

# **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 FIVE**

## **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 2.51 pm****Ms MARIJA ROSA****Private Citizen, examined:**

**The CHAIR:** On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; 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. We have Hansard here recording proceedings for the Parliament. 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 that you might say outside 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, do you have any questions about your attendance today?

**Ms ROSA:** No, I just want to say thank you for allowing me to appear.

**The CHAIR:** It is a pleasure.

**Ms ROSA:** I have never done anything like this before, so if I stuff up, please take that into account!

**The CHAIR:** There are no right or wrong answers!

We have allowed around half an hour, so I will just invite you to make some opening remarks.

**Ms ROSA:** I was going to say I would prefer for you to ask questions and I will answer them.

**The CHAIR:** Okay. Obviously, you registered an interest in appearing before the committee, so what is it that you want us to take away from your evidence today?

**Ms ROSA:** I think everybody has the right to be heard, for starters, and everybody has the right to make their own choices. That is it, in a nutshell.

**Mr R.R. WHITBY:** What personal experience have you had, Ms Rosa? Have you had loved ones confront this end-of-life decision, and what impact did it have on you?

**Ms ROSA:** I am getting emotional now. I had 24 members of my family pass in one year—that is, extended family—so I was confronted with that quite often, in different scenarios. What was poignant for me was my younger sister. It was obvious that she needed help and she was not getting it. I came from WA and I told her that if she needed me, just call—that is all she had to say. I said, "If you need me, I'll come", and she did.

**Mr R.R. WHITBY:** Where did she live, sorry?

**Ms ROSA:** Pardon?

**Mr R.R. WHITBY:** She was interstate, was she?

**Ms ROSA:** She was in New South Wales.

**Mr R.R. WHITBY:** Right.

**Ms ROSA:** When I got there—I did not go to look after her because I could not look after myself, let alone to nurse her and come to her, but to find the help that she needed was virtually impossible

because I was given the run-around. The numbers you were told, we were just getting passed around, passed around and passed around until I came to the end of my tether and said, “I’ve got two numbers left that I can possibly think of.” One of her daughters came in and I said, “Take this; I can’t deal with this anymore. Not just now, anyway.” She finally got through to somebody to come and see her. Then, after more rigmarole—months of rigmarole—she was finally told that she could receive palliative care but it never happened because she passed away before that could eventuate. To me, the whole process was prolonged needlessly. I am going to say that I have obviously had to face this for myself and to find that form, that directive—I could not find it. I do not even know where I expect it to be now, but I know I went to a number of places to find it and I could not find it. I finally found it, but it was no good to me in my state, the state I was in or am in.

**Mr R.R. WHITBY:** Is it a difficult document to navigate, to fill out?

**Ms ROSA:** I did not bring your form because, obviously, I am thinking you would be familiar with it, but because I had a copy of my sister’s, I crossed it all out. I found that very hard to navigate as well. The print is too small; it is too complicated. There were two lots of forms. You had to go from here to there, to here to there, and it is just my concentration—I am sure for a lot of other people, it would be the same; you just cannot do that. So to my mind, it needs to be simple, big print. I have done my own amalgamation, if you like, and I would like you to take that, if you would.

**Mr R.R. WHITBY:** Thank you.

**The CHAIR:** Thank you.

**Ms ROSA:** You can put your own ideas to it, but thank you all, because you have made me sit down and actually tackle it. I have not done anything about it, except I told one of my sons and my niece, “This is what I want and you”—not my son, but my niece—“will be the one to make sure it happens.”

**Hon COLIN HOLT:** Have you registered with your GP? Did you go and see your doctor —

**Ms ROSA:** I told her, but that is as far as it has gone. Like I said, I have not filled this form in.

**Mr R.R. WHITBY:** So it is a verbal instruction?

**Ms ROSA:** Verbal, yes.

**The CHAIR:** Just bear in mind, we can stop the hearing at any time, Ms Rosa; you just let me know. You have not filled in the health directive, but you have given verbal instruction?

[3.00 pm]

**Ms ROSA:** We laugh about it. I do not know what it was, but I sat down at the telly one day and I saw this program. It was a man at the piano with a puppet. It was singing this ridiculous song about all the problems you are faced with in life. It just went on and on and on. But at the end it was, “You’re not going to worry about it when you die, so why worry now?” It just cracked me up. I was going through a lot of issues myself. I told son about it. He rings me up every now and then and he says, “Mum, you’re going to die!”, and I laugh because why worry about it. Okay; we have to take steps et cetera, but a lot of issues are small. They are not worth worrying about. I can still laugh.

**Mr J.E. McGRATH:** How is your general health now? Obviously mobility is a bit of a problem, but you look in pretty good shape.

**Ms ROSA:** That is what a lot of people say, but you do not see me when I am at home. My taxidivers know more about me than anybody. They hear me crying. I am not going to go into my health problems, but looks can be very deceiving.

**The CHAIR:** Ms Rosa, I understand you obviously spent some time in New South Wales with your sister. Have you had experience of palliative care in Western Australia?

**Ms ROSA:** Palliative care?

**The CHAIR:** Yes.

**Ms ROSA:** Not for myself, no.

**The CHAIR:** Or for family members?

**Ms ROSA:** Because most of my family members are in New South Wales.

**The CHAIR:** Are in New South Wales? Yes.

**Ms ROSA:** I think there is an expectation that if you have family around you—I do not have any—family will fit the bill. They will not necessarily be there, for their own personal reasons—whatever they are—maybe they just cannot face what is going on.

**The CHAIR:** Do you think palliative care would be appropriate for you at your end-of-life stages?

**Ms ROSA:** It depends what you mean by palliative care. Yes, but not to prolong my life. It depends on the situation. Of course, you do not know what you are going to face, but I do not personally wish to be here just to prolong my life. I personally believe in quality of life, rather than longevity. That is going to be different for every person. What their limits are is theirs. It is not yours; it is not mine. Thinking of that, I have seen people commit suicide because they have come to the end of their tether. They have had enough; they cannot deal with anymore. “Whatever that law is, that’s it; I’m done”, and so they have committed suicide. But what is sad about that is that they have had to hide their feelings and their intentions for fear that their loved ones would be dragged into some mess that they did not create, and I do not think that is right either.

**Hon Dr SALLY TALBOT:** Ms Rosa, do you get any sort of home care from any health professionals at home?

**Ms ROSA:** I have been—can I say this? After I think 2015, I was granted level 3, and then things changed; I do not now understand all that. So I did not receive it, then things changed and I finally was given level 3 funding in the middle of November. I still have not received it.

**The CHAIR:** For a home care package?

**Ms ROSA:** For a home care package, yes. I was getting level 2, but it is an upgrade.

**The CHAIR:** Yes.

**Hon Dr SALLY TALBOT:** Do you know why it is taking so long?

**Ms ROSA:** No, but that is a big issue for everybody, I am sure. It is like, “I need this help now.”

**Hon Dr SALLY TALBOT:** Yes.

**Ms ROSA:** I need this help now, and I know that there is limited funding and we need more staff. But you have some big issues to grapple with, and I think you need to take the bull by the horns.

**Hon Dr SALLY TALBOT:** You have a couple of local members here in the room, so we might come and have a talk to you after.

**Ms ROSA:** Yes; okay.

**The CHAIR:** Is there anything else you would like us to know, Ms Rosa, in relation to this inquiry?

**Ms ROSA:** No, but I would like to read my statement here.

**The CHAIR:** Yes.

**Ms ROSA:** Basically this is my statement for myself.

**The CHAIR:** Yes.

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**Ms ROSA:** Basically, I want the right to make my own choices about living my life now and on the journey to the final chapter and in due course the end, especially if I am left in a state of lingering ill health, debilitation and dependence on the goodwill of others. Here I wish to state that if it becomes legal and there will be no blame attributed to others who assist me, I wish my life to be ended if there is no hope of recovery and returning health. I wish the right to choose to do this when I deem it right for me. I would prefer to gather my loved ones around me and bid them farewell in a calm and relaxed atmosphere than to linger. A party first, of course! I know of people who have committed suicide because they were in too much pain for them to bear any longer. They had had enough. An ugly, painful solution for everyone concerned. They would have preferred an easy crossing over, end to life, with family and friends, partying, saying goodbye et cetera. Instead, they must hide their feelings and intentions and die alone so that loved ones cannot be prosecuted by the legal system. We are kinder to our pets. It is rather interesting that if we treated our pets this way, we would be prosecuted for cruelty to animals. At the present, I would rather be treated by a vet. Thank you.

**The CHAIR:** Thank you, Ms Rosa. Thank you 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.

**Ms ROSA:** Excuse me. I am not on the internet.

**The CHAIR:** We will post it out to you.

**Ms ROSA:** It might take 10 days to get here. It has happened, I tell you.

**The CHAIR:** We will make allowances.

**Hon Dr SALLY TALBOT:** We will use carrier pigeons!

**The CHAIR:** We will use our discretion.

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. Ms Rosa, thank you very much for taking the time to talk to us today.

**Hearing concluded at 3.08 pm**

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