TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Mornington — 29 October 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

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Witnesses

Dr Peter Lynch, clinical director, aged-care medicine, and
Mr David Goldberg, general counsel, Peninsula Health.

The CHAIR — Thank you very much, gentlemen, for being here. I would like to welcome Mr David Goldberg, the general counsel from Peninsula Health, and Dr Peter Lynch, the clinical director, aged-care medicine, from Peninsula Health. I thank you both for being here. Before I invite you to make some remarks I will 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 in the next week or so, and transcripts will ultimately be made public and posted on the committee's website. We have allowed a bit over half an hour for your time this afternoon, and again I thank you both for taking time out of your schedules to be here. I invite you to make some opening remarks, and thereafter the committee will have some questions. Thank you.

Mr GOLDBERG — Thank you for the opportunity on behalf of Peninsula Health. Just very briefly, my name is David Goldberg and I have been general counsel, Peninsula Health, for about five years, and prior to that I was in a legal and industrial role at the Australian Medical Association Victoria, so I certainly have some experience in this, and in fact I recall the last time the AMA took a position on some of these end-of-life issues, and it is familiar, and it has come up again, obviously in the context of this inquiry. On my right is Dr Peter Lynch, who is Peninsula Health's clinical director of aged care and geriatric medicine. Peter, would you like to talk to your experience?

Dr LYNCH — I graduated over 40 years ago now and finished training as a specialist physician in the early 1980s, so I have pretty widespread clinical experience. My current position is aged care medicine, but I initially trained in general medicine and I have worked overseas and in the Northern Territory, and in the public and private sector in Victoria. I have actually had a bit of an interest in this area.

First of all I was aware of the previous session of this committee in the 80s that went around and worked for about two years and which people like Carolyn Hogg and others were involved in — sorry to pick one name but that is one that stands out; there were many others — which led to the Medical Treatment Act. I am familiar with the formation of that, and indeed the initial workings of the act both from a general public policy viewpoint and from the clinical viewpoint. Also I happened to be working in the health service, and I do not think it has ever been revealed publicly which health service it is and I will not mention it today, where the actual case of BWV came from. The interesting there was that clearly the health service was very sympathetic to the issues with BWV, but the interpretation of the health service and all the best legal advice was that this was what the Medical Treatment Act said, which led to the Supreme Court case.

David has read the decision, and what was interesting to me is that the decision actually drew a lot on the legislative intent of the upper house in passing the amendments to the Medical Treatment Act. The view was put there in Justice Stuart Morris's decision that in fact what actually went into the Medical Treatment Act at that time was not quite exactly what was the legislative intent of some of the members of the house. As we know, that led to practice changes as pursued of the BWV finding in the Supreme Court.

I have to say as a clinician that really made a big difference because up until that time certainly hospitals were of the view that it was an unintended consequence of the Medical Treatment Act that people did not have the right to refuse food and water administered in those particular ways. Our practice did change a lot after that, whereby hospitals, wards, clinicians no longer necessarily provided food and fluid to unnecessarily keep people alive when that was not the primary intention. That is, sorry, a bit of a long introduction, but I have seen a bit in my time since I have been around.

Mr GOLDBERG — We had the benefit of looking at — I cannot confess to looking at all the 1012 — a substantial number, but no doubt the committee has had the benefit of substantial input in both oral submissions and written submissions. I think my view would be guided by you, but really what we can best add is more by way of whatever the committee sees fit to ask us. Really we would be quite brief. You have received many touching submissions but also many substantive submissions from all sorts of bodies, and I am sure you are aware of the law so I do not need to talk about that.

I suppose what I would reflect on really briefly from my perspective working in a health service — and again I would be pleased to expand by way of questions if it is an area of focus — is that advance care directives are very difficult to enforce, very difficult to understand. I think something like a central repository would be a very good idea, similar to organ donation. I have seen that in some of the submissions, and I would support something like that because I think it would breed both publicity and education but also a formality. I think you might consider that in the context of the refusal of treatment certificate not being a particularly useful or used document because of its probably same intent but much more limited application. Certainly I know the ambos would say, ‘You get to a body and how do you know the veracity? Your first obligation is to provide emergency care. You have been called to a scene; you provide the care. You do not look at the document’.

When Dr Lynch and I were having a chat about this earlier, there is a purist view of, ‘Well, they are enforceable’, but in reality you do not know who has written it if it is an informal document. Sometimes you have the benefit of it looking more like a formal document, but quite often you do not. You do not know when it was written; you do not know if it is current. It is very often in layperson’s terminology: ‘I do not want heroic measures’ — what does that mean to a doctor? ‘I do not want dialysis in any circumstances’ or ‘I do not want a drip’ — what does that mean? So I think the enforceability and interpretation is a real issue. Obviously the more people can express their wishes at an early stage the better, in which case anything that can be done to reinforce that from Peninsula Health’s perspective and from my perspective as a legal practitioner would benefit the community.

Futility would be another area that I would comment on. I think it is not well understood, even by clinicians at Peninsula Health, even those experienced in this area — Dr Lynch confirmed this with me today — the difference between when it is decision-making of a person or their family and when we are moving into the realm of medical futility, which, by definition, is a medical decision. Too often the problem with making it a family decision is that you are saying, ‘The medicine is now futile. We have an obligation not to provide care in circumstances where that care would be futile because we cannot do harm, we can only do good, and it is causing more burden than benefit. Do you agree?’. I think that is an impossible thing to ask somebody because in fact in some cases what I think a family might hear in the wrong case is: ‘It is causing too much burden to keep your daughter alive. We think we should withdraw the ventilator. Do you agree to kill them?’.

I think that discussion happens and is managed beautifully most of the time within a health service setting, but the difference between when something is medically not indicated to be done or medically indicated to be withdrawn and when it is in fact something that should be the autonomy of a decision-maker needs to be better understood. It is the same example as medicine is not able to be provided on demand. You cannot walk into your doctor and say, ‘I want antibiotics. I am not sick, but I want them’. Well you can, but a doctor ought not give them. It is a similar sort of concept, which I think is a real challenge. It manifests itself at Peninsula Health with NFR — not for resuscitation — orders, which are actually medical decisions. So it is a medical document that ‘This person is not for resuscitation’.

I am not saying in any way that the family should not be involved in that discussion, but the good clinicians, from my observation, will manage that conversation with a family so the family understands that a decision has been made based on the evidence and then can negotiate how that decision plays out, as distinct from: ‘You can negotiate the medicine’. I think that that difference perhaps could be better articulated through, potentially, reinforcement through legislative supporting the case law around futility.

Euthanasia or physician-assisted suicide I do not think are for a public health service. I have reflected deeply on this point and spoken to clinicians, and I have certainly seen the submissions of other health services on this point. It is a matter for this committee and certainly not for legal counsel from a health service to offer a view on whether this is something that should be embarked upon. What I would say from a health service perspective is that it is clear that the medical professional associations and the brunt of medical practitioners do not support euthanasia at the moment, and this might be a changing sphere. The primary reason is what is perceived as an inherent conflict in the doctor-patient relationship, which is to provide care, and then there is the palliative component to that.

I think in a public health service there is an extra layer of potential conflict, which is that relationship between the machinery of government and the people. At the moment you come to a hospital to be comforted or to get well or to have a condition managed; you do not come to hospital to be killed, for want of a better word. So there is that sense of active, from my view. If this committee were inclined towards supporting a form of active, passive, or physician-assisted suicide legislation, I would say that it needs to be done in a way that is not simply a conscientious objection choice of individual doctors within the health service; it should be separated from the health service in a more formal way. I appreciate that that brings some difficulties around equity and consistency. I do not think there is an easy answer. If there were, I suspect we would not be here. They were the only areas that I specifically wanted to reflect on. Other than that I think we were both happy.

The CHAIR — Thank you both for that. I would like to start with a comment and then with a general question. I am not sure if you have seen the list of witnesses we have had today, but the majority of those would be very familiar to Peninsula Health. I think it is fair to say that there has been a great deal of working together between the council and various community organisations and the medical profession and Peninsula Health that has come up with a fantastic framework on the peninsula. Peninsula Health should be congratulated; it is obviously central to so much of that. That is by way of a statement.

To put it back to both of you, particularly given your extensive experience with the Medical Treatment Act, we have had a lot of evidence that that act has served Victoria well. It came out of a process similar to this — as you referred to, Doctor — some time ago. Noting the points that Mr Goldberg has made about advance care directives and some of the case law that has been developed, what other aspects of the Medical Treatment Act do you think require change to contemporise it with current medical practice in Victoria? That is a very general question.

Dr LYNCH — I certainly agree with what David said about the refusal of treatment certificates. They were a well-intentioned thing but from a practical viewpoint were not great. I might have to veer here a little bit and speak as a clinician who has been very interested in this area over the last year. I have been to about four or five national professional conferences, which have all talked about end-of-life-type issues and so on. I know you have heard from the Austin and the Respecting Patient Choices people.

I am not sure if you are aware that the college of physicians met in May in Cairns and there was a bit of controversy, which got some local coverage, about inviting Dr Syme and then disinviting him. I actually spoke at the annual general meeting and said that that was a bad thing to do. I also said I did not agree with Dr Syme, but I thought he should have been there to put his viewpoint because I think he puts it particularly well.

From my point of view I think there is an awful lot of devil in the detail here. Whilst I referred with some respect to the legislative framework that grew up in the 1980s and so on, Victoria also, if I could just switch to another area, in-vitro fertilisation reproductive legislation — sorry, David, you have not vetted this bit. We jumped in and we were one of the first jurisdictions in the world to introduce quite prescriptive legislation in that area. At the time I was a supporter; I was keen. In fact in a later life I had some administrative responsibility for that in the department, and it was a nightmare. These areas are very, very difficult to legislate for.

So on the question you asked about the Medical Treatment Act I am responding as a clinician and saying that, whilst I agree with what David says about advance care directives and central deposits and so on, these are very broad documents. Even this week I have dealt with two or three cases where there has been an ACD in place, and it really has not addressed any of the specificities of the clinical situation, and I think David agrees. In fact I had a chat to a couple of junior doctors about this two days ago. They said, ‘Well, what’s going on here?’. You have heard from the department and next year we are bringing in a formal system in the hospitals for recognition. There has to be a process documented where an advance care plan or directive has been looked for and recorded and so on and so forth.

The reality is that they are often very general documents. It is a good thing that residential care is doing them because a significant percentage of the population die in residential care. It is good that they do not have inappropriate transfers to acute hospital, but they are producing very general plans that in no way address the specific challenges. I do not think I have actually seen an advance care plan that has had anything like the details of specificity — apart from giving a general direction about a person’s pre-expressed priorities, if you like — or that has come anywhere close to helping us with some of the specificities we have dealt with in a clinical situation.

We take it on board. I regret to say I think we have to go back to ethics and professionalism here and people understanding community attitudes. I think we do understand community attitudes. For instance, Barwon Health — and I am not sure if they presented this to you — did a survey of people’s attitudes. They asked them about four simple questions or gave them four choices, and 90 per cent said they want dignity, 90 per cent said they want pain-free, 90 per cent said they do not want burdensome stuff. I think everyone agrees with that and I think ethically in the profession people are taking that on board. Only 7 per cent of them — and I think this would fit with our clinical experience — said, ‘I want prolongation of life at whatever choice’. That is the ethos

I think most of the working doctors at Peninsula Health and elsewhere understand and work in that frame. They understand they are working with a community; that is basically their set of areas.

I am constantly amazed — and I am at risk of sounding like a politician here — at the good sense — —

The CHAIR — That is okay.

Ms PATTEN — Nothing wrong with that.

Dr LYNCH — I am afraid even Malcolm Turnbull said in relation to gay marriage, 'I would always rely on the good sense of the Australian community'. But I am just staggered at how responsible and sensible most people in the community are about this. I think even 7 per cent is a bit high; I would say it is about 2 per cent who have said, 'We want Mum kept alive no matter what'. It is 1 in 300 or something, in my experience.

There is a lot of goodwill; I think there is a lot of understanding. Whether you can legislate for these things, I am sorry, I am not so sure, on the basis of my 30 years of experience on this. I think a lot has to go back to good intentions, good communication, good professional practice and understanding community attitudes.

Mr GOLDBERG — I would have to say on that very point, again exercising my mind are the grey zones. When I was at AMA Victoria I would have said that you need to make it safe for doctors not to be charged. But of course no doctor has ever been charged. If I take a different example around people who express the desire to die in a certain way deserve to die in a certain way, then I would argue that people who express a desire to live or do not express a desire might have implied the right to continue to live in a certain way. How do you then tackle withdrawal of PEG tube nutrition and hydration? If you say that you could legislate to allow people to have their life taken by choice, then if they have not made that choice, do you not need to legislate to protect them to be allowed to continue to live, by extension of the same ethics? I test that on medical students, because I am a lecturer at Monash University, and if you want to argue one, I think you have to argue the other. I actually prefer the grey. For a lawyer that is unusual — —

Mr MELHEM — No, that is quite common. Otherwise you would be out of business if it was black and white.

Mr GOLDBERG — That is true; that is right. We cannot do everything right; otherwise you would not need me. No-one comes to me about their good day.

Mr MELHEM — That is right. We need you.

Mr GOLDBERG — But to me that grey zone around, for example, the doctrine of double effect with morphine or around futility actually forces consensus. It forces that discussion, because if you could say, 'I'm sorry, but we're entitled and we're turning it off and it's going to be at 2 o'clock today', I do not think that is good for medicine, even though it might be precise. Whereas I think good communication and relying on that relationship is actually fostered quite well. That is not to say that there are not some enhancements, which we have talked about, but on the whole I am not an alarmist. I do not see a lot of doctors thinking, 'I'm going to get sued or criticised by the coroner for good communication and a well-managed patient care'. I do not subscribe to the alarmist side of it, so my submission is that that would not be the motivation for legislative change.

On that basis, unless it was something major, to me it is the ACDs and the refusal of treatment certificates, the definitions of palliative care and treatment, which again are that grey zone which the courts — as Dr Lynch referred to, for example, the Gardner case — have interpreted in a way that I think is in keeping with forcing the conversation: 'We think this is no longer in the patient's interest'. But no-one can argue with me that in two circumstances, the same medical facts might elicit two different responses by way of management plans. So it might be futile for me to continue to have my nasogastric feeding, but not if my mother is coming back from overseas to say goodbye to me, and yes, you are not treating me, you are treating my mother, but I do not think anyone would say that is unethical for a day or two days — and that happens regularly and I would not refer to that as assault. The danger of legislating is that you create situations where people cannot negotiate because you create rules rather than an environment would be my comment.

The CHAIR — You do not think you can legislate for a framework that enables or perhaps even facilitates that discussion?

Mr GOLDBERG — Yes, I think you can, and you see that in things like the Carers Recognition Act, which talks about the importance of recognising carers. Often they are a reflection of the case law as it exists at the time. You can do that, but to me it does not pack as much punch. If it is essentially a guideline, then it is a different form of legislation than a prescriptive type of legislation. I certainly would not have a view opposing that. I suppose I am saying the uncertainty that exists at the moment I do not see as a particularly risky or unworkable one.

Ms PATTEN — When you opened, you were talking about if we had an advance care directive that was in a central repository so that ambulance services knew and things like that, but are you now saying that that still should not be hard and fast? So it might be in a repository, the ambulance driver gets there, but that driver might still be able to make a decision as to whether to adhere to the directive or choose another action?

Mr GOLDBERG — Yes, sorry, I should clarify it. There are probably two statements. The first one is I think some level of formality as distinct from a common-law document that I can scribble would assist because, as Dr Lynch said, it comes in all forms and rarely is it useful to the circumstances, which means you might well not be upholding what the patient wants because you cannot understand what the patient wants because it does not fit at least a minimum criteria. So a central repository might improve formality, and it might also improve awareness across all the clinicians. You did allude to the collaboration on the peninsula between parties. Obviously we could tell you about thousands of instances where ambulances get called, where there was not meant to be an ambulance called, it gets called, they will resuscitate once they get called. I have sympathy for that position. Some people do not, but to me they are emergency services, they are called out to an emergency, they are not lawyers and while you are sitting there quibbling, there is a patient.

That will always be a challenge — and wills are the same thing. My express wish today does not mean my implied wishes tomorrow are not different. There is a bit of literature out at the moment around: do you really know what your reaction to a situation is before you are in it anyway?

If you actually look at the case law, it is quite interesting. You have the case of Rossiter, who had lost all use of his body but had use of his faculties, and said, ‘Don’t feed me, don’t hydrate me’. The nursing home, I think it was, went to court, the Western Australian Supreme Court, and sought instructions as to whether they could uphold this patient’s wishes, and the court said ‘So long as there is proper informed consent of the benefits and the detriments, absolutely you can. But we don’t think you have yet, so go back, explain it to him,’. He ended up dying of an infection, but nonetheless there was this idea that if he reached a level of informed consent — which is what medicine is most used to, benefits and detriments..

In advance care directives, if you look at Hunter and New England, it actually says you do not have to have a basis at all, and in fact it does not have to be informed consent. It just has to be clear. So there is an issue around clarity. But let us say it is clear — ‘I don’t want a drip in any circumstance’ — it does not have to necessarily be a position that was reached through an informed consent process. Which is interesting because it is a different expression of self, but I think that will continue to make it difficult for doctors. If in the moment an ambulance is called, how do I know that something that you formed a view of at some point in time — yes, it is on a repository and I am aware of it — applies to the way you think now? But I do think it is more likely to enhance consistency and over time more likely to potentially build within it, ‘And I understand that that means that when I am in a situation where I might need to be resuscitated, I do not want to be and therefore I will die’.

They are the sorts of statements that might be quite useful and give ambos and doctors a lot of comfort that this was reached not under duress and with an informed consent-type process. Does that address what you were asking?

Ms PATTEN — Yes, thank you.

Dr LYNCH — Could I just comment to amplify this point a little bit? I am not sure whether you have had Karen Hitchcock appear in front of you. She wrote the essay that came out in the Q*uarterly Essay* a couple of months ago called *Dear Life*. She had pretty extensive ABC coverage for that, and is going to be on *Q and A*, I think, on Monday week — or that is what she told me a while ago. Her essay very much addresses a lot of these points. She has been labelled anecdotal but she is basing it on her experiences at the particular public hospital that she works at, where people have come in with advance care plans or directives, and she actually wants to change their mind. So this was a general document that was done with a well-intentioned ACP-type person over a cup of tea 12 to 18 months ago. But when they got in the situation, they wanted to cling onto dear life for another six months if they could — to see the grandchildren, have their next birthday, see the grand final this year or whatever. To them t was not futile to live for another six months. So in many cases they accepted having some treatment that they thought they would not accept.

One of the points she puts in her essay is that so far our frameworks have not had a vigorous review process. This is what you have got for six months or a year, and then it has got to be redone or whatever, which amplified my point about the lack of specificity with the generality and the need for revisiting in the actual clinical situation, where it is all so much more complicated than any of these documents I have ever seen.

Ms SPRINGLE — Just to clarify, because we have had a lot of people testifying who are saying we need more advance care directives, more planning, we need more communication and it needs to happen a lot earlier. What you are advocating for is doing that, but having checks incrementally so that they are up to date, or not having them at all? I am not quite clear, to be perfectly honest. I hear what you are saying is that: how are you ever going to know that it is up to date? How are you ever going to know unless it was done on the spot? So I would appreciate a bit of clarity around that.

Dr LYNCH — I will try and answer that as I see it. Obviously a few years ago it was foreseen — and we actually think this is a bit of an American narrative — that a whole lot of inappropriate things were being done in hospitals. I think this goes back to the 1980s where maybe that was true. There was the genesis of the Medical Treatment Act, and at that time the medical enduring power of attorney and so on was set up. Obviously people formed the view that advance care planning and advance care directives were a useful thing.

One of the contexts, incidentally, it came up in was about 14 years ago, in the context of what the state regarded as excessive emergency demand on the emergency departments, with people being brought in from residential care to the emergency departments. I agree that that should not happen, it is an unnecessary thing to happen and it is not necessarily compatible with quality of life. That was one of the settings where I remember first hearing this coming in, as a sort of state program or whatever.

I get that people thought this was a good idea in general terms, but I just have to say my experience is that it is a very general sort of process. As I say, something that someone does 18 months previously that is very, very general — 'I wouldn't want this; I wouldn't want that' — often has to be revisited at the time. We actually convert them into what we call resuscitation plans, which have a lot more specificity — you probably heard about this in the Respecting Patient Choices program — than the advance care plans.

I cannot say that doing an advance care plan is a bad thing. It is obviously a good thing to talk to your family. It is a similar thing in relation to organ donation. It is a good thing to talk about it and tell your family and so on and so forth, and form some view. It is just that I think the overwhelming view is that it really needs to be — it has to be — revisited. It has to be noted, with the contents noted, but it has to be revisited and, if you like, reworked and redone in the often very, very complicated specifics of the clinical situation.

Mr GOLDBERG — I think one of the reasons why our position might be a bit confusing is that we are probably reticent to throw the baby out with the bathwater. It is better to have them than not have them, but I would exercise caution. If you get 1 million more of the current sorts of advance care directives, I am not sure that that is your best way forward. That is probably where you are getting the message from.

What I would say, therefore, is that there could be two mechanisms: one is your expression of wishes in a layperson's language, and then there is some mechanism for converting that into something like a medical document that then tried to re-express that to you in medical terms that made it clear, and then annually as best you could you reviewed it and agreed that it was still your intent, and I would not say that in the absence of which it is not your intent; I would not go nearly that far. But if there was some mechanism for allowing people to express themselves on a piece of paper and formalising that in a way that is making it more interpretable by the medical profession — more of a living document that has a veracity to it — that is what I would be advocating. So if there was a way of constructing that legislatively, I certainly would support that, certainly not advocating doing away with them and definitely not the intent of them, which is absolutely important.

Dr LYNCH — Could I just elaborate for a second? Whilst still generally endorsing the idea — we had a chat at lunchtime, and we will not mention any particular people — I know there are probably some enthusiasts for the ACD/ACP process who have appeared in front of you who actually believe that what we are going to get to or they think we are going to get to is that everyone is going to have an advance care plan or directive. They are just going to come into hospital and say, 'Here it is. This is what I'm going to have; this is what I want'. It is never going to work that way, and I think it never should — and it certainly does not at the moment.

A couple of weeks ago I was at a seminar at the Alfred, where I think someone put it rather well. It may have been the chap from Barwon, but I cannot quite remember. He said that complex treatment options in hospital are like going into a restaurant where the menu is written in a foreign language and there are about 40 options — all in a different language you do not speak. The role of the docs is not to just say, 'What do you want?' or 'What did you want 18 months ago?'; it is to go through the pros and cons of these choices on the menu, explain the language, translate the menu, go through the pros and cons of each dish and then jointly decide what the meal is going to be. The idea that you can do that 18 months previously, when you do not even speak the language or know what the menu is — how realistic is that, really?

Ms SPRINGLE — I guess my response to that, from what we have heard, is that often that does not happen to people, that they do not get that robust communication from doctors, and therefore they are not really acutely aware of exactly what the options are and the repercussions of each option. To that point, we have also heard that when a patient gets to ICU, it is actually far too late to be doing an advance care directive. I guess that is also where the confusion comes in for me. We have that feedback from a lot of different quarters; it has not come from just one submission. If it is too late or there is some sort of mental incapacity — it might be dementia; there might be all sorts of reasons why an advance care directive cannot be updated really regularly — there is a sort of hole in your argument there, from what I can gather.

Dr LYNCH — Basically, once you are in emergency or acute hospital it is actually too late to do any, by its nature, advance care planning. You are actually into what I call real-time, joint decision-making, which should be based on the basic ethical principles of autonomy, beneficence, non-maleficence and justice. I would argue that predominantly it is more often than it is not. Most commonly and most likely, if people are not coming in from residential care, they are going to come in without a formal ACD/ACP program. So we are already in that situation, and we have to go through that process of complex joint decision-making — if you like, going through the menu and translating it out of the foreign language and so on. If there is an ACP, of course the contents of it need to be noted and it needs to be worked through as best it can be and honoured and respected, in which case you are often going to have to go back to the surrogate decision-makers.

Mr GOLDBERG — I think even with the law in this area, if you look at cases to do with 17-year-olds, we say that mature minors have the right to make their own decisions. Then you look at a 17½-year-old Jehovah's Witness, who was the leader of the flock, by definition of the court, and understood his rights and had absolutely received a level of understanding of the benefits and detriments and had refused blood transfusion. The court said, 'Using our parens patriae jurisdiction, we are going to enforce that you must have blood', knowing full well that if this happens in six months time, this kid is now an adult and the law draws an arbitrary distinction, which is meant to be met by 'mature minor'. So we still have paternalistic views I think in the law, and I think we still have paternalistic views in medicine, which is interesting because I think the hospital in that case was happy to take guidance from the court but felt very uncomfortable without the guidance in simply doing it.

So, 'How do you legislate?' back to 'Can't you legislate a framework?'. If you legislated the current framework, I would say that that case is arguably very strongly against the principles that we try to uphold around, 'If you can reach a level of understanding, you have autonomy of decision-making', and yet the courts can be quite paternalistic and a lot of people would say that that is a sensible thing, to protect somebody — and values come into it.

I think the medical profession deals with that every day, and an advance care plan, as it is constituted at the moment, at least starts a conversation if people are aware of it. Sometimes people are not aware of it. Of course, an advance care directive is just one expression of someone's advance care ideas. They might have said something else entirely to their current spouse. They might have recently gone on a spiritual journey.

Ms SPRINGLE — One last question. On that, a couple of weeks ago we saw Charlie Corke, who has the My Values framework — and that is values based, so it is quite general. Is that something that you think is workable?

Mr GOLDBERG — I think if it was coupled, as I said before, with some interpretive document for medical reasons, it might go some way to allowing for the patient's layperson's values and wishes, which are the most important bit to try to capture in a medical context. I think by itself it is inherently not going to achieve what it is intending to achieve. I think that is the brunt of my submission on this point, which is: if you actually want to enhance patient autonomy and getting the patient's will, you have to allow the patient flexibility, and you cannot be too rigid about, 'We won't accept an advance care plan that's not done in a certain form', because I think that is clearly not within the intent. You have to be flexible about how a patient might access it, but you have to have some mechanism for enforceability and understandability and therefore the likelihood that that is interpreted.

I have no problem with values as a starting point, because I think that is where most people come from. How that gets interpreted for successful implementation may be a legislative mechanism and then also a best endeavours type approach as well to put it into a medical context with an approach at the very least.

Mr MULINO — I do not have a whole lot to ask here. I think the conversation has been really interesting and has explored some challenges in legislating for advance care planning and advance care directives that we probably have not discussed in detail yet. I think you would probably agree, and I think most people agree, that having a central repository to as best as possible be able to quickly test the validity and currency of a document is a good idea. But I find your evidence or testimony around what is the purpose of this document and the analogy with the foreign menu quite interesting. I think Charlie Corke would probably agree that the challenge is whether the document is supposed to be about ticking off which of those elements of the menu you want and do not want in advance. It is tricky because you are trying to take consent now to a point in the future but also because you are never going to be able to include all the elements of the menu in a document. It becomes unworkable.

My reading of the situation is that is why people have veered more towards a document that is about prompting sensible discussions either with the patient or their family and about trying to have a more informed discussion if the patient is not able to take part in that with the family, where families do not necessarily instinctively jump to more treatment. It sounds as though you would be more comfortable with an advance care directive and planning framework where it is more about informing discussions rather than rigidly ruling in or out specific treatments.

Dr LYNCH — Yes.

Mr MULINO — Yes, and that is probably where most of the values-based or principles-based advocates are heading as well.

Dr LYNCH — I would just say rather than trying to rigidly rule in and out, because you are just not going to get through the 150 options on the menu.

Mr MULINO — Yes, and the menu is probably changing all the time as well.

Dr LYNCH — The menu is changing all the time. There are items on it that did not exist a few years ago. And others are coming off, by the way.

Mr MULINO — If we were to head down this path, would you see a value in a template that is strongly encouraged, say? It might be in regulations, for example. It may be that it does not rule out other documents that may attempt to capture people's views. We do not really have that with wills, but it may be that there is some use in trying to standardise this to some degree at least so that the medical profession can make that jump between the language in the document and treatment decisions easier so that they are not constantly trying to face those challenges.

Dr LYNCH — So would this be like a template that, say, exists under the Medical Treatment Act for a model advance care plan or directive in general terms?

Mr MULINO — I guess there are various ways it could be done. It might even be less formal. It might be something the government puts out and encourages councils and nursing homes to use. It might be that the government, if it goes down this path, could do it in more or less prescriptive ways. But do you see advantages in more standardisation?

Dr LYNCH — Some, but we already do have some of those templates. They exist and are put out by various organisations. The residential care sector is using some, the Respecting Patient Choices or advance care planning programs have got some. Peninsula has a joint one, which you have probably heard about today — or it was developed jointly between the sector and so on. They do exist. I do not know if David has got a comment about whether a new or additional or auspiced or more higher authorisation of it would have value.

Mr GOLDBERG — I think it is one of two ways. Either leave it as a free-for-all from a patient perspective and then have some sort of mechanism for putting it into a context that was rigid but that happened behind the scenes so it did not involve the patient side so you did not put barriers before patients who might do it a different way. Even if there is an encouraged process, it certainly would not be one I would imagine that would rule out any other form of advance care directive. I am not sure how far that gets you. Maybe it is more when a hospital or an aged-care facility or a GP is presented with one of these, or when it goes onto the repository, whether there was funding or however it happened, there was an obligation or some sort of mechanism or at least encouragement for that to be interpreted into a standard-type document that was closer to a medically understood consistent document across the state. I agree that there would be a value in it. Regarding the method for that, I suppose there are a number of ways that could happen, as you say. You would not want to put too many barriers in the way. At the moment patient literacy rates are very low.

Mr MULINO — But I am thinking maybe something simple like all health providers having to use the same template.

Mr GOLDBERG — Yes, potentially. On the peninsula we are very integrated, and we are geographically integrated as well. We have a lot of integration with our nursing home sector, so I could see the potential for us to want to enhance a standard template quickly, whereas maybe in a less integrated setting or a more tertiary setting that accepts from everywhere they might find more value in that more generic setting. I suppose just thinking ahead that is why I am saying that perhaps if it comes in maybe there is a suggested form, but in whatever forms it comes there is some way of trying to get consistency at the back end of that through that discussion at the time that was produced, hopefully through some sort of central mechanism. That then might be a way to achieve what I think would be that goal of what you are asking.

Dr LYNCH — Can I just mention that with that idea you are getting close to looking at ideal models. The ideal is that we all have a personally controlled electronic health record that we carry around and it would be on that. Of course that has had enormous problems in uptake. You might be interested that one of your predecessor parliamentary committees — I am showing my age again, but I think this was in about 1990–91 and it was a review of the Victorian health system — came up with a recommendation for a Victorian healthcare smart card, which was actually one of the first recommendations for this sort of model. But that is now 25 years ago, and where is the Victorian healthcare smart card? It will take a while.

Mr MELHEM — It has been a great session. There has been a lot of body to it that I have picked on, and it has confirmed my thinking. Let me ask you this question. A terminally ill person with six months or whatever period to go, which medical professionals have agreed on, decides that, ‘I don’t want to wait until the end of the six months. I want to go in three months or whatever time. I want to do a few things, and then I want to go on that day’. Should we legislate for or how can we allow that person to go to buy the pill? I will use that word. That person says, ‘I want to take it on that day, with my family’, but without exposing the doctor or their family. Is that a possible scenario, do you think?

Mr GOLDBERG — I would say that I am pleased to not be on your side of the table. I think personal views would abound, no doubt. When I was at the AMA I believed that passive euthanasia happens anyway by another name, which is the doctrine of double effect. I think there is a difference that is more than semantic these days, I have to say. I think that is an important difference. If we start trying to distinguish it, we might undo the good work there, which does not go to your question. The AMA took the view against it, and I thought, ‘You’re failing patients really because death is a big part of life, and a 100 per cent mortality rate is the only predictable statistic. Who better to be involved than doctors?’.

The medical profession does not professionally share that view, and I do not think you could force them to. If you are not going to force them to, you would want safeguards, and I think everyone accepts that. Again I think from a public health point of view, I would say that it is an issue where I do not think the medical profession is ready to integrate into a public health setting. So whether you think that that patient should have that, I would say of all the models I have seen overseas — and no doubt you have or will review more — I am not sure how many of them are government funded and publicly available. I am mindful that if it is only privately available, then you have issues around discrimination. That is why I would rather be on my side of the table, because I get to walk away without having to produce a paper.

But I would say that I think the inherent difficulties for the medical profession are amplified at a second level for public health. There is already a perception of ‘You just want my bed’. Let us pick organ donation. I can say, ‘I want my organs to be donated; I want them to be donated’ until the moment that I can no longer speak and then as soon as I die, my next of kin says, ‘I don’t want his organs to be donated; we won’t donate them’. The law does not say that; the law says donate, but the medical profession will not do it. So in reality the way public health works I think the community’s relationship to a public hospital is that of a place where care and comfort is given and not a place where people can have their death arranged. I say that not to underplay the debate about whether it ought to happen, but from a public health perspective I am challenged on the notion that it should happen in a public health setting.

Ms PATTEN — Yes. It is so interesting because in looking at other countries or even other states in the United States, the medical profession is behind it; they are fully supportive. I wonder why the Australian medical profession takes a different approach to the Californian medical profession, the Oregon medical profession, the Dutch medical profession and the Belgian medical profession. What is it about Australian doctors? Not all Australian doctors obviously.

Mr GOLDBERG — Dr Lynch is an Australian doctor, so I will hand you over to him. Before I do I might say that I would reflect that back to you in the other way of saying if it is about patient rights and autonomy and patient advocacy, there is also a fair few American states that would say, ‘Unless you can show me the evidence that the patient wanted to not have all measures taken for them when they are incapacitated, then you keep in the tubes. Unless you can show me actual evidence of their intent towards that, then maybe we will not treat but we will certainly continue to — —

A lot of America will not accept the distinction that Australia draws around nutrition in the PEG tube feeding. That is the same argument. Maybe it is a more autonomy-based ‘We’ll give you what you want’ type culture, and the British culture is much more around the futility. We take from the British jurisprudence. That would be my guess. Maybe we are more conservative by nature.

I am not reflecting on whether that is good, bad or otherwise; I think it just is at the moment. I think it is clear in most of the submissions you have received from the medical profession that it would not be supported and integrated well enough at this point. Some have said, ‘If you’re going to do it, we think psychiatrists need to be involved’ and ‘If you are going to do it, we would do it like this’. But in terms of representing the profession as a whole, I have not seen too many of the doctors’ professional associations which have said, ‘We think in Australia that this is a good model’. Certainly plenty of doctors disagree with that. But I do not know. Dr Lynch, why do you think Australian doctors are different?

Dr LYNCH — I was going to say I have been around long enough. One thing I have never claimed to do is speak on behalf of all doctors. I would not think in any way I am necessarily representative. I guess in terms of an answer to your question, first of all as representatives of Peninsula Health we do not have any views other than what David said. In terms of your scenario, of course within the current ethical framework we can do a lot of things that are not going to keep that person unnecessarily alive and in a poor quality state and so on and so forth.

It is a bit hard to know what to say about this. Inasmuch as I have ever reflected on whether this should be available or not, the one thing I have been sure of is that it has to be provided somewhere else by some other person or group; I just do not think it belongs in the mainstream health service, if you like. Maybe the euthanasia advocates say the same thing.

I know it is a bit late, but you opened a Pandora’s box here. I would have to put my view that the legislative attempts that have had a go at this have made a complete botch-up of it, like the Rights of the Terminally Ill Act in the Northern Territory. I worked in the Northern Territory for a while. I think most people would say that was a complete botch-up. I am not sure that some of the overseas models are actually working all that well, but that is my 20 cents worth.

Mr MELHEM — That is why it is the last question.

Ms SPRINGLE — Just on that — it has completely fallen out of my head. Leave it; it has gone.

The CHAIR — Just while you are thinking of it, I would like to make two observations, if I may. First of all, Mr Goldberg, in relation to the medical associations, I absolutely accept their position. I will just make the observation that the evidence we have received from doctors at different levels of seniority in various healthcare services around Victoria has been interesting. Some have articulated the view that you have articulated; some have seen some form of voluntary euthanasia as the next iteration or an uncontroversial aspect of a hospital's operation. I think in Bendigo we heard evidence to that effect, and elsewhere.

We have had evidence from Doctors for Choice — I think that was the organisation's name — who asserted that half of doctors would support some form of voluntary euthanasia. I just make the point that as a member of the committee I am, and I think all of us are, very concerned to reflect the views of doctors in any report. It is that lack of clarity around the views of doctors that causes me concern. It is probably not something you can answer. I would just make that observation from the evidence we have received over months from various locations around Victoria.

Dr LYNCH — Mr Chair, if you are suggesting that there is a lack of unanimity amongst the medical profession, I think that is probably fair enough. I was only being half facetious before. The idea that there is some kind of universal view among the medical profession on anything is just a myth. Are you referring to Dr Harvey's group of people who appeared in front of you? Was that Doctors for Choice? I read that transcript. You asked them how many members there were and I think the answer was 80 or something like that.

The CHAIR — One hundred I think. From memory he did assert that he thought about half of doctors — —

Dr LYNCH — I think there are different views; I do not think there is any monolithic view amongst medicine. I think some of the terminology can sometimes be confusing. There has been some reference made to the Peter Singer — what is the other author's name? I cannot think her name. Helga? — and Helga Kuhse study in the early 1990s, in which they surveyed doctors. I was actually one of those doctors surveyed. The terms of the survey were actually about helping people to die and so on, which I said I was in favour of and that I had been involved in. They subsequently wrote that up as being in favour of active euthanasia. So there can be great differences between terminology and usage.

The CHAIR — Absolutely. I will just make one other observation, if I may. Mr Mulino has put these questions to other witnesses. Dr Lynch, I was interested in your comments about the Barwon Health analysis and your observations that most people you deal with are quite rational and reasonable about their expectations and the healthcare provision they want at a particular time.

Again, we have heard other evidence about a 90-year-old person coming into emergency care, being resuscitated, being in ICU for a couple of weeks and having all sorts of extensive and complicated procedures undertaken, when perhaps originally that person may not have wanted to be resuscitated. The general proposition is that there are many people in the system who are receiving medical treatment that they do not wish to have. I was interested in your evidence. In effect I think what you were saying was that most people are now receiving the appropriate care and the appropriate medical treatment for their stage of illness.

Dr LYNCH — I am actually holding some overheads. We did a presentation, 'To Palliate or Not To Palliate' in June. We looked at the Frankston Hospital figures, which I am not sure are in a form I can give you. But in general terms we looked at all the medical wards, the surgical wards and intensive care. The conclusion from the study, which was done by one of the senior physicians who reports to me, was that basically there was not a lot of inappropriate care going on, which was consistent with the general thesis that I put to you.

Regarding the case you mentioned, undoubtedly there must be some cases like that, but it is a worst-case scenario and I honestly think it is increasingly in the minority. I would have to say that over the years I am increasingly seeing more and more examples of good practice in this area. I can think of the things that used to be said to me. I can remember a senior doctor saying to me 25 or 30 years ago, when I suggested that we should not provide all this burdensome treatment, 'We can't play God', as if it was to play God to not do stuff and not to play God to do all this stuff. I have not heard that for about 15 or 20 years, I must say.

At Peninsula Health I am increasingly and pleasantly surprised at some of the great practices I see, even in the emergency department, which is often one of the groups — and this is quoted — that has discussed with the family whether it is really worthwhile intubating and sending the patient to ICU and so on and it has been jointly decided that it is not. I have to say that through my eyes and from my experience increasingly we are seeing fewer examples of the terrible example you have just given and more and more examples of good practice.

The CHAIR — Thank you for clarifying that.

Ms SPRINGLE — Going back to the idea that medically assisted dying should sit outside the public health system, do you have any thoughts about access and equity and how that would be addressed? You talked about discrimination, but in my mind access and equity is a real issue when you start to privatise things.

Mr GOLDBERG — Yes. Obviously this is going beyond my remit as a general counsel for a public health service so I do not have a view on whether it should be a publicly available service. I do not think it could be integrated into the current mainstream public health service. If there was a separate mechanism which was public or public-private or whatever it might be that involved doctors who wanted to be doing this sort of thing, or who were happy to be doing this sort of thing, and developed facilities, protocols and processes and integrated them in a way that worked, I am not ruling that out. I just do not think you could be in one of the beds in the medical ward where you are being euthanased next to a person who is being treated next to a person who is going on the palliative pathway, when at best what you are hearing is there is 50 per cent support. That means 50 per cent of the doctors there do not want it, and within that 50 per cent — at best, if you like — there will be divergent views on when, how and what.

I suppose if you had the additional overlay in public health around the perception of what public health is meant to be — to me it is more about supporting primary health and better health outcomes and better health solutions — I am not sure that that messaging at the moment, and maybe it will mature over the next 20 or 30 years, is consistent with the possibility that you can also come to a public health service to die. I use emotive language like to ‘be killed’ because obviously people die every day in public health services, but in the context of palliation and in the context of emergency, I think it would be a big jump for the community. Noting the access and equity argument, you would not like it to be something that was available — —

Ms SPRINGLE — Or exclusive.

Mr GOLDBERG — Yes. Obviously one of the things that would challenge this committee is that if they really want to people with money can already go and do these things in other countries — to some extent. Maybe that is only the privileged — I do not know how privileged you are if you are in this situation. So I am not necessarily either against or for it being a public service; I just do not think it could be integrated.

The CHAIR — Dr Lynch and Mr Goldberg, thank you both very much for your evidence this afternoon. It has been most informative for the committee.

Mr GOLDBERG — Thank you for the opportunity.

Dr LYNCH — Thank you.

The CHAIR — The committee stands adjourned.

Committee adjourned.