

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Mornington — 29 October 2015

Members

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Witness

Mr Tom Valenta.

The CHAIR — Mr Valenta, thank you very much for being with us today, and thank you for filling this current spot. We do appreciate it. Before I invite you to make some opening remarks I will just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with a proof version of the transcript within the next week, and the transcript will ultimately be made public on the committee's website. We have allowed approximately half an hour for our time today. Again I would like to thank you for being here with us. After you have made some opening remarks, the committee will have questions.

Mr VALENTA — Thank you, Chair. I am very grateful for this opportunity. I am also delighted that the committee is examining this end-of-life choice topic; I think it is time. My reason for being here is that I lost my wife, Marie, to Alzheimer's disease in 2009. She was 54 when diagnosed, and she died at age 61. Soon after being diagnosed her ability to communicate was severely reduced by a condition called dysphasia, which is common with many forms of dementia. This gradually developed into aphasia — a total inability to communicate. For about the last 18 months of her life — she was in a nursing home for nearly three years — she was in either a semi-vegetative or a vegetative state, so communication was obviously non-existent.

Back in 2003 when she was first diagnosed we became involved with Alzheimer's Australia, worked as advocates and did a lot of publicity and that sort of thing. In 2007 a book I had written, a memoir, was published. Sorry; I have only bought four copies. I did not realise we would have five people.

The CHAIR — No, that is okay. We can share.

Mr VALENTA — You will see that it is not just our story but the story of 13 other families who were going down a similar road.

From my personal experience and from the anecdotal evidence gathered while researching and writing my book, plus ongoing voluntary work with Alzheimer's Australia Victoria, I submit that there is a need to reform legislative and regulatory matters for these particular end-of-life issues. Firstly, the advance directive. I would like to see the advance directive given the same legal status as a will. I would like to see the advance directive be made freely available in a simple, clear format, such as the enduring powers of attorney and guardianship, simply because most pro forma documents that I have on my hard drive are complex and difficult to follow, and finding them online, as was mentioned earlier, can be quite a challenge. One exception is, I think, the South Australian department of health's, and I am happy to say I had some input into that. It is just a four-pager — it is simple to follow. If the advance directive has clear legal status, dementia sufferers and others who are unable to articulate their views as they approach end of life will have the opportunity to make their desires clear while they are still *compos mentis*.

Second topic: pain management. When Marie was in a nursing home in a semi-vegetative and then a vegetative state, there were times when she was clearly in pain or distress. Professional staff agreed with me that her facial and body contortions indicated her distress, and yet they were reluctant — very reluctant — to administer additional pain medication for fear of her dying and the potential loss of accreditation for the nursing home. Doctors who I consulted, and there were three, were also initially reluctant to increase her pain medication for fear of being embroiled in a coronial inquiry. One doctor said to me, 'It only takes one person to complain, and I can't be looking after my other patients because I've got a coroner's inquiry to be attending'. Finally her pain relief was increased, because I stamped my foot for long enough, and she was clearly pain free for the last five or six months of life. Her death certificate says she died from a chest infection and Alzheimer's, so the connection between pain medication and death cannot be established, and even the loopy people would not try.

What kind of system is so inhumane that it deters health care professionals from administering appropriate levels of pain relief for fear of a bureaucratic or a legal backlash? Surely we can amend, streamline, update current laws and regulations to cover this kind of situation. I know I am not the only person who has brought this type of scenario to you.

Three: Marie's death has made me more mindful of my own mortality. I have articulated my views to my three adult offspring and their spouses and will state in my advance directive that I have no wish to have my life prolonged when I have zero quality of life. So a request for physician-assisted dying, or whatever is the most pragmatic, will be in my advance directive.

As a footnote, let me say that there was one wish of Marie's that I was able to honour. We both committed ourselves to organ donation or donorship many, many years ago, and therefore I donated her brain tissue to the Victorian Brain Bank Network. I mention this for two reasons: brain tissue may hold the key to finding the causes of Alzheimer's and other forms of dementia, and two of my six grandchildren live with the genetic life-threatening condition cystic fibrosis. For people with CF, organ transplant is a common life-saving and life-extending procedure. I suspect that if advance directives do become more common, one benefit just might be an increase in organ donation. How often do we hear the loved ones of people who are dying say, 'We don't know what their wishes are in this regard'? I think organ donation could be a real plus if we can get advance directives proliferating through the community. Thank you.

The CHAIR — Mr Valenta, thank you very much for your evidence and again for sharing such a personal story, and congratulations on writing the book that you have presented to us — thank you for providing those copies to us. You mentioned the South Australian department of health pro forma has a simple plain-English advance care directive. Do you know whether, by having such a document in a more accessible, easy-to-understand format, that has led to an increase in take-up of advance care directives?

Mr VALENTA — I do not know. I met the lady who was the senior officer with the department of health when I was working with the Consumer Dementia Research Network, and she asked me to review it. The one that she presented was just about 20 pages. I said, 'You've got to get it shorter'. They were going to take it to COAG and see if they could get it accepted nationally. I am afraid I lost contact with this lady. I would be more than happy to follow up if you think it could be helpful.

The CHAIR — Through the secretariat we might have this discussion. That would be useful.

Mr VALENTA — A point was made earlier, and I have come across it as well. I think I have addressed every Rotary club in Australia with this, and I have done one on cystic fibrosis as well. I hear commonly, 'I'm not computer literate. Where else can I find one?'. At many good nursing homes on the front desk is your enduring power of attorney, your guardianship, but no advance directive. That is just one way we could do it, and I think it would work really, really well.

Ms PATTEN — Thank you, Mr Valenta. It looks like there are some really beautiful stories in there.

Mr VALENTA — Thank you.

Ms PATTEN — We have been talking about advance care directives and specifically for people with dementia the issues that arise. Much of our conversation has been about a directive that people can change, so it is a living document. So zero quality of life might mean something when you are 30, but it could mean something very different when you are 70. Even Alzheimer's Australia, the Victorian branch, noted that there was some difficulty in honouring an advance care directive for a person with dementia. Do you have similar concerns to them? If your wife had set out her advance care directive when she could, do you feel she would have kept to that?

Mr VALENTA — Yes. That is one of the very lively ongoing debates I have with Maree McCabe, and I hold her in the highest regard — do not get me wrong.

Ms PATTEN — Likewise.

Mr VALENTA — We all change our mind — we all change our direction and our desires — but what you do when a person is in a vegetative state if they have expressed a desire when they were still able to? One of the good things that Marie and I did was while she was still *compos mentis* we went to our solicitor and we drew up an enduring power of attorney, we drew up enduring guardianship et cetera. At that stage I was totally oblivious to advance directives, and I think most of the community was as well. So, yes, I understand it has got to be a living document, and I do not have a problem with that, but there is a point at which to say, 'Okay, this was last updated when our loved one was capable of doing it, now we must take it forward'. She was a practising Catholic; I do not think she would have considered voluntary euthanasia, but she certainly feared pain and suffering. All she would have wanted was to have that controlled, and I had to get the iron bar out to make it happen with the medicos and with the professional staff at the nursing home.

Ms SPRINGLE — Thank you for your very powerful testimony about your story. We have heard a lot of testimony around not just advance care directives but about the culture — our culture and our lack of will to talk about death and dying openly and how it is very important that that happens very early — and also on another note how health professionals and medical professionals do not really encourage it. I would be interested to hear your response to that from your personal experience and also from the research that you have done to create your book.

Mr VALENTA — Can I lighten the mood for 1 minute. My older boy, Paul, who is the family comedian, I said to him at one stage, ‘Look, if I just get to the point where I’m just totally useless to everyone, take me out the back and shoot me’, and he said, ‘It’d be a great pleasure, Dad, but you’re not worth going to jail for’. I understand the complexities and I understand the nuancing and all of that. I just feel that with the advance directive, where people have that option and want to take it up and have the conversations with their families, it should have the power of a will — the legal power. I understand that in common law it can be upheld. I am not a lawyer, I do not understand — but I know the difference between common law and statute, obviously — but if it had the power of enforcement or whatever you want to call it, I think we would just be so much better off and people would not stand around a bedside saying, ‘What the heck do we do next?’. Does that — —

Ms SPRINGLE — No, not really.

Mr VALENTA — Sorry.

Ms SPRINGLE — No, that is okay. It is very valid, but my question is more around how we encourage people to start having these conversations. It is one thing to have a framework legally there that is binding, and that is very important, but what we are hearing time and time again is that there is no real will to have the conversation to begin with with your medical practitioner, with your family, with your loved ones — that it is not really something that people want to talk about.

Mr VALENTA — That has not been my experience as a public advocate. When I go and give a talk at a Rotary club or a Probus club or something like that, my first question to them before I start my talk is, ‘Hands up anyone here who has got a loved one or had a loved one, or someone close, who’s living with some form of dementia’. Half the hands go up — at least half the hands — and you get people coming up to you after it, saying, ‘I’ve got this situation. What do you suggest I do?’. I say, ‘Read the book’.

Ms SPRINGLE — But are they wanting to talk about end-of-life choices in particular, and, from what you hear, is it something they are talking about with their doctor?

Mr VALENTA — With their doctor — I am not at all sure. There is a general, widespread belief and understanding in the community that dementia is a one-way road, that we are still nowhere near holding it back, curing it — call it what you will. It is still so far away, so people understand that it is a terminal condition. So the conversation, when they have a loved one who has just recently been diagnosed, seems to me, from my anecdotal experience only, to certainly progress down that road — ‘You realise this is going to end in tragedy, don’t you?’.

It happened way back: it is not to do with dementia, but when my father was diagnosed with angina the GP took Marie and I aside and said, ‘You realise this only goes one way?’. So we started preparing ourselves. Yes, it took eight years, and since 1992, when he passed away, there have been a lot of advances medically and scientifically, but in dementia — nothing. So when you get to understand that this is a terminal condition and that it is going to progress — every case is different, as you would know, but it is only going to progress to one outcome — then I think conversations are more likely, and highly likely, to be held.

Mr MULINO — Thank you. I totally agree with you that if we go down the path, and I think we should, of making advance care directives or similar documents more widely accessible, we need to make them simpler. I think with wills we have seen a lot of progress over the last couple of decades, where they were unnecessarily unwieldy when, really, most people just care about how much goes to the kids or the grandkids, and you do not need 20 pages of gumpf.

Just in relation to that, we have heard some evidence from people working in that area that they think the best way to simplify advance care directives is to make it values based or principles based rather than trying to get into all the specifics. Interestingly, one of the questions one of the researchers posed was around, ‘When my

quality of life gets too low, take me out the back and shoot me. Agree or disagree?', and eliciting a response from the person. Do you agree with that broad principle — that if we make these documents simple, they should try to get the person's broad values and the principles that they think should go in them?

Mr VALENTA — I do, and in fact, after being tipped off by Lilian, I went in and did a MyValues study myself, so thank you. Yes, I think it is a really good place to start — a very good place. 'Take me out the back and shoot me' — I did not see quite that scenario, but, yes, it gives a family a very clear picture, if they do not have it already, of where their loved one stands on end-of-life issues. I am hoping that mine will be a valuable tool for them.

Mr MULINO — Yes, thank you.

Mr MELHEM — Thank you again. On dementia, I was just saying to earlier witnesses that I am actually dealing with it at the moment — my mother-in-law suffers from dementia. She is about to turn 90, and we could not find her directive for care the other day when the ambulance came — the advance care plan or directive. That zero quality — how would you come to that conclusion in that situation? I was faced with that on Tuesday. She bounced back, she is not in pain and she is comfortable. Do we look at the pain management, which you talked about in your case and in Marie's case, where it is sort of managing the pain and then slowly going, versus what some other people might argue, 'Look, I want to make a decision. I want to take a pill and go'? How do you balance the two? Especially with our family; we now have to make a decision in a dementia case.

Mr VALENTA — Look, what I have learnt with my time so far with Alzheimer's Australia is that every single case is different. We know every case is different. In our case, when Marie went into a vegetative state, her day was being taken out of her bed, hand washed by the nursing home staff and put into one of those tub things — one of those recliners — where she lay all day, every day, for months. She did not recognise anyone who walked into that room. She did not respond to any sort of stimulus. I asked that she not be force-fed, and they agreed to that after my GP co-signed my written request. In her case it was pretty clear that there was zero quality of life.

As far as your mother-in-law goes and as far as other people whom I am aware of go, it is such a difficult call, and I wish I could give you a straight answer, but I cannot. I know that when people enter a state where there is no reaction, no response, where the only feeding that is done is force-feeding or spoonfeeding — whatever you want to call it — then can you point to anything that indicates quality of life? But where there is some cognition, where there is some recognition, where there is a little bit of communication between that person and another, then, yes, erring on the side of caution would be my position, I suppose.

Mr MELHEM — Obviously you have done a lot of work and that is great, and I admire the work you have done, but just on that subject, what practical changes would you, let us say, see the Victorian government implement? We are doing that review, and the government is doing some work. From your experience, in dot points, you talked about giving the advance care directive the same status as a will, but in practical terms, in dot points, what would you like to see changed from your own experience? I know some of it might be repetitive.

Mr VALENTA — Okay. The advance directive, I think, is fairly straightforward. In terms of pain management and in terms of the way regulations govern nursing homes, I would like to see those reviewed to see whether they can be updated or modernised or whatever you say. If you walk into any nursing home, and I have walked into a few, and just have a joke with them and say that you are there to check their accreditation, they go into total panic mode; they go into meltdown. I have seen it done. I have not done it myself, but I have seen people do it just for the fun of it, and goodness me!

So can we streamline — can we look at humanity? Of course we do not want to see people treated appallingly. You know, I am an old journo. That is where you see the headlines — you know, kerosene baths and all of that sort of nonsense. But there has to be a way of streamlining the way it is done so that people can, with a very simple device or process, say, 'Tick! Yes, this person is suffering. We can give them extra pain medication'. If one GP says, 'No, I won't touch her, because of a coronial inquiry', well, do we have a list of three or four other GPs? So a simple procedural thing, I think, could be achieved to make it easier. I am talking about division 1 nurses and care managers in nursing homes. I am not talking about people who are there just to clean floors and give people baths and things; I am talking about professional healthcare people. So I would like to see the whole process reviewed. Let them come forward, the main players — the Bupas and these sorts of people — and make

submissions on how they could balance their duties and responsibilities more easily and more readily. Does that answer the question?

Mr MELHEM — Yes, that is very practical.

Mr VALENTA — I would like to see that spread out to the GPs as well, because when I researched that book, so many people said they were so disappointed with the reaction of the GP in diagnosis and in treatment, and yet we know it is the coming economic and social tsunami.

Ms PATTEN — I know that Alzheimer's Australia in Victoria is doing some great work on pain scales to assist with that. If I could go back to the advance care directive, currently the general idea of them is as a refusal of treatment document, so, 'Don't give me antibiotics if I'm at this point'. Do you think there is room in an advance care directive to be more proactive — say, 'If I get to this point, I would like some physician assistance with dying'?

Mr VALENTA — Yes. But again, make it a person's choice. I think that is the underlying thing, though. Marie was a practising Catholic; I am agnostic. We never had an argument about religion. Everything else, sure. So make it a choice.

Mr MELHEM — You never won an argument, did you?

Mr VALENTA — I drew a couple.

Ms PATTEN — So, yes, you think we could have a more active voice in that directive?

Mr VALENTA — Yes, and that comes through when you read and go through the MyValues thing: 'Would you in this circumstance want this?'. I think that is great; it is a pragmatic and logical process to follow.

The CHAIR — Is there anything further you would like to add before we close?

Mr VALENTA — I would just like to thank you all very much for hearing me and for proceeding with this. I am hearing nothing but fabulous feedback from everyone I speak to — Alzheimer's and various other organisations — about the work this committee is doing. So please keep going!

The CHAIR — We appreciate that, and we appreciate your evidence today. Thank you very much.

Witness withdrew.