

# **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 ONE**

### **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 12.30 pm****Mrs KATHLEEN AMY TRENDALL****Senior Citizen, examined:****Mrs PATRICIA MARSHALL****Retired Public Servant, examined:**

**The CHAIR:** Good afternoon, everyone. Welcome to the Albany hearings of the Joint Select Committee on End of Life Choices. This is a public hearing. 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 Hon Nick Goiran; John McGrath; Hon Col Holt; Reece Whitby; Dr Jeannine Purdy, who is our principal research officer; Hon Robin Chapple; Hon Dr Sally Talbot; and 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 that you might say outside today's proceedings. Please be advised the committee may decide to go into closed session, depending on the nature of your evidence, and you are welcome to request a closed session at any stage.

Do either of you have any questions about your attendance today?

**The WITNESSES:** No.

**The CHAIR:** Before we ask questions, did either of you want to make a brief opening statement?

**Mrs MARSHALL:** If I could, please.

**The CHAIR:** Yes, please do.

**Mrs MARSHALL:** First of all, I would like to thank you for allowing us to come and address this committee, because this is an issue which people of our ageing generation have given a great deal of thought to over many years. With that, we have prepared this short statement, which I will give to the committee afterwards—some suggestions for consideration by the committee. The need for laws in Western Australia to allow citizens to make informed decisions regarding their own end-of-life choices is applauded. However, the terms of reference need to be broadened to include the views of articulate seniors who have given serious and considered thought to choices which will most directly affect them in the not-too-distant future. End-of-life choices are not only about pain and terminal illness; the medical model of managing the end of life when experiencing chronic or terminal illness and the role of palliative care is an insufficient model for many seniors. The questions of loss of self-autonomy and human dignity, conscious awareness of physical or mental deterioration and the realisation that meaningful participation in life has come to an end are very important considerations for the elderly and should be included in any discussion of end-of-life choices. The process of ageing brings an increasing awareness of one's own deterioration and detachment from what is perceived as a complete life. It is only when this process is directly experienced that it can be fully understood; therefore, it is necessary for those making decisions to change the law to take some advice from those who may choose a voluntary and dignified end to their life when they perceive it to be complete.

**The CHAIR:** Mrs Trendall, did you have a statement?

**Mrs TRENDALL:** No; it was a joint statement, which we compiled together.

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**The CHAIR:** What has driven you to give evidence today? What is the main point that you would like the committee to take away from your evidence?

**Mrs TRENDALL:** From my point of view, the process of ageing I find fascinating. At the age of 87, I realise that younger members really cannot conceive the process that one goes through as one ages, even if one is fit and healthy, has no pain and takes no medication. It would seem to me that we should be given a choice when we feel that our life is no longer complete, we notice perhaps mental deterioration, or we know that we are going to be dependent on someone else. So I feel that perhaps this should be taken into consideration, and seniors—I do not mean everyone, but perhaps people over 90—should have an option to choose to end their life.

**The CHAIR:** If that option were ever to be available or proposed, what kinds of safeguards do you think would need to be in place?

**Mrs TRENDALL:** Obviously, family would have to be made aware of this. I am not sure. Could you clarify what you mean by “safeguards”?

**The CHAIR:** Who should it not be available for?

**Mrs TRENDALL:** Who should it not be? People who do not want to choose it. I think it is very much an individual choice and I do not think many people would choose, if they were fit and perhaps, as I say, not in pain or terminal, or would even want the option. But there is a percentage in our society who perhaps think that way.

**Hon COLIN HOLT:** What about the risk of coercion or family pressure? How would you manage that?

**Mrs TRENDALL:** I find that an interesting thing in view of the current abuse of the elderly. My personal feeling is that the elderly, if they are being abused or coerced, would in fact be so disillusioned, particularly if this were family members, that they would actually welcome an end to their life.

**Mrs MARSHALL:** Could I say something to that as well?

**The CHAIR:** Yes.

**Mrs MARSHALL:** Whenever this question has been discussed in the past, this question always comes up: what about the unscrupulous children putting pressure on the parents? I think, and certainly in my own case, we do make provision. You can make a statutory declaration with legal things to say this is what you want at the end. Those of us who think about this make our views very clear to our children that when it comes to the end, we do not want to linger on in the palliative care unit, just waiting for the end. I think when you have made that—it used to be called a living will; I think that concept has been overturned now by other things—clear declaration when you still have control of your faculties which has been legally notarised, it would be sufficient. But I agree with Kathleen that when you reach that stage, when you feel that you are being abused—remember, when elderly people are abused, they often feel that they are not able to speak up because the people who are doing the abusing are often their nearest and dearest —

**Mr J.E. McGRATH:** Could I ask you, Mrs Marshall, how old you are?

**Mrs MARSHALL:** Seventy-seven.

**The CHAIR:** A large part of the inquiry is also looking at the role of palliative care. Have you supported someone through palliative care yourselves?

**The WITNESSES:** Yes.

**The CHAIR:** Do you think it is adequate? Was it an adequate support for your family member or loved one?

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**Mrs TRENDALL:** Yes, I think palliative care is adequate for those who choose to end their life by going into palliative care. It is very good, yes.

**Mrs MARSHALL:** I nursed my own mother. She kept all her faculties and her physical capacities right until she was 96, but she did go to the stage where she was tired. She used to say, “I’ve been here long enough. I’m tired; I want to go.” Unfortunately, towards the end she started to get problems with her lungs, but we did have excellent domiciliary nursing assistants, which came via Silver Chain, who came to the house and who helped us to nurse mother at home so she was saved from having to go into care at the end. So she was in fact able to die at home with her family, and that, I think, is something that we would all wish at the end.

[12.40 pm]

**The CHAIR:** Yes, certainly we have had evidence that most people would prefer to die at home. Do you think that is a viable option for this region?

**Mrs TRENDALL:** Yes. I nursed my husband at home with the aid of palliative care nurses and it was what he wanted. I think it is an excellent choice if that is your choice.

**Mr R.R. WHITBY:** Ladies, whenever anyone raises this issue, it is quite contentious, as I am sure you understand. People have religious convictions and moral convictions, and I guess it is up to everyone to make their decision on what they would do. So, as a committee we are looking at what options should be available to people with different viewpoints. What would you say to the people who have a different view—a view that this should never be contemplated? What would you say to them?

**Mrs MARSHALL:** I would say, “That is your view and if you have religious or moral convictions that support the continuation of life at whatever cost—fine, you do it. But that is not my view and I shouldn’t be bound by the religious or moral views of other people.”

**Mrs TRENDALL:** Yes. I would have thought that the inquiry was to make laws for individuals regardless of their faith or views. Each individual is an independent person and as long as their choice of an end does not in any way impose on any other person, I do not see that there need be any controversy.

**Mr R.R. WHITBY:** I know that there is quite a population of retirees in Albany, so I guess anecdotally this is an issue that gets discussed a fair amount in the great southern.

**Mrs MARSHALL:** In considerable detail and frequently! Because when you are —

**Mr R.R. WHITBY:** So we have come to the right place!

**Mrs MARSHALL:** You have come to the right place because you get to an age where you have not got many more years left and you start to think, “I’ve done everything useful in my life that I’m ever going to do and I’m eking out the rest of my life on whatever small amount of capital I have been able to accumulate.” Then there is ill health, and I think one does perceive one’s own mental capacity deteriorating. When you start to think, “How much longer am I going to go on?” and then, “What will end when I can no longer control my bodily functions, my finances, my social life?”

**Hon ROBIN CHAPPLE:** You mentioned an important word there—“capacity”. We talk about informed decision-making. Is there a place for assessing the capacity of a person to make that informed decision—that is, if you wish to go down a process of hastening your end and you are giving that indication to others? We need to be able to test capacity; what you think we need to do around that?

**Mrs MARSHALL:** What do you mean we have to test it? Surely one would know—well, one might say one would know. I mean, I am aware already—and I am not as old as perhaps some of my

contemporaries—now that I am losing my capacity for language, for rational thought and comprehension. You perceive this yourself, over time.

**Hon ROBIN CHAPPLE:** Okay, so if you were to go down this path, would you say you would have the mental capacity to make an informed judgement at this stage?

**Mrs MARSHALL:** I hope so.

**Hon ROBIN CHAPPLE:** Do you think there is a stage where you may not have that capacity?

**Mrs MARSHALL:** You might not, but of course, that is the point at which you have to go, isn't it?

**Hon ROBIN CHAPPLE:** Okay!

**Mrs MARSHALL:** Well, I believe that. I do not expect anyone else to believe it, but of the people that I speak to, you would be astonished how many people in their 70s and 80s are hoarding up their OxyContin, their sleeping tablets and all the other stuff for when they might need them. I think we have to be very careful about this because we do not want to implicate our GPs who might have prescribed these drugs at some time or another.

**Mr R.R. WHITBY:** Have there been deaths that have been brought on because of stockpiling of drugs or other actions in Albany, do you think? Have people actually taken those steps?

**Mrs MARSHALL:** Yes.

**Mr R.R. WHITBY:** You do think that has happened?

**Mrs MARSHALL:** I know it has. I know of one person that did this, certainly.

**Mr R.R. WHITBY:** Who stockpiled medications?

**Mrs MARSHALL:** Yes.

**Mrs TRENDALL:** I think the truth of the matter, too, is that they really do not know. They think that perhaps accumulating pills might be a useful way but they really have no clear thoughts as to how to do this. That is why there needs to be some sort of legislation, or something—some clear process that can be followed by everyone.

**Mrs MARSHALL:** So it becomes not a criminal act in later life.

**Hon Dr SALLY TALBOT:** I have three questions. The first one, Mrs Marshall, we saw in your account of the conversation you had with the staff, that you had talked to your GP about an advance health directive.

**Mrs MARSHALL:** Yes.

**Hon Dr SALLY TALBOT:** It sounds like your GP poured a bit of cold water on the idea that it was a way of giving you —

**Mrs MARSHALL:** Oh no, it was Mrs Trendall, not me.

**Hon Dr SALLY TALBOT:** Oh, was it Mrs Trendall? Sorry, yes; it was just an account in the narrative that we have.

**Mrs TRENDALL:** Yes. We actually have the same GP; is that right?

**Mrs MARSHALL:** Yes.

**Hon Dr SALLY TALBOT:** Do you both have advance health directives?

**Mrs TRENDALL:** Yes.

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**Mrs MARSHALL:** Yes—copies in the hospital, copies with the GP, but if you collapsed in your home and the St John Ambulance men come, they are compelled by law to revive you. You can have “do not revive” tattooed on your chest, but they will still revive you.

**Hon Dr SALLY TALBOT:** One of the suggestions that has been made to us is that perhaps there should be some central registry of advance health directives.

**Mrs MARSHALL:** Yes, that is right, because they do not know. There is one at the hospital, but it might be at the bottom of your thick file, and nobody can find it.

**Hon Dr SALLY TALBOT:** Yes. So do support that idea?

**Mrs TRENDALL:** Yes.

**Mrs MARSHALL:** Yes, definitely.

**Hon Dr SALLY TALBOT:** Has it occurred to you to update your advance health directive at any stage? Can you foresee a situation where you might reconsider, or add or subtract things?

**Mrs TRENDALL:** I suppose if we did, we would update it, but you do not know.

**Hon Dr SALLY TALBOT:** But neither of you have done that to this point?

**Mrs MARSHALL:** No, but the point I made earlier that one’s views change as one gets older—the nearer one comes to the end, the stronger you believe.

**Mrs TRENDALL:** Yes.

**Hon Dr SALLY TALBOT:** Yes. Something that has been raised with us several times is about people making AHDs before they are in the situation where they might have had a terminal diagnosis and they might then change their mind. Have you had your AHDs for a while?

**Mrs MARSHALL:** Yes. I would have had one since they first came out, for five or six years, certainly.

**Mrs TRENDALL:** I have been a member of WAVES since the late 70s, early 80s.

**Hon Dr SALLY TALBOT:** I wondered if I could just ask you two other quick things. Sometimes when people talk about that trajectory into old age—advanced old age—it is described as a kind of increasing misery. So, you lose all your friends, you have just talked about your money dwindling; there is not much to live for. So the people who do not agree with you would say, “It is up to society to remove the misery. If we remove the misery, then these people won’t want to die.” Do you have any comments about that?

**Mrs MARSHALL:** Why? Why would you want to do that?

**Mrs TRENDALL:** I could not see society improving the financial position of very elderly people.

**Mrs MARSHALL:** Quite the reverse!

**Mrs TRENDALL:** I had not intended this, but my mother lived to be 100 and she was fine, mentally. She had a hip operation at the age of, I think, 90, and she had a marvellous 100<sup>th</sup> birthday. But she had said previously that her friends were all dead et cetera. Three weeks before her 101<sup>st</sup> birthday—I have two sisters in the UK—she said, “It’s going to be my birthday soon” so my little sister said, “Yes, but it won’t be quite such a big party.” She said, “Yes, I thought that, but I don’t want it anyway.” With that, or two days later, she gave up eating and died 10 days later, essentially of starvation. The doctor, when he came to write the death certificate, said to my sisters, “All I can write is that she died of old age.”

[12.50 pm]

**Hon Dr SALLY TALBOT:** That is a very powerful story.

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**The CHAIR:** Was she provided with any sedation or pain relief during that period?

**Mrs TRENDALL:** No, she refused it.

**The CHAIR:** Can you tell us why the doctor did not write “starvation” on the death certificate?

**Mrs TRENDALL:** I have no idea. This was in England and I suppose she thought old age sounded better than starvation. It was her choice. She had not been deliberately starved, so I think it was a reasonable choice.

**Hon Dr SALLY TALBOT:** Have you had a chance to look at the Victorian legislation?

**Mrs TRENDALL:** Yes.

**Mrs MARSHALL:** Yes.

**Hon Dr SALLY TALBOT:** Do you have any comments to make about the Victorian legislation?

**Mrs TRENDALL:** It had lots of amendments.

**Hon Dr SALLY TALBOT:** What do you think of that model?

**Mrs TRENDALL:** I think it is a good start.

**Mrs MARSHALL:** As far as it goes—it has to go a bit further.

**Hon Dr SALLY TALBOT:** In what way?

**Mrs MARSHALL:** Well, in the way that we are speaking of now. Going back to the point that you raised earlier about when do you know—you are probably aware of this, but there is a psychological theory of human development which is detachment in old age. When you start to get to a certain stage in life, you gradually start to detach from things. It is not a case of being fed up with life or not having the—you do not want to be involved in things. You start to detach from home, from the interests that you had, and the theory is that at the point when you become completely detached, then you are ready to die. There is controversy over that theory in that they say, “Is it society that detaches from the old people because they are not involving them in the mainstream of life, or is it that the old person actually detaches themselves?” As I have got older, I realise that it is not society that detaches from the senior members, it is that we detach ourselves. You realise that you do not want to be in it anymore.

**Hon Dr SALLY TALBOT:** So it is a natural part of life. It is not a pathology?

**Mrs MARSHALL:** Yes. I am not saying that this theory is one that is generally accepted.

**Hon Dr SALLY TALBOT:** But this is your view.

**Mrs MARSHALL:** It is my view.

**Hon ROBIN CHAPPLE:** I did note that one of you said that the only time you visit your doctor is to get an extension to your driving licence.

**Mrs TRENDALL:** Yes, that is me.

**Hon ROBIN CHAPPLE:** Congratulations.

**The CHAIR:** Is there anything else that you would like to add for the committee today?

**Mrs MARSHALL:** The only thing I can think is that there has to be something done about these advance directives. They have to be somewhere central and they have to be binding. The other thing is I think some of that persecution of GPs, friends, relatives who are there at the end is removed. It is not a criminal act.

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**Hon COLIN HOLT:** I do not want to risk patient–doctor confidentiality, but what does a doctor say when you raise these conversations with them?

**Mrs TRENDALL:** She says, “Have you consulted your family?” And you tell her, “Yes, this has been a long discussion.” The family is aware of one’s views but do not necessarily hold those views themselves. But they are happy for you to hold them.

**Hon COLIN HOLT:** I would assume you push them a bit—the GPs—into how they can assist.

**Mrs TRENDALL:** I do not, actually. I regard myself as one of her most un-remunerative patients. I do not push my luck. I am there to get my driving licence.

**Mrs MARSHALL:** But that is not the point. I am a remunerative patient because I am quite sick. I respect the fact that she is bound by the law and that she is bound by what she must do as a doctor. As far as she is concerned, I would not want to put her professional respectability in any kind of danger. This is why there has to be a change in the law. I am not going to break somebody else’s rice bowl just for the sake of fulfilling my own wants and wishes.

**Hon Dr SALLY TALBOT:** I think both of you indicated that you have nursed people at home through to the point of dying. Did you both have palliative care nurses or health professionals coming in to help?

**Mrs TRENDALL:** Yes. When I was nursing my husband, a palliative nurse came each morning to help to shower him. There were two, actually, and they were both called Emma. So we called them Emma One and Emma Two. One came one day and one came the next. They were marvellous—very good.

**Hon Dr SALLY TALBOT:** And the same for you, Mrs Marshall?

**Mrs MARSHALL:** Yes, nurses used to come in the morning to help us get mum up and in the end she could get up herself. But if I can just tell you a little anecdote: when mum was having a bad time, she could not breathe and she was in the emergency at the hospital. The earnest young doctor was saying to me, “Look, her heart is failing—da, da, da, da. We could fly her up and put a stent in her heart.” When I conveyed this to my mother, she said, “They can’t possibly be serious.” She realised that intervention at that stage of your life is nothing short of madness, not to mention a waste of taxpayers’ money.

**Mr S.A. MILLMAN:** Mrs Marshall, you have mentioned in respect of the advance health directives that they ought to be binding.

**Mrs MARSHALL:** Yes, definitely.

**Mr S.A. MILLMAN:** I have struggled with some of the evidence that we have received as a committee because I always proceeded on an assumption that a doctor–patient relationship was like a solicitor–client relationship. It was private and confidential between the two of them. A lot of what we have heard during the course of gathering evidence is that the doctors take into account the advance health directives but they are treated as relatively fluid documents. They consult with family and loved ones and the support networks and all the rest of it to try to see whether or not strictly applying the advance health directive is the most appropriate course of action. I do not disagree with you that they ought to be binding, but how does that as an idea sit with what is happening in practice in terms of the way that they are actually being applied?

**Mrs MARSHALL:** I think that how they are being applied is not satisfactory because they do not take into account the wishes of the person who has made the directive. As far as I am concerned, I do not think whether I live or die should be in the hands of my children. My doctor might say, “You can go on for another 10 years”, but do I want to?

**Mr S.A. MILLMAN:** That is a very helpful answer. Thank you.

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**The CHAIR:** 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 of 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. On behalf of the committee, I would like to thank you, Mrs Trendall and Mrs Marshall, very much for your evidence today and for taking the time to come and talk to us.

**Mrs MARSHALL:** I would like to say thank you for letting us put our view, because it is a view that needs to be made and we are very glad that we were able to do that. I am not expecting wonderful changes, but if you start thinking about it, it would be something.

**Hearing concluded at 12.57 pm**

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