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 SEVEN

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 2.33 pm

Mr WARNAR SPYKER
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 Mr Simon Millman; Hon Dr Sally Talbot, who has just stepped out; 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 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 does not apply to anything you 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, and the audiovisual recording will be available on the committee's website post the hearing. Do you have any questions about your appearance today?

Mr SPYKER: No.

The CHAIR: Before we begin with our questions, did you want to make an opening statement?

Mr SPYKER: Sure; I will just say a few words. Firstly, I would like to thank you very much for the opportunity not only to make a written submission some months ago but also, to my surprise, to be called up to give evidence. I had not expected that, but it was a really pleasant surprise and it is a real privilege to be able to share my perspective and my own personal story. I think death is a very difficult subject to discuss. It is a very harsh reality to face. In some ways, I think it is because death is unnatural. We were created or made to live. I think all of us accept that life has an intrinsic value. That is why facing death is always a difficult space to come into. I, myself, was faced with it at a fairly young age, as you might have seen in my submission. It was certainly a very difficult process to work through.

I will say just a few words about my personal story. I had been married for six years when my first wife, Eloise, was diagnosed with cancer. At the time I had been working some years as a solicitor and I think two months previously had commenced my own firm in partnership with someone else, so this was a huge blow. It was unexpected. We had two young children at the time—two boys aged one and three. When she was diagnosed, it had already spread; it was secondary to the liver. The situation seemed particularly dire at the start, but with the chemotherapy treatment her condition stabilised to some degree. She was in remission for probably about four to five months or so, and then the cancer came back. That was probably about 10 months into the disease. At that stage I think we knew that when it came back, it would be terminal. It was an aggressive form of cancer. Really, from that point on we were facing the reality of death, and of life without her. We tried various options for treatment. We tried chemotherapy. We tried radioactive spheres, which at the time was a fairly new form of treatment. All of those helped for a short period, but in the end the cancer continued to grow.

The total journey, from the very first diagnosis up until the time she passed away, was about 16 months. That last period, I can certainly say, was a difficult period. It was difficult for her and difficult for us. We saw her role in life change. She was obviously a mother of two young children. She was

a wife. She was a chartered accountant. All those things slowly but surely dropped away. I must say that we really saw our role around her as supporting her. That was really what we were called to do. She was vulnerable in many ways, I suppose. She did not know what the future for us was going to be and was concerned about that. The last month was in and out of hospital.

[2.40 PM]

I have always been very thankful for the medical care that was available. It was superb. Every time we needed it, we could get a doctor's appointment. About the last two weeks she would have been in the Mount Hospital. During that period she finally came to peace with the fact that she was going to pass away. I remember—it was less than a week before she passed—that one time she said to me, "I'm ready to go and be with the Lord." That was an amazing peace that God had given to her. I remember saying to her, "Well, I'm not ready." I did not feel ready at that time. A couple of days later she slipped into a coma. She was obviously receiving some form of pain-relieving medication—I do not know exactly what. She had had some agitation prior to that. She went into a coma. At first we did not even realise—it was some hours later. We thought that she might just be napping, but then we realised she was in a coma. For four days she was in that coma. I stayed in the hospital the whole time. It was a strange time of life. I slept in the room. Every morning I woke up and there she was still alive, and so we lived another day. That four days, for us around her or at least myself, was actually really a time to come to the realisation of what was going on. At the end of that four days I was ready—as ready as you could be—and really at peace with what was happening. I saw that last sort of stretch as God's way of making us ready, even though she was in a coma. As I said, during that period she was not in any distress. All of a sudden she breathed her last, and that was it. I must say that my first thought at the time was that I would like to go where she was going. I had a strong conviction that she had gone to heaven. I thought that would be nice. But then you recognise that you are not and that you have a task. I had two young boys, obviously, to care for. In the succeeding 13 years, we have been very blessed in many ways and really moved on with life.

It has actually been an interesting week as I have reflected on this, because I do not spend a lot of time thinking about it. When I got the call from the committee, I thought it was good to focus on it and to remember the blessings as well. As I see that last stretch—those last weeks—it is actually beautiful memories that I have of that period. That is a period where we could support her and she could support us. I firmly believe that God, in his time, took her life. For me, one of the main issues with euthanasia—it is not the only issue—is that terminally ill people are very vulnerable. They feel like they are a burden. They feel dependent. They feel they are not contributing anything positive anymore. It is for us, as family members and the wider community, to surround them with love and to say, "You are not a burden. We are here for you. We are here to care for you. Your life is important, right down to that last moment." As I said in my submission, I think the strength of a society lies in how we care for its weakest members. If there is a message given that, okay, you do not have any prospects of much life left so it is not worth living anymore, I recognise that not everyone is going to take that choice, but the message is there. In a society where there are many vulnerable people, suicide is an issue. Everyone who would face it cannot see a way forward. It is for us as a community to surround them and show that there is a way forward and we are there for you. Those are certainly some of my thoughts and personal experiences that I wanted to share with the committee. Thank you very much for that.

The CHAIR: Thank you, Mr Spyker.

The CHAIR: Thank you Mr Spyker. We appreciate you coming to speak to us, particularly about something you perhaps have moved on from and that brings you back to that time, so we acknowledge how difficult that can be for a number of witnesses. It sounds as though, despite the

trauma of your wife's diagnosis and illness and the impact it had on your family, that her passing was well-managed under palliative care. Is that pretty accurate?

Mr SPYKER: It certainly was. I can certainly say that the medical treatment was superb and at no time was she in any particular distress. I certainly had no issues with that at all.

Mr J.E. McGRATH: On that subject, you said your wife just drifted off into a coma. Was that induced? Was there any treatment given to help her go into that state or was it just natural?

Mr SPYKER: Yes, I think it was natural. She was obviously receiving some form of pain relieving medication, but there was nothing to my knowledge that induced the coma. In fact, I remember we were sitting there on a Sunday and chatting and eventually she stopped chatting and we thought she was sleeping. The following morning, a Monday morning, I woke up in the room and thought I would go and make a cup of tea, so I walked over to her bed and said, "Would you like a cup of tea?" She opened her eyes and said, "Yes, please", and then closed them again, and those were her last words. So when I say "coma", she was effectively sleeping, woke up momentarily, and then for the next three days, I think, stayed in a coma.

Hon ROBIN CHAPPLE: Was your wife in considerable pain leading up to the point of the coma?

Mr SPYKER: She was in quite some discomfort. She experienced a lot of fluid retention, fluid build-up, around the abdomen and that was causing quite a bit of discomfort. Perhaps it was the pain relieving medication that caused it to be bearable—I would say it would have been, because at times there was talk about, "Let's have some pain relieving medication in order to make her more comfortable."

Hon ROBIN CHAPPLE: Do you know if she was on what we call a pump, which is where they actually provide the medication by a tube?

Mr SPYKER: I must say that at the time I was not completely across exactly what she was —

Hon ROBIN CHAPPLE: Usually it is a sort of box that sits over to one side.

Mr SPYKER: Yes. She was certainly on an IV drip; I think that was more just for fluids.

Mr R.R. WHITBY: Mr Spyker, this is 13 years ago now, I understand. Did your wife have an advance health directive, or had she discussed what she wanted to come from her end of life at all?

Mr SPYKER: No, she did not have an advance health directive. I am not sure if that legislation had been passed at that stage; I do not think so.

Mr R.R. WHITBY: She was diagnosed with a terminal condition, and it sounds as though her pain was quite minimal compared with what other patients can endure. Did you have a discussion with her about what her options could be in terms of pain relief or how she would cope with what could have been quite a painful end of life?

Mr SPYKER: I do recall that as being a difficult subject of discussion—death always is, and certainly at a young age perhaps even more so, because it just seems so unnatural. We spoke to some degree about my life after death, where that would go, and what she was comfortable with, in a sense. We did not talk specifically about any pain relieving options; I think we were always just very comfortable and confident that the appropriate medical care was available. I do recall one discussion with the specialist, and this was during the period while she was in a coma, about resuscitation. Myself and the specialist agreed that there would be no point to resuscitating, simply because we knew it was an advanced cancer. We had the discussion and I said, "No, I am fully comfortable that if she passes, we will not resuscitate."

Hon COLIN HOLT: I think you might have answered my question, which is really about the time when you were in discussion with the doctors and your wife about futility of treatment. At what point did you get to the point where you go, "Let's just make her as comfortable as possible", and what sort of decisions you made after that point?

Mr SPYKER: I remember the treatment options being quite a tricky discussion in a sense. You always want to have hope, I guess, that the treatment will work. She was 32 years old and in many ways had her whole life ahead of her. But at the same time, you sort of face this reality of, "Well, it's going to get worse." It was sort of a unique condition in the sense that the cancer that was diagnosed was secondary to the liver, and the primary site had never really been identified until right at the end, being bowel cancer. I do recall that even in those last few weeks we were still considering options about bowel surgery or some form of treatment, but I think that was to some degree perhaps ignoring the larger issue—that the secondary had taken over. I would say it was really only a matter of weeks before she passed away that we said, "Look, there's no useful purpose to be gained by any further treatment." I think we just really accepted that it was the Lord's will that she was going to be taken, and she was at peace with that at some point. I think that would actually be the time, when the treatment finished, when she said, "I'm ready."

Hon COLIN HOLT: Thank you.

Hon ROBIN CHAPPLE: You mentioned that death is difficult to discuss. What do you think drives people into that area where it is difficult to discuss? Is it just something you do not want to talk about? I have heard of it before and I am trying to work out why death is difficult to discuss, so, as you mentioned it, I just thought I might ask you.

Mr SPYKER: I personally think it is because we have been created to live, and in that sense life is about life and death is a result of sin. It is unnatural, in a sense, although we all know that we are not going to live forever—everyone knows that, so we all have to face up to it. I come across it a fair bit in my line of work as a lawyer. I do quite a bit of estate work—wills and EPAs, and sometimes, quite rarely, advance health directives; only a couple a year, really. I did some wills recently for people who were in their 70s. They had never done a will before and I think they had just always sort of put it off. I do not know; I am not sure why.

Mr R.R. WHITBY: You said you have helped clients fill out an advance health directive and that it is very rare. We are trying to work out why. We think we know and have a good idea. How do you find it? Do you think it is a very cumbersome document to sit down and go through? Do you have any advice on how it can perhaps be improved?

Mr SPYKER: It is a fairly lengthy form and needs a lot of signatures on it. Normally, the substance of it is fairly brief. Normally, the substantive lines are just, "Do not resuscitate" or "Do not unduly prolong life in the event that there is no prospect of quality of life", or something to that effect. I think a lot of people are just comfortable, perhaps, that others will make those decisions when they come to that point in their life. They do not see a real need themselves to have to go into that territory and to have to think about, "Well, if this happens, then that will happen." In order of how common these documents are, in my experience the advance health directive is the least common, and the enduring power of guardianship more so, which is effectively to say, "We'll leave it to someone." We do lots of wills, and I think most people think, "Oh, my executor will deal with that when they have to", although of course I tell them, "The executor's not dealing with you while you're alive", but often the executor is also the next of kin, and they just think, "Oh, the next of kin will make those tough decisions." Perhaps it is partly the unpredictability of it, because there are a lot of different scenarios that might happen, and rather than consider all of them, they just say, "I'll leave it for someone else to make that decision."

The CHAIR: Mr Spyker, thank you very much for taking the time to give evidence to us today. A transcript of this hearing will be forwarded to you for correction of transcription errors. Any such corrections must be made and the transcript returned within 10 working days. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. Thanks very much for taking the time to come and give evidence today.

Mr SPYKER: A pleasure, thank you.

Hearing concluded at 2.55 pm