

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 ALBANY
WEDNESDAY, 7 MARCH 2018**

SESSION FOUR

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 2.24 pm**Ms JENNY RICKERBY****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 inquiry. My name is Amber-Jade Sanderson and I am the Chair of the joint select committee. We have Hon Nick Goiran; Mr John McGrath; Hon Colin Holt; Mr Reece Whitby; Dr Jeannine Purdy, our principal research officer; Hon Robin Chapple; Hon Dr Sally Talbot; and Mr Simon Millman. It is important that 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, this privilege does not apply to anything you might say outside of today's proceedings. Please be advised that the committee may decide to go into closed session, depending on the nature of your evidence, and you are welcome to request to provide closed evidence at any stage.

Before we begin with our questions, do you have any questions about your attendance here?

Ms RICKERBY: No.

The CHAIR: We have allowed around 25 minutes to half an hour today for this hearing and I am happy to invite you to make some opening remarks if you would like.

Ms RICKERBY: Did you all know what I had to say?

The CHAIR: We have a summary from your conversation with Lorraine, but why don't you give it to us in your own words.

Ms RICKERBY: I suppose I am here really to maybe represent my mum and my dad and, when I thought about afterwards, my husband, because he was on life support and I turned it off. I have not mentioned that before. He had an accident and I know damn well that if he had had a choice, that is what he would have wanted. It is basically what both my mum and my dad might have wanted.

Mum had breast cancer, but she had so many allergies, she was allergic to so many foods and medications, that in the end to take medication, morphine, just made her violently ill, but in the end she had to take it. They had her on anti-nausea drugs which also made her feel a bit crook. My sister is here, all the family are here; we were all with mum at certain stages and mum certainly would have, maybe, given the opportunity, taken her own life, put herself out of misery. She did have an advance health directive and I was really, really interested to hear what the previous lady was saying about that, because I feel it is really important and, yes, definitely more information should be put out there. Mum's health directive she did through a lawyer and she had actually put on there that she did not want pain relief, so when she first went into hospice, she was there for a whole month. For the first two weeks, she was refusing it and then when it got so bad—I mean it was awful—she had to change her health directive, and thank goodness she was still of sound enough mind to be able to do it. If those sort of things are put out there, I think those things need to be explained really well to people, because I have made one myself and I have done exactly the same thing—no pain relief—and I must go and change it, even though I have not got around to doing it, but it is really important. You were talking about the health register, how you collate all that information when they are made, I am not sure, but anyhow that is another thing. So, that was my mum.

My dad, he was always very pragmatic about life and he always felt that if you not worth anything, you might as well just not be on earth. When he got crook, he had cancer as well and then had an operation and got an infection and when he got the infection, he said, "I don't want to be here", sort of thing. Even though he had further radiation treatment and it burnt his face and he could not eat—it was just awful and that is another area that needs to be looked into, really; what happened to dad. He got to the stage at which he could not eat because his mouth and everything was so badly burnt that when Vicki and I went up to hospital to see him, because he was in Perth at that time, we walked in the room and we did not even recognise my dad. We just walked back out again; that is how bad it was. Nobody at the radiation clinic was doing anything about it. They were just continuing to give him radiation and there was no asking him how he felt, if he was eating or anything, because, obviously, the cancer ward there just have not got enough funding, staffing or whatever to look after people. Dad was not one to complain. I mean, both he and mum both walked all the way from Crawford Lodge to the cancer thing every day. They were in their 80s. So, dad got to the stage he went to Bethesda and all he wanted to do was die, so he basically started to heal up, but he basically refused to eat and drink. He just starved himself to death and he made a comment that his dad only took four days to die, but it took dad nearly two weeks, and he would have, definitely.

The CHAIR: This is very difficult. Can you describe that two weeks for us?

[2.30 pm]

Ms RICKERBY: He was just basically lying in bed. He ended up eating like a little bit of ice cream because it was nice on his mouth, things like that. It was really great because he was actually in hospital until he went to Bethesda, he was only moved there within the last week, when it was obvious he was not going to—he had counselling, of course, with the chaplain. But in all honesty, just at the beginning of the last two weeks, he had the opportunity to see all his family, all his grandchildren and everything like that. Everyone in the family knew what dad's stance was on it and dad just did not want to be here anymore because he felt he was not of any use to anyone and he also had further cancer. He did not want to go through what he saw mum, his wife, go through, so he just gave up. It was lovely that he had that opportunity with all the grandchildren and his family to basically say goodbye. The whole family was very supportive of dad. It is not until you actually see someone go through it yourself, the whole family do, and accept what that person is saying to them that they do not want to be here and why should I be here and why cannot I just go? All my kids and Vicki's and my other sister's children were all of the same mould. We all believe the same thing now; that somebody should have that choice. I believe if dad had had a button he was capable of pushing to inject himself, he would have done it. As to whether he might have done it maybe too early for everybody or whatever, I mean nobody knows what a person is going to keep on going through as time goes by. But it is his decision, it is his life.

When mum was really crook—do you mind if I read you this?—I wrote a little thing that was published in *The Sunday Times*. This is how I felt. Mum gave her permission for me to put it in. I called it "Shame". I said, "Shame on all you good doers out there who think you have the God-given right to say how a person should die. We have no say about who our parents are; we do have a say as to what we become. Then we are told by strangers how we should die. My beautiful mum, with my dad, has raised a wonderful family with children, grandchildren and great-grandchildren, and they all love her. My beautiful, independent, strong, self-sufficient, creative, wise, intelligent mum is now being told by the law that she has to die a slow and painful death. Mum has many allergies and one is to medication. Mum has cancer and at the age of 82 walked twice daily to the radiation clinic enduring treatment twice a day. Four months later, she had radiation treatment again. She could only tolerate a small amount of chemo. Unfortunately, the radiation treatment didn't work. Two months later, the cancer was in mum's bones. Mum has now fought pain that most

could not tolerate until it became so bad she had to take more morphine, which she's allergic to. Now she lies in bed virtually motionless as any movement causes her to be in chronic pain and violently ill. Even though drug induced, mum's brain is still coherent. She has trouble speaking, putting food in her mouth and going to the toilet and she is in pain. What right does anyone have to dictate to my gorgeous, intelligent mum that she has to live like this just waiting for some part of her body to stop functioning so she can die? How can this be right? My mum wishes to die with dignity and no pain. What mum is being put through is bureaucratic torture." That is how we all felt.

The CHAIR: Thank you, Mrs Rickerby, for those accounts. It is really important that we hear directly from people who have experienced this. I just want to go to the example you gave around your father. Your dad made a decision while he was in hospital. Did he have full decision-making capacity when he made that decision to stop eating and drinking?

Ms RICKERBY: Absolutely.

The CHAIR: And then he was moved to hospice—is that right?

Ms RICKERBY: Yes.

The CHAIR: Did the hospice support his decision to stop eating and drinking?

Ms RICKERBY: Well, they always offered like a little meal or anything like that, but they did not force him to eat.

The CHAIR: Did they provide him with sedatives and other pain-relieving medication in those last days?

Ms RICKERBY: Yes, they did.

Hon ROBIN CHAPPLE: Just as a supplementary to that, obviously, when you stop eating and drinking, your throat and mouth gets very dry. Were they facilitating that dryness and helping him out?

Ms RICKERBY: Yes, he was given a little bit of ice, but initially when his mouth was all burnt et cetera, he could not swallow and he could not drink because it was too painful. It was not until such time as when it started to heal that he was able to start eating and drinking a little bit more, but he had already made the decision that he just did not want to be here. He was very, very dehydrated.

The CHAIR: With regard to your mum, we have heard evidence from surveys and also practitioners that palliative care pain relief does not work for around one to possibly five per cent of patients. It sounds like your mum was possibly in that category.

Ms RICKERBY: When they started giving her morphine, that actually helped her pain.

The CHAIR: It did work. But she had an intolerance to it, the side effects, was that nausea?

Ms RICKERBY: Absolutely, very sick.

Hon ROBIN CHAPPLE: When they gave her the anti-nausea medicine, did that help or did that create other problems?

Ms RICKERBY: No, it seemed to help a bit. She was still in a little bit of pain, but not to the same degree as to what she was previous. I think also probably what happened is in her own mind she started to accept that she was actually going to die. We believe she really did not want to, she still had so much to give; she was amazing. I do not know. I just know that on her birthday—she died three days after her birthday—she actually had chocolate cake, which she had not eaten for 15 years because she could not, she was allergic to it. She was allergic to so many things it was not funny.

The CHAIR: Did they live locally?

Ms RICKERBY: Mum, yes.

The CHAIR: So they had to go to Perth to travel?

Ms RICKERBY: Mum was in hospice down here and dad was up in Perth, because he was actually in Perth having the radiation treatment and then they put him into Bethesda there, rather than come back down here. It was easier and better for dad, and my other sister lives in Perth so he had family up there as well.

Mr J.E. McGRATH: You talked about your husband and you said he was on life support and you actually turned it off.

Ms RICKERBY: I gave permission, yes. It was in Thailand.

Mr J.E. McGRATH: Can you tell us what the circumstance was, what his illness was?

Ms RICKERBY: He had a motorbike injury; it was a head injury. He was actually in Koh Samui. He was actually under the care of probably one of the top three brain surgeons in the world.

Mr J.E. McGRATH: It was a situation that he was not going to recover from.

Ms RICKERBY: Absolutely no way, and he would not have wanted to keep going as somebody who is totally incapacitated and just being kept alive on breathing facilities et cetera. That is one question I have. My mum and dad were totally coherent, but what happens to somebody when they have an accident and they are incapacitated and they cannot say what they want, who makes the decision for them? I appreciate the closest family certainly do, but there is no facility for that decision, probably, maybe to be made, to have that end-of-life choice. The family make it for that person.

Mr J.E. McGRATH: But in that circumstance you would like to think that someone like yourself could make that choice on behalf of your husband?

Ms RICKERBY: Exactly. I did not make the choice myself; my children were there too. It was a family decision and that is the way it has got to be, I feel.

Hon Dr SALLY TALBOT: That was an incredibly moving story about your parents, Ms Rickerby. I really admire you; you have become a warrior for the cause. I do not know whether you set out to be one, but you are certainly right up there leading the argument for change and I really respect that.

You highlighted a couple of the intrinsic problems with advance health directives. We have now heard dozens and dozens of hours of evidence about this matter. The problem that both your parents had, I think, was that their advance health directive was not entirely relevant to the situation they ended up in. Would that be true? I think you said that your mum said no pain relief.

[2.40 pm]

Ms RICKERBY: Correct, and dad did not have one, but mum certainly did—I do not think dad had one.

Hon Dr SALLY TALBOT: Your lack of certainty about that is one of the points that we raised with you. Many people have suggested to us that there needs to be some kind of central registry so that when you make an AHD, it is lobbed somewhere so that everybody knows you have got one.

Ms RICKERBY: I reckon that is a very good idea, absolutely, yes.

Hon Dr SALLY TALBOT: I wonder also whether you have any general comments. If you were starting from scratch with the AHD form, which you are obviously familiar with, and, as you know, it is pretty well blank, how would you change it?

Ms RICKERBY: I am really sorry, but it is a little while ago since I filled mine out. I honestly do not know. I would actually have to look at the form now.

Hon Dr SALLY TALBOT: Maybe if I give you a couple of ideas that other people have raised with us. At the moment, the form is basically blank. It says, “In the event of X, I consent/or refuse the following treatment”, and then it is blank. Some people have suggested to us that maybe it should be a kind of tick the box of possibilities, in the event of —

Ms RICKERBY: And then also have “Other” down the bottom in case people confuse it, definitely.

Hon Dr SALLY TALBOT: I do not want to press you on it if you have not given much thought to it.

Ms RICKERBY: I have not, really, because basically ours were just, no resuscitation, no drips keeping you alive, no artificial means of keeping you alive.

Hon Dr SALLY TALBOT: And then the regular reviewing of the AHD to make sure that it is still what you want. As you say, if your mum had been past a certain point when she wanted to request pain relief, she may not have been able to do it.

Ms RICKERBY: Exactly. As I said, I have made mine out, and I have not changed it, and it has actually got that on there. I think I made mine out before mum, and I actually spoke to her about it and she —

Hon Dr SALLY TALBOT: You are now on the official parliamentary record as having requested pain relief!

Ms RICKERBY: But who is going to access that information! Sorry. Something went through my mind that I had to tell you. No, I cannot remember what it was.

Mr S.A. MILLMAN: You were talking about the fact that you had made yours out before your mum, I thought.

Ms RICKERBY: Yes, but my brain is like—my filing cabinet is pretty full and things get jumbled up in it.

The CHAIR: I know the feeling! Can I ask—this is a personal question—but did your mum request no pain relief because she was allergic to it?

Ms RICKERBY: Yes.

The CHAIR: Can I ask why you have requested the same thing?

Ms RICKERBY: I have absolutely no idea! It would probably be because I did not really honestly know what I was doing—ignorance.

The CHAIR: But having seen your parents go through that journey you now—your thinking has shifted?

Ms RICKERBY: Oh my gosh, yes. Next week when I get time, I will go and change it!

The CHAIR: Good idea!

Hon Dr SALLY TALBOT: But you will leave the other provisions?

Ms RICKERBY: No resuscitation—yes, definitely.

The CHAIR: If a framework were to be introduced, as legislators, which allowed for people to access some sort of voluntary assisted dying program, for want of a better word, who should not be eligible?

Ms RICKERBY: Can you say that again? Sorry.

The CHAIR: I guess what I am trying to get at is safeguards. Who should not be able to access a voluntary assisted framework?

Mr J.E. McGRATH: For a start, maybe those who do not want it! They would be the first, would they not?

Ms RICKERBY: Absolutely.

Mr R.R. WHITBY: I mean people whether they have a terminal disease or they do not, or whether they have a sound mind or they do not?

The CHAIR: We have had some evidence from seniors who are advocating for a position that they have gotten towards the end of their useful life, as they see it, and they are running out of means and they are disconnected from the community, and then there are those who advocate for those with terminal or chronic illness who have an imminent end of life.

Ms RICKERBY: Well, certainly those with a terminal illness should definitely have access. As to who not, as you say, those who do not want it.

The CHAIR: You do not have to answer it. That is for us to answer.

Ms RICKERBY: It is a pretty big question and it is not one I take lightly. I would have to really think about that.

Mr J.E. McGRATH: I think the point the Chair was making is that if you get to a stage of life and you are old and you do not have any friends anymore, they have all gone, you still do not have a disease or anything, but you would rather not be here, should those people be given that opportunity or would they need to have some reason —

Ms RICKERBY: It is their life. I reckon everybody should be in control of their life and it is their choice, regardless also, to a degree, whether they have family or not. It is their life. Why should someone else dictate what they do? It is like suicide. That is basically what it is. I have an uncle who committed suicide. He was aged probably early 60s. He had a medical condition. It was not that bad, but he was quite depressed, I think; in the end and he shot himself. That was his choice, and as his sister, my auntie, said, he was a very brave man to be able to do that. He did not want to be here anymore. It was sad for everybody else around, but it was his life. I really believe that people have that choice. Then you get into the younger areas as well, like children. I have just had a friend whose son committed suicide. That must be absolutely dreadful. But does that mean that they should also have the right to have that choice to take their own life? It is a big question. I do not know how to answer it—nobody does. Sorry.

Hon NICK GOIRAN: Mrs Rickerby, thanks for coming today. One of the difficulties for the committee has been to get this information out into the community. Believe it or not, not everyone follows closely what happens in Parliament! In the notes that we were given and in the phone call that you had, you indicated that you were not aware of the inquiry until someone showed you the advertisement.

Ms RICKERBY: Exactly.

Hon NICK GOIRAN: Was it just a friend who showed you the advertisement?

Ms RICKERBY: Yes, a friend who knew my mum very well. He knew how I felt about it, so he just sent me a photo in a text, SMS, and I put it on—that is what I wanted to say before—my Facebook page. I actually put it around the wrong way because I could not turn it over—I am really not very good—and I had three people who said, “Jen, can you turn it around, please.” So I am sure that there are a couple of people here who would have rung up to participate because of that, for sure. I did not know that the committee had been set up. My sister in Perth, she is very closely associated in government and all that sort of things, and she did not even know it had been set up. It was very quiet.

The CHAIR: Interesting. Mrs Rickerby, thank you very much for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. 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 of evidence. Thank you very much for your time today. It was really important evidence, sharing your personal experience with us. We really appreciate it.

Ms RICKERBY: I wish you all luck. You have got a hard job.

The CHAIR: Thank you.

Hearing concluded at 2.48 pm
