

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
MONDAY, 30 APRIL 2018**

SESSION SIX

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 1.55 pm**Ms GILLIAN HENDERSON****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; Dr Sally Talbot is joining us shortly; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; 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 the community who is willing to share your personal experience. 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. I advise that the proceedings of this hearing will be broadcast live 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, Ms Henderson?

Ms HENDERSON: No, I have no questions.

The CHAIR: Would you like to address the committee?

Ms HENDERSON: I would. I would like to make an opening statement, which I have written because I thought it was more appropriate, but, obviously, when I answer questions I will be able to be less formal.

Thank you for the opportunity to give this evidence in person. It means a lot to me and my parents would support me if they could. Meanwhile, I have my husband, Richard Hobbs, here supporting me. I am going to start by briefly telling the story of the death of my mother-in-law, Richard's mother, my father and then the one whom I wrote the submission about, my mother.

Firstly, my background: I was brought up in a medical family of two generations. Birth, life and death were subjects of discussion at the dining room table on a daily basis. I came to Australia in my 20s as a physiotherapist to work in intensive care at Royal Perth Hospital. It was there I formed my adult ideas on death and dying with much reading, especially at that time of Elisabeth Kübler-Ross.

Now to the death of my mother-in-law in 2010. She was 89, a wee Scottish widow. She had been a sniper in the British Army. She was about this size. Her name was Agnes and she had never been to a doctor and she made it clear that she never wanted to go to one. I guess she was fortunate she had no medical issues. She was fiercely independent and worried that she might lose control of her life. She told me clearly that she did not ever want to go to hospital. She was found dead one morning in her own bedroom having suffered a massive gastric bleed in the night. This was considered a fortunate death by all of us. We knew her feelings and, although it was sudden, it felt right.

My father, a GP, Lindsay, died in 2009, aged 85. He had a type of leukaemia, which he elected to have treated with blood transfusions for some months. He then decided he was using up all the blood transfusions that he had given throughout his life as an amazing blood donor so he decided to stop. So, he was admitted to the local cottage hospital where he had been the doctor all of his

working life. He was treated with palliative care and put on the pathway that was used at that particular time. After some weeks of dying, he lost his patience with the doctors looking after him. These were doctors who he had trained as a GP trainer and he said to Steve, his doctor, "Steve, I am taking an unconscionable time to die." This was a "please help me" in his own inimitable fashion, but there was no help, just time spent with more dying.

Now to my mother, the wife of the GP we just heard about, also a GP. They met during medicine and were married for nearly 60 years. Dr Janet, as she was known, had been unwell at her home for a year, first with stroke and then increasing CCF, congestive cardiac failure, so her heart was, basically, wearing out. She had been in and out of the local cottage hospital where her husband had died only two years before. It was 2012 and she was getting more frightened, shortness of breath, likelihood of falling and a sense of not knowing what is coming next. I was on the other side of the world, having been back and forwards for many weeks in the previous year. My siblings felt that she had to go into care, but she absolutely refused. They phoned me to discuss this. I realised I was the only offspring willing to talk to her honestly about her choices. This is about choices; that is what we are talking about.

I phoned her up and spoke to her wonderful carer, Lorna, who I had not even met at this stage. Janet had suddenly required more help at home and this had been organised. I explained to Lorna the conversation that I was about to have and asked her to sit with Janet and listen in, which she did. We are firm friends now. I talked to my mother from the other side of the world about her situation and what her options were. I explained that she had the option to cease all treatment, just to be made comfortable and just die. Her heart was worn out. She kept saying, "I would have treated people better than this. I would have had them getting over all this much better than the doctors do nowadays." But I explained to her that she was really past medical care. She was actually very relieved and she said she had forgotten that she actually had that option. So, she had been so medicalised with her background and then medical treatment of CCF, which goes on and on, that she had forgotten there were any options or choices. She did say that she did not want to go to hospital again and would I promise that she would not have to do that? I said, "I will sort it out." She was clearly relieved at the discussion. I asked her if I could ring her GP and set it up and she said yes. This would have been one of the most difficult phone calls I have ever made, to my own mother, discussing her death, but we knew it was the right thing to do. This I could only do because historically we had talked about this.

I phoned the GP, she agreed my mother was rational and would get it underway that afternoon—great advantage of small places. It all could be managed at Janet's home with palliative care nurses from the Marie Curie organisation. As I wrote in my submission, the first week of dying at home worked well. She was *compos mentis*. She was chatting. She was given morphine to alleviate the breathlessness, which, of course, is very frightening at that stage when you feel as if you are drowning because your lungs are filling with fluid. It is a very scary situation. She had oral morphine and midazolam for the other symptoms, and these were orally. I arrived back at this stage not expecting her still to be alive. So, we are now a week in to her dying. The next six days were horrendous. She required catheterisation virtually as soon as I arrived. I had to help at 10 o'clock at night because there was only one nurse; there was no doctor available. I had to go and get the equipment from the local hospital and then I actually helped catheterise her. I would have done anything at this stage. She developed pneumonia and had sputum draining from her mouth, while the noise of her breathing was terrifying. I have worked in intensive care for years. I am used to this stuff. This was my own mother at home. It was awful.

I could not actually stay in the room and watch it. She was now often unconscious and had a syringe driver in place for drugs. She would wake and she would be furious if there was somebody there

who was not helping her die. I ended up alone with her at night. One night when there was no—in fact, there had been a nurse there. She had woken and she had said, “Get out of my room. If you can’t help me, go away”, and they had called me. I ended up alone with her at night. There was nobody available. After a desperate plea from her, I injected enough midazolam into her syringe driver to make her unconscious. How I wish I could have helped injecting to help her die. But I knew the outcome would be a legal case if it was found out. The drugs were all there on the dining room table.

It took her another 18 hours for her to die after that incident and I could not be in the room with her due to the horror of the situation. I was not with her when she finally died, but a lovely Marie Curie nurse was. How sad is that, that she had no family there?

I come today to tell you from the heart that we need to be given the option to choose when enough is enough. Palliative care is important, but including provision for assisted dying at the time of choosing of the patient surely is both humane and ethically sound. In the final stages, the outcome is inevitable and the doctors should not be legally bound to prolong life for another few days that the patient does not want to live. Old age is a terminal condition.

In both my parents’ cases, if they had had the option of an assisted death or a death by their own hand with a suitable drug at the time of their choosing, they would have had a more peaceful end and my memories would not have to be tinged with those final harrowing days.

The CHAIR: Thank you, Ms Henderson, for sharing that account. Do you think both of your parents had access to good quality palliative care?

Ms HENDERSON: Yes, I do.

The CHAIR: But I am making the link that I think they were not quite managing their symptoms; is that right?

Ms HENDERSON: No. That is exactly right. Obviously, my father just took a long time to die, having made a decision, and my mother was agitated, desperate, and not being managed, despite the MM deals, the morphine and the midazolam. But you have to give the right doses and it has to be done in an efficient way. Yes, they had palliative care.

Hon ROBIN CHAPPLE: You mentioned the name of the organisation that was providing the palliative care.

Ms HENDERSON: It was providing the nurses. They are the Marie Curie nurses.

Mr R.R. WHITBY: In the UK, we are talking about.

Ms HENDERSON: We are talking about the north of Scotland. I think it is the Macmillan nurses here, but I am not sure.

The CHAIR: You mentioned that your mother had almost forgotten that she could withdraw from treatment. We have heard a lot about the futility of treatment. Do you think that people understand that they do not need to have medical treatment necessarily?

Ms HENDERSON: No, I do not, because she as a rational person and a GP would have known those choices, but I think when you are so wrapped up in it, you actually—well, I think a lot of the general public has no idea and she had simply forgotten.

The CHAIR: Do you think that perhaps doctors understand that there is a point of futility, necessarily?

Ms HENDERSON: I would like to think they understand. I do not think they always give that choice.

Mr S.A. MILLMAN: What makes you say that?

Ms HENDERSON: Because I have worked in hospital settings for many years where everything is done to prolong life and very rarely is the discussion had, which takes a lot longer in any situation, to discuss the other options.

Mr R.R. WHITBY: In the UK, do they have our equivalent of advance health directives?

Ms HENDERSON: Yes, we do.

Mr R.R. WHITBY: Your mother had one.

Ms HENDERSON: My mother had not made an advance health directive, but she had written a “do not resuscitate” letter, which I had arranged to have on the front of her notes for every admission. She had handwritten that many years before. They now have advance directives. Certainly, that age group probably do not look at doing them at that age. It is one of my big things here. I ask all my friends to do an advance directive.

Mr J.E. McGRATH: Talking about assisted dying—there are two schools of thought on this—most people say when people are close to the end of life we all accept that is when people should be helped, so that they can die with dignity and say goodbye to their family, but these are people with only hours or a few days to live, very close to the end. It has also been suggested to us that maybe some people with other conditions that might not at the time be life threatening, but are going to affect their quality of life who might want to make that decision earlier; do you have a view on that?

Ms HENDERSON: Yes, I do.

Mr J.E. McGRATH: Can you separate those two?

Ms HENDERSON: I absolutely can. I believe that we should have control over our living and dying. I do not want to live under a medical model of medical care, so I choose not to have lots of medical care that might be offered to me and, in the same way, I would like to be able to choose at my time when I leave this world, and it may not be for a terminal illness. I think we are living such a very long time now and it may be a whole mix of small chronic conditions that just make life unbearable. Once that stage is reached, I feel very strongly that we should be able to have that choice.

Mr J.E. McGRATH: So you would be talking about things like motor neurone or Parkinson’s disease.

Ms HENDERSON: Absolutely.

Mr J.E. McGRATH: Those sorts of debilitating diseases that might not have a shorter life expectancy as some others. Do you think people should have that right if they did not want to carry on in that condition?

Ms HENDERSON: I think when your quality of life is such that you would prefer to be dead, I think that that is a reasonable choice to make. Everybody will make that decision from a different point of view. It will be amazingly personal what one person can deal with. We read all these amazing stories of how people carry on despite awful chronic conditions and other people may say, “Actually no, that is not what I want.” I think we should really have that choice.

Hon COLIN HOLT: I take your point about life being unbearable; that can be both physically and mentally. Where would you draw the line in terms of a mental issue or a mental illness in terms of making a decision about how life is unbearable? Any thoughts on that?

Ms HENDERSON: I think this is probably one of the most difficult decisions to make and this is where we run into the things like dementia and Alzheimer’s and things like that. If I just look at the dementias and things separately from other mental conditions, I think if you have done an advance directive prior to developing some sort of dementia, I see no reason why that advance directive cannot be fulfilled. We have this extraordinary idea where somebody has to say whether you are

rational or not—some psychiatrist or doctor has to say whether you are rational. How do we decide who is rational? This is an existential problem.

Hon COLIN HOLT: It sure is. We have heard some evidence that some doctors do not have access to advance health care directives or even take notice of them. Would you say that we have a cultural issue around discussing death and the medical fraternity are not good at it either?

Ms HENDERSON: I would say, absolutely, a firm yes to that. We do not discuss death. We do not discuss it at home. We do not have people dying at home like we used to. You do not see your grandmother laid out in the front room anymore. We do not discuss death there and in hospitals death has become something that is not discussed unless you have some really clever doctors. There is more and more of this coming out. People who have worked in intensive care all their lives are now writing books about how we are over-medicalising death and that somewhere along the line somebody has to say, “Enough! Let’s discuss this. Let’s not do anything more here.” I would have to say that I feel disappointed about the AMA and its position on this. I feel grateful that the College of GPs has said that they are for this and so have the student doctors.

Hon ROBIN CHAPPLE: It is interesting that you come from a medical family and have medical training. Often one of the issues that is raised with us is between self-administration and the doctor-assisted administration. As somebody who has worked in that area, what would your views be about doctor administering? Let me put it another way. Your parents were both medical professionals. Would they have been willing to participate?

Ms HENDERSON: Of course. When they were younger doctors and they were working in the old-fashioned GP environment they did this all the time. They brought babies into the world and they helped people leave the world. It was all considered perfectly reasonable. They did it with the patient in mind, with the patient’s discussion, with the family in mind and then the doctor would come along and things would be helped along. It was only really in the 1970s and 1980s when we got a big change and the right-to-lifers and other student doctors of my parents came along and said, “This can’t happen any longer. We can’t be doing this. Doctors shouldn’t be allowed to do this” that things changed. In the old days I think it worked very nicely but it would be much better to have a situation where there were some sort of guidelines for doctors and guidelines for patients.

Hon NICK GOIRAN: Ms Henderson, what was it that they used to do in the old days?

Ms HENDERSON: They would just give a little overdose of whatever drug was appropriate at that time and, in fact, it was often sleeping tablets, which are no longer available now but given in enough dosage would cause death.

Hon NICK GOIRAN: Sleeping tablets—but they are not available anymore?

Ms HENDERSON: Yes. They are available as—they are not available now.

Hon NICK GOIRAN: Not legally available.

Ms HENDERSON: They are not legally available now but there are ways of doing very nice peaceful deaths.

Mr S.A. MILLMAN: I am interested in hearing further from you about advance health directives, particularly with what you have commented on with respect to capacity and how advance health directives can operate over time as circumstances change. For arguments sake, I might prepare and finalise an advance health directive setting out a particular set of wishes and then I might suffer from dementia or Alzheimer’s or something like that so my particular medical circumstance has changed. Is it your view that what is contained in the advance health directive at the point of capacity carries through irrespective of the change in circumstances or is it a more fluid

arrangements than that where doctors and patients and family members gather together to try to ascertain at some later stage what the patient's true wishes might be?

Ms HENDERSON: I think it is very difficult to ascertain at a later stage. I think people are rational when they make their advance directive. You do not sit down and make an advance directive without thinking this is actually what I want. If something changes and you were still rational, you would presumably change it. If you are not, then I think that that advance directive should stand. One of my biggest concerns about my own advance directive, which is in a cupboard at home but I carry a card in my wallet saying I have an advance directive, on my phone I have an advance directive. I really feel that I need to have it tattooed on my chest because if I am taken unconscious into hospital, I will be medicalised.

[2.20 pm]

Mr S.A. MILLMAN: Do you have any suggestions for us as to how we might improve record-keeping so that people like you do not need to have it tattooed on your chest?

Ms HENDERSON: The tattoo seems to be the only way because at least with the defibrillator they pull your clothes off. It is no good on your wrist. I have thought of wearing it on a MedicAlert, but they will not always look at that before they do a defibrillation. In terms of my future, that is one of my concerns.

Hon COLIN HOLT: You may be able to answer this. I do not know. We will give it a go. In the final hours of your mum's passing, you say that you applied Midazolam and you knew the dosage that would make her unconscious and comfortable but not to the point of passing away. I assume, with your mother's knowledge, she would know the dosage rate as well. At the point that you had to do it she was incapable of doing it?

Ms HENDERSON: She was totally incapable. She was semiconscious.

Hon COLIN HOLT: You may not be able to answer this. Before she got to that point she would have known the solution for herself potentially before she got to that point.

Ms HENDERSON: She had a box—a shoebox—of medications that she had stashed away over the years. My sister used to say, "It's alright. Mummy knows what she's going to do. She's got the shoebox of medications." When she had a stroke a year before she died I got the shoebox out and I went through it to see if there was something there that we could have used reasonably and there was not. There was not enough of anything that was suitable. There was Valium; there was lots of Valium. But you cannot take your life with valium. By this stage I had read a lot about end-of-life choices and I knew what worked and what did not work. There was nothing there that really would have worked.

Hon COLIN HOLT: By the time she got the midazolam in enough quantity, she was physically incapable of applying it?

Ms HENDERSON: Absolutely. She had already been dying for 13 days by then. She was in and out of consciousness. What a terrible situation. She would have known. I am not so good on my drugs and I was very frightened to overdo it.

Hon COLIN HOLT: Did she make the decision "I might just wait and wait and wait"? The decision was taken out of her hands, I suppose, in terms of her physical capacity to do it herself. When did she get the Midazolam prescribed?

Ms HENDERSON: She was not given Midazolam until she made the decision to stop all treatment. Midazolam and morphine were only brought on board once she had made the decision to stop treatment because they are treatments for the symptoms of dying.

Hon COLIN HOLT: The solution came along after she had made the decision?

Ms HENDERSON: Yes, that is right. In her early days, I can remember her, when we were travelling in European trains, handing out sleeping tablets to people. Those were the really good sleeping tablets that would have worked. But, of course, they all became illegal.

Hon NICK GOIRAN: Why did those sleeping tablets become illegal?

Ms HENDERSON: Because you could commit suicide using them. This was at this stage when the valiums and all the ones that end in “ium” came in in the 1970s and so on because it was discovered that if you took enough sleeping tablets you could commit suicide, whereas with those sorts of things you cannot.

The CHAIR: The circumstances you describe at the very end of your mother’s life are probably best described as terminal sedation.

Ms HENDERSON: Absolutely.

The CHAIR: It is a practice we have heard a lot about in this committee. Do you think that is a well understood practice in the community?

Ms HENDERSON: No.

The CHAIR: I am interested to know why the nursing staff in your mother’s case were not prepared to provide terminal sedation.

Ms HENDERSON: They were not providing the end point. They were really being careful about sticking to the law. I think that was partly because we had doctors there who had been trained by my parents and who were going to be very carefully looked at if they should have helped the old guys out. I think they were just being very careful but at one stage I said to a doctor who appeared the next morning after I had given the Midazolam. He said, “You can’t actually do anything wrong now.” I wrote that in my diary and I thought: I wonder if that is him giving me permission.

The CHAIR: How did you know the right dose, because that is quite a specialised area.

Ms HENDERSON: I did not know the right dose. In fact, I should have been looking it up. I should have known exactly what to give her. We had a drug chart on the dining room table and all the drugs laid out. On drug charts you sign off when you give and how much you give. The dose that they had been giving was 0.2 of something or other so I just gave the same and I kept giving that every 10 minutes until she was asleep.

The CHAIR: She did not regain consciousness.

Hon ROBIN CHAPPLE: You talked a lot about health directives and end-of-life directives. Are you seeing a serious link between those directives and decision-making about the end-of-life? We have not actually dealt with that. We have advance health directives at the moment which talk about a whole range of things, but we do not mention the bit we are not supposed to mention at the very end. Are you saying that if we do have some legislative framework around the end-of-life choices that those advance health care directives should be part of that process?

Ms HENDERSON: I think the more you can bring it all in together, the better it is going to be. At the moment we have advance care directives sitting out here, not attached to anything.

Hon ROBIN CHAPPLE: Obviously, in those advance health care directives we have DNR—do not resuscitate—but we do not go to the next stage and say dose me up until I am out of here sort of thing.

Ms HENDERSON: In fact, on mine I have said that. Absolutely. I have said that if euthanasia is legal at this stage I am dying, I would like to be euthanized.

Hon ROBIN CHAPPLE: That answers my question.

Ms HENDERSON: There you go. You just add it in to the bottom.

The CHAIR: Do you think that people who are reluctant to commit suicide would possibly access voluntary assisted dying if that were available?

Ms HENDERSON: I think there are some people who are not able to do it themselves for various physical reasons. Therefore, I think there needs to be a provision for doctor-assisted if you are unable to swallow or you are unable to get your hand to your mouth or anything like that. Basically, when people are that old and infirm just managing—and they are worried and they are frightened. I think that having some sort of assistance—it does not even need to be from a doctor. It can be from a family member. We should allow the families to be involved in this. We do not need doctors to help someone take a drink. We can do it in our families. We then discuss it beforehand. I want people to talk about it and say, “When I feel like this, this is what I would like you to do.” I told my children they are to put me in a wheelchair and push me over a cliff. I am sure I will work out a better way but we have discussed these things all through life.

[2.30 pm]

Mr J.E. McGRATH: There are a lot of people out there who die, some probably a painful death, but if they gave them the choice, they would still say, “No, I don’t want to end it. I want to hang in”, even if it was for another day or a few hours. What you are saying is that you are just talking about a choice for people who want to take that —

Ms HENDERSON: Who want to take that choice. This should absolutely only be their own choice. This is not anything where we help people who do not want help. When you do the reading around this, most people will hang on to life with their nails and whatever—they will hang on to life. We are talking about a small percentage who need help or need the ability to be able to choose. But most people want to keep going. I do not think we need to worry about them. If they want to keep going, that is great.

The CHAIR: Ms Henderson, thank you very much for your evidence before the committee today. 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 it is not returned within this period, it will be deemed to be correct. New material cannot be added by 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 transcript of evidence. Again, thank you very much for giving evidence today, Ms Henderson; it is very helpful for us.

Ms HENDERSON: It was very nice to be able to tell it to somebody and that something might come out of it.

Hearing concluded at 2.31 pm
