

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Melbourne — 23 July 2015

#### Members

Mr Edward O’Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Mrs Inga Peulich

Mr Cesar Melhem

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

#### Witness

Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care.

**The CHAIR** — I declare open again the Legislative Council’s legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I welcome Associate Professor William Silvester, the president of the International Society of Advance Care Planning and End of Life Care.

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. Witnesses found to be giving false or misleading evidence may be in contempt of Parliament. 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 published on the committee’s website.

We have allowed an hour for this part of the hearing. I invite you to make an opening presentation. I note Ms Fitzherbert has to leave us at 4.15, so I apologise for any disturbance.

**Ms FITZHERBERT** — It is not a walkout. I just wanted to let you know that.

**The CHAIR** — The committee is very appreciative of your time and for your preparedness to appear in front of us. We look forward to hearing from you. Thank you very much.

**Assoc. Prof. SILVESTER** — Thank you very much. Although I am the director of Respecting Patient Choices program, which is a federally funded and partly state funded program, and I also chair the Decision Assist program, which is a \$15 million program funded by the federal government to introduce advance care planning and palliative care to aged care and general practice across Australia, I am not appearing in that capacity at all. I am appearing here as the president of the International Society of Advance Care Planning and End of Life Care. After this if you wish that I provide some sort of written submission with references to support it, I am very happy to do so. I will take your direction on that.

We believe at the international society that the main focus on improving end-of-life care and recognising end-of-life choices is about improving the delivery of palliative care and the delivery and provision of advance care planning.

I would like to bring to your attention that there has been some good research. People who were dying were interviewed and they indicated that from their perspectives the five most important elements to improve their care at the end of life and deliver a good death were, firstly, delivery of palliation — they did not use that term; they talked about not suffering; secondly, not having prolongation of dying; so if they were dying, ‘Don’t draw it out’ — not that they want to die sooner than otherwise, but they do not want it to be drawn out; thirdly, they want to maintain control over what is happening to them; fourthly, they want to relieve any burden upon their family, particularly around decision-making or physical or psycho-emotional burdens; and, fifthly, they want to strengthen relationships with loved ones before they die.

The reason I emphasise these is because if you think of those five key elements to assist someone to die well, they can all be delivered by delivering good palliative care and by delivering advance care planning. Particularly, not prolonging dying and delivering good symptom management is really about palliative care, but the others — the ones about maintaining control, about relieving the burden upon families and about strengthening relationships — are all delivered through advance care planning.

I trust that you have heard from other people about advance care planning to the point that I do not really need to define what it is. There are certainly excellent definitions now available, including through the Australian Commission on Safety and Quality in Health Care’s national consensus statement, which was recently released. In essence it is about ensuring that doctors and in fact all health professionals have the understanding, the awareness and the skills to be able to talk to patients and their significant family members about what that person wants if they reach a point where they can no longer tell us. You can see immediately why that improves the delivery of control.

We have been doing advance care planning for some time in many settings, including internationally. From my personal experience, having done advance care planning with patients, where you have established what they do and do not want if they reach a point where they can no longer contribute to decisions and they are not expected to survive or if they are not going to return to an outcome that would be acceptable to them, and having helped them to appoint a substitute decision-maker and to record what their wishes would be, I am amazed by the

number of times that I have gone to walk away and someone has called me back and said, 'Look doctor, I didn't tell you, but in fact I've been thinking about euthanasia, and now that you've been able to lift such a weight off my shoulders and I can now be sure and confident that I am going to get the care that I want at the end in the way that I want, I can now concentrate on living as well as possible. I don't have to think any longer about getting Nembutal or saving up all of my prescription tablets or whatever so that I can do something before I lose control, because now I can see that even when I reach a point where I no longer have control, I will still get what I want and I will not get what I do not want'.

The position of the international society is that we do not support euthanasia. One of the reasons is because even just having the debate about euthanasia actually detracts from the real and important discussion about how we improve the provision of palliative care and the provision of advance care planning as a normal part of the care that doctors and nurses deliver.

Indeed the studies show — whether we are talking about in Europe, in Holland or in Oregon — that the taking up of the options under euthanasia or physician-assisted suicide only ever make a difference in probably between 0.5 to 1.0 per cent of all deaths. Yet we know, day after day, that there are thousands of people who are not getting the death they want simply because we are not providing the advance care planning in their palliative care. That is the reason why we focus on that, rather than on something that is small and contentious and gets a lot of media, because this is the important bit.

The benefits of advance care planning that we have seen in the literature that our society looks at are that not only does it increase the likelihood that a patient's wishes will be known and respected at the end of life but also that they will have a greater level of satisfaction about the care they are receiving not only at the end of life but even before that. There have been some great studies showing increased confidence and comfort with their GP, with their physician and with their nursing staff, simply because someone stops to talk to them and asks, 'How are things going? Do you have a good understanding of your illness and your treatment options? Have you thought about who would make decisions for you if you no longer could?' The fact that someone is spending the time to talk to them and listen to them makes a huge difference in their level of satisfaction and in the level of satisfaction that their family has about the care they are receiving.

So we improve end-of-life care, we increase the likelihood that wishes will be known and respected, and we improve level of satisfaction. There has been one study, maybe more, which has shown that advance care planning also decreases the risk of depression, anxiety and post-traumatic stress symptoms in the surviving family members of people who have died. That is because those family members have been involved in the discussion. They have a clear understanding and awareness of what Mum or Dad would want instead of when the doctors, who invariably turn to the family when they can no longer talk to the patient or even when they can still talk to the patient, say, 'Your mum is deteriorating. What should we do?', going, 'Oh, my God, I don't know. We never talked about it. I'm not sure. What do you think, Doc?', and the doctor says, 'Well, we can do the following', and they say, 'Yes, let's do it' and what ensues is the conveyor belt of doing a whole lot of things that do not actually deliver the outcome they wanted. Then the family gets traumatised after Mum dies, thinking, 'Why did we agree to that? Why didn't we know what Mum wanted? Why did we allow the doctors to do something that in fact if you think about it, Mum would never have wanted? If we had only stopped to talk about it and the doctors had only asked us'.

That is why they end up being traumatised, days, weeks, months later, thinking, 'I allowed Mum to die in a way that she would never have wanted. I let Mum down'. That is where advance care planning can make such a difference, where you talk about it in the cool light of day when no urgent decisions need to be made. When Mum is watching something on the telly and she sees someone in a nursing home and says, 'I would never want to be like that', that is a conversation to encourage rather than saying, 'There, there, Mum; don't talk like that'. You actually need to support it, encourage it and document it so that then when difficult decisions need to be made, everybody is on the same page. We have seen that in work that is being done in nursing homes, in general practice and in hospitals right across the board.

What we do want doctors to be focusing on these days — and I am just bringing this to your attention in order to put in context what you decide from the legislative perspective — is that we want doctors to concentrate more on diagnosing dying or the risk of dying. You may or may not have heard of 'the surprise question', which is the question where you ask a doctor not 'Is Mrs Jones going to die?' but, 'Is there a chance that Mrs Jones will die over the next 6 to 12 months?'. The beauty of that question is that you are not asking them to

play God, as they do not like to do, and you are not asking them to be definitive about their prognosis, but you are asking them to think about if there is a possibility. And if there is a possibility, then that is the time we should be talking to that patient and that family about what to do and what not to do.

If you ask the average doctor in the hospital about whether this is relevant, some people do not see that it is relevant. But there was recently a study published where they looked at 25 000 or 10 000 — a large number — admissions to Scottish hospitals. In fact, I can tell you. It was 10 400 inpatients in 25 Scottish hospitals in 2010. They then followed all of those patients for 12 months. Overall it is amazing to find that 29 per cent of those patients died within the next 12 months. Many of them were elderly, and in particular those who were male who were aged 75 or over — 50 per cent of them died within 12 months. These are the same sort of figures across the world.

So if you have someone over the age of 75 who is male and you know that 50 per cent of them are going to die in the next 12 months, why would you not go and talk to them and their family about, ‘Look, Mr Jones, I am pleased to see that you are getting better from your pneumonia’ — or your heart failure or your kidney failure or whatever — ‘That is fantastic and we hope to get you out of hospital soon, but if you are to get sick again, can you give us a sense of what you would want, and can you tell us who you would want us to speak to if difficult decisions need to be made’? That is the old adage of ‘Hope for the best but plan for the rest’, or ‘Hope for the best but plan for the worst’. That is not removing hope, and in fact the research shows that the more you talk to patients about this, the more you give them hope because they can see that you are being honest and realistic with them and you are helping them to concentrate on the reality without saying, ‘You are definitely going to die, but if something was to happen, let us plan for it, in the same way that you have insurance for your house’. When I last checked the medical research, we are more likely to die than to have our house burn down. We all have house insurance yet we do not do advance care planning.

Coming back to my list of things that we want doctors to do, we want them to be better at diagnosing dying or diagnosing people who are at risk of dying. Secondly, we want them to see end-of-life care as their responsibility. Just because you are an interventional cardiologist does not mean you can abrogate your responsibility to make sure that when you have an elderly person dying of heart failure that you do not make sure that there is good provision of what that person needs. Many people do not realise that if you have heart failure or if you are on dialysis and you are over a certain age, your median prognosis is probably about two years. In fact your prognosis is probably worse than many cancers. With cancer we focus on palliative care and end-of-life care but with the chronic diseases of lung disease, heart disease, kidney disease, which are burgeoning as our population is getting older, we do not take seriously our responsibility to make sure we care for patients right to the end of their lives. So that is the second thing — seeing end-of-life care as their responsibility, and if they can deliver it, great. If they cannot, call for help. Do not just ignore the problem.

The third thing is that doctors need to get better at looking for advance care directives. There are many people who have filled out advance care directives that are recorded, they may be at home in the bedside table, they may be recorded electronically in the hospital system, we are looking forward to them being recorded on the PCEHR, or what is now called myHealth, and yet the doctors are not actually looking for this. So all the effort that patient has gone to, whether supported or not, is completely ignored by the doctor. We need to get the doctors better at talking to the competent patient or the family of the patient who is no longer competent about these things, and we need to get better at prescribing palliation.

It always disturbs me when you hear about doctors being called up to the ward to see someone who is dying and it is simply because the doctor has not written up the morphine or the other medication for the shortness of breath or the pain that patient is going to have simply because they did not do a ward round at the end of the day and think, ‘Who could possibly die tonight, and have I written up the appropriate medications?’. We need to get the doctors also not being scared of prosecution. I have had times when GPs do not prescribe the morphine because they think that because the patient may die a bit sooner than they would otherwise, they are at risk of prosecution. We need to get the doctors better at deprescribing things that are no longer going to help, at stopping unnecessary investigations and always considering and acting in the patient’s best interests. If in some legislative way we can ensure that doctors are doing this and are not worried about whether the family is threatening to take them to court or demanding certain things be done, that is where we need to educate the doctors that, ‘You are more at risk legally if you prescribe a treatment or deliver a treatment that is not in the patient’s best interests, even if the patient or the family are demanding it, than by withholding something that is not going to help’. There are any number of cases that have been shown in the western medicine system where

doctors have been successfully sued for doing something they did not think was in the patient's best interests but was being demanded, and yet I am not aware of a single case where a doctor has been successfully sued for withholding something they did not believe was in the patient's best interests.

New South Wales is the only jurisdiction that does not have a statutory advance care directive. Victoria is the only jurisdiction that does not have an up-to-date advance care directive. We have had a refusal of treatment certificate for decades now. When we first started looking at this we realised, in consultation with the public advocate's office, that although refusal of treatment certificates have been around for more than 20 years, the number that have been sent to VCAT, which is what you are supposed to do under the law, has been minuscule compared to the number of advance care directives that have been filled out. I remember Julian Gardner telling me when he was the public advocate that just the name 'refusal of treatment certificate' is alienating. They do not want to upset their GP or their specialist, particularly the elderly patients who treasure that relationship.

The second thing I am sure you have heard about is the fact that patients can only record something on a refusal of treatment certificate if it applies to a current condition. I think that is particularly disarming for the many elderly people who may be well but frail. They have heard that, contrary to what they see on *ER* and *Chicago Hope*, if they were to have a cardiac arrest and receive CPR, they are not going to survive. People in nursing homes — the success rate of CPR in cardiac arrests in nursing homes is somewhere between zero and 0.5 per cent. If you went to a surgeon and he said, 'Yes, I'm happy to do that operation but it has a 0.5 per cent success rate', clearly you are going to get straight up, walk out the door and maybe even report him to AHPRA for practising medicine that is so bad. Yet we do not give patients on the refusal of treatment certificate an opportunity to say the things they do and do not want even if they do not have that condition at this time.

**The CHAIR** — Associate Professor, I will ask you, if you do not mind, to perhaps come to the conclusion in the next few minutes of your presentation so we have time for questions.

**Assoc. Prof. SILVESTER** — Sure. I have just got four more points. We have insufficient expectation of doctors to make advance care planning and end-of-life care a core part of their business. We have not focused enough on the importance of the medical decision-making where the doctors making the decision in the patient's best interests, having informed the patient appropriately, have gathered their view and approached it using a shared decision-making process. And we need triggers through regulation, through providing sufficient funding to trigger advance care planning discussions at the appropriate time, whether it is a new illness, a certain age, a recent admission to a nursing home or any other particular circumstances.

**The CHAIR** — Thank you very much. I will ask the first question and just pick up on your point about the refusal of treatment certificates or advance care directives. I note your point that in Victoria it applies only to a current medical condition. We heard evidence earlier from the Department of Health and Human Services about what exists in other jurisdictions, and you alluded to the common-law position in New South Wales and the statutory position in other jurisdictions. How do you address the issue of people's changing perspectives for illnesses in the future that they do not yet have and their perspective of what that means or the treatment they may wish for that as time goes on? How do you accommodate future wishes, understanding that people might change their minds down the track?

**Assoc. Prof. SILVESTER** — You are raising the issue of, 'How can they possibly know what they want in the future if they have not got it at the moment?'

**The CHAIR** — Correct.

**Assoc. Prof. SILVESTER** — The research has shown that when advance care directives have been recorded, and if you of course inform the patient, the family and the health professionals that it is not set in stone and can be changed at any time, when you go back and review how they change over time if people repeat or re-record their wishes, if anything over time they put more and more restrictions or limitations in place. That is reassuring to us because what really lies behind your question is, 'What if they've said they don't want something and then later when they become sick they can no longer communicate with you and they miss out on getting something that they actually would have wanted by the time that event occurred?'. It has been reassuring to see that advance care directives, when they do get reviewed, if anything those people put more restrictions in place rather than removing the restrictions that are already there.

If there is any risk of having an advance care directive and someone misses out on something, that is completely outweighed by the fact that there are many people who end up getting a lot of things they did not want simply because they never put an advance care directive in place. If you were going to look at it in terms of a lesser of two evils argument, you reduce the harm much more by having those in place, by educating them and health professionals about making sure they get reviewed every time the patient re-presents, whether it be in general practice as a 75-plus health assessment or whether it be when they get readmitted to hospital or they are seen in outpatient clinics. In that way we make sure that they stay up to date.

**Ms SYMES** — Thank you very much for your presentation. Picking up on your view — and also I think you mentioned it was Julian Gardner’s view — that refusal of treatment certificates by their very title are combative, would you envisage that an advance care directive could absorb the refusal certificates? Would you envisage that they should operate under a different title, or can you merge the two?

**Assoc. Prof. SILVESTER** — I would recommend that we come up with a new statutory document that has a new name and has new provisions. We can look at the uptake of advance care directives in other jurisdictions to provide guidance as to what works and what does not work. There are common-law documents that have been used across Australia, but these days a lot of the jurisdictions are trying to promote their statutory documents because it obliges the doctor to follow it and not ignore it. In New South Wales there is a common-law document but there is the 2009 Supreme Court case where it was set out very clearly in the declaration that advance care directives, if they are valid, they need to be taken into account — the doctor does not have the choice to ignore them. But I would still recommend that we have a statutory document here with a new name and with those provisions that mean we are not restricted to current conditions. I would suggest that we replace the refusal of treatment certificates with something that will meet patients’ wishes.

**Ms PATTEN** — Thank you, Professor. I was very interested in a couple of points. Obviously advance care planning has been something that we have been talking about today and the triggers for advance care planning. You seem to be quite in line with the Grattan Institute’s position. You mentioned maybe having a regulatory model. Do you think that it is something that we should be enforcing at certain points, whether it is men over 75 going into the hospital or entering an aged-care facility?

**Assoc. Prof. SILVESTER** — I think that regulation is very useful to guide clinical practice. I often say to people that you can tell everyone why it is dangerous to drive through a red light, but if there is a red light camera, it changes practice. I am aware that the uptake of advance care planning policy and directives and the change in practice did not shift for many years until the ACHS standards indicated that it was an expectation now that advance care plans would be looked for and be promoted and be reported appropriately. What changed with that coming out in six months was greater than what had been achieved in the previous 10 years. Again, it is about accreditation. It is about having that regulation to ensure that people get with the program. Our society would support that.

**Ms PATTEN** — To follow up, you mentioned that in other jurisdictions where voluntary euthanasia or assisted dying is lawful, less than 1 per cent of people actually take that up. I was wondering: do you have any idea about why that 1 per cent does? Why are they different from the other 99 per cent? Is there something clinical about that 1 per cent? What are your thoughts?

**Assoc. Prof. SILVESTER** — I would probably only be in a position to speculate on that in the same way as you; I have had no personal experience with that. We have members of our international society committee who are based in Europe who are also not supportive of taking it up. I presume it is a small number who, despite getting good palliative care and despite being able to record what they do and do not want, have reached a point where their suffering is greater than their desire to still live. When I hear people talk about euthanasia or in fact when I hear patients say to me that they want to die, when I drill into it they do not actually want to die, they just do not want to live any longer the way they are living.

So if, for example, someone has oesophageal cancer, and I have had personal experience where the mother of someone I know was dying of oesophageal cancer. She was still living alone, she had great dignity, she had reached a point where she could hardly eat. She was not in pain but every day it was harder to get out of bed and she knew it was going to reach a point where she could not. She said to me, ‘Why is it that I cannot have access to something when I have reached a point where my suffering is too great to continue like this? Why would I not be able to have access to something like that?’. She did not need more palliative care unless you are a

palliative care physician who goes for the ‘admit them to hospital and go for the terminal sedation’ approach. In her circumstance, I could not actually argue against her case.

**Ms FITZHERBERT** — Do you think Victorians are well informed about their existing rights under legislation in terms of end-of-life choices? And what could we do that is practical to address that?

**Assoc. Prof. SILVESTER** — I do not think they are at all well informed. Many health professionals are also not well informed. I think really the only way to move that forward is to have a properly funded public awareness campaign. I have been involved in organ donation for nearly 20 years at a Victorian and a national level, and the initiative of the previous federal government of putting money towards public education made a huge difference. Occasionally we saw public awareness about organ donation being raised by the David Hookes case and other cases like that, but then when there was sufficient money put towards a public awareness campaign it reached a point where as an intensive care specialist when you have got a dying patient, families are more than likely now to bring it up. It has made a huge difference, and I see strong parallels between the whole organ donation debate and the organ donation awareness publicly and getting the health professionals to take it seriously, take it on as core business, and this whole area about improving end-of-life care as well.

I do think it needs to be funded. I believe one could put a strong case for the money that we would put into that. The primary purpose is to improve quality of care at the end of life, but it would also positively impact on the health budget, which would then mean that we are delivering care to the people who want it, need it, benefit from it. So much of our health budget is spent in the last six months of life on people who if you stopped to ask them, would say, ‘No, look, I didn’t want all that, I wasn’t going to be delivered a quality outcome that was acceptable to me. It would have been much better if you had not done all these things and given me a chance to go home and be with my family and loved ones when I die’.

**Mr MULINO** — Thank you very much for your submission, Professor. I have two quick questions. The first one relates to the fact that in this space people’s preferences vary considerably in terms of their values, the kinds of treatment they would like and so forth. It may also be the case that people’s preferences might vary in terms of what kind of planning they feel comfortable with and how formal they would like that planning to be. I just would be interested in your views as to what you would think about a multitiered regulatory arrangement where there might be, for example, a legislated mechanism which might be relatively formal but perhaps also an option which is less formal, easier to enter into but also easier to change. It might be that that variation in options gives a greater uptake.

**Assoc. Prof. SILVESTER** — I would see the two-tiered approach not being so much in having different documents because that can then lead to confusion about which one we are looking at, and indeed a formal advance care directive is very easy to revoke and to rewrite. I would see the two-tiered approach more in terms of the practice. So the first tier would be you are expected to go looking for any advance care documents the patient may have completed. If you cannot find it, you need to make sure that you go and speak to the patient if they are competent, and the family if they are not — both together if the patient is competent — and to identify what their wishes might be, including their wish not to document something. Then if they do wish to document it, you would ensure that you support it to be documented and then having documented it make sure that it is stored electronically so that it is accessible by all.

**Mr MULINO** — The second question also relates to uptake. This seems to me to be similar to the challenges we face in relation to a lot of other important life choices; for example, people making choices about financial products like mortgages and superannuation. We know that there is often a low level of engagement — people will often not read documents, they will often make default choices even if they are inappropriate. I think some of the ideas that you have put forward but also the Grattan Institute put forward about linking engagement with this process to other processes, like making a will or being discharged from hospital, are really interesting. I think those kinds of trigger points have been used in other areas of important life choices as well. I would just be interested in whether there is much empirical evidence around which ones have been effective in other jurisdictions at generating greater engagement.

**Assoc. Prof. SILVESTER** — That is a good question. I do not know a lot about that, but if you wish, I can take it as a question on notice, look into that and then send something through in writing before the end of July.

**The CHAIR** — That would be great. If I may, just to pick up your original comment, we would love to receive any submission you would wish to make in this area.

**Ms SYMES** — I have a particular interest in organ donors but also whether end-of-life choices for people who wish to be organ donors is something you have considered.

**Assoc. Prof. SILVESTER** — With my medical consultant for Donate Life Victoria hat on, I can comment that we always find it very useful that if someone has indicated they do not want to be on life-prolonging treatment for a long time — for example, a ventilator — but if by being on a ventilator if, for example, they were to have a stroke or a brain haemorrhage or a car accident, that would then facilitate organ donation, they would really appreciate the opportunity to be able to record that, because it then gives clear guidance to the family. Otherwise they feel caught. They say, ‘Look, Mum didn’t want to be on life-prolonging treatment but she also wanted to be an organ donor. Where do we go with that?’. If they have that opportunity to record that clear direction, then it means we can still reassure them that we are not going to leave them for days or weeks on a ventilator if they are not going to have a quality of recovery that they would see as acceptable or if they are not going to recover at all but they would not mind being on a ventilator for one day or two days if it means that they then progress to brain death and then can become a multi-organ donor.

**Ms SYMES** — So it is already a factor that is considered?

**Assoc. Prof. SILVESTER** — It has not been built into the common-law advance care document, but I do know that in some jurisdictions some of the health professionals who drive advance care planning in their area do include a question about organ donation in their documentation, and I know our society would support that.

**Ms SYMES** — Are there instances where perhaps someone is in their final days or hours of death and by virtue of having to get to the end unaided they therefore can no longer be organ donors? Say if a life-support machine is turned off and they do not die soon enough and have other organ failure, is that a completely different issue?

**Assoc. Prof. SILVESTER** — Yes. I am just trying to work out exactly what your question is on that.

**Mrs PEULICH** — Do you mean early organ harvesting?

**Ms SYMES** — Sort of. Are there cases — I do not know — where somebody wishes to be an organ donor — —

**Assoc. Prof. SILVESTER** — But they will not progress to brain death, for example?

**Ms SYMES** — Quickly enough, yes.

**Assoc. Prof. SILVESTER** — These days the two pathways to becoming an organ donor are either because your brain injury is such that you progress to brain death and then you are officially declared dead under the Human Tissue Act and then your body is taken to the operating theatre and that is where they are able to then retrieve the organs, or it is recognised that you are not going to progress to brain death but the family and the doctors are aware that that person wished to be an organ donor. Then treatment is withdrawn, and they progress down what we call the DCD, or the donation after cardiac death, pathway. So that certainly exists, and in fact Victoria has been leading Australia in the increase in the donation rate.

I am not sure if you are aware that we can be very proud that Victoria has been numerically leading donation rates in Australia, and quite a lot of that has been about the fact that we have had a very active donation after cardiac death program. And that is not just for those people who may have a severe head injury but will not progress to brain death who would not want to end up like that and the families agree with the doctors that it is appropriate to withdraw treatment. Treatment is then withdrawn and they die within the 60 minutes that is required in order to retrieve certain organs. But equally it applies to people who may have end-stage heart failure, respiratory failure or liver failure, who also indicate that they do not want to live like that. Treatment is withdrawn, and then they again die in a short enough period of time that they can end up becoming donors of other organs.

**Ms SYMES** — Do most people die in that 60-minute window?

**Assoc. Prof. SILVESTER** — The detail is: if you want to try to retrieve the liver, you need to die within 30 minutes of treatment being withdrawn; within 60 minutes for the kidneys; and within 90 minutes for the



lungs. Again, if you wish I can get information sent to you on this. I know it is sort of off-topic, but if that is of assistance?

**Ms SYMES** — Yes. Is there a gap in that death could be hastened in those situations where, rather than waiting 2 hours, you were able to obtain organs to save other people's lives? At the moment I assume that doctors are not able to hasten death at that point?

**Assoc. Prof. SILVESTER** — No, it is still against the law, because that would really be physician-assisted suicide for a different reason — or physician-assisted dying to be more accurate — in order to either assist the patient who wants to die, which is physician-assisted suicide, or assist the person to become an organ donor.

**Ms SYMES** — But, presumably, there is no point of reversing that? If you have turned off the machine, you cannot reverse it then, can you?

**Assoc. Prof. SILVESTER** — That is true, but still — —

**Ms SYMES** — But you are still not able to hasten — —

**Assoc. Prof. SILVESTER** — If in the intensive care unit the doctors administer morphine or midazolam or any other medication, it is still under the premise that the patient is seen to be suffering, and so you are treating the suffering; you are not deliberately trying to hasten the person's death in order to facilitate organ donation.

**Ms PATTEN** — They would have to be in pain?

**Mr O'DONOHUE** — Just for the benefit of the committee, in the last Parliament a committee of the Legislative Council considered the issue of organ donation and how to increase organ donation rates, so there is a considered report which the Legislative Council has previously tabled.

**Mrs PEULICH** — I think many moons ago in another capacity I helped to launch the multicultural database for organ donors, because the rates amongst multicultural communities for donating organs was very low. I assume that is probably still the case. Professor, are you of the view that there ought to be mandatory end-of-life plans for, say, all men over 75 years of age. Is that correct?

**Assoc. Prof. SILVESTER** — No, I did not say it should be mandatory. It is still up to the individual as to whether they want to complete it. What we need to encourage — and whether it is by regulation or not of course is up to you — is health professionals making the patient and their family aware of the whole issue of advance care planning, making sure that they are well informed about what is happening now and what may happen in the future, and making sure they are aware that they can fill a document out if they wish to. It is still of course up to the patient.

**Mrs PEULICH** — I would have thought it would be as popular as mandatory testing of older drivers, and it would be a very brave politician who would vote for it. I have another question: you clearly believe that there is an economic benefit in assisting those who perhaps want to short-circuit the last period of time of life and cutting back on the expensive treatment of perhaps those who may be waiting for organs to be donated, so there is sort of benefit from both ends. Is that part of your submission today?

**Assoc. Prof. SILVESTER** — I would be careful putting all that in one sentence — —

**Mrs PEULICH** — So would I.

**Assoc. Prof. SILVESTER** — Because it starts to conflate the issue of organ donation — which I was not intending to bring up today, but I was answering a question — versus recognising that advance care planning, by ensuring that people are not getting something that they did not want to get, means that valuable resources are directed more to those people who, A, can benefit, and, B, want that particular treatment.

**Mrs PEULICH** — Can you understand, Professor, that some people would have a real dilemma in embracing that sort of medical view, especially, say, those from multicultural backgrounds or the survivors of the Holocaust or perhaps any other brutal regimes where state-sanctioned death is something that is the antithesis of what they believe in?

**Assoc. Prof. SILVESTER** — I have not said anything so far that supports state-sanctioned death.

**Mrs PEULICH** — It seemed to me that perhaps you thought that there was a place for a more robust ending of life in those cases where there were no clear benefits for prolonging it. Am I oversimplifying your view?

**Assoc. Prof. SILVESTER** — I think so.

**Mrs PEULICH** — I am glad to hear it.

**Assoc. Prof. SILVESTER** — Because again it is all about patients' choices. This is not about withholding treatment a patient may well want, and in fact my personal experience with advance care planning has at times been to ensure that the doctors actually go and speak to the patient, whether you see the doctor standing outside in the corridor talking to the family, and then remind the doctor by saying, 'Look, you may actually want to go and speak to Mrs Jones. She's in the room. She is probably hearing what you're saying, and she has got a view', through to a case I had where a patient's admission to intensive care was being discouraged by the doctor. This was not at the Austin Hospital; it was at a private hospital. Because I was on call for the intensive care unit, I said, 'Look, I would be agreeable to that, as long as I'm reassured that the patient has had an opportunity to express a view'. The junior doctor then went and spoke to the patient, and indeed the patient did want treatment, and it was because of my intervention from an advance care planning or patient choice perspective that that patient ended up getting the treatment that led to them remaining alive. So, as I have said, it is not about euthanasia, it is not about state-sanctioned death, it is not about deliberately withholding things; it is about identifying how we can help the patient, what their views are, and what is in their best interests.

**Mrs PEULICH** — For the inarticulate, the illiterate and those who perhaps do not have the language skills, for the babies and for those who suffer from dementia, how would that be managed in such a scheme?

**Assoc. Prof. SILVESTER** — You have mentioned a number of different cohorts of our population. We are of the view that advance care planning can be done not only with the competent patient but indeed with the family of the patient who is no longer competent. The way that discussion occurs is by saying — well, there could be two scenarios.

Firstly: 'We went and had a talk to your mum today, who's been here, who's in hospital, who's going back to the nursing home tomorrow, and she indicated to us that if she were to get sick again she would not want to come back to hospital. She'd rather stay in the nursing home and be kept comfortable, surrounded by family and friends. What do you as a family think about this?'. Usually they just have a look of relief on their faces that someone has finally brought up the very issue they did not know how to bring up. They were worried because they thought the staff would think they were trying to pull the plug on Mum. They were just so relieved that someone was talking about what has been concerning them.

Or, secondly, you go and have a talk to the family and say, 'Look, we're not in a position to talk to your mum about this, but there is a chance that she is going to deteriorate tomorrow or again in the future. Have you ever talked to your mum about what she would want under the circumstances and what she would view as an acceptable quality of life so that we as the doctors can be guided as to what we can aim for?'. That is usually where they say, 'Mum talked about it only six months ago when we were watching something on telly' or, 'Mum has said very clearly for the last six years, because she's lived with me as the daughter, about what she does and does not want'. They are just so pleased that someone has brought it up in a way that they did not know how to bring it up. Then that can be documented on a common-law document on behalf of the non-competent person about what they would or would not want.

The one that is filled out by the competent person we tend to call an advance care directive; the document that is filled out by the family on behalf of the non-competent person we can call an advance care plan. I do not really mind what we call it as long as we give them an opportunity to reflect upon it, discuss it between themselves over their Sunday lunch, come to some conclusions about what Mum would want — because remember, it is about Mum, not about themselves — in true substitute decision-making style and get it documented. Then everyone is on the same page so that when the urgent call comes at 3 o'clock in the morning that 'Your mum's just had a stroke' or 'She has deteriorated again' we all know what to do and we do not do silly things.

**Ms PATTEN** — Just to follow a little bit on from that, you said in your opening statement in discussing end of life and getting that conversation happening and starting with the advance planning there, that your mum

might look at the TV and say, 'Well, I don't want to ever be like that'. I wonder, if that is a person who is unable to walk, unable to talk, but is not dying, is there a way to express that in an advance directive?

**Assoc. Prof. SILVESTER** — Definitely. That can be recorded by that person. We do not encourage patients to say the things that they do want, particularly around things they do not know — for example, I would not come to you and say, 'If you were to get pneumonia, would you want a ventilator? If you were to have a heart attack, would you want CPR? If you were to have something else, would you want dialysis?'. I would ask you to concentrate more on what would be an acceptable outcome. So if you had said to me, 'In my job, in my whole life, being able to communicate, being able to talk to family, being able to think intelligently and make a contribution to society is the most important part of my life essence, and if I reach a point where I have a stroke or a haemorrhage or a severe car accident and I'm not going to return to anything like that — I'm just going to end up in a nursing home being fed by a nasogastric tube — I don't want any treatment,' then that guides us. So whatever you turn up with, that helps us to know.

**Ms PATTEN** — Would that mean in that case with that person you could refuse food and sustenance?

**Assoc. Prof. SILVESTER** — Correct, yes. I have personal experience of a patient who was a dialysis patient. He indicated, 'I'm very happy to be on dialysis but if I lose the ability to walk or talk or feed myself, I don't want ongoing treatment'. About 11 months later he ended up having a stroke. The renal physician and the neurologist, who were both involved in his care when he was admitted to hospital, indicated that if he had not filled out an advance care plan and if he had not supported not only them but his partner to make the difficult decision about not putting down a nasogastric tube and just keeping him comfortable, they would have found it very difficult, even though the stroke left him bedbound, unable to understand or communicate anything, unable to feed himself. The renal physician said to me — lovely, lovely doctor — 'I would've really struggled with this. I would've insisted on treatment and he would've ended up in a nursing home, coming in by ambulance three times a week to the hospital to have dialysis until he died from something else'. That is how it actually works in practice.

**Ms PATTEN** — Yes. So, in that case, that person is not dying of anything.

**Assoc. Prof. SILVESTER** — No, he is on dialysis.

**Ms PATTEN** — But in my case, the woman is not dying of anything but she has severe dementia and she has lost her ability to walk or recognise her family, and that was the image she was pointing to on the television to her children, saying, 'I never want to be that woman drooling in the corner of a nursing home'. That is when we can start to — —

**Assoc. Prof. SILVESTER** — I am glad you brought that up, because this business of advance care planning is not about going round pulling the plug on people, like you were raising. That does not mean you go into the nursing home and say, 'Dementia — pull the plug! Stop the feeding! Do this! Do that!'. It is just about knowing what to do if they deteriorate from a physical illness from which they may die. So, again, it is not about euthanasia, because euthanasia is where you deliberately take someone's life, whereas this is about not intervening medically if they would not want it in a situation where someone has a condition from which they could die.

**Ms PATTEN** — Is spoonfeeding them a medical treatment?

**Assoc. Prof. SILVESTER** — You would know there was a Supreme Court case here — the BWV case — where putting down the spoon is not regarded as a medical treatment. It is only when you intervene with nasogastric or PEG feeding in that particular case. But if the patient gets to a point where they can no longer feed themselves and they are in a nursing home because of dementia, and the family are of the view that at that point Mum would not want this, they can then turn to the GP and say, 'At this stage, we don't want to see Mum suffering. What can you do to keep Mum comfortable? We don't want to start feeding her artificially. Mum's had a wonderful life. She is now only a shadow of the former person that we knew and loved — and still love. Let's keep her comfortable'. That is where we deliver better end-of-life care. If we have had that discussion beforehand — the advance care planning — then it supports and facilitates that whole process, rather than leaving the family struggling with that decision.

**Mrs PEULICH** — On the same theme, if I may, a friend of mine recently had a father-in-law receiving palliative care. They were on watch, and her husband is an osteopath, so he understands a little about medicine. After observing, they realised he was not being cared for properly. They had stopped feeding him. The man came out of hospital; they brought him home, they started feeding him and he got a bit perky. He perked up, he was sitting up and regained some of his capability. How can a regime prevent those types of scenarios where unfortunately not all doctors get it all right. When my father was about to receive palliative care I was assured that during his treatment he would retain a lucidity which would enable those last-minute conversations, which I was denied and never had. That is not to criticise the palliative care program, but it was clearly not accurate advice from the practitioner. Is there any regime that can prevent the overzealousness of medical practitioners?

**Assoc. Prof. SILVESTER** — I do not think any regime or regimen of practice is going to prevent some things happening, and I think that is largely because as doctors we cannot always get it right. We do not always know exactly what is going on. Our ability to prognosticate is still limited. We can prognosticate as a group but not on an individual case. That does not detract from the fact that advance care planning can still help in a lot of cases, but it is not going to fix or cure everything.

**The CHAIR** — Associate Professor Silvester, the committee thanks you very much for your time today, your presentation and your thoughtful answers to our questions. We look forward to receiving any additional information you wish to provide to the committee. As I said previously, a transcript will be provided to you in the coming days. Thank you very much.

**Assoc. Prof. SILVESTER** — Thank you for your attention.

**Committee adjourned.**