

# **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 EIGHT**

## **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 2.58 pm**

**Mr WILLIAM JOHN SPANBROEK**

**Private citizen, examined:**

**Mrs KATHERINE ANNE McBARRON**

**Private citizen, examined:**

**The CHAIR:** Thank you both very much, in particular Mr Spanbroek, for giving evidence this afternoon. 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, who has stepped out; Mr John McGrath; Dr Jeannine Purdy; Hon Col Holt; Hon Nick Goiran; Mr Reece Whitby; and Hon Robin Chapple. The purpose of today's hearing is to discuss the end-of-life choices and the adequacy of the existing laws and resources 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 within Parliament House and via the internet. The audiovisual recording will be available on the committee's website following the hearing. Do either of you have any questions about your appearance today?

**The WITNESSES:** No.

**The CHAIR:** Did you want to make an opening statement, Mr Spanbroek?

**Mr SPANBROEK:** Yes, I have no notes, I just speak of my experiences. My case was Michael Watkins, who is my son—I am not the biological father—who was a young man in the Navy for five years. In the Navy, they considered him to be a person not suitable for the Navy because of certain actions that he did or could not handle the job. Their neurologist said there is nothing wrong with Michael. My wife and I got our own neurologist who diagnosed him with juvenile Huntington's, which is a genetic disease that he acquired from his biological father. We looked after Michael ever since he was 21, when he was asked to leave the Navy. We had numerous discussions and lots of very good discussions with the Navy about why he should be in it, because the Navy never diagnosed him and he became quite active by wanting to be active, but he could not. He never got fidgety or anything like that. With the disease, they start to lose their ability to swallow. Eventually we had to have a PEG inserted and fed him intravenously through the PEG. Having done that, we had him at home for the last year. He was really in a bad condition. He lost bodily control over his bowels and could hardly walk, and then finally he finished up having a brain haemorrhage. We took him to the hospital where our neurologist was looking after him and he was given painkillers, morphine and what have you. We kept saying to the neurologist, "Peter, he is in pain." He said, "But I have given him the limit of morphine; I cannot give him anymore", and he said, "But he is not in pain." Well, I can tell you the last thing he said. He lifted his head from the pillow and said, "Bullshit". He was in hospital for five and a half weeks, and every night we drove home my wife and I said to each other, "He won't be there tomorrow." Five and a half weeks later, he passed away. His case was very highly publicised on TV and the newspapers and several prints all around Australia. My wife and I are on the path of advance health care, which we campaigned on. We went to every politician with a letter of support

and an A4 photo of Michael one day before he passed away, where he laid in bed like a skeleton weighing far less than 30 kilograms.

I also had experience with my father-in-law who was in a nursing home for two years. Every morning we used to go there. People in the nursing home, strange old people, would ask you, “Can’t they do anything for us?” They just did not want to be there. I have never seen anyone who is looking forward going to a nursing home. So, in that regard, I have experienced that we should have a choice at the end of life. What do we do with the end of life? Are we going to suffer like my father-in-law did for two years in a nursing home, or like Michael? There should be a way that we can alleviate the pain and let these people have a dignified end to their life. The living wills went through Parliament—it took us a number of years. The then Attorney General, Jim McGinty, will attest to it that he rang me the morning after it went through Parliament and thanked us for our contribution. He actually said, “If it wasn’t for you two, I couldn’t have got it through.” That is my experience. I would now like hand over to my daughter, Katherine, who has her side of what she experienced with all this.

**Mrs McBARRON:** I do not really know where to start, to be honest. It is all going around in my head, but I really just want to represent the youth and be a voice for those people who cannot be here whilst I physically can be, because, you know, my family has experienced so much death over the years. I am 39 and I am pro-choice. I believe everybody has the right to die with dignity. That is based on my life experiences and the hardship that my family has been through since I was a young girl. I am talking about, as from the age of six, I lost my biological father. He had Huntington’s disease. He gassed himself in a car. It was outside a children’s school across the road from our house. My grandmother passed away. She had a reasonably quick death. She had angina and she had an angina attack and she passed away fairly quickly. My grandfather on the other hand was in a nursing home for years and years. He had the heart of Phar Lap—it was stuck in a body that he could not do anything with. He was so frustrated and was begging my mum to do something. Having to watch that over the years has just been heartbreaking. He ended up having 19 strokes, and he did not have a terminal illness. These are the things that I really want to make you aware of in putting this law reform in place, making sure that you are covering families that are really going to need it. Because it may not be terminal illnesses as such that people have, but those people are still going to require help, like my grandfather. Then my brother passed away, which my dad has told you that story. That was heart-wrenching to watch. Five weeks and the image of him, I cannot even begin to explain how traumatic that was to see my mum go through that, more than anything. That broke my mum’s heart; that just tore her to shreds. After that I lost my two half-brothers, both gene positive. They were diagnosed in their mid-30s, and one of them attempted suicide twice. And now my mum. I have lost my mum, and I have lost her to a broken heart. I do not have my mum here and I am fighting her battle. She has fought the battle her whole life, because she would never fit in the box. She was always outside the box and having to fight for everything—fight for funding for my brother to keep him out of a nursing home in his early 20s. They were like, “Well, sorry, we can’t give you funding because he does not fit the criteria.” I am just tired of my family fighting, and now I am fighting not just for my family but for all the people who are going through this. It is not fair. Considering all of that, I think I lead a pretty happy existence and I am full of life and I enjoy life, but come the time—I was diagnosed as gene positive when I was 25; I have Huntington’s. This is my greatest fear, to have to die in pain, because I have seen that and I do not want to go through that. That is why I am here today.

**The CHAIR:** Mrs McBarron, I will ask you directly as someone who has obviously been diagnosed as gene positive: what options would you like available to you at the end of your life?

[3.10 pm]

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**Mrs McBARRON:** Everybody is different. That is what I think needs to be considered. I have a family of gene positive brothers and fathers and everybody was different. I just want to be able to—if it gets to the point where I do not have a quality of life, that I am able to end it. It is about the quality of life. I think that is really important, and everybody has a different interpretation as to what that is, but I do not think anyone has a right to say, “You can’t do that, because that’s against the law.” If somebody is not enjoying life and they do not have a quality of life—my brother did not have a quality of life for five weeks in hospital, but they made him sit there because it is the law. That is not a quality of life, ideally. He was 29. He was the only juvenile Huntington’s patient in WA at the time so he was pretty much a guinea pig. I got to witness the intensity of Huntington’s. It was quite aggressive, the type of suffering he was going through and the changes he was going through. It was just horrible to watch. I just know that when it gets to the point where I do not have a quality of life and I am struggling, I will not be able to tie my shoelaces or be able to feed myself, I will be falling over and hitting my head, all of that sort of stuff—I do not know when that is—but when I am not enjoying my life, I do not want to get to the point of my father or my two half-brothers. I want to be with family and do it on my terms and celebrate my life and do it the right way and say, “See you, guys. My time is up; I have done enough.”

**The CHAIR:** Who do you think should ultimately decide that quality of life? Do you think that is a decision for the doctors or the individual?

**Mrs McBARRON:** Sorry, can you repeat that?

**The CHAIR:** When it comes to deciding on quality of life—it is a very subjective term—do you think that should be a decision for the doctors or for the individuals?

**Mrs McBARRON:** The individual, yes. The individual knows, and if doctors do not listen then the individual is just going to take matters into their own hands.

**Mr J.E. McGRATH:** Further to that question, you are aware of what has happened in Victoria with the legislation. If you lived in Victoria, you would be disappointed with that legislation —

**Mrs McBARRON:** Yes.

**Mr J.E. McGRATH:** — which has put a six-month time limit on it and it has to be an end-of-life situation. Someone in a situation of having Huntington’s would probably not be able to avail themselves of that right to make a choice about their end of life. Would you say that our committee might be letting you down if we did not support what you are putting to us today?

**Mrs McBARRON:** Yes, definitely. But I do not think I am the only one. There are so many other people who are going to be let down by these decisions. I am just asking you to take into account different scenarios. Do not make a law just because some other country is doing it. I think this is an opportunity for you guys to really assess what we need as a society and whether it is going to make a change to people, because you are going to be back here again talking about the same things because there are all these people who are not happy with the laws that you have made. I think society just has become complacent and people are not prepared to change and I think it is important that we do change and make a good change, and then we do not have to go back through this again. Make it something that will—I do not know.

**Mr J.E. McGRATH:** What about you, Mr Spanbroek? Would you agree with the suggestion that the Victorian law would not be enough for someone in Katherine’s position?

**Mr SPANBROEK:** No, it would not be enough, because the law should encompass every possibility in every illness. As Katherine said, everyone is different. For a person in a nursing home or a person dying of cancer or with what Michael died of or they are dying of emphysema, they are all different.

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It should not be six months. Far from it. We should do better than that and we have the opportunity to do better than that.

**Hon ROBIN CHAPPLE:** Thank you very much indeed, Bill. Your son Michael, you said, was in hospital. Which hospital was that?

**Mr SPANBROEK:** Mount Hospital.

**Hon ROBIN CHAPPLE:** There was an understanding that people wanted his pain and suffering to end. Was that conveyed to the doctors?

**Mr SPANBROEK:** Yes, it was. The neurologist was quite well aware of it. The different healthcare personnel were well aware of it in the hospital and from the neuroscience unit as well.

**Mrs McBARRON:** My brother had a high constitution as well. Drugs and things would affect him very differently from, say, you and me.

**Hon ROBIN CHAPPLE:** I was not particularly aware of the level of Huntington's. I have just done a quick google here and juvenile Huntington's is very, very rare anyway.

**Mr SPANBROEK:** Yes.

**Hon ROBIN CHAPPLE:** I think that is something we are going to have to look at as well.

**Mrs McBARRON:** It is only rare because the testing has only become available, but there are more people in WA now who have it. You have to remember that this testing only came out in the 1990s.

**Mr SPANBROEK:** Yes, late 1990s.

**Mrs McBARRON:** Bunbury is massive. There are so many people in Bunbury now who have the gene. In the last year, I have had two other people come up to me and say that they have got Huntington's in their family. Years ago, you would not hear of it. There is a lot of awareness now and a lot of resources from the neuroscience unit here. They are travelling to Bunbury and Esperance and helping families. They are awesome there. They are really good. It is increasing, I would say. But at the time, my brother was the only one in WA known to have juvenile.

**Hon COLIN HOLT:** You have been incredibly courageous and I just wonder if I can push that courage a little bit more. You have obviously expressed how you want to be looked after later in life when you develop Huntington's. I guess you have written it down or you are going to fill out an advance healthcare directive.

**Mrs McBARRON:** It is a psychological thing for me. I am gene positive, but I would not do that until I am actually symptomatic.

**Hon COLIN HOLT:** I guess that is where my question wants to go to. If the symptoms develop, how are you going to express your end-of-life care and how do you think people will make a judgement around your quality of life at that point and how would you like to see that played out? They are very difficult questions, I understand; I am sorry. If you are not ready to share them, that is completely fine. I guess I am really exploring how we can help people with Huntington's disease.

[3.20 pm]

**Mrs McBARRON:** It is the million-dollar question. I do not really know that, other than I will know when I know I am not enjoying life, because I am a pretty positive person. My brother was amazing. Like typical Huntington's patients, you will see that they get quite aggressive and depressed. There is a high rate of suicide. My brother was totally the opposite. He was amazing. He was really inspiring and was really active and he had a really great quality of life, and that was because of the care he was given. I think care is important. That is quality of life when you are getting good care. But if you are not getting good care, like in the case of my half-brothers, they probably were not getting the

best care and they were just disengaged. Once you get past that—I do not know. I cannot tell you when or how I am going to be, because I have had all these different scenarios in front of me. I really just know that there will be a point when I am disengaged from life and wanting to be here. I do not want to end up holding a gun to my head and ending my own life. I know that I want to go in the right way. I do not want to do that to my family. That is the last thing that I would do. I have seen them go through that and how painful it is. I would much rather it be an informed decision and me say, “Right; it is time now. I am not enjoying my life. Let’s do it the right way.” I think they get closure as well. It is like when you put an animal down. We did recently. It was the most weird experience, but it was actually quite good. You are putting your animal down. It was so humane and all of us were around this little dog. That is the way I think it should be. We do not give ourselves, as human beings, the opportunity to do that.

I am pro-choice. I am not judgemental. I am happy for everybody to have their own views about it. But there is no room for that in politics or in the medical industry. They need to be non-judgemental. You need to be able to have these conversations and not feel like you are an alien and they are like, “Why are you thinking about death, because you’re only 40?” But it is true. You do have to. I have confronted my mortality by going through the testing. I know what my life could possibly hold for me.

**Hon Dr SALLY TALBOT:** I am so sorry I missed the beginning of your evidence, having been called away, but I am glad to have heard some of your testimony this afternoon. I wondered if I could take you—this really is a segue to the questions that other members have been asking you—to the question of capacity. This whole question about how people handle their own decisions at the end of life becomes very complicated when you have to take into account that the person is actually making a decision on their own behalf. You get into much more complex territory when you are trying to make decisions on behalf of somebody else. But if we can just talk about someone making a decision on their own behalf, was it your observation—I know these are difficult questions to answer and please do not if you do not feel able to—that your brother retained the capacity to make those decisions?

**Mrs McBARRON:** Yes.

**Hon Dr SALLY TALBOT:** Did he keep that capacity right until he died?

**Mrs McBARRON:** No. He was mentally there, but physically he was unable to talk. Someone with Huntington’s—it is very hard to explain it. He struggled speaking, but his brain was there.

**Hon Dr SALLY TALBOT:** Could he communicate in other ways?

**Mrs McBARRON:** Yes.

**Hon Dr SALLY TALBOT:** How would he communicate with you?

**Mrs McBARRON:** Computer.

**The CHAIR:** So he had cognitive capacity?

**Mrs McBARRON:** Yes. The same with my grandad.

**Mr J.E. McGRATH:** Further to that, did your brother indicate that he was ready to end it; he did not want to keep going the way he was?

**Mrs McBARRON:** He said no. He had a brain haemorrhage. He did not die of HD; he died of a brain haemorrhage, but that was all of a sudden. We did not see him. From that point, he had an inability to speak. He was pretty much incapacitated in a hospital and we never spoke to him again after that; that was it. From that time that he fell over at home to the time he died, there was no communication at all. We have to remember living wills were not even a thing then either. He had

said to my mum that he did not want to suffer, and to my dad. The guilt that my mum always hung onto was that she let him suffer, and that was something that she could not get past. It broke her. She died of it, really, because she was broken.

**Hon ROBIN CHAPPLE:** Thank you very much indeed, and I really appreciate your frankness. Not knowing enough about Huntington's—I am obviously of the understanding that you do—is there, in a normal progression of Huntington's, a point where people lose capacity?

**Mrs McBARRON:** Mental capacity?

**Hon ROBIN CHAPPLE:** Yes—the ability to make cognitive decisions.

**Mrs McBARRON:** It is very hard to say that; you would probably need to speak to a neurologist. I would say that most people are different. My brother was very intelligent. It was like he was trapped in this body—very frustrating, highly intelligent. You can see other people and they do not always look there. I do not know. It is hard. With the cognitive stuff, you are also talking about—I do not know. It is very hard to tell.

**Hon ROBIN CHAPPLE:** We need to do a bit of research, I think.

**Mrs McBARRON:** The thing is that I did not see my dad, so I do not really have anything to gauge it from. I was very young. I have only seen patients coming in and out of the neuroscience unit. It is very hard to go on observation only.

[3.30 pm]

**The CHAIR:** Outside of your own family, are you aware of people who have been diagnosed with Huntington's who have taken their own life subsequent to that diagnosis?

**Mrs McBARRON:** No, I do not know anyone specifically.

**Mr SPANBROEK:** The social worker at the neuroscience unit has told us that people have taken their own life, but she did not put a number on it or anything. It is quite common amongst that disease.

**The CHAIR:** Thank you both very much for coming today to give evidence. It is very, very important for us and very important evidence.

Thank you for your evidence before the committee today. A transcript of this 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. If it is not returned, 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, please do so in an email attached to the transcript.

Thanks very much both of you for taking the time to give evidence today. It is very much appreciated.

**Hearing concluded at 3.30 pm**

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