off and had not killed her and secondly, the benzodiazepines and various other drugs she was on she was in withdrawal from and she was becoming unmanageable. I then broke my promise and got an ambulance and got her down to the hospital. I told the hospital what had happened and subsequently we had the police, psychiatric services and various other people really giving us a going over. I have been a justice of the peace for about 34 years and I fully understood the laws relating to helping people die or what have you and the police eventually were satisfied that I had not. But it was a racking situation and when my wife recovered in hospital and came home, the first thing she did was round on me and say, "Why didn't you smother me while I was unconscious?" Which was pretty horrible to hear too. However, she thought things through for a while and decided that she would not do that again and she would go along and try to make clear to people who were caring for her as her condition worsened that she did not want to be kept alive by artificial means, that she did not want her life prolonged to the detriment of any kind of standard of independence, dignity, comfort, continence et cetera. She probably had a couple of quite reasonable years out of it living in a wheelchair and variously not being able to do a lot of the things that she wanted to, but she had a reasonable life.

In August 2016, she got very sick with pneumonia. She spent two and a half days in the emergency department at Peel Health Campus where there was nowhere else to put her, nursed in an area set aside for four people with eight people in it in full view of the public coming and going—incontinent, both of faeces and urine, unable to be nursed because the staff in the nursing profession down there, both the regular staff and agency staff they had, were too busy chasing after drug addicts and people who were making a bloody nuisance of themselves. So I, my stepson, her son by her first marriage and two other people more or less nursed her in the emergency department through that time. We supplied her with medication and showered, changed and cleaned her up et cetera. The help that we got from the emergency department was that we could use their linen and basically they would keep an eye on what we were doing, but they were not doing anything much else to help, which was not particularly encouraging. One of the things that was made clear to us when she tried to kill herself was that she should have filled in an advance health directive, which would have supposedly stopped the advent of care that she did not want that was going to keep her alive. After the episode in August she was home for a little while, she got steadily worse and she was diagnosed again with pneumonia about a month later. The doctor involved palliative care in the situation and palliative care were attending on a daily or multiple times a day basis as necessary and they were remarkably helpful and incredibly human and I have nothing but praise for them.

[2.40 pm]

At the end of October she got extremely sick again, which obviously she had pneumonia, and the doctor at palliative care who had spoken to my wife—and my wife was completely capable of speech, thought and rationality, which was probably not the case by the end of November—the doctor had had it made clear to her by my wife verbally that she did not want any further treatment, she did not want under any circumstances to go back to hospital and if she reached the point where she did not have any future other than that sort of care, she wanted to be kept pain free and fear and anxiety free with sufficient opiates to keep her knocked right out and just let her go. The doctor wanted to admit her back into hospital. The doctor and I had a fairly long and intense discussion about whether or not she should be admitted to hospital. In the end, the doctor made the point that she was not suffering from an immediately terminal condition, that she was lingering along quite nicely, but the pneumonia was treatable, and if the doctor did not treat that pneumonia, then the doctor was in breach of her, I presume, Hippocratic oath, insofar as she should have been able to treat that and it was not necessarily artificially prolonging my wife's life, so she went back to hospital. I am too much of a gentleman to scream too loudly. She was there for about 10 days and

they certainly treated the pneumonia but from there on she was incapable of any kind of interchange or thought or discussion. She could start a sentence, she would get about four words into it and it would trail off into gobbledegook—not words, but bits of words. She deteriorated quite significantly during December 2016 and at the end of December between Christmas and New Year she was fitted with this perfusion apparatus that provides direct access to the painkillers and things that she was on. However, in the next 10 days she basically drowned slowly. Her lungs continued to fill up. No matter what the doctors did, they were not able to do anything about it, nor were they able to put her out sufficiently that she was unaware of it. On the Wednesday before she died, she was absolutely terrified. She could not breathe properly, even tipping the bed up that her feet were five feet off the ground and her head was a foot off the ground and trying to help drain out her lungs. Her eyes were bugging out and she was throwing herself around; she was terrified and that should not have happened. The palliative care people came that day, they helped stabilise her and they were as good as they possibly could have been. I think they were there three or four times that day and she should have settled down, but from then on she just gradually quietly drowned. And the palliative care people were doubling the medication that she was on every day, and it still was not taking away consciousness nor anxiety. With all due respect to the people who were speaking before—and I am not commentating on them at all—I think that if that was God's will, it is a pretty dodgy prospect.

I do not for a minute think that people should be in a situation where some doctor or some government sits in judgement on whether they should or should not die at a particular time, but I do believe that if she had made clear her intentions both in writing and verbally that at some point, when things were obviously reaching the stage that they reached in the first week of January 2017, I or somebody else could have said, "Enough. Let her go."

Without pointing any finger to the way things happened in the 1960s and 1970s in nursing homes, that would have happened, and it would not have been a discussion and it would not have been a problem. Her attending doctor would have given her sufficient pain relief and it would have relieved the pain. They are not game to do that now because the penalty for murder is a little bit higher these days. But that is effectively what was happening and nobody gave a second thought to it. It was normal, it worked and it was humane. I would hate to think that anybody had to go through what my wife and, I suppose by remote control, I went through in those last few months of her life. It was a dreadful experience. Palliative care did everything they possibly could to help and it was not enough.

I would like the Parliament to make available through legislation a situation where, in circumstances like that, properly regulated by obviously duly qualified doctors and psychiatrists or psychologists or whatever else was necessary, there is opportunity to put your hand up or have somebody put it up for you, as I would have done, and say, "Stop there; let her go. Give me the injection and I'll give it to her." I was not going to kill her, but I would have.

The CHAIR: Mr Philip, thank you very much for your evidence today.

Hon ROBIN CHAPPLE: Absolutely.

The CHAIR: That is a very harrowing account —

Mr PHILIP: It was a harrowing experience.

The CHAIR: — of the last couple of years of your wife's life. If I heard correctly, your wife attempted suicide but remained at home with you for four days —

Mr PHILIP: Yes; that is correct.

The CHAIR: — when the attempt had failed?

Mr PHILIP: The attempt failed after four days but, yes, I was aware of it and I was looking after her. I was not about to ring the medical people. It was not what she wanted and I was not going to go against what she obviously and with heartfelt meaning wanted.

The CHAIR: That must have been an incredibly difficult four days, Mr Philip.

Mr PHILIP: It was not good. I had a lot of help from other people. It was not just me. Through the first night, I was sleeping next to her, just waiting for her to stop breathing.

The CHAIR: At the end of your wife's life, you had, was it, the Silver Chain home palliative care service?

Mr PHILIP: Yes.

The CHAIR: They at no point put your wife into a deep sedation?

Mr PHILIP: No.

The CHAIR: They could not manage that?

Mr PHILIP: No, they would not. I asked them to.

The CHAIR: They would not?

Mr PHILIP: Two of the doctors attended her at different stages—two of the specialist palliative care doctors. They both said, "The sedation will be increased as we think", but she was never in such a state of sedation that she was unaware, at least at a visceral level, of what was happening to her.

The CHAIR: So she was never comfortable at that end?

Mr PHILIP: No.

The CHAIR: Do you know what the medications were that they used at the end of her life?

Mr PHILIP: The main one was Dilaudid, which is a hydromorphone hydrochloride. I believe it is around about eight times stronger than oxycodone or morphine. She started off on six milligrams a day of that on 27 December and she was on 60 milligrams a day on 7 January when she died, and it was not enough.

Hon ROBIN CHAPPLE: I am going to call you Bill. Thanks, Bill.

Mr PHILIP: Please do.

Hon ROBIN CHAPPLE: There are quite a number of questions I have arising out of this. I feel very sorry for what you and your wife had to go through. When did palliative care actually start?

Mr PHILIP: From memory, sometime around about the middle of October.

Hon ROBIN CHAPPLE: So that was how long before your wife passed?

Mr PHILIP: She died on 7 January, so two and a half months.

Hon ROBIN CHAPPLE: Do you know who provided the palliative care?

Mr PHILIP: Do you mean who organised it or where the palliative care came from?

Hon ROBIN CHAPPLE: Where they came from.

Mr PHILIP: It came from the Silver Chain palliative care people.

Hon ROBIN CHAPPLE: Visits were quite regular and they could be called in whenever the situation got really bad?

Mr PHILIP: They could be called in, and they were.

Hon ROBIN CHAPPLE: Obviously, we have been out with Silver Chain and we have experienced how good they are in this situation. Was the doctor involved in your wife's case from Silver Chain or was it the normal GP?

Mr PHILIP: No. It was always Silver Chain. The palliative care service comes with doctors.

[2.50 pm]

Hon ROBIN CHAPPLE: It was very interesting what you said earlier on. As somebody who had been in the nursing home business, you referred to the fact that, in the old days, this situation did not occur because a doctor or somebody would actually help the patient pass on peacefully. That is the second time we have heard that from people who have been involved historically.

Mr PHILIP: It is true.

Hon ROBIN CHAPPLE: What do you think changed?

Mr PHILIP: I think that the forces of law and order became obviously more threatening to the doctors than they had felt it previously was, so that the doctors felt that they could not take that step anymore for fear of being prosecuted. That is my own personal opinion. I have a number of friends among the various doctors who attended over the years at the nursing homes with which I have been involved and I have never talked it through with them, but my understanding was it got too bloody scary.

Hon ROBIN CHAPPLE: The doctors from Silver Chain who were treating you—I do not want to be ageist here because I am an old fellow —

Mr PHILIP: Not so much as me.

Hon ROBIN CHAPPLE: Yes, about the same, I think. Were they younger doctors, newer doctors or were they older?

Mr PHILIP: I would say 40s to 50s, give or take.

Hon ROBIN CHAPPLE: So they were experienced doctors?

Mr PHILIP: Yes, and extremely competent too.

Hon ROBIN CHAPPLE: We have heard anecdotally that younger doctors are more imbibed with the whole idea of keeping people alive, whereas older doctors tend to be more mature and circumspect around the issue.

Mr PHILIP: When she went to hospital at the end of the suicide attempt, when I got her to hospital in 2014, there was certainly an attitude of "why the hell had things gone that far" among the doctors in the emergency department. They referred the Peel and Rockingham community psychiatric service to her. She was visited for about six months after the suicide attempt by, I think, a psychiatrist, a psychologist and a mental health nurse on each occasion. I think they paid about three or four visits. Basically, I do not think any of them felt that there was any concern as to whether my wife was sane or sensible. They used to spend most of the time laughing with her because she could tell a damn good story. They certainly were not going away thinking, "This one's one we've got to lock up" or some such.

Mr S.A. MILLMAN: Just on that last point, Mr Philip, you talked in your opening statement about some criticism that was made of your wife for not having an advance health directive and then there was the debate that you had with the doctor about the readmission to hospital. Was there an understanding from those medical practitioners of that 2014 history when your wife had attempted suicide and all the intervention that she had received after that? Was that somewhere in the medical records or was that carried through?

Mr PHILIP: My understanding is that all the intervention in terms of the Peel and Rockingham community health service and, for that matter, the police was documented in the emergency department's notes, but I was not privy to those. Does that answer your question or is there something I have missed there?

Mr S.A. MILLMAN: Maybe I can try to explain what I am trying to get at, and I will ask another question before I get back there. Had you and your wife discussed your attitudes to voluntary euthanasia or heroic intervention in the final stages of life?

Mr PHILIP: Absolutely—over the years, not just when she was sick.

Mr S.A. MILLMAN: Just in terms of how that was conveyed to the medical practitioners who were attending on her, what I am trying to understand is whether or not there was an understanding of the fact that she had made an attempt to commit suicide in 2014, that you were reluctant to have her readmitted to hospital, and that there was a context in which she would be more than happy to pass away in the ordinary course without additional intervention, and whether or not the people who were treating her medically appreciated that?

Mr PHILIP: One of the mistakes I made along the track and she made was that I was not aware until 2014 of the need for an advance health directive. Part of the reason for that was that my mother died in Melbourne in 2008, having had a stroke and being in a fairly substantial coma. My two brothers and I sat down with the people who were running Monash Medical Centre's whatever ward she was in and discussed her condition and the fact that she did not have a swallowing reflex and that she was not responding to any kind of stimuli, she was being fed with a tube and hydrated with a tube and she had a catheter in. We said, "Why are you doing that?" and they said, "We've got to do that unless we're told otherwise." My brothers and I all said jointly, "Take it out; stop. Keep her pain-free and keep her from being frightened", and they did. Simple; great. She died about five days later and she died as she wanted to die. She had made that abundantly clear to her sons with words along the lines of, "If you don't make sure that I get looked after like that, I'll come back and haunt you." My mother was a very determined character; you would not want to have her on your case! I discussed with my wife after the suicide attempt that she should fill in one of these advance health directives and she said, "You can always speak for me and you can run the show; you don't need that." I could not really argue in terms of the experience in Victoria where they had said, "Okay; fine. No problem."

Mr S.A. MILLMAN: But your experience in WA was different?

Mr PHILIP: My experience in WA was unfortunately very different.

Hon NICK GOIRAN: Mr Philip, after 7 January last year, did you hear from Silver Chain at all?

Mr PHILIP: Yes.

Hon NICK GOIRAN: Can you just indicate how many times and what was the nature of those conversations?

Mr PHILIP: I received about three or four visits and some phone calls, some written material in the mail and then follow-up calls about that, and a card on the anniversary of her death this year.

Hon NICK GOIRAN: In any of that interaction those three or four times was there any request by Silver Chain for, if you like, feedback about their service and what your experience had been?

Mr PHILIP: I am sure I have given them feedback. I am a little bit hazy about some of the details there. I certainly was extremely pleased with all the intervention they did. As I said, it was just not quite enough. I have no comment other than praise for the workers of Silver Chain or the underlying philosophy. As far as I can determine, it certainly seems to be pointing in the right direction in terms of ameliorating suffering.

Hon NICK GOIRAN: Was that feedback that you would have given them feedback that you would have volunteered? As best as you can recall, did they specifically ask you?

Mr PHILIP: Among other things, I wrote to the head of Silver Chain without being asked.

Mr J.E. McGRATH: Thanks, Mr Philip. You said in your submission —

> I do not advocate the widespread use of suicide as being relevant to all older people.

This committee has had a number of people come in with all kinds of suggestions about what the government might be able to do to assist people. Most have been for people at the end of life, like your wife's situation—very close to the end of life. Others have suggested broadening the scope to people with no quality of life or due to some situation. Would your suggestion be that anything that was introduced by the government should be restricted to people at the end of life or would you agree that it could be made more widespread?

[3.00 pm]

Mr PHILIP: My own personal view, which I would not want to inflict on other people, is that it should be kept as tight as possible to people in a situation where there is no help other than to help them die. I get offended with, I think, the argument that it is God's will and leave it to God, but I do not believe it is my choice to say what happens to somebody in a situation other than that which I am discussing now.

Mr J.E. McGRATH: If someone had a degenerative disease that was not instantly life threatening but they had lost their quality of life as that disease became progressively worse, would you think that if they were of sound mind, they should have that option to say, "I don't want to continue"?

Mr PHILIP: Yes. They should have that option, but under no circumstances should there be any kind of, "You're doing the right thing by knocking yourself off, so let's go", nobody offering a little bit of assistance and a push towards making that decision. I had a friend who was a doctor, and a damn good doctor, who died of motor neurone disease about 20 years ago. He would have had any number of different ways of ending his life and he chose not to. I feel that that was a reasonable choice for him. I think motor neurone disease is possibly the number one way I do not want to die.

Hon COLIN HOLT: Thanks for coming in, Bill. I have a question for you for a bit of clarification. Your wife got diagnosed in March 2014 and then quite quickly got her affairs in order and attempted to take her own life?

Mr PHILIP: Yes.

Hon COLIN HOLT: Afterwards, she had some quality of life by the sounds of things, obviously with visiting psychiatrists and actually had some good times after it.

Mr PHILIP: Yes, she did. In fact, in June 2016, we travelled on a ship to Bali and Lombok and places like that. She had a very good trip.

Hon COLIN HOLT: What was it that triggered the suicide attempt? Was it just the fear of the end? What was it that got her to the point of taking such drastic action so quickly after the diagnosis? Are you able to tell us?

Mr PHILIP: Yes; she did not stuff around when it came to making a decision. She was brave enough and tough enough to follow through on it. I was not terribly pleased about it. I did not think that it was time to do that, but I was not going to resist her. I loved her. She was my wife for a long time. We went through a lot together. We had two of our kids killed. We have a drug addict as a third child. There was an awful lot of stuff in there. She said, "Enough".

Hon Dr SALLY TALBOT: Bill, if we were living in Victoria currently and your wife was diagnosed with the condition that she was diagnosed with in 2016 —

Mr PHILIP: 2014.

Hon Dr SALLY TALBOT: Yes, 2014. In Victoria, as you probably know, there is a new law that says you can access voluntary assisted dying if you have a diagnosis that says that you are likely to die in

six months, or, in some conditions, 12 months. Do you think that your wife would have wanted to access that option?

Mr PHILIP: I am sure she would. Unfortunately, the Victorians also had a 12-month qualification period. While I was born and brought up in Victoria, I do not think I could con her into thinking that she had been there then.

Hon Dr SALLY TALBOT: The other part of that equation, apart from the diagnosis and the time line, is that you have decision-making capacity. I think from part of your story, shortly before her death, it sounds as if your wife might have lost that.

Mr PHILIP: She lost the capacity by the beginning of December. When I say "lost the capacity", she lost the capacity to communicate. I think she had had a series of minor strokes. She could still swallow; she could still eat; and her eyes followed you; but she could not in any way meaningfully hold a conversation or indicate yes, no or anything, but she had made very clear for a long time before that that what she wanted to happen was she wanted to die.

Hon Dr SALLY TALBOT: It was just a matter of weeks before she died that she lost that capacity to make decisions?

Mr PHILIP: That is correct. I think an advance health directive or some similar thing saying, "When I've lost that capacity, if I'm in a terminal situation, I want to die." I think about the right time would have been somewhere between the middle of December and the end of her life. But I would plumb towards the middle of December end of it because everything in terms of independence, dignity, any kind of stimulus that was enjoyable had gone by then.

The CHAIR: Mr Philip, thank you very much for your evidence today. A transcript of the hearing will be forwarded to you for correction of transcribing errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached. If it 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.

We really appreciate you coming to share your experience with us today, Mr Philip; it is very important

Mr PHILIP: Thank you very much for giving me the opportunity. I made a late submission. I was not expecting to get anywhere with it, but I am not terribly well organised. My wife was much better at that than me.

The CHAIR: We are very glad you did. Thank you very much.

Mr PHILIP: I appreciate the opportunity and I also appreciate the gravity of the work you have to do because there are so many different opinions on this. I hate the idea of inflicting my opinion on anyone but I really feel you needed to hear that story and I thank you for listening.

Hearing concluded at 3.06 pm

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