

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 TWO

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 10.34 am**Mrs GRYTSJE DOUST****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 and I am the chair of the joint select committee. We have on my right, Mr Simon Millman, Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; Mr Reece Whitby; and Hon Robin Chapple on the far left. The purpose of today's 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 may say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. The audiovisual will be available on the committee's website following the hearing. Could you please just introduce yourself for the record.

Mrs DOUST: My name is Grytsje Doust and I live in Albany. I retired from work a year ago where I was working prior seven years as the PA of the CEO of the Great Southern Development Commission. Prior to that while I was still living in Perth, I was working in event management. I am originally from Holland, the Netherlands. I met my husband, Jon, on a kibbutz in Israel and, to cut a long story short, that is how I ended up in Australia.

The CHAIR: Do you have any questions about your appearance here today?

Mrs DOUST: No. Marion has been very helpful. I have had various emails and conversations over the telephone, so at the moment, no, I have no questions.

The CHAIR: I am happy to hand over to you, Grytsje, if you want to make a statement for the committee.

Mrs DOUST: I understand that the committee would like to know a little bit about my personal experience about euthanasia with my mother. This happened in 2006–07. In 2006, my mother was diagnosed with acute leukaemia. She had been suffering from myeloma for the previous seven years and she knew that at one point the condition could turn malignant, which it did in September 2006. I was in the Netherlands at the time when she was diagnosed. I quickly went back home for four weeks and then came back to Holland because my mother had indicated right from the beginning, after a long talk with the oncologist and her GP, that she would choose euthanasia. The prognosis at the time was she was given approximately another five months. I returned to Holland, I think, towards the end of October and we then started to set things in motion.

The first thing my mother had to do was to make what they call a living will. That was one of the criteria she had to do. The next step was that her GP, who was actually going to perform the euthanasia, had to have a meeting with her oncologist because they both had to agree that she was—even though it sounds a bit strange—a suitable candidate and that her condition was definitely terminal. My mother was 76 at the time and she was told by her oncologist that they had more or less decided in the medical world that to treat her for her acute leukaemia would be quite horrendous. She was given a choice—if she wanted to, they would treat her, but they would actually recommend not to treat her. So she chose not to be treated and to more or less go into palliative

care straightaway. My mother wanted to stay at home; she did not want to go into hospital, so over the coming months, we nursed her at home. Once it had been decided between the oncologist and the GP that she was a suitable candidate, the whole process was set in motion, because of course there is lots of paperwork and legal implications that have to be sorted out beforehand. In the meantime, my mother would have numerous blood transfusions, which, up until about Christmas that year, was giving her still a reasonable quality of life. But it came to a point that that did not work anymore.

[10.40 am]

What happened also was that an independent medical person who was a doctor but also a psychologist came to the house for quite an intensive interview with the family. At first he wanted to speak to my mother alone because he wanted to make sure that she had made the right decision and that there had been no pressure from the family. Basically, we do not know what was actually discussed in that 45 minutes because we were not allowed to know what was happening. Then the rest of the family was asked to come inside and they were the people who would be present once the euthanasia was going to be done. That was myself, my brother and his wife, and my father. It was kind of a roundtable discussion which was quite I would not say harsh, but quite some confronting questions were asked for everybody. I think they did that because they really, really wanted to make sure that there was not any coercion and that my mother had made the decision completely by herself. Of course, we were very concerned about my father. I, for instance, was asked a question, "Do you want your mother to have euthanasia so that you can go back home to Australia?" They were quite in-your-face type of questions. When that was completed, he went away and I think then that discussion was discussed again with the oncologist, probably some other people and the GP. What at the time I found quite interesting was that the GP who was performing the euthanasia—my mother was not his first patient—was a very religious person. I found that in the situation quite interesting. I still to this day regret a little bit that I did not ask him, because he was such a religious person, why he was doing this. Unfortunately, he passed away himself a year later.

When the time came, when the situation was deteriorating and her health was really fading, the biggest maybe issue and the biggest problem for my mother was, although she never faltered in her decision, the biggest decision she was going to make was the time came that she had to give a day and a time that this was going to happen. That took her a long time—that probably took her almost two weeks. Of course neither me, my father nor my family were in a way allowed to talk to her about that—maybe in a roundabout way—because it could not be seen that we were pressuring her in any way, which of course we would not have done. But that was a very, very difficult decision for her and she agonised over that quite a bit. But she did decide in the end and it was going to be a Friday at eight o'clock in the evening. So we advised the GP. He set in motion anything else that had to be organised for that day. What happened was the GP came to the house at two o'clock in the afternoon and he inserted a cannula in her hand. Then he left and he said he would be back just before eight o'clock that night. That day gave us those six hours to gather the family and be with her. She was quite weak at that time. She was ready as well. She had had enough. She was bedridden by that stage and very uncomfortable but very alert. Also, a stipulation was that at any time that that was going to happen, my mother would have to have the mental capacity to say, "Yes, this is what I want."

If, for instance, she had lost consciousness on that afternoon, then the whole thing would not have happened. So we said all our goodbye, which, of course, was very emotional, but she did not waiver. She was amazingly alert and strong. The GP arrived just before eight o'clock. He advised us that there is a person waiting outside in the car who has to be there approximately half an hour before.

He waits and then another half an hour after the procedure is done and then come in the house just to make sure that everything had gone according to the regulations. The GP came and he had to ask my mother, “This is now the time and this is what you want—shall we go ahead?” and at that point she has to say this is what I want. He then put an injection in the cannula. What was quite amazing is how quickly it was because it was a matter of seconds that she just fell asleep. My personal opinion about euthanasia going through these nine weeks with her, the process, the way it was handled by the doctors, the legal profession, the support, it was wonderful and it gave my mother a lot of power because she was in charge. She could say, “No, I don’t want to go into hospital”, “No, I don’t want to do this”, “This is how I want it; I want to be at home, “This is how I want it done with my family around me. I know there is no hope for me, that it is terminal”. It also prevented her to go through those last agonising maybe another couple of days or a week, because that is what it was leading to. It was becoming for her personally, because mentally she was still all there, it became very, very difficult. All in all it was—maybe it is a strange word to say—a beautiful procedure and it gave my mother such peace of mind. We supported her in that. The first four weeks was the hardest for my father because I think up until the last moment he still believed that a miracle would happen and she would get better. We supported it all the way. That is probably more or less where it is at.

The CHAIR: Thank you, Grytsje. We really appreciate you sharing that experience with the committee. It is very important for us to hear the range of experiences people are having. That is very valuable for us.

Hon ROBIN CHAPPLE: One of the issues is that obviously there was quite a bit of process involved. Was that you felt in anyway an impediment or was it a good process? There was quite a bit of time involved, I understand. Grytsje, can you run us through some of that time line?

Mrs DOUST: My mother was diagnosed at the end of September that year. She indicated that she wanted to do this straightaway. I had to fly back to Australia, came back in late October, early November. I cannot remember the exact date. The whole process, there were periods of nothing happening in between for those two months. She died on 6 January 2007.

Hon ROBIN CHAPPLE: If I may, I am looking at the administrative process involved and what the time line was around that, if I can.

Mrs DOUST: It was quite spread out. The first was the living will requirement then the discussion between the oncologist and the GP because they had to ascertain that she was a suitable candidate, if you want to put it that way. Once that was agreed, which we were not involved—any legal paperwork was happening probably outside. Then in, I think, early December, we had the psychologist coming to our home, which was that 45-minute interview with my mother and then with the rest of the family. Of course, the GP would come and visit in the interim. She had numerous hospital visits in the interim because of blood transfusions. But everything else was conducted outside of us. We had no other interaction with other legal people et cetera; that was all done outside from us. But it was agreed and she was approved.

[10.50 am]

Hon ROBIN CHAPPLE: Did that take two weeks, a month?

Mrs DOUST: Depending on the condition, I probably would say if the patient decides maybe two or three weeks before it is possible that the patient might pass away, it can be done in that time line as well. It does not necessarily have to be months.

Mr J.E. McGRATH: Further to that question, Miss Doust, you spoke about the oncologist talking to your mother and the family on the way through. The first advice was life expectancy of about five months after first being diagnosed.

Mrs DOUST: Yes.

Mr J.E. McGRATH: On the way through, was there any further advice that the oncologist said, “Well, if we continue the treatment maybe she could last a bit longer than the five months”, or was the advice, “No, it’s going to be futile”?

Mrs DOUST: He was pretty spot on because I think by the time she was diagnosed, the leukaemia had already been there for a couple of months. I remember when I arrived the first time in August 2006, she was already quite ill. We visited him around that time and really the official diagnosis and paperwork did not actually come through until I think it was at the end of September. She had the blood transfusions, which gave her a bit of quality of life, but she came to a point, the body just did not accept the transfusions anymore and then nothing was being done. She had no treatment after that at all. It was just left to run its course. She was at home, we nursed her at home the whole time.

Hon NICK GOIRAN: Mrs Doust, thanks for coming and speaking to the committee. Just one question for you; the GP gave your mother the injection on her last day, do you know what was in the injection?

Mrs DOUST: I am not really sure. I did not ask at the time. I was surprised at the speed of it. Apparently, it is two substances. One puts her almost in an instant coma and then something happens then—the heart stops. I would imagine that it would have been barely noticeable by my mother, it was so quick.

Mr R.R. WHITBY: Mrs Doust, you mentioned in your submission that your husband’s family members have quite a different end-of-life experience. Can you explain a little about that and why they chose such a traumatic option?

Mrs DOUST: My husband is Australian so there was no other choice for them then to go through the process. John’s father died of melanoma and his mother died of a heart condition. My father, he passed away two years ago. He had terminal bowel cancer. He would have had the option knowing that his wife had chosen euthanasia and the option for him was there as well. I had that discussion just briefly once with my father. Even though he had seen how it benefited my mother, he could not do it. He outright dismissed it for himself.

Mr R.R. WHITBY: You mentioned your husband’s uncle and aunty.

Mrs DOUST: Yes, absolutely. I do not know whether you remember the case in 2014 in Albany. That was John’s aunty and uncle. Jean was his father’s sister and her husband. They were in their early 90s. Jeff had severe Parkinson’s disease and Jean had multiple sclerosis and was partially paralysed on one side. They committed suicide.

Mr R.R. WHITBY: Can you tell me what impact that had on their family?

Mrs DOUST: Absolutely devastating, yes. It is four years ago, but it still runs emotionally in that family very much so because it was so unexpected. I believe that they had contacted a group earlier that year and, of course, nothing could be done. To make that decision was, for the family, dreadful because I am sure John will not mind me telling you, and perhaps you know, they shot themselves and that for the children to find was terrible. I think if they had been given the choice because their bodies were completely a mess but they were mentally so alert. They refused to go into care, they wanted to stay at home. That is my personal opinion, of course, but I feel if they had been given the choice of euthanasia—I am very much in favour of euthanasia and not just because of the experience with my mother—it would have been a good outcome for them but in a sense also for the family, because the family has to live with this idea in their minds for the rest of their lives of how they ended their lives.

The CHAIR: Grytsje, I refer back to the experience with your mother. Your mum made this decision. Did she have access to good palliative care at the end of her life?

Mrs DOUST: Absolutely, yes.

The CHAIR: So it was not a decision made because she felt she could not necessarily access the services that she needed to access.

Mrs DOUST: No. That in the Netherlands is excellent. You have the choice. Everything was at our disposal. It was literally a matter of picking up the phone and the help would be there. We had to get a special bed in the house, of course. With the leukaemia, she was not in pain so until mid-December she was still mobile. We managed to take care of her ourselves between my brother, his wife, my father and me. Fortunately, they were living next door to an ex-nurse who had just retired from an aged care home and she would come to assist us, to help us as well. Whatever we wanted was just a matter of ringing and that was told to us by the doctor. Whatever we needed, we could get if necessary.

The CHAIR: Did you feel as a close relative that the process could be opened to abuse or misuse by other relatives?

Mrs DOUST: No. I cannot see that happening because it is very strictly controlled. I believe the final legislation in the Netherlands did not come through until 2002. I believe that in a sense it is still a criminal act to do euthanasia and just about all the legislation has been created around it.

[11.00 am]

At that time, anyway, it could be used, especially with the psychiatric assessment of the family, because they are obviously very conscious of coercion maybe by family members et cetera, yes. It is very strictly controlled.

Hon NICK GOIRAN: Mrs Doust, I am interested to hear you say that your mother had access to palliative care. In Western Australia, I am the co-chair of the Parliamentary Friends of Palliative Care, so I have a very keen interest in this area. What palliative care did she have access to?

Mrs DOUST: We could have asked for a live-in nurse who would have come to the house. If we felt that we were not managing, we could have requested a nurse to come and stay. We could have asked for people to come to the house to wash her, dress her. Even if we needed assessment in an emotional sense, we could have asked—there is a bureau, so it was always a phone call away in a sense. Of course, she refused go to the hospital. She insisted that she wanted to stay home.

Hon NICK GOIRAN: Would there have been any cost in the event that the family had to ask for the live-in nurse?

Mrs DOUST: No.

Hon NICK GOIRAN: Thanks.

Mrs DOUST: Also, which I forgot to mention, after the procedure was done, the person who was outside waited for half an hour, and then he came inside, and the GP was still in the house as well, because he then wanted to ascertain that everything had been done according to the rules, so we had to answer questions, the GP had to answer questions, and documents had to be signed. It is not just that it happens and then we are left. A person straight away comes to make sure that everything has been done properly.

Hon COLIN HOLT: Hi, Grytsje. Was mum in any pain, or how was that managed?

Mrs DOUST: No, she was not. With acute leukaemia, in her case, she had no pain. Once the blood transfusion stopped, she had extreme fatigue, weakness, and she was losing a lot of weight but,

fortunately, she was not in pain, no. But leading up to the day, yes, she was getting very weak and it was starting to get ugly.

Hon COLIN HOLT: Thank you.

Hon ROBIN CHAPPLE: Thank you very much indeed. In relation to the palliative nurse that you could have had, is that provided by the state?

Mrs DOUST: Yes, I think it is. You have all these organisations, probably similar to Silver Chain, that you can call on and that will be provided if a patient is being nursed at home.

Hon ROBIN CHAPPLE: You did say that that nurse could have been live-in?

Mrs DOUST: Yes; I believe so, yes.

Hon ROBIN CHAPPLE: That is quite different from our Silver Chain or systems.

Mrs DOUST: Yes. That would of course depend on the circumstances as well. If it was a situation with my mother and just my father, who was elderly at the time, who was not coping. My mother wanted to stay at home. If there was no other person available to stay overnight, then that would have been provided, yes.

Hon ROBIN CHAPPLE: Lovely; thank you.

The CHAIR: Are there any further questions for our witness? Is there anything else you would like us to know, Grytsje?

Mrs DOUST: No; I would just like to say that I am very pleased that there is such a committee now which is looking into perhaps legislation in WA and, hopefully, following the path of the state of Victoria and maybe in the future the Netherlands, Switzerland and Canada.

The CHAIR: Thank you very much for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of 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. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. Thank you very much for your evidence this morning. We really appreciate you taking the time to talk to us, Grytsje.

Mrs DOUST: Thank you. I was very happy to do so.

Hearing concluded at 11.04 am
