

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 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**

Hearing commenced at 12.45 pm**Mr NIGEL HAINES****Private citizen, examined:**

The CHAIR: Mr Haines, 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; Hon Dr Sally Talbot, who has just stepped out very briefly; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; Mr Reece Whitby and Hon Robin Chapple.

The broad 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 our community who is willing to share his personal experience. It is important 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 experience today?

Mr HAINES: No, not at all.

The CHAIR: Did you want to make a statement for the committee?

Mr HAINES: Yes, I have a prepared a statement that I have in front of me, but also just a couple of photographs of the person we will be discussing, if that is okay with the panel. There are two photographs there. The first one was taken in 2004 just as she diagnosed with dementia. She went on to get Alzheimer's. The second photograph is four years later.

Part of the submission will address some of the questions you asked previous witnesses. If you can indulge me, I will read some of the excerpts from my submission.

The CHAIR: Absolutely.

Mr HAINES: Thank you.

Tenth of January, 2006. This is when Suzie was still living at home. Whilst there are moments when Suzie becomes quite lucid, this morning Suzie was very unsettled and was trying to ask questions about her illness. She eventually said that she was tired of being ill and wanted to go back to the way she was. This communication took around half an hour to understand, as she continues to have difficulty articulating her thoughts.

Fourteenth of January. Suzie had another bad night last night, needing constant reassuring. In the early hours of this morning, still upset, she frightened me. She woke me sobbing and asked me why she could not just die in her sleep. This feeling of hopelessness she has, I find, I, too, am beginning to share. There is absolutely nothing that can be done to alleviate it. I guess she could be drugged up to the eyeballs and sit in the corner like a zombie, but is that any way to live? After a close friend of ours died of cancer after a long illness, I said that if a doctor diagnosed me with cancer or anything terminal, once I was told I should not be driving I would check myself out. Seeing Suzie sobbing her heart out, I cannot help but think I should be helping her to do likewise. I should not be writing this,

but I am just putting down my thoughts. I emailed the doctor to see whether there is any medication that might minimise Suzie's feeling of helplessness.

Sixteenth January. On Saturday evening, Suzie scared me like never before. During our time together, we have never really argued, certainly not with raised voices or nasty comments. But on Saturday evening around 9.30pm, she fell asleep in front of the TV as she normally does. I tried to gently wake her. She woke up startled and said to me something like "Now, I know what you are up to." I said, "What do you mean?" and she said, "Don't deny it". I carried on questioning her but her body language was very aggressive with her hand on hip pointing a finger to my face. She was mumbling incoherently and went around the house looking through the curtains saying, "Yes, I knew it." and "Yes, I thought so." This went on for about three quarters of an hour. As I said, it really frightened me because I could almost see hatred of me in her eyes and nothing I could say would calm her down. The panic attacks are increasing. Last week, the doctor called me to say he had received my email and was arranging for the psychiatrist to see Suzie and they would prescribe something else to help her.

Twenty-fifth January. I am really struggling to cope now. Last night we had an early night but Suzie woke up at 4.45 am crying and saying she was frightened of the dark. It took around half an hour to calm her and then she was okay again. However, whilst she was having her shower she got upset when she put her head under the water. She became agitated and from then on it was a major job to get her dried and dressed. She was insisting that her panties were not hers and that her jumper and jeans were on back to front, which they were not.

Thirtieth of January. At 2.30 am I got up and went to the toilet. When I got back to bed, Suzie was awake and asked me what I was doing. I told her and asked if she wanted to go to the loo too. She said yes. I pulled back the covers for her but she became angry and asked what I was doing. I told her that she said she wanted to go to the loo but she strongly denied this. I thought that by apologising and saying it was my mistake, this would placate her but it did not. She went right off at me. She got out of bed and started to shake me. It did not hurt me but really scared me. I managed to get her back on the bed and basically hugged her until she calmed down. This, I think, was mainly due to me sobbing in desperation. We fell asleep until 5.00 am when she woke up and wanted to tell me that I was sick and that she would look after me. I thanked her and asked whether we could just go back to sleep for another half an hour. She started to argue again so I had to get up.

Seventh of February 2006. I now have to take showers with Suzie as she hates it and just sobs the whole time. Email to friend: Thanks for all your help yesterday. I am sorry to have burdened you. Suzie has deteriorated further this morning and broke down crying as she did not want to have a shower. I had to take her in the shower with me. It was heartbreaking washing her as she sobbed. It is truly an evil disease.

Twelfth February. Last night during one of Suzie's more lucid moments whilst we were lying in bed, she broke down sobbing and begged me to help her by not letting her wake up in the morning. It was tragic and I felt so helpless. I even counted the number of sleeping pills but whilst there might have been enough for one, there certainly was not enough for both of us and I could not go on without her.

Fourteenth of February, Saint Valentine's Day. Suzie has been admitted to Joondalup Hospital's psychiatric ward after a nasty turn. She never returned home. Email to friend: I saw Suzie today. I wept when I saw her sitting on a chair with her hands between her legs all hunched over. She recognised me and tried to smile. She is so confused and the medication keeps her in a zombie-like state. This is what is planned: we have secured a permanent place in a great nursing home, The Cove, but she must be admitted on Saturday so that she has a room allocated. As the tests at the

hospital will not be done until next week, I am taking her from the hospital to the nursing home on Saturday and then taking her again on Sunday. That way she is registered to that room and short of inciting a riot, she cannot be kicked out. I was later to regret that throwaway line. Next week the brain scans will be done. This will give them an insight as to what else has gone wrong to cause such a drastic decline in her condition. It may also assist in giving a prognosis as to what quality of life and longevity she can expect. At the moment though, I am only interested in the fact that I can spend more time with my baby.

Third of March. Received a call from Peel hospital advising that their social carer arrangement did not cover after 9.30 pm and if Suzie became violent, would I give them permission to use padded hand and ankle cuffs. On the basis that it would minimise the risk to Suzie, and having absolutely no other alternative, I agreed. Thirty minutes after that, I received another call from Peel advising me that they had four staff members restraining Suzie and were attempting to administer sedatives directly into the bloodstream. They had called for an ambulance and she was about to be taken to Fremantle Hospital's psychiatric ward. At the moment I am unsure as to what they intend to do with Suzie because Fremantle is not equipped to handle ongoing violence; yes, they now class Suzie as a violent patient. Unless they can stabilise her within an acceptable time, she will be going to Graylands, which is not exactly the place that we thought our baby would be seeing out her autumn years.

On 7 March, Suzie was admitted to Fremantle psychiatric hospital. Today, I went and saw Suzie for the first time in 10 days due to having to go interstate on business. It was gut-wrenching. She looked so old and haggard and shuffled along. I could not keep the tears back and it took a few seconds for her to recognise me. She had a black eye from one of her violent bouts last week and she moved the top half of her body rather than turn her head at the neck. She is now under the Mental Health Act, which, whilst a formality, confirms that they can hold her against her will. At the last hospital she assaulted another patient. I spent just over an hour with her walking around the small garden they have and sitting for a few seconds before she would get up and gesture to me to do another lap. She mumbled most of the time and it was extremely difficult to understand what she was trying to say. Strangely, every time we sat down she looked at me and with a faint smile said, "I love you." I'm going up tomorrow to see her again and meet her latest doctor.

Twentieth of March. I went and saw the psychiatric team and in a nutshell they asked whether there was a DNR—do not resuscitate—in place. I confirmed there was and referred them to the notes provided to the previous hospital. They also asked to what extent it should go and I said as far as the law would allow. I confirmed that it was Suzie's wish to be an organ donor and that if she passed away and five other people were given new leases on life, she would be very happy. She has moments of aggression but more moments of loving. She would go up to one of the nurses and give them a hug. When she becomes aggressive they simply put her in her room until it passes. She will be in Fremantle for at least another two weeks so we may possibly lose her room at The Cove, which, indeed, we did. During a lucid moment today, she put her hands to my cheeks and said, "How could you let this happen?" I knew what she was referring to.

Fifth of May, email sent to numerous friends: as many of you would be aware, I had to let Suzie go on 15 February this year when she was admitted to Joondalup hospital because the carers were no longer to handle her at home as she was going through the violent stage of the disease. Usually this can be handled because the patient is normally elderly. However, as you all know, Suzie is extremely fit and strong and this caused major problems. In the next few weeks she went to various hospitals but they were unable to handle her and so she was admitted to the secure wing of Fremantle psychiatric hospital where she remains today. She has not recognised me for some time now. It is a gut-wrenching experience and I would not wish it on anyone. Seeing the person you love so much

either with shoulders hunched over pacing the ward or curled up in the foetal position. I asked how long we could expect Suzie to endure this living nightmare—five, 10 or 15 years? The response was like a double-edged sword—so sad but with a sense of relief. I was told that if she was really unlucky, she would have to endure another five years but it was more likely to be two years or even as short as 12 months. As we know, it was indeed the worst-case scenario, another five years.

Fifth of June. Today when I visited, Suzie walked for a few paces and then curled up on the floor in the fetal position for a couple of minutes, then got up and repeated this for the 15 minutes I was with her. She has had four sessions of the electro-convulsive treatment, or elective shock treatment. I kissed her head and she became angry. I try to avoid doing anything that will upset her but if something interrupts her routine or you try to get her to do something that she is not happy to do, she becomes distressed. She is in a permanent state of angst.

Suzie was admitted to Greenfields aged-care facility in November 2006. I visited her every day that I was in the state, sometimes for only a minute, but enough time for me to kiss her, apologise for not doing anything to end her suffering and tell her I loved her. This is the last entry in my journal: Suzie passed away at 3.45 am on 9 May 2011 at the Greenfield's aged-care facility. For the last three years of her life, she was in a vegetative state, which is so demeaning and sad to see.

Finally, this a copy of my letter to *The West Australian* newspaper —

...

I have just lost my darling wife to Alzheimer's.

She suffered terribly for more than seven long years, the last five being in care due to the severity of her condition.

She was still in her 50s when she finally passed away, but right up to when she went into care she would work out, in the gym, at least four times per week.

Her strong heart was what was against her being able to pass away years earlier.

Whilst all other parts of her body were shutting down, her heart would not allow her to pass away.

She was a strong believer in organ donation and the right to choose when she would say goodbye to her loved ones. Sadly, because of our laws, she was unable to experience either belief.

Like so many others who have experienced seeing loved ones pass away, in such tragic circumstances, I call upon our law makers to allow us the right to make such a choice for ourselves.

Now, before I'm inundated with condemnation from Right To Life advocates saying that I'm misguided, I say this to them.

If you have walked in our shoes, I respect your views but please do not tell me how to conduct my life.

[1.00 pm]

How I leave this earth will not affect you in one iota. If you have not walked in our shoes you merely have an opinion, but no experience.

The difference between pro-euthanasia and right for life is simple.

One is stating a view that asks for a choice, for themselves.

The other is forcing a view, and an outcome, on someone else regardless of their views and, in most cases, forces them to die in pain and without dignity.

...

In the meantime our politicians should have the strength to accommodate the wishes of individuals who want the right to choose when to say goodbye, with dignity.

The CHAIR: Thank you very much, Mr Haines, for your evidence and your submission to the committee. It is really important evidence and you cared for your wife for a long time. Suzie's condition was one that is particularly difficult for legislators in this area, I think. In your submission, you have called for legislation that would allow people to end a life at their choosing. One of the biggest considerations around that is a person's capacity to make that decision. Dementia and Alzheimer's, I think, is a particularly tricky area. How could legislators provide that choice for Suzie?

Mr HAINES: I would like this panel to at least come to the conclusion that, yes, there should be some mechanism in there and have some mechanism worked out. The only thing I know about the Victorian state legislation is the fact it is for someone who is terminally ill. Of course, Suzie died of pneumonia, which is the way most Alzheimer's people die. At the time, she was not terminally ill. What I am saying is that we should all have the right to put on paper that if my health gets to a certain state, I wish to choose voluntary euthanasia. Goodness, if you were to go and see Suzie in the hospital curled up or crying—even though she could not talk to you, she would be curled up in the foetal position, crying. That to me says that if, before I get to that state, you cannot work it out, goodness me, there is something wrong. The old cliché: if I kept my dog in that condition, I would be prosecuted. There has to be a way—it might not be a fair way off—of maybe looking at other legislation so that we can come to a point and I can say, "If my condition gets to X, Y, Z, I should be allowed to do that." I am telling you now that if I get diagnosed with Alzheimer's, I am checking myself out. I am not waiting for legislation; I am sorry. I heard about that poor man's mother. I will be doing that, I tell you, because there is no way I am going to go through that—no way!

The CHAIR: Did Suzie have an advance health directive or advance care plan?

Mr HAINES: What is that?

The CHAIR: Did she put on paper her wishes for doctors, essentially?

Mr HAINES: I became her enduring power of attorney, but she made it quite clear to everyone. Two things she got passionate about, especially after seeing some of our friends pass away, tragically, through extended cancer, and that was the fact that she believed in voluntary euthanasia, and also that she wanted to be an organ donor, and that is the thing that is hard—there is no doubt about it. But there was no formal thing written out. The closest thing I had to that was a DNR. I knew she would want that. I have got to tell you the number of times she would wake up at night asking not to wake up in the morning.

Mr R.R. WHITBY: Mr Haines, thank you for being here today and telling us your story. Back in May 2005, when Suzie was first diagnosed, did she express a view about an end-of-life choice at that point? I take it she had capacity at that point.

Mr HAINES: Yes, she started to, but I said that there was nothing we can do. I think she was diagnosed in 2004, not 2005. I noticed when I was going through that there was a contradiction, because when I was talking about the lady who diagnosed her—I think I called her a piece of work or piece of art or something—the dates were wrong. At the time they said that to her, she said, "Well, we have to end it." I said, "You can't."

Mr R.R. WHITBY: You had a discussion of what would happen and how things would —

Mr HAINES: Yes. I was in denial first of all, saying that it would be fine; it will get better. But there was nothing we could do, short of do not resuscitate.

Mr R.R. WHITBY: If we had a law that allowed voluntary assisted dying at that point?

Mr HAINES: We would have signed up straight away, absolutely. But I knew there was nothing there and I tried to get her mind off the grim side of things to, “We can work through it.”

Hon COLIN HOLT: Perhaps I could ask Mr Whitby’s question in a slightly different way. Was there an opportunity between when Suzie was diagnosed, and as progression went on, when she was very capable of making a decision about what pathway she wanted to go down, so if some legislation was available, she knew she had Alzheimer’s and she knew she was going to die from Alzheimer’s, she could have easily done an advance health care directive?

Mr HAINES: Absolutely, but she had lucid moments. In my journal, you will see that if she saw me get upset and I would start sobbing, she would suddenly kick into mothering me. That was in the early stages. In the later stages, she was not capable of doing that. Yes, most certainly. That is why I am saying that for me, personally, there is only one disease worse than Alzheimer’s and that is motor neurone disease.

Mr J.E. McGRATH: When Suzie first got Alzheimer’s, you were obviously very positive because you said, “You’ll come good; we’ll get you right.” Was that your belief or did you know—obviously you know more about Alzheimer’s now than you did then?

Mr HAINES: I watched the movie *Iris*, with Jim Broadbent—I cannot remember the actress—and I tell you what, that was like a handbook for me for Suzie. I knew there was going to be sundowning; I knew she was going to get violent and I was ready for it. With dementia, I thought, okay, we can keep her fit. She was very, very active. Initially, I thought she is not going to be able to go back to work. She was having trouble, forgetting things, and her boss was saying, “She’s not handling it”. So I knew that was the case, and I thought, okay, fine, if we can keep her fit so that it doesn’t get worse; or, if it does, it will be really slow. But as I said in my journal, it just went bang. She was going into the Cove, which is low care, but straight away when she got violent, suddenly, bang, they could not take her so she went to high care. There are mechanisms in place. I would do anything, if there are any panels or anything like that. I believe it would be beneficial for people who have walked in my shoes—there are lots of people; you interviewed them today—who would be able to help and maybe give some guidance. But all I am saying now is that if there was legislation, I could sit down and I would say, “Right, if I ever get to a state where I can’t do boomp, boomp, boomp, boomp”, all of them, not just, “I can’t do that, but I can do them”, there has to be a way of doing it. There has to be a way.

Mr J.E. McGRATH: Further to that, as the chair said earlier, this is a difficult one for legislators to get their heads around or to put in proper processes, because you have a situation where someone has not put in those directives and they are not doing too badly and their family says, “You can maybe recover, or we can work through this”, and suddenly, as in your case, it just happens quite quickly and you are not prepared for it.

Mr HAINES: As I say, if you can put it ahead of time. We know it is not going to be easy. It will be damn difficult and hard. It will take a while to get there. We have to start moving in that direction now. There has to be a situation where you can say that person has gone past that point and their will is that they want to say goodbye with dignity, and that is it. For someone to say, “It’s too hard”—I am not saying that you are saying that—or for legislators to say, “It’s too complicated; we can’t do it; let’s put it on the backburner and concentrate on the environment”, or something like that, is totally, totally wrong. I have had only one discussion with someone who said that I was wrong, and

I invited them to Fremantle to have a look, but they refused. Once you have been through that or seen it, you tend to think, well, okay, maybe there might be something in what they say about voluntary euthanasia, rather than just discount it on religious grounds or something like that. If someone is talking on religious grounds, I will not even enter into a conversation with them because I do not want to change their religion, but they are never going to change my feelings after what I have been through.

Hon ROBIN CHAPPLE: In 2005, Suzie had capacity. When do you think in that journey between 2005 and 2011 she lost capacity?

Mr HAINES: To make a choice?

Hon ROBIN CHAPPLE: Yes.

Mr HAINES: Within months.

Hon ROBIN CHAPPLE: Within a month?

Mr HAINES: It would have been months. At that time she would have said, "Okay, whatever I need to sign, I'll sign it", because she knew what was ahead of her. The one thing we did not know was time. We honestly thought, as I said in the submission, that it would be fairly quick when they said two years or maybe a year, because the mental side was going down so quickly. But the heart would not give up. It just kept pumping, damn it.

Hon ROBIN CHAPPLE: Then back in May 2005, you and Suzie had made a decision, and at that time, because you were not aware of them, if she had made some advance directive, "that if I get to this point". It appears that whilst we are talking 2005 to 2011, in fact Suzie would have been without capacity by the end of 2005 or the beginning of 2006?

Mr HAINES: Yes. She would not have had the capacity. She certainly would not have had the capacity by the time she was admitted to Fremantle psych because you could not communicate with her.

The CHAIR: Mr Haines, you provided some photos of Suzie. Are we able to make these public?

Mr HAINES: Absolutely.

The CHAIR: Are you happy for them to go up with your submission?

Mr HAINES: That second one I did not take. I was very tempted a few times when she was going through an outburst to take a photograph, but I thought no, I will not. That photograph was taken by the nurses. I think they made a birthday card or Christmas card for me. That is the last photograph ever taken of Suzie.

Mr R.R. WHITBY: What was the time period between these photographs?

Mr HAINES: Four years, I think it was.

Mr R.R. WHITBY: It would have been 2004, perhaps, the first one?

Mr HAINES: That was 2004 diagnosed. That is four years after the boat, so that is 2008. Yes, she was like that for another three years, or worse for another three years. She lost a lot of weight from the second photograph. She lost a lot more weight; she was like a skeleton when she passed.

The CHAIR: Is there anything else you would like the committee to know?

Mr HAINES: Do something, please.

The CHAIR: Thank you, Mr Haines, 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. 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 to the committee. Again, thank you very much for taking the time, and I apologise again for keeping you waiting today.

Mr HAINES: You cannot rush these things.

Hearing concluded at 1.13 pm
