

CORRECTED TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Melbourne — 15 October 2015

Members

Mr Edward O'Donohue — Chair

Mrs Inga Peulich

Mr Daniel Mulino

Ms Nina Springle

Ms Fiona Patten

Staff

Secretary: Ms Lilian Topic

Witness

Associate Professor Charlie Corke, Intensive Care Specialist, Deakin University.

The CHAIR — I declare open the Legislative Council’s Legal and Social Issues Committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome Associate Professor Charlie Cork, intensive care specialist with Barwon Health and the vice-president of the Australian and New Zealand Intensive Care Society. Professor, thank you very much for joining us this morning.

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 proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee’s website. We have allowed approximately an hour and a half for our session today, including your presentation, as well as walking you through our own material. I would like to again welcome you. Thank you for being here, and we look forward to your presentation.

Visual presentation.

Assoc. Prof. CORKE — I thank you for inviting me to present to you. I am extremely pleased that this committee is investigating these issues, which are very complex and important issues. I think that perhaps the most appropriate thing for me to do for the committee would be to go through my presentation and then to answer questions, which will elucidate the things that you are interested in, together with the things that I have presented to you.

My interest is in understanding personal values and the values of individuals as they relate to end-of-life decision-making, and this is predicated on an understanding that the decisions about escalating and de-escalating treatment at the end of life are extremely complex, extremely emotional and extremely difficult. They are difficult for patients, they are difficult for families and they are difficult for doctors. They have profound implications because over the last decades our ability to prolong the end of life is massively more than it was just a few decades ago, so we have the ability to prolong the end of life much more than we did before, but we do not have the ability to make good decisions, and actually we have a number of things in our systems that complicate those decision-making processes. So values are very important. We need to know what people value and we need to recognise that knowing values may help us deliver better patient-centred care. This presentation is available to you. I will go through it quickly.

Saving life is the ultimate medical priority. It is clearly the thing that drives the medical profession and medical practice. Survival is the outcome that we measure for research, and it is the outcome we measure for quality — the main outcome that we look for. The doctor who saves against all odds is the hero. There are, however, a complex number of things that drive the way we look at intervention or not intervention at the end of life. Attitude to life: if you look down this list, you see the non-interventional attitudes, so attitude to a completed life, ready to go, is clearly very different from someone who has an uncompleted life — lots yet to do. Attitude to death is inevitable and natural, or it is avoidable, and it is just about a disease that can be fixed.

Prepared and accepting versus fearful and unprepared; intolerant of disability and suffering versus willing to accept disability and suffering to live longer; concerned about prolonged invasive treatment on the non-interventional side versus reassured by the availability of treatment on the interventional side; quality is essential to those who have non-interventional attitudes, whereas being alive is the most important thing for the other group.

Dignity: going on too long is undignified versus human dignity is enhanced by struggle. So you can see by looking down this list that it is really very nuanced, which way you go, and for some people one of these things will really be the red-light thing for them, and for other people it may be all of them. You may go all down one side or the other, and some people may pick and choose a bit. So it is extremely complicated. It is extremely important to know where someone is, how they think and who they are.

In order to look at this further I did work with the University of Technology in Sydney, who have a centre for the study of choice, and this uses mathematical and psychological choice theory, which is something that got Daniel Kahneman his Nobel prize. We worked with them to look at these end-of-life things using best-worst scoring, and what we found is that there is 7 per cent of people who have a very aggressive approach to it. ‘All human life is sacred’ was the thing that they liked the best, and anything to do with ‘I’d rather die’ got right

down the bottom. This is an important 7 per cent because these people exist. Fighting to the end, never, never giving up is very important to this group of people, but there is only 7 per cent of them. It is probably unfortunate if we use the same thing that works for them for the other 93 per cent, and that is perhaps the problem and the message to take away today.

There is another group that are concerned and willing to forego treatment in order to not get to a place they do not want to go to — 61 per cent. Then there is a fence-sitting group that are concerned but they are not particularly willing to give up things to get there, and this fence-sitting group is quite interesting in that as the respondents were older they tended to move into the orange group — the 61 per cent who did not want it — while the 7 per cent, however old they are, keep the same views. I think that is something we could probably recognise in our own personal experience, that people who have these very tough views tend to go on and have the tough views forever.

Interestingly the number of times that people had ever thought about or discussed end-of-life treatment wishes: those who had not discussed it, the percentage that had not discussed it, were much more likely to choose — we had a range of treatments from nought to eight which got increasingly nasty and increasingly less effective. What happened in the study was those who had never talked about it were in the group who picked everything. If you have never thought about it, you go all the way. If you have a little think about it, it does not look so good. Our problem is how do we get people to think about it.

With that in mind, MyValues is something that has been funded to the credit of Victoria by the Victorian health department. It is about values. It is about taking this discussion that we are doing with the Respecting Patient Choices model of advance care planning and talking to nurses, which is difficult to scale up and is expensive, but MyValues is about the kitchen table discussion and helping people to think about the issues in a way on the internet in their own home easily, and we now have several thousand who have done it. This is the website; here it is: ‘Your voice when you can’t speak for yourself’.

We had to put this on it because it is a government website and it looks really nice, and people felt that they were going to be asked to bring out their credit card at any time, so we had to put that it is not for profit, supported by the Victorian government and free to use. It is interesting but true.

Here is one of the first questions: ‘I’m concerned that medical treatment will not be taken far enough’, and certainly the questions on the websites allow people to go both ways and to express their enthusiasm for medical treatment at the same time as expressing a desire not to. It is not about saying no; it is about saying who you are and how you think. It is a Likert scale, from strongly disagree to strongly agree. For the questions behind it there is an algorithm that looks for consistency, because the questions are all somewhat related — the concepts. So if you have said no to one thing, then with something a bit similar we would hope you went ‘no’ as well, and if you do not go ‘no’, then maybe that is something you do not feel very strongly about. There is a whole load of stuff behind it that can give us quite a lot of information about the way you think.

Here is my report. There is my current profile, and I can share it with my family, which is important. When I share it with my family — I can sign my report, and interestingly after we created these reports in the development phase we showed them to patients and said, ‘Is that you? Are you happy with it?’, and the feedback was, ‘Yes, I’m happy with it. It wasn’t actually what I thought I’d say or I thought I thought, but it is me’, which I think was useful because it said that people do not really understand this stuff until they actually do it. This allowed them to do it. We then got them to sign it. Signing it says, ‘Yes, I think it’s all right’. If you sign something, you are sort of accepting.

Then you share with your family, and when you share it with your family, the family are asked to respect it, because we know clinically that when people come in expressing plans for the future, the family need to be in with it. If the first time they ever see it is in a crisis, they react very badly, and they do not accept it. They need to be included. Doctors also need to be included, and this is the process we are going onto now. It is also easy to print out a little card that goes in your wallet. I have mine in my wallet.

These are just some examples for you to show you the way in which people think. Question 43: ‘If I become unable to look after myself then I would rather be cared for in a nursing home than to be dead’ — strongly agree, 3 per cent; agree, 19 per cent. It is not wildly popular.

The opposite question is: 'I would rather be dead than have to go into a nursing home (long term)'. It is exactly the opposite question, just asked the other way, and here strongly disagree is 20 per cent. That is pretty binary, but we are not seeing nursing home outcomes as — there is a number who are quite happy, but a lot of people do not want to go there, and forcing people to go there does not seem to be an appropriate act for people who do not want to.

'Never, never ever give up and "try, try and try again" is a good summary of how I feel about medical treatment': 7 per cent agree with it, 2 per cent strongly agree and 7 per cent strongly disagree with the statement. There is the 7 per cent again.

"Just push me off a cliff" and "Take me to the back paddock and shoot me" are a good summary' — I am sorry, but that is what people say. You hear it, so let us have it in the medical environment. Let us not pretend that there is a discussion that goes on around the Christmas table that we are never going to talk about in medical circles. With this one only 30 per cent disagreed with that, but that means 70 per cent are quite happy with it or reasonably happy with it. Over 50 per cent are happy with it. We translated it into Arabic, Chinese, Greek, Italian and Vietnamese. Interestingly we had two problems. Firstly, the Italian version changed it to 'Roll me gently down the hill', and I said, 'No, you can't do that. That's not what we mean'. But that is just being Italian. The Arabic guy said, 'I can't do paddock. Can we do back alley?', and I said yes. This is a thing that occurs in all cultures, so let us not pretend.

'I would not want my doctors to override my expressed treatment wishes (stated in advanced) even though they may disagree with my choice': disagree, 4 per cent; strongly disagree, nil; agree, 87 per cent. 'I would not want my doctors to override what I want'. That is a real problem because doctors generally think that they should do that — they should override what you think if you are wrong.

On the other hand if we turn the question around to, 'I would expect my doctor to override my treatment wishes if they believed that, under the circumstances, these were not in my best interest', 25 per cent agree with that, but we still have a lot who do not; we still have 75 per cent who do not agree with that. So this thing about autonomy is very strong providing we listen to it and we let people say it.

'I would want to do whatever is necessary to avoid dying' — 9 per cent.

'It is important to me to 'go the distance' even when treatment is unpleasant, until it is absolutely clear that the treatment can never work' — 20 per cent agree with that.

So we have some really interesting results. They are very similar to what we got from the UTS survey about how the population feels about this whole thing. We have a population who have views that when they are thinking about it are quite fixed. We have a medical profession who do not listen to them at all and assume that everybody wants to go on as long as possible, whatever it takes and at whatever cost in terms of independence, dignity and other things, which I will show you in a moment.

We are now integrating this into general practice. I think it is very important that general practitioners — one of the problems is that we have such a discrepancy between acute health being run by the states and general primary health care being run by federal, the big costs in end-of-life care being the state and the funding for general practice being federal. Getting GPs involved in doing this properly would be fantastic, but there is a complication given our structure.

Getting this now into general practice — we have a sidebar here in general practice where if we were to run a study again funded by the state here to get general practitioners to invite patients to do MyValues and then discuss the results of them with their patients. In Geelong we have 15 practices just about to start. So I am very complimentary about the work that is being done in Victoria, and I would like to tell you that we are far ahead of any other state. Having just come back from Munich as a keynote speaker, we are far ahead of anywhere else in the world, so you should be very proud of where we are, but there is so much more to do, and we should consolidate on our lead.

Just looking at how the personal values report is helpful, we just published this in the Australian *Anaesthesia and Intensive Care Journal*. A frail patient has had a sudden collapse. That black bit of brain on the left there is all dead and infarcted. He has two choices. Death is almost inevitable without aggressive support, but if we do

give him aggressive support, then he is going to be severely disabled. So he has a choice — we have a choice — as to which way we go.

When he comes into hospital without any guidance, more than half of the doctors will submit him to neurosurgery to take off the top of his head, let the pressure expand, treat it with ventilation, blood pressure control — all the aggressive things. We then show them a report and share that with the doctors, and they massively change and are comfortable. The feedback was that, ‘This is the information I want. I now understand what matters to the patient. This is very important’. Even the few who continued, when we looked at their explanation they said, ‘We’ll continue until the family comes, and then we’ll stop’, so none of them went on having got the information. It was the information they needed.

We need a process to get the patient, the doctor and the family together and to agree on a plan and have it focused on the patient’s rights and interests. It is interesting to me how many relatives I see where we say, ‘What would Mum and Dad want?’, and they say, ‘They would never want it. We say, ‘What should we do?’, and they say, ‘Treat’.

Ms PATTEN — They say what?

Assoc. Prof. CORKE — Treat them. It is odd.

The CHAIR — Why do you think that is, Professor?

Assoc. Prof. CORKE — Because that is how you show you love someone. It is not strong enough; the thing we do at the moment is not strong enough to withstand the pressure of the crisis. It is a very complex thing. I think for ourselves we know when we are in a situation with our own families how hard it is; it is very hard. So we need to do something. We cannot just do a little bit of this. It has to be done well in order to withstand the pressures of the time. That is MyValues.

I would just quickly like to finish by telling you something we have done. MyValues takes a while to do. You have to register online and everything. It is difficult to do in hospital, so we have done a little thing to help for what matters most for the hospital. This has on it ‘Maintaining dignity’, ‘Avoiding pain and suffering’, ‘Living as long as possible’ and ‘Remaining independent’. In the first box there is ‘Vitality important’, ‘Somewhat important’, ‘Neutral’, ‘Of little importance’ and ‘Not at all important’. You can make them all ‘Vital’ if you want to. The problem is if you make them all ‘Vital’ is that I cannot work out which one we should work with, but some people want to make everything ‘Vital’.

So what do you think they do? Here is the answer: on ‘Maintaining dignity’ 85 per cent say ‘vitality important’, and on ‘Avoiding pain and suffering’ 81 per cent say ‘vitality important’. ‘Remaining independent’ is sort of between ‘vital’ and ‘somewhat’; it is not quite so important as the other two. ‘Living as long as possible’ is a complete outlier; it spreads across at 6 per cent. That is the 7 per cent again. We have got them again; they come up every time — 6 per cent or 7 per cent. But 12 per cent say, ‘not at all important’, and 21 per cent say ‘of little importance’. Will you trade ‘Living as long as possible’ for losing those other things? Possibly not.

The next thing we did is make them say, ‘Which one of those do you want to tell your doctor?’, because we thought just maybe, when you are talking to your doctor, you want to put ‘Living as long as possible’. You might want to tell your doctor you want to live as long as possible and tell your family that independence and dignity are very important. But do not tell your doctor that because they might back off. No. This is a sample of 125 people. We now have up to 500, and the picture looks very similar. ‘Living as long as possible’ does not cut it if you talk about it in the context of the things you have to trade. It is only good if you do not talk about what you might have to trade for it. The problem medically is we do not really talk about that.

We are about to do a study again. We have put in for funding, but it has not come through. We have been waiting six months. We did a survey of the oncology patients at Barwon Health and looked for any patient-centred words in the notes — any comment in the notes about what mattered to the patient, not about their white cell count, not about the tumour size, not about that, but about what mattered to them. Five per cent had any sort of patient-centred comment in the notes.

So we thought the project is to put ‘what matters most’, and let us see whether dignity, independence, pain and suffering or living as long as possible are vital to the oncology patient — that we can then have a conversation

with them about making sure that the thing that is vital to them is not compromised. I think it would be magic. It could be good. We are waiting for funding. This is an area that is not funded. This is the orphan of medical care. We are spending millions every day on treatment that people do not want. The future involves a massive increase in the ageing population, and every year, as you know, the medical technology becomes more fantastic and more expensive. We have new oncology drugs that can extend life by four weeks at \$100 000. You are paying for them. I think I will leave it there.

The CHAIR — Thank you, Professor. Thank you for walking us through the MyValues website, which I was looking at online. It works on the phone as well as on devices.

Assoc. Prof. CORKE — Good. Yes, it is a nice website. There is a glitch with it at the moment. I am sorry; that is typical. I think it must be you guys. Coming here, it glitches up, but I will deal with it as soon as I get out of here.

The CHAIR — No, thank you. That is most informative for us. You touched at the end there on the attitude of healthcare professionals and the conversations healthcare professionals have with patients. Obviously that is the other side of the equation that you have identified through the MyValues website and also the What Matters Most that you have tabled, in the hospital environment. We have heard other evidence from doctors and healthcare providers about the challenges associated with funding — for doctors to be able to have that time with the patient to talk about their wishes. Do you want to comment further on how we could encourage the profession to be more engaged with their patients, and who should be engaged with their patients?

Assoc. Prof. CORKE — In answer to your last question, the answer is everybody. How it could happen: we have a fee-for-service structure across most of medicine, which is inappropriate for the way in which patient-centred care is best delivered. Changing patients' expectations that they will be the focus of the interaction, I think, is very important. In terms of how legislation or policy should change in order to do that, I think that is challenging. I think it is a big task.

The CHAIR — Have you got any suggestions?

Assoc. Prof. CORKE — I think we need a lot of little things to do. I think certainly from a federal point of view general practice payment for this would be essential. Perhaps we are coming in at exactly the wrong time when the feds are worried about all items, but I think this is an essential item. It could be involved in age assessments as a normal part of routine care. That would be something that should certainly be pressurised for, I believe. Within hospitals, I think expecting hospital boards to deliver patient-centred care is important, and looking for evidence for it in the way in which I have just talked about — perhaps the oncology patient, looking for that sort of thing.

The CHAIR — Who should take the lead in the hospital environment, because again we have heard evidence from practitioners and from others that someone with complex needs may have an oncologist and a range of other specialists giving care but no-one actually taking a holistic view.

Assoc. Prof. CORKE — The fragmented super speciality does not help the situation at all. Perhaps general practitioners continuing to have a holistic interest in their patient and being a patient advocate would be helpful. I think we need to change a generation. I am interested that I do a lot of teaching for medical students who get patient-centred care and shared decision-making and making decisions with the patient based on what is important to the patient, but we see that disappear as they move into the hospital environment, and the pressures of work and the medical model makes them less effective. So we need to protect that and work on it.

The CHAIR — I will just ask one more question before we go to others. Can you give us the numbers on how many people have completed the MyValues — —

Assoc. Prof. CORKE — Around about 1000.

The CHAIR — And the Changing Patient Expectations?

Assoc. Prof. CORKE — About 300 for What Matters Most. We have not done any promotion for it. It has been organic, that number.

The CHAIR — Yes.

Ms SPRINGLE — You have touched a little on the changes that you perceive need to be made to the health sector to see improvement in this area. In your opinion, do you think it could be achieved through small shifts in certain areas, or are we talking about major reform of current practice?

Assoc. Prof. CORKE — I will take your second question: does it need major reform? I think the answer is yes. I think that we have spent money and a lot of effort in establishing excellent palliative care. There is more we could do, but we have gone a long way. Certainly during my career it has gone an awfully long way. However, this point of decision is between are we treating and doing everything to save this life or — I am not going to say ‘doing nothing’ — is our focus on making sure that the person is comfortable and allowing them to die?. When you come to that point, that fork in the road, tell me about the medical school education that helps people define whether we are treating this patient to save them or we are making them comfortable. It is not a curriculum thing. Tell me about most doctors and how they come into a clinical situation and they are making this decision with the family about which way we go. Do they have the skills and the language and the things to do that? No. It is a very, very difficult decision point and we do not focus on it.

We do have a lot of stuff around it in terms of medical model training about focusing on treatment, so that encourages that. We do have families who push to do everything for that, and ‘everything’ involves everything medical. Standing back just feels just so uncomfortable — not doing anything: ‘You don’t love him. You don’t care. You don’t even want to try’. All those words make it very, very difficult. But clearly 100 per cent of us die. What has happened over the years is that death has now become very complicated, very technological, and unless we can have the ability to stand back and understand how we help families to stand back, how we help doctors to stand back, it is going to get worse.

I think understanding the values about people — but we have done a thousand. I do not want a thousand; I want 20 million. How do we move from that to getting everybody to do it? The vast majority of people who come into hospital have done nothing, absolutely nothing. You say, ‘What do they want? And I can tell you now, all the sons go, ‘Mum’s tough, she would want everything’, and all the daughters go, ‘Mum would never want any of this’. Then the rest of the family just line up, and we do not know where to go. It is very, very difficult, and we generally just carry on.

Ms SPRINGLE — Just on that, yesterday we heard testimony from several groups that talked about the need for a heightened public discourse around dying and good dying. Do you have any thoughts around how we can promote that conversation?

Assoc. Prof. CORKE — I made a film called *In the End*, which was shown on *Compass*. I thought — because I am cute — that the government would look at this and say, ‘This is important, this is part of a dialogue; we should do more of this’. The girl who made it paid half of the cost of making the film from her dad’s will — the money that he left her. So it was not funded, and she put the money into do it. We did it, it got shown and it got really good feedback. Nothing has happened since, and that was five years ago. We are doing nothing. We are just fiddling while Rome burns.

Ms SPRINGLE — So what should we be doing?

Assoc. Prof. CORKE — I think we should be doing lots. We should be having this discussion. We should be opening up the discussion. We should be funding these things seriously. At the moment funding comes in little grants and little bits of money here and there. Again, I am going to be very positive about Victoria. We are much better than the others, but this is a sideline. Dying and decisions around dying is not sexy. It is tough, and a lot of politicians hide: our health system is here to save life and save everybody and do everything. More scanners and more radiotherapy machines and more everything is wonderful, but this is something that does need tackling, and it is fantastic to have the opportunity to talk to you today.

This is vitally, vitally, vitally important, and there are all sorts of things we need to do, but we need to ramp it up to be very important. There are other things we are saying are very important in our state and in our country that we are preferencing massively above this. My real concern is that if we do not do anything — and I value the health system that we have I can see it grinding to a halt, doing treatment that people do not want, that people do not value and that bankrupts the system and stops us doing anything of value.

Ms PATTEN — Thank you very much. I was fascinated by the slides you showed about the man with the brain tumour and how just having that information completely flipped all the doctors. We have been hearing it

is much easier to give a treatment than it is to have a conversation. So in changing that medical culture of just treat at any cost, is it as simple as just letting the doctors know what the patient wants?

Assoc. Prof. CORKE — Yes, but in a context of also sharing it with your family, because it is awkward if you say to the doctor what you want and the family all come in and say, ‘That’s not what she wants at all’. So if the rest of the family come in and say, ‘Of course, that is exactly what she’d say’, we understand that, and even better if your doctor says, ‘She’s been going on about this for ages; it is exactly what she wants’. If you can get the doctor, the patient and the family all in line, there are very few doctors that will override it.

We are just looking for that level of confidence about stepping back. I think you have to give doctors credit that when this goes to courts, courts look for huge levels of confidence to not treat. So do not blame us. It is like that. You need a huge level of confidence that you are doing the right thing. Letting someone ‘die’ — feels bad, and you need great confidence that you are doing the right thing.

Ms PATTEN — Just following on from that, with the at-hospital forms — the simplified version — that you did, were you aware that that family and the patient were at odds?

Assoc. Prof. CORKE — We would know that anyway, in general terms.

Ms PATTEN — Yes, and is that quite common?

Assoc. Prof. CORKE — There is quite a lot of work to do between getting someone in the — if someone has not said it before they arrive in hospital and then they say, ‘I don’t want to be treated’, you know that you need to facilitate it when the family come in, because the family bully them something shocking. Family find it very confronting. You can see why.

Ms PATTEN — I completely understand that, yes.

Assoc. Prof. CORKE — So doing this in advance is important, but people do not get it. People get why you should do a will; they do not get why you should do this.

Ms PATTEN — That is the challenge. Thank you.

Mr MULINO — Thanks very much for your evidence, and I found your whole methodology and the results from your survey really fascinating. My first question was: obviously this is of great use to individuals and families, and the results are really powerful both in terms of the introspection it generates and the discussions within families. But one of the results that was interesting was that 90 per cent do not want the decisions or choices or values overridden, but clearly in practice it can happen, for all the reasons you talked about. I think you have alluded to the fact that a lot of the value from this could be in improving practice and potentially being included in curricula in health practitioners courses. Have you had many discussions where you have put some of the overall results to doctors, and what have their responses been, for example, to some of the results that might have been surprising or counterintuitive?

Assoc. Prof. CORKE — It is surprising to doctors. It is a surprise that there are other things valued so highly, and so partly what I am doing is communicating this discrepancy. Some take it on board better than others, but most doctors want to do the right thing. They absolutely want to do the right thing, and they want enough evidence to help them to feel comfortable that they are doing the right thing. My feeling is that most people want this. Most doctors want this. Most doctors are comfortable to not put people through stuff which they know to be arduous if people do not want it. Inevitably we want to treat people who want to be treated and people who want to be treated to get better and go home, or try to, and those who want to be comfortable we want to make comfortable. We want to do the right thing but we need information, and most people are happy to have the information.

Mr MULINO — My sense is that a lot of the professionals that have given evidence feel that we are close to best practice, that we are very good as a medical system here but that many of the choices doctors and nurses confront are very complicated and involve families with conflicting views and that their training could be enhanced. Do you think that the medical profession would be open to strengthening training in this area and that some of these results could form part of that?

Assoc. Prof. CORKE — Yes. I mean, I would agree with them. I think we have probably close to the world's best medical system or delivery of health care that is close to being second to none, and certainly most of what I do is fabulous and people get better and go home, and I am only talking about the small minority who are in big trouble.

But the small minority worry me because I have always been disturbed about doing horrible things to people and watching suffering upsets me. So I think that we are good, but I think if you ask the question — which surveys have asked — ‘Do you feel you are pressurised to do the wrong thing a lot?’, most doctors will say yes, depending on their speciality. I do not think eye surgeons would say that, but for general life-support things we are feeling that relatives are very pushy, patients are very pushy, wanting things that are not effective. Certainly within my field of intensive care there is a strong feeling of being pressurised to do the wrong thing quite frequently, and a number of my colleagues talk about looking forward to retirement to get out of it, because it is so unpleasant.

Mr MULINO — Just a couple of questions on the questions and the results. Some of these questions are, you might say, fairly straightforward and some are a bit more complex and open to ambiguity. Given the cross-referencing that is going on in the background, I imagine that with some of those more ambiguous and nuanced questions there might be scope for people to answer in a way that is perceived as being inconsistent. I am just wondering: what is the degree of inconsistency?

Assoc. Prof. CORKE — In general terms it is quite low. It is around about 15 per cent, but human beings are inconsistent. That is part of us; we are not computers. So, ‘Do you want to pay more tax?’, ‘No’, ‘Would you like more services?’, ‘Yes’, that is inconsistent, but we all do it — all your constituencies do it. That inconsistency is part of being human, but actually the inconsistency is relatively low. When we see very high inconsistency it is often that people are either not doing it seriously or their thought processes are completely gone or in trouble. The inconsistency is part of just making sure that there is some reliability there. Look, we are all a little bit inconsistent, and I think that is the beauty of being human.

Mr MULINO — Because ideally what you want is to disentangle the inconsistency that is due to uncertainty versus the inconsistency that is due to the questions being complex.

Assoc. Prof. CORKE — They can say they are uncertain as well, but they are both there. If you are completely rigid about all this stuff, you are probably a difficult person to live with. It is all tough, and inconsistency is what we do.

Mr MULINO — The last question I have is one of the things I think is of interest is the degree to which people's views change. I think you said that one of the broad patterns is that people veer towards less intervention the older they get.

Assoc. Prof. CORKE — It is sicker and frailer. It is not age: it is sickness and frailty. We must not think it is age. You get some very elderly patients that are still well.

Mr MULINO — That is broadly consistent with the lived experience of a lot of the health practitioners who have talked about their conversations. I guess my question is: do you have any evidence or is the dataset able to say anything about whether people's views change, for example, due to life events, like having children, getting married, losing a spouse? I am just interested in whether those kinds of things can affect people's views.

Assoc. Prof. CORKE — I can tell you two answers. Firstly, in terms of that little short one, when we did the pilot with younger people, having children and having commitments makes you do living as long as possible over everything else. You will take everything to live as long as possible. It is about requirements of others, and that actually happens in older groups as well. There can be a thing where I am not talking to you about anything you want; you have such a requirement to look after a partner or a child or whatever that you will trade everything to do with dignity, suffering and everything else in order for that role. But that is important for me to know. If I know that, then that is how you think. That is vital for me to know — really important. I hope that answers your question.

Mr MULINO — Yes.

Assoc. Prof. CORKE — And the other thing is, the thing about all this advance care planning thing, people say, ‘Of course, when it comes to the crunch everyone changes their mind’, but the cognitive psychologist would say that the thing you think about when you have got plenty of time and you think about it over a long period has value, and at least I would like to start from that. I can have a discussion with you and say, ‘Previously you said this: do you think now, because we have now diagnosed this, that and the other, that you think differently and how far do you want to go and how far do you want to change your views?’. It would be great to start from that thought, rather than say, ‘What we’re going to do is to screw that up, throw it in the bin and start from a blank slate again, and I’m going to put the gun to your head and frighten you’. I would like to start from that, but I am not saying it is fixed in time. Nothing is ever fixed. This is about people, it is about values, it is about what matters.

The CHAIR — Before we go to Mrs Peulich, if I could just follow up with a quick question. There is some debate about the legal nature of advance care directives and these sorts of plans. You have sort of partially answered that.

Assoc. Prof. CORKE — I think you can anticipate my answer.

The CHAIR — Yes, but for the record, please answer.

Assoc. Prof. CORKE — I do not think the law can answer this. This is about people. It is about values. It is about what makes them tick, and a signature on bits of paper and typed things are generally not what most people feel like. What most people say is, ‘I would like my views to be respected’, ‘I’d like me to be respected’, ‘I’d like my wishes to dictate the way my medical care goes’, as opposed to writing something firm and signed and countersigned. That does not accord with most people’s attitudes. The only area where we have it very clearly is with the refusal of treatment form, and I think you would probably have had submissions from others about the difficulty of not being able to clearly refuse something that you have not got as a pre-existing disease, and I certainly would agree that this is a limitation. I think it is part of human autonomy to be able to refuse something on what you think about it in the future and not to have to have it. It is very difficult, because things like cardiac arrest happen all the time. Very regularly people do not know they have heart disease before it happens and the outcome. I think they could refuse things without having it, and I think it was a deficiency in the act, which is otherwise a super act, to put that in. I would not personally object if that was rectified.

Mrs PEULICH — My apologies for being late. I have a question about your 1000 respondents. What are their demographics? Are they all predominantly oncology patients?

Assoc. Prof. CORKE — No, not at all. In my values, they are general population. They tend to be 50-plus, and more 60-plus, so the older group who are beginning to think about it. We do not collect a lot of demographic data on them. They are across Victoria, across the country.

Mrs PEULICH — Your point is right that it is about values. I would have thought there would have been a clear contrast in values amongst them. You say that some of them are so fixed they would make bad cohabitants, and maybe that might be true. But I would have thought that the whole notion of planning for one’s death was very much a white Anglo middle-class concept — one not as readily embraced by our multicultural communities, many of whom have come from difficult situations of conflict or trauma, to whom life is precious and for whom perhaps even thinking about death, let alone planning for it, may actually be seen as a jinx. Are you able to comment on that?

Assoc. Prof. CORKE — Yes. You are right: the ethnic group is not strongly featured in the MyValues thing. That is an issue for us as a community — how we engage ethnic groups in this planning — because the same things apply and the families can often be very aggressive in how far to push things. We need assistance and funding and support to be able to communicate this to those groups as well as to the Anglo group.

Mrs PEULICH — Do you think it is just a question of communication rather than values?

Assoc. Prof. CORKE — I think it would be really interesting to investigate. We do not know. The things about dignity, pain and suffering, and independence may be different, but I suspect that there are some human things in it, universal human things.

Mrs PEULICH — This whole notion of dying with dignity — I come from a multicultural background and I have never seen an undignified death. I have seen undignified life but not undignified death. I guess that is the difference in values.

Assoc. Prof. CORKE — I would agree. I think what I am talking about is undignified life prior to death or undignified prolongation of the dying process, which we definitely can see, and a number of ethnic families struggle with that hugely.

Mrs PEULICH — As I do.

Ms PATTEN — I was quite struck by these results: most people did not choose ‘unsure’. That was quite amazing. You would think that some would have filled this in. Is that just because it is a brilliant survey?

Assoc. Prof. CORKE — I have no idea. I would love that to be right. I think the other thing is what we would like to do is to develop this survey. These questions come from all the literature, all experience and all sorts of places. They are probably not the last version of questions. But again to refine things and develop them, make it shorter and make it that as you answer questions, perhaps new questions pop up that are related to you and the way you have done it — these are all very expensive things. Effectively at the moment we are doing it with a little bit of funding from one state, in Victoria, one hospital, me — it is very hard. The PCEHR, which has cost an unbelievable amount of money and has had up to now very little impact, is costing over \$1 million a day. One day’s worth of that would transform my life. I am not saying it is a bad thing — it might work — but it is about balance of priorities. This has such a low priority that it is not having the effect. It is not being able to be developed as fast or as effectively as it could be — this whole area. Victoria is a powerhouse, and with some support — and I would love, as I say, some more pressure for federal support and some more Victorian support — it would be fantastic. Please, rest on some laurels, but not too many.

The CHAIR — If there are no other questions, we could look at the website in more detail.

Assoc. Prof. CORKE — You might put mine up.

The CHAIR — That would be great. Perhaps we could just walk through it.

Assoc. Prof. CORKE — If you want to, you can, otherwise I will just show you mine and what it does. It depends what is most effective.

The CHAIR — If you do that, we can concurrently work through it.

Assoc. Prof. CORKE — It takes a little while to fill in. You can come and go at it.

The CHAIR — The aim is to get a better understanding of the questions and how they relate to all of us.

Assoc. Prof. CORKE — You will struggle because you are younger and you have families and you have other things. You will find it much more difficult. As you become older and frailer, the consistency gets much better. The issues are tough for you guys, because you are not in the zone, which is a good thing.

The CHAIR — Perhaps if you can bring yours up, Professor, and then we will talk through it as well.

Assoc. Prof. CORKE — To the question, ‘I am concerned that my medical treatment will not be taken far enough’, 84 per cent strongly disagree or disagree with that statement.

The second one, ‘My best interest is most likely to be served when the treatment limits that I have expressed in advance are respected’, and 90 per cent agreed with that.

‘The reason to plan in advance is to make considered choices about treatment in a crisis. Any choice I make should be followed in an emergency where I am unconscious’, and 90 per cent agree with that — over 95 per cent in fact.

The CHAIR — That is an interesting answer, because there are so many variables involved in that.

Assoc. Prof. CORKE — I know, but it is about autonomy and the value people put on autonomy. Because they may not actually have a plan in advance, so it may be a theoretical thing in their mind. A lot of people have

not actually got a plan in advance; they are just saying, 'If I have one, I want it respected'. It is about autonomy. People are really tough with autonomy — they like it.

Ms PATTEN — Yes, it is amazing how firm people are.

Assoc. Prof. CORKE — Except in the actual event.

Ms PATTEN — Yes.

Assoc. Prof. CORKE — 'I am more concerned about the process of getting ill and dying than I am about actually being dead' — again, 90 per cent.

'It is important to me to keep fighting for life and battle on in the face of suffering' — this is important. This is about the value of suffering, and 60 to 70 per cent do not agree with that.

'I would not want my family to decide how far my treatment should go. I want to control this for myself' — 80 per cent. So it is important, but then a lot of people actually do nothing and let their family control it.

'I am concerned that medical treatment for me may be taken too far' — 70 per cent agree.

'I would want to do whatever is necessary to avoid dying' — less than 10 per cent agree with that.

There are some clear concerns that easily come out of this stuff.

Mr MULINO — Professor, could we just go back to question 9?

Assoc. Prof. CORKE — Yes.

Mr MULINO — That was one that you put up on slides earlier. Basically, 60 per cent are saying they would rather be dead than go into a nursing a long term. That would appear to me to be one where maybe people's views might change, firstly, when the decision is very imminent, and secondly, they may not particularly like the experience at first, but if you get used to it and then your grandkids start visiting you in a nursing home and you make some friends, that seems to me to be one where you would not want to take that too much on face value.

Assoc. Prof. CORKE — Unless I do not want you to double guess me, in which case I do not want you to double guess me.

Mr MULINO — That is a pretty stark statement.

Assoc. Prof. CORKE — Yes. If the person themselves is able to have a conversation later in terms of, 'Well, earlier on you said you did not want to, but now how do you feel about it? The kids can come and visit you', and they say, 'Well, okay, I now feel like that'. But what if you unconscious and we need to put you through a lot of treatment in order to get you to the nursing home, and you had said no, but maybe if I put you through life support and a month in hospital — unconscious for that period of time — and then you come through and you wake up? Maybe you have had a massive stroke and things, and you have said that no, you do not want it, and I say, 'But maybe you will, so I will treat you in case you change'. But you have also said the autonomy thing — do not double guess me. What should I do? I think I had better take what you say, and I am probably going to be confident about that. You might say I am wrong to listen to what you say, but if I take that attitude, I am going to treat absolutely everybody all the time and take nothing that anyone ever says. The place that that takes you to in terms of decision-making is very hard. It is about saying that what everybody says is unreliable and we must overrule everybody. It is tough. It is a tough place to go.

Mr MULINO — I agree with you in terms of withholding treatment. I think if somebody says, 'I do not want that treatment', even if they are unconscious, then I agree with you. I do not think anybody should override that or it should be extremely rare that you would. I guess that question just jumped out at me as being one that is harder to operationalise than withholding treatment, because the choice about going to a nursing home is usually a different kind of context.

Assoc. Prof. CORKE — But I suspect that is because of your values, which are important, which are saying that probably a nursing home is not the worst thing that could ever happen to you. But I think there might be

other people in the room who just see it as a pointless — as my dad did — waste of time and a demeaning place. He thought somebody wiping his bottom was appalling and he did not want it, and he just did not want to go there. And he would far rather die than go there, and he did.

People are different, but knowing that a nursing home is not your red-button issue — and I just take you, because you raised it — so somebody's red-button issue, the nursing home is not the thing, but perhaps we will talk about pain and suffering or perhaps we will talk about independence. Although independence goes with a nursing home, because it is about staying home and not going there. It is about being cared for, your right to be cared for, versus your indignity to be cared for.

Mrs PEULICH — Can I just ask a question on your methodology?

Assoc. Prof. CORKE — Yes.

Mrs PEULICH — So these are the full range of questions that would have been asked through the survey?

Assoc. Prof. CORKE — Yes.

Mrs PEULICH — In that order?

Assoc. Prof. CORKE — In that order. They do not randomise. We did randomise them at the start, but it was again a funding issue about randomising the question order.

Mrs PEULICH — I mean to be honest with you if I was asked to open up the survey, I would struggle to find some consistency as well, because I think the questions are all over the place. Have you thought about clustering them, according to — —

Assoc. Prof. CORKE — They are clustered in themes, but they are scattered around so that you do not have the questions right next to each other, asked the other way. They are scattered around. In the early stage we had it randomising, but we do not have enough money to do that.

Mrs PEULICH — You don't think there are too many questions here?

Assoc. Prof. CORKE — I think there are probably a lot of questions, but because the decision we are going to make based on it may be very significant, enough information about you to get a feeling for the doctors that this is you — this is what matters — is very important. In the UTS one we did 13 questions in the Centre for the Study of Choice thing. We did 13 questions, but I do not think it was enough. When we showed it to doctors, they said, 'Well, that's sort of like a start, but it does not give us enough stuff. Give us more'. So it is a balance between the amount that we need to get some sort of start for a feeling about what is important to you. At the end of the study you have a chance to write whatever else you like, so if there is other stuff that has not been covered, you can write it down. People have often had experiences of treatment that they are happy to have or have again or treatment they have had and would never want again. We have seen others go through things that they do not want.

This can be an introduction to then going and having an hour's discussion with a facilitator and writing a more formal advance care plan that has actual refusal things in it — actual treatments you do not want.

The CHAIR — Professor, I am interested in question 12, 'My religious belief makes it important that I should accept treatment to avoid dying'. In your experience, how much of a pivot point is religious belief for people?

Assoc. Prof. CORKE — Tiny in Australia, I think, as these figures suggest.

The CHAIR — And that reflects your practical — —

Assoc. Prof. CORKE — Yes, but it would be really important to know who those few people were, because that is going to be very important. That is their red-button issue.

Ms PATTEN — It is interesting doing it young. Some of the questions — if my heart stopped today, I would probably say yes.

Assoc. Prof. CORKE — Yes. I would expect you all to say yes, and that is fine, because that is probably what I would do. If you collapse here, I am going to come and resuscitate you.

Ms PATTEN — Yes, but if I am 92, I might not want you to.

Assoc. Prof. CORKE — Yes, you might not want me to — or if you are sick or if you are tired. I see lots of patients — older patients — who say, ‘I’m waiting for God to take me’. They probably do not want massive stuff. I know they do not — that is what they are suggesting. They are tired; they are looking forward to finishing.

Ms SPRINGLE — But surely that is the argument for keeping this up to date and reviewing it regularly.

Assoc. Prof. CORKE — Yes. There is nothing to stop you; it is online. There is nothing to stop you doing it again, and we have a prodger in there to come back in a year’s time and say, ‘Would you like to do it up?’. It will be interesting to see how they evolve.

Mr MULINO — And do many people update it?

Assoc. Prof. CORKE — We have not had it going for long enough yet.

The CHAIR — Just in the remaining 5 minutes or so that we have, Professor, do you want to highlight any other particular questions of significance or questions that stand out to you?

Assoc. Prof. CORKE — Not really. I think they speak for themselves. I think they are just interesting, and they are just very different from what we do. At the end of it we have asked people who have done it to suggest other things that they think are not in it that should be in it. We have had very little. There is the ‘burden’ one — ‘I don’t want to be a burden’. We have left that out a bit because ‘burden’ is rather emotive, but perhaps it should be there.

The CHAIR — What has the feedback been from general practitioners that this has been shared with?

Assoc. Prof. CORKE — The study is only just starting. Inevitably the ones who have signed up to do it are the positive, vibrant general practices and general practitioners. Their view is that MyValues has a chance to give them something, so it is like selling life insurance to someone who has already told you they want life insurance and has already told you what sort of life insurance they want. It makes the process easy. Our hope in doing the study with them and in getting patients to come with MyValues is they will say, ‘Heavens! Is that how you think?’, and you say, ‘Yes, it is’. Okay, so we ought to appoint somebody as an agent and we can use this as a template, and we have done it, and it costs very little.

Again, I would compliment Victoria on a thing — that we value the medical enduring power of attorney. We complicated it a little bit recently, but still the medical enduring power of attorney is a fabulous appointment. It values that thought about decision-making at the end by a person you trust over the Queensland approach, which is the signed document, witnessed, and what you write down is the important thing. Victoria has done it well, again. Appointing a great medical power of attorney and giving that great medical power of attorney some great instruction is the goal.

There is mine. There are my ‘strongly held views’. I have signed the form. There are the people I have shared it with. What we are doing at the moment in the project is to share it with hospitals and share it with GPs so you can send it automatically into the GP software, because the GP software is where they work and where they live. If it is in their software system on the computer, it is real; if it is a piece of paper that is outside it, it is a nightmare. So we want to get it in there. Again, we have, funded by the Victorian government, a project to get it into the GP software, so this will be people doing what matters to them, getting it into the software. I hope that that will be a game changer to change the way in which we have patient-centred care focusing on what matters to people, driven by the GP.

I just finish on the thing I think is most important: — the best outcome is that you have a clear view about what is important to you, that your family recognises it and accepts it and that your GP also understands it and endorses it. In that situation we have the best planning situation we can have and you have appointed a great family member who is advocating for you. We have the structure — say, with the medical enduring power of

attorney — with our legislation already. We have some good runs on the board with what we are doing in Victoria for advance care planning. We have done a lot; we can do a lot more. We must do a lot more.

Ms PATTEN — You mentioned that, looking at your views — —

Assoc. Prof. CORKE — I look after a lot of bad patients, and I am also a pragmatist. I have no desire. If you asked me what I think, I am a bit like my dad. I have no desire to go to a nursing home — absolutely pointless. I want to work up until the day that I die, and the thought of any my daughters giving up their job to look after me is, for me, a nightmare. I am also a bit concerned my wife will look after me, so I have appointed my daughter as my enduring power of attorney so she does not keep me going.

Ms PATTEN — So on that, obviously a lot of GPs and medical practitioners have filled this out. Have you seen that trend?

Assoc. Prof. CORKE — The other thing to realise is that with all advance care planning, when we look at our people who do advance care planning at the moment through our program down in Geelong, we have got an outpatient one and also, funded by Barwon Health, we have a GP one, so people can do it in their GP clinics. The state cannot afford to fund that otherwise, but Barwon Health are funding it in order to get good guidance for when people come into hospital. So it is visionary, but it comes out of Barwon Health funding.

The CHAIR — Yes, we had evidence about this when we were in Geelong.

Assoc. Prof. CORKE — So that is fabulous, but it is not happening anywhere else. But who comes? Ex-nurses understand — they know, they are there. So it is educated ex-nurses. Physios: physios know what not rehabbing looks like; they come. Old doctors come. They all — not all, but lots of them — have advance care plans. So we have a highly intelligent, articulate, medically-informed demographic who are doing advance care planning. Our problem is that the rest of the population have no idea.

Ms PATTEN — Are their results quite different from the rest of the population who has done this?

Assoc. Prof. CORKE — Do you mean when they come into hospital?

Ms PATTEN — No, I mean when a general practitioner makes this advance care plan.

Assoc. Prof. CORKE — We have not started it yet.

Ms PATTEN — There is no comparison; all right.

Assoc. Prof. CORKE — Do you want me to say something about this? Sorry, they have just given me a little note here to help me. The other thing that we have in the project that we really would love to do is an electronic signature — a proper electronic signature — for the GP. When you are in a GP surgery, at the moment what we have to do with death certificates and what we have to do with all these forms is print them out, sign them with a pen and rescan them back in again. It is insane. It is annoying. It means that there is a block and it means stuff does not happen. It clearly is possible, given that the GP is logged on as the GP, so it is very unlikely to be somebody else who is logged on.

If we could do a signature where the person does like you do in a post office, where you do your signature on the thing, and it did it with all the metadata — this signature was created at this time on this program in this place — you would have to say, ‘I’m sorry, that wasn’t me. Somebody else was logged on to my computer and in there, it wasn’t me, and they did my signature looking exactly like mine’, it would be so much better. I think that it is right up there.

Unfortunately we got some advice from lawyers saying, ‘Is it legal?’, and the lawyers did the thing and said, ‘Within the meaning of the law it is not currently legal’. I think we have come to a point in technology now where with combined metadata an electronic signature — I am not talking about an electronic signature where you just paste your signature in, but something that is actually captured at the time with all the data around it — would work, and it would revolutionise what GPs could do for all of these signing documents and other things. It would be, I think, a game changer, and anything that can be done to assist that would be highly, highly, highly beneficial.

The CHAIR — Thank you, Professor. On that note, we might leave it. Thank you again for your time and for walking us through your program. Thank you for your evidence today.

Assoc. Prof. CORKE — Good luck doing it. If you have older relatives that are challenged by the issues, please get them to do it. It helps the thought process and the discussions as well as actually doing it.

The CHAIR — Thank you.

Assoc. Prof. CORKE — Thanks a lot.

Witness withdrew.