

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 5 August 2015

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Dr Karen Detering, Respiratory Physician, Respecting Patient Choices Program, Austin Health.

**Necessary corrections to be notified to
executive officer of committee**

The CHAIR — I declare open the Legislative Council’s Standing Committee on Legal and Social Issues public hearing in relation to the inquiry into end-of-life choices. I start by welcoming Associate Professor Daryl Jones, consultant intensive care specialist and medical director, critical care outreach at Austin Health; adjunct senior research fellow, department of epidemiology and preventive medicine at Monash University; and adjunct associate professor at the University of Melbourne; and Dr Karen Detering, respiratory physician, Respecting Patient Choices program, at Austin Health. We thank you both very much for your preparedness to be here tonight but also for the invitation to visit you at the Austin in a couple of weeks. We are very much looking forward to learning more about what you do and seeing firsthand what you do. The committee is very appreciative of that opportunity.

Before we start I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today’s evidence is being recorded. You will be provided with proof versions of the transcript within the next week or so. Transcripts will ultimately be made public and posted on the committee’s website.

We have allowed a couple of hours for our session tonight, and I understand you have a presentation of about 20 minutes. We look forward to hearing your presentation. Thereafter the committee will have questions. We have the full committee tonight. Again, thank you very much for being here at this time of the day. We look forward to hearing what you have to say.

Visual presentation.

Assoc. Prof. JONES — Thank you very much for the opportunity to present. I am going to talk briefly about what I call acute end-of-life care for hospitalised patients. As you alluded to, I am an intensive care specialist. I see patients who are very unwell and acutely unwell, and I see the end-of-life care issues that occur within the context of such clinical deterioration. I am going to talk briefly about trajectories of dying and dying in intensive care and phases of end of life and give an overview of deteriorating patients. Then I am going to talk specifically about a concept called rapid response teams and their evolving role in providing acute end-of-life care in hospitalised patients, a bit about uncertainty, particularly in the context of advancing technology, barriers to providing end-of-life care and then some potential solutions.

As an interlude, just briefly, a disclaimer. You have introduced me and my qualifications. I have done a lot of research in and around deteriorating patients. Two potential conflicts: I am an external adviser for one of Melbourne’s public hospitals and I obtain a bit of a salary for that and I have also received a grant from the Australian Commission on Safety and Quality in Health Care, but none of those moneys went to myself. It all went to the grant, so there is potential for an academic bias in this area.

On trajectories of dying, these figures were published more than 10 years ago now. They describe four trajectories of dying, the types of ways patients can die, which I think are quite useful to outline. There are sudden deaths, such as someone having a massive heart attack or a massive clot, or they die of a motor vehicle accident. That is relatively sudden but relatively infrequent and obviously very traumatic. There are patients who have a relatively advanced and rapidly progressive disease like a very aggressive cancer which is not curable. The one I am going to talk about most is the condition where the patient has a gradual decline due to multiple comorbidities and they have interrupted episodes of clinical deterioration and may or may not get back to their baseline level of function. The fourth is where patients have typically degenerative conditions and die without major episodes of deterioration.

On patients who pass away in intensive care, approximately 1 in 10 of our patients die. It might surprise people to hear that this death is rarely sudden and unexpected. It is actually quite uncommon for patients to die in intensive care despite our best efforts: they fail to respond to therapy that is actually the minority of deaths, perhaps 10 or 15 per cent of all the deaths in intensive care. In the majority of deaths, the intensive care clinicians can often anticipate or predict the patients who are actually going to die. The withdrawal of attempts at curative therapy are quite staggered and gradual, and it is done in conjunction with the family and the other treating clinicians.

It is because of this reason, I think, that intensive care doctors are over-represented in this type of research and literature and these types of presentations — because we have evolved a good understanding of which patients

will respond to artificial life support and those who will not, and we are very, very experienced and adept at communicating about death and dying with our patients and their relatives, something that some of our other clinicians are much less comfortable with. For example, this is a brief article by myself and two of my colleagues about strategies to improve communications with patients and relatives. Professor Ken Hillman from Sydney, who I can highly recommend — he would contribute very much to this discussion — has written a brief article on some barriers to appropriate management of patients in end-of-life care, and I am going to allude to some of those dot points later in my talk.

Very briefly, we actually see a lot of patients who die when their death is actually not unexpected. These patients are frail and need a lot of supports. They often have a lot of medical comorbidity and advanced failure and dysfunction of their organs, and they have conditions which are known to have poor outcomes. They may present to the hospital with a condition that has a known poor outcome, like a large stroke or a very bad infection in the abdomen, and after admission they sometimes do not improve despite optimal therapy and/or they develop additional problems. They do not even get over the initial problem they presented with. There are even now frailty scales, and these are being increasingly validated, to guide clinicians and the community and clinicians communicating with patients and their relatives to semi-objectively measure this degree of frailty.

I want to talk now not about intensive care but my major area of interest about the uncertainty in death and dying that occurs on the ward and the issues around end-of-life care that occurs on the ward and particularly focus on this type of deterioration, where patients have a gradual decline in their level of function and vitality and experience episodic deteriorations. Although we have this graph now available to us, if you can imagine at any one point on that deterioration, it is not obvious whether the patient will actually get back to a reasonable level of function or not. It is easy to be wise in hindsight but sometimes exceedingly difficult to predict which patients are going to recover or not at the time when they deteriorate. I am going to talk more about that uncertainty later.

This is a diagram that staff from the Austin developed for and in conjunction with the commission. Although it is very stylised I think it provides a useful structured framework. It talks about one year when a patient has a diagnosis of a condition which is known eventually to lead to their death — or their premature death. They may or may not have had very many hospital encounters during that period, but they have encountered a clinician who may or may not have conveyed that life-limiting condition to them in variable terms. If these people are hospitalised, they usually return to independent function. Subsequently in the months leading up to the patient's death they become increasingly frail. They may have repeated hospitalisations, they may actually have a much higher risk of death and they often do not return to their previous level of function, so they are having functional decline. This is the pointy end of the stick, as I call it — the last week of somebody's life. This is often where my staff and I get involved — where the patients are hospitalised in their last hospital admission, and they suffer a deterioration in the hospital wards. I am going to talk about that a lot more.

Dr Detering is going to talk about advance care planning, which really operates in the months to years before the patient passes away. Palliative care is the symptom relief associated with that terminal decline, and as I say, in the last week of life the intensive care unit and the rapid response team, which I will explain in more detail, really are increasingly becoming involved in assisting with these decisions and management. Dr Detering is going to talk about advance care planning, and as she will allude to, the focus of this is to discuss the patient's values and the choices they want towards their end of life, and the role of the doctor is to contextualise in the context of what is reasonable and what is going to provide a reasonable likelihood of responding.

But what I see and what my staff see is something very different. We see patients who come into hospital and who may or may not be quite unwell at presentation but who subsequently experience clinical deterioration, and this occurs in about 1 in 10 — up to 1 in 5 — hospital admissions, so it is surprisingly common, obviously of varying severity. The greatest challenge is to predict patients who will have reversible deterioration and can get back to some quality of life. In these cases we want to avoid morbidity and mortality versus those where the deterioration is irreversible and is part of the dying process. These patients are not deteriorating but actually dying, and in these cases the aim will be to provide good symptom control and a spiritual death — and I do not mean that in the religious context; I mean it in the much broader context — and to ensure that the patient has a good death. Increasingly people are trying to define what a good death is and to ensure that the patient actually dies with dignity.

In this top scenario we want to provide early and aggressive therapy with an early intervention, whereas in the bottom scenario we want to avoid aggressive, burdensome, painful, uncomfortable therapies and optimise the time that the patient has with their loved ones so that they can have a good-quality and dignified death. But in both situations we need to provide the right care in the right place at the right time, and this is exceedingly challenging. This is a very simplified schematic diagram, but practically and at the bedside and at the coalface it is extremely difficult to determine on some occasions one from the other.

This is where the rapid response team comes in. A rapid response team is not dissimilar to the traditional cardiac arrest team that we have in hospitals and that you will be aware of from popular television, except that we respond before the patient has a cardiac arrest, and I will talk about that a bit more. They are usually quite senior clinicians and are usually experts at responding to deteriorating patients. They are often based in the intensive care unit but not always. They are called when the patient is suffering a level of deterioration. Either the patient has abnormal vital signs, severe pain or problems with their breathing, or alterations in their conscious state. These are the calling criteria. In the past staff in the ward did not always recognise that the patient was deteriorating, and so now we have given them objective criteria. The details are not important, but they are based on patients' vital signs and clinical status, and there is an expected response to that. The intensive care, or the staff, come with a trolley, and rather than jumping on people's chests and doing heroics it is a relatively calm and considered process whereby experts assemble and a crisis is assessed and hopefully resolved. This is a new concept that has developed in the last 10 or 15 years of hospital medicine.

In the past the original aim was for us to go out and prevent cardiac arrests and adverse events and preventable morbidity, but increasingly the rapid response team is being involved in providing what I call acute end-of-life care. It is not hard to see why in hindsight, although we never envisaged this at the outset when you look at our calling criteria. The patient has an obstructed airway, or noisy breathing. The patient has difficulty breathing or low oxygen levels. The patient has low blood pressure and is not making urine. They have drowsiness or an altered conscious state, or they have pain and discomfort. You can see that it is very difficult to distinguish deterioration from somebody who is actually dying, and that is why rapid response teams are being called to see patients.

This is a topic that interested me when I was a trainee, and I found it an immense source of frustration when I was somewhat less mature than I am now and I thought that I knew everything and that it was very clear. It is very unclear, and it is very difficult to sort these out, so I have embarked on some research to try to objectify this to a greater extent. The first was quite a detailed study but only in seven hospitals, and we did a prospective study and involved two international centres. We looked at every single rapid response team call that occurred in a month in those seven hospitals. Some patients get more than one call, so there are more calls than patients. We found that of those patients who had no documented limitations of care — so no restrictions on the intent of care that was going to be provided — they still had an in-hospital mortality of approximately one in eight. So it became increasingly apparent that these were extremely sick patients, and perhaps that is not surprising when you look at the calling criteria that are called for them.

What was more interesting, and the primary focus of the study, was that approximately one-third of all of these patients had some sort of issue around end-of-life care. This is not an uncommon or insignificant statistic; it is a very common phenomenon, and it reflects very much our anecdote as junior trainees when we go in to see these calls. In two-thirds of these cases the patient already had an existing limit of therapy, so the doctors had had an informed decision, almost always in conjunction with the patient and their relatives, that intensive, aggressive, burdensome therapy was not going to be provided — but in 1 in 10 of all of the calls it was newly implemented after this call had occurred. So there was an acute crisis where there was a decision under distress and duress where we had to decide, or the team had to decide, whether a patient would or would not receive invasive and burdensome therapy.

These patients had an exceedingly high mortality — almost one in two died during that hospital admission. As I alluded to in the previous slide, it was perhaps not surprising when we looked at the differences in those who did and did not have an end-of-life care call. They were older, and not a little bit older: 50 per cent of them were more than 80 years old, versus 66 years old for those who did not have limits. They were usually medical problems as opposed to operative surgical patients, so they came in with lots of comorbidities with a medical problem. They were less likely to be home, so a quarter of them came from some sort of supported accommodation, and they were much less likely to go home, so three-quarters of the patients did not go home from that admission. Surprisingly, half of them survived that admission, so this was not a death sentence. The

clinicians were still continuing active care but with appropriate, considered and consulted limitations, and they were much more likely to die in hospitals, so three or four times more likely to die in hospital.

That was a small study, highly dedicated, and we did increasingly large studies to look at the magnitude and scope of this problem. In a more detailed study over 10 years in 35 hospitals, we looked at the outcomes of nearly 100 000 rapid response team calls to see whether this was generalisable, and we similarly found that approximately a quarter of these patients died in hospital, and that the rapid response team reviewed approximately a fifth of all of the patients who died during that period. This is a common phenomenon, and it is something that is becoming an increasing trend and an increasing burden on intensive care services. More recently, in the last financial year from ANZICS — the centre for outcome and resource evaluation — there were at least 93 000 rapid response team calls in the 138 hospitals that contributed data. This is a very substantial issue in Australian health care.

This approach where clinicians go out and urgently see patients who are deteriorating and adjudicating on life and death decisions or end-of-life care has strengths and limitations. It provides rapid symptom relief for patients who are actually dying, and we almost always have senior clinicians involved in this process as opposed to quite junior clinicians. There are clearer communications with the family because of the maturity and seniority of the clinicians, and it avoids the patient undergoing non-beneficial care.

If there is uncertainty, because intensive care is often involved, we admit the patient to intensive care for what we call a trial of intensive care, where the patient is treated and we observe over a short period to see whether there is a response or not. Where there is uncertainty, there can be admission with some caveats on that admission to the intensive care, so that we are not allowing patients who might have benefited from intensive care slip through the gaps.

But I think it has got a number of disadvantages, and this is the thing that motivates me to work with people like Dr Detering and Ken Hillman in Sydney. It is a very reactive approach, and sometimes the family or the parent unit may not be present, because these calls are occurring out of hours. The patient is often very unwell and can variably contribute to these discussions, so often it is left to surrogate decision-makers to make the decisions in consultation with clinicians, and I think that that is a very stressful thing to expect families and patients and their relatives to do.

I will pause there and move on to another area. I think one of the reasons that all this is happening is because of the uncertainty that occurs with prognostication and the improving technology that we have in our healthcare system. In the past, even in the 40s and the 50s, patients would simply have not been offered therapy because they were not strong enough for an anaesthetic or there was nothing more that clinicians could do. That is simply not the case now. There is almost no patient that a modern anaesthetist with modern anaesthetic techniques cannot get through an operation unless they are literally at death's door. The difficulty is in predicting not whether the patient can survive the anaesthesia but whether they will survive the post-operative course and get to a return of function. In 2015 — I am sure I do not have to tell you this — people are living longer, the therapies we can provide are broader, and intensive care can literally keep people in a state of suspended animation, where we are not actually saving their life but we are actually preventing an inevitable death. It can be very difficult to predict which patients are going to live and which patients are going to die.

Why does all this happen? Why is there such difficulty and why is there such complexity? Ken Hillman, as I alluded to, has written about the barriers to providing end-of-life care. As I have just alluded to, there is uncertainty about patient prognosis and the likelihood of response to therapy. Patients and their next of kin and societal expectations are changing constantly, partly because we have a consumeristic society but also because of the unrealistic expectations which are portrayed on television, where nobody ever does badly. I think that that is contributing significantly.

There is sometimes — not often but sometimes — suboptimal consideration of patients' choices. I have seen situations where they do not seem to have even been explored, which I find quite frustrating for multiple reasons. As clinicians and undergraduates we are taught not to fail, that somebody getting sick on their watch is sign of failure. I think we need to address that, as I will allude to.

Sometimes clinicians, particularly specialist clinicians in very high level specialties, cannot appreciate the patient's condition in the overall picture of the patient's overall disease burden. Intensive care physicians are generalists, and we have a better appreciation of that. Sometimes clinicians lack confidence or the

self-perceived competence to have these difficult discussions. I think they perceive there is a lack of time, and I always contend that it is quicker to have an appropriate discussion up-front than to be having repeated difficult discussions when the family are trying to always catch up about where their loved one is at.

Deterioration often occurs out of hours. We do not always staff 24/7 and there are least resources and the most senior doctors are not always available to have these difficult discussions. In cases where there are multiple teams involved in one patient's care due to the complexity of patients, there is often no one team taking ultimate responsibility for having the difficult end-of-life care discussions. I might just skip through that slide actually.

What potential solutions can we come up with for these problems? I think this is one of the reasons why we have been asked to come, because Austin has a number of strategies to improve this. I am one of the clinical leads on a program called CLEARx decisions, which stands for consultant leadership in end-of-life care advance care planning and treatment decisions. This is a program whereby a group of very senior clinicians on the senior medical staff association executive have developed some guidelines and guiding principles and then gone and promulgated those to the senior medical staff of the hospital. The idea is not to be prescriptive and tell clever people what to do, but to give some guiding principles about what we would like them to do in their area and their acting as local champions.

We are educating clinicians, particularly doctors, and we are starting this in medical school, that comfort care is not failed care, that a good death in a patient who is always going to die is actually a success. That is something we stress in the intensive care unit when we make the switch from curative care to comfort care. We are trying to improve communication skills and emphasising starting the conversation as early as possible in the course of a patient's decline so that there are no surprises.

In nursing and allied health, who spend a lot more time at the patient's bedside, particularly nursing staff, at the Austin we are starting to empower the nurses to speak up and advocate for their patients and talk about the experiences of the discussions they have had with the patients and their relatives.

We are increasingly looking at coordinated responses. We have a situation where we have less than 50 cardiac arrests per year at our hospital. We have a resuscitation coordinator, and we have more than 1000 deaths, but we do not have an end-of-life care coordinator, so I think we need to emphasise that dying is a part of life. Increasingly we are linking the rapid response team with palliative care, so that the rapid response team makes the referral directly to palliative care. This is beyond my remit and my scope, but I think we also need to start educating the community so that they are comfortable with having discussions about death and dying, and particularly having discussions about how and where they want to die. Charlie Corke from Barwon Health in Geelong, I can highly commend, has a video called *In the End* and he has got a website called 'MyValues' where people can register their choices and preferences online. This is a valuable resource that might be used in the future.

In summary, the patients that I see often have quite a predictable decline — at least for myself and my colleagues, perhaps not others — and I feel very strongly that death and dying should never be a surprise in these situations. Unfortunately, it sometimes is. Hospital clinicians cannot always reliably diagnose that a patient is dying. Often it is left up to intensive care staff to assist in this adjudication and this diagnosis. I have listed several barriers for providing good end-of-life care and the need for coordinated approaches, particularly in hospitals, because that is where a lot of our patients die; educating clinicians and members of the community; and increasing people's comfort with talking about death and dying. Thank you very much.

The CHAIR — Thank you very much, Associate Professor.

Dr DETERING — Thank you. I am pleased to be able to come and share some of my experience. With the first couple of slides, I thought I might give some context to both myself, and the advance care care planning program at Austin Health. I have worked at the Austin Hospital now for getting on around 20 years, and I actually started my journey there. My background is I am a respiratory physician — a lung doctor — and I have got into this area through my work particularly with motor neurone disease patients but also with many other lung patients that often fit the disease trajectory that Daryl was talking about. I also have worked and continue to work at the hospital as a clinical ethicist, so in that role I find myself regularly involved in complex issues that patients, families, staff are having at the hospital, and invariably they involve issues around end-of-life care and appropriateness of care, sometimes ethical issues et cetera as well. I think I have a great job because I get to do lots of different things, but I often end up back in the end-of-life care space in some sort of fashion.

I work in the advance care planning program at Austin Health, which is a program that many people have heard about. There are a number of arms to the program. We have an Austin Health advance care planning arm to the program, which is essentially what I am going to talk about tonight. However, I also do some work with the Victorian Department of Health and Human Services around the Victorian implementation strategy. I spend a day or so a week working with them and I have had quite a bit of input into the strategy and into implementing the strategy across Victoria.

I also work in programs with the commonwealth Department of Health, so we get funding from time to time and currently have a number of projects we are working on with them. There is also a program called the Decision Assist program, which is a program funded by the commonwealth Department of Health focusing on end-of-life care and advance care planning in aged-care facilities and Community aged care services. That is the program that is led by Professor Bill Silvester, and he has a team of people around Australia working with him on that project. We also do some research and currently have some NHMRC research funding doing a project in cancer. It is useful to see that we do lots of different things. I think many people have heard of us either as a Respecting Patient Choices program or the advance care planning program. Austin Health has been a leader locally, nationally and internationally in this area for some time.

Without going right back, it is worth thinking a little bit about what we are talking about when we are talking about advance care planning, because I find in work in this area sometimes there is quite a bit of confusion. The definition here is from the recently released national consensus statement. I like the definition, and it is very similar to the working definitions we have had for a while. It is a process of planning for future health and personal care — that is fairly obvious — whereby the person's values and preferences are made known so they can guide decision-making at a future time when the person cannot make or communicate their decisions.

As you will see, I will keep coming back to the bit that I have underlined there, because I think it is critical and I think it is what makes it work. It is actually not about death, although many people that undertake advance care planning or have had an experience with advance care planning may ultimately go on and die. It is actually about improving care now and at the end of life. It is mostly about allowing our patients, our people, to have a say in their care now and in the future.

When we have an advance care planning discussion, we are aiming to do a number of things. The first thing we are really trying to do is to work out how decisions will be made if that person becomes unable to make their own decisions, so we will try to find out how they would like this to occur. We do not tell them how the decisions will be made, but rather discuss with them how they can be made, obviously if the person is able to make their own decisions, we are going to go and talk to them.

Then we need to work through what will these decisions be. How will they be worked out? There are a number of factors that need to be considered. We need to think about the individual's goals, values, beliefs and what they consider to be a reasonable outcome. I will touch on that a little further in a moment. We need to find out what information the person, their family and others might need to facilitate and assist with this. They may not know what is wrong with them. They may not understand that they have an eventually fatal condition. They may want some further information. They may want to understand what dying is going to look like if they have the surgery versus if they do not. They may have some very specific views about treatments they do not want.

I do not believe patients should be — and I am going to put allowed in inverted commas — 'allowed' to opt in to treatment. I do not think that patients can go around saying, 'Excuse me, I want a heart transplant', 'Excuse me, I want this', and a lot of the advance care planning efforts have asked patients to make those decisions.

I will come back and talk about decision-making around that. It is not to suggest for a minute that patients do not have a really active role in decision-making, but I think we have dumped a lot of the treatment decisions and the treatment communication on patients and families — and it is actually the healthcare people who need to facilitate discussions and subsequent treatment. I will come back and explain exactly what I mean by that a little bit later. Also when we do advance care planning we want to find out about other wishes regarding care. Do they want to come to hospital again? What are their priorities? What do they want? Then obviously if we have a discussion — although the discussion is a critical component of this — we want to be able to communicate it so that in the future we know what is there and can activate that.

So ideally it is around designating the decision-maker. That may be a legal designation or it may be a slightly different way of determining who it is we need to talk to if the person cannot talk for themselves. The sorts of

questions we will ask people is: how would you like decisions made if you cannot make them for yourself? That may include who and it may include exactly how they want those decisions made. Does person A want to tell person B exactly what they want and to follow it exactly, which may be one way of doing it and it may be a very valid, reasonable way. Or does person A want to appoint a trusted family member or friend to actually be what we potentially call the in-the-moment decision-maker — a little bit like what Daryl was talking about before. Or do they want various things? There are lots of different ways that people can do this.

I think we need to be really careful about being overly prescriptive about how people should want their decision-makers to act. I stress this a little bit, because I will talk to you in a moment about some work we have been doing in the non-English-speaking background population as well. I think this is a broader way of thinking about things. If you really think about what is our problem as a healthcare professional, if we cannot talk to the person, it is that we need to know who to talk to and how to navigate through the decision-making process. Then ideally we want to create some sort of written plan so that is available where people find themselves. I think also the plan can be very helpful to the decision-makers to say, 'Well, this is what has been said before. This is what has been written'. It is very helpful if we have those things. However, we do not have to write it down. We do not have to have formal documentation either for this process to work.

This is a study that I led. It is a little old now; it was published in 2010. We did it at the Austin in 2008. Now it is a little bit of a no-brainer, but back then we did not really know whether advance care planning made a difference to people. Did it really make a difference to things that matter? Were we hurting people? Were we hurting relatives? We did not know. So we did the study at the Austin hospital. We had 309 patients who were randomised to two different groups. Half of them got what we call coordinated advance care planning, and I will show you exactly what I mean by that.

The first thing we found was that of the people who were offered advance care planning, 81 per cent took it up and completed it. So people wanted it, which was important. We did not really know before this study and before some other subsequent work. What we also found from this study was that people were actually able to express views and make choices. Again perhaps, thinking back, maybe it was not so surprising, but at the time we did not really know. There was a lot of discussion around: maybe we are just going to hurt people. Maybe we actually just need to get on and make the decision and be a bit more paternalistic about these things, but people want to be involved and can be involved.

With the people who got advance care planning, the patient and family satisfaction was higher. We went and talked to them. We engaged with them. They found that that was helpful. And we found in the study that patients' end-of-life wishes were known and respected much more if they had advance care planning than if not. I stress that most of this was not about following the wishes, but it was actually about knowing the wishes. If we actually know the wishes, we are pretty good at following them with our process — not always, but mostly.

The other thing is that there is often a lot of discussion. Since we started talking about this, people have said 'You're just trying to save money'. Interestingly there was no difference in mortality between the groups, so we were not going around bumping people off. It is not a huge topic for now, but I think in the areas of costs as well there has been a little bit of work going there, but it is about patient care. If we happen to make it at least cost mutual or if it saves money, that is a bonus, but we are actually here for the patients and the patient care.

There are also important outcomes for the surviving family members. This is partly how I got into this area. When we get the death wrong, not only is it bad for the person themselves, but it is bad for everyone else who hangs around after them. In the study, where the patient received advance care planning, the surviving family members were much more satisfied with the quality of the patient's death and they had improved psychosocial outcomes, so less risk of post-traumatic stress disorder anxiety and depression. Again there has been further work in this sort of area.

I am a doctor; I deal with patients. When we talk to people you hear these sorts of things all the time. This slide shows a couple of the statements from our family members in the patient group that got advance care planning: 'He had a very peaceful death, just as it should have been, and I would like to thank all staff for this'. When we get it right, people are usually grateful. 'Even though we already knew what he wanted, it was great to be able to talk about it so openly', so we were facilitating an open communication process with the family.

Unfortunately we see the following things as well, and to some degree we still see them even though this was now about seven years ago: 'Mum didn't want heroics. I was horrified to hear she had received 45 minutes of

CPR. She didn't want it. All anyone had to do was ask'. This lady was 82 years of age, she had multiple medical issues. She spent six weeks in our hospital and not one staff member actually asked what she wanted. 'The doctors kept asking Dad if he should be resuscitated. I didn't think they should keep asking. But they also told us it wouldn't help him. It was obvious to us he was dying'. We hear this all the time — this sort of mixed message: 'He is dying, but' and we have a different conversation. We need to stand up as doctors and be honest and open with our patients and families and listen to what they have to say and not confuse people and give them mixed messages, because this is really confusing for everybody.

I just wanted to touch on some of the other work. The study that we did was in English-speaking, competent patients. One of the criticisms around the study was, 'What about everybody else?'. So subsequently we have gone on and done some work in our non-English speaking population. We have just published some work in elderly Italian and Greek-speaking patients, and they showed very similar outcomes to the first study. With some of our commonwealth funding we are now doing some work in Italian, Greek, Chinese and Vietnamese populations in Melbourne and Sydney. We are also doing some work in dementia groups of patients, so again we have done some pilot work, often with the family members rather than the person themselves, and we are getting some somewhat similar outcomes with dementia, and again one of the current commonwealth projects is doing some more work in this area.

Other significant outcomes — and this is national and international research outcomes, and there have been a couple of really good systematic reviews in this area as well — reduction in aggressive medical care, including hospitalisation and the use of ICU. It does not mean these treatments are wrong, but if patients are not able to benefit and do not want to receive them, then we do not want to be doing these things to our patients. Furthermore, advance care planning increases the likelihood of dying in the preferred place. That does not say 'dying at home'. Dying in hospital, dying in a palliative care facility, dying in an aged-care facility are all fine. We should not tell people where they should die but rather ask them, based on what is going on, where they think might be an appropriate place for them to be.

The other thing is that there is a lot of concern that we are harming people, but there are numerous studies now that show there is no increase in depression or worry in patients, and in fact it improves hope if we are open and honest. Patients are not silly. They usually get that something really bad is going on and they often appreciate the conversation. Having said that, we do not force it. If somebody does not want to have these conversations, they do not have to. The other thing research is showing includes reducing moral distress in healthcare providers. When you work as a staff member, particularly our nursing staff, they often have to sit and watch bad things happen every day to their patients, and I think this can be really hard. When we get these things right the patients get better care, the families are better looked after, the staff usually feel much better about what is going on. They are all important because we want our staff to come to work and do a good job.

At the Austin Hospital a lot of our advance care planning is done through what we call advance care planning facilitators. We have a patient who is referred to us. This is one of our advance care planning clinicians, who is a nurse. She comes along and she will have a facilitated conversation with the patient. Then we try and get some outcomes, so we may get an outcome that either the patient does not want to undertake advance care planning or does not wish to complete it, or they may complete it but not want to write anything down, or they might want to complete the conversation and write some things down, and I will touch on how we might do that.

I will not go into a lot of detail around the legal components, but when we talk to people around this stuff, the law bothers them. But what we do at the Austin, and essentially in Victoria, is we have the Medical Treatment Act documents that we use. The medical enduring power of attorney is a mechanism to appoint a substitute decision-maker, and there is a refusal of treatment certificate. We fill in medical enduring powers of attorney commonly, but we do not often use the refusal of treatment certificate, and there could be a discussion about why that is.

Most of our advance care planning is on various common law type documents. This is the Austin Health one. It does not have to exactly look like this, but a sort of common-law advance care directive, and there are a number of them around. We do spend a little bit of time talking to our facilitators around how to get this information down in a way that is helpful and is going to be useful if we need to actually act on it.

Just very briefly, this is a busy slide, but it just shows some of the work that our clinicians are doing. I might add that we have an EFT of less than two people doing this work at the hospital. Again, we have people running around doing all sorts of other things, but that is what we have in the advance care planning area. Our staff are

seeing a little over 1000 patients a year, having discussions. Why I really put this up is that on average around one-quarter or maybe one-third of patients will appoint a substitute decision-maker — so appoint a medical enduring power of attorney and complete the paperwork. About 20 to 30 per cent will complete an advance care directive. Essentially what we are talking about there is our Austin Health advance care directive or something similar. A very small percentage — 1 or 2 or maybe a few more per cent — will complete a refusal of treatment certificate, and they are often patients who are going outside of the hospital where the ambulance may get called and where we want some sort of guarantee that the patient will feel protected and that the ambulance will feel protected.

Our advance care planning clinicians generally spend a little over an hour is what we spend over a number of sittings with the patient. When we think about effective advance care planning approaches — and I guess that is sort of what I spend a lot of my time doing — how do we make it work in our complex health environment? Obviously we want to have advance care planning conversations. I put there ‘with adults’, although there is work happening in the adolescent and paediatric field as well, so it does not just have to be adults. We want to create an effective plan, selecting and preparing our substitute decision-maker, and preparing them is important as well, so working through a little bit about what it is they might need to be thinking about and what it is their role may entail in the future. We want to hopefully write some things down. We want the plans available when we need them, and we want them to inform medical decisions.

When we think about how we translate advance care planning into treatment orders, a person might be in Woolworths or whatever and collapse. An ambulance is called. They zip along to the Austin Hospital. In our emergency department the staff need to access the hospital systems, and this is our electronic system at the hospital. There is an alert that says that there is an advance care directive present, and then they can go and find it and have a look and read it and do whatever else is needed. Then what they need to do is transfer it into some sort of treatment order. This is our current resuscitation plan, which is sort of like a not-for-resuscitation form, or a limitation of treatment form. Right at the moment we are actually developing and about to launch a new form, which is similar to this but a goals-of-care form, and the slant is a little different, but it is how we translate and communicate our urgent medical treatment responses so that we know whether to call Daryl and his team to come and do various things or what we are going to do if there is an urgent problem that needs solving or if the patient deteriorates.

The other thing, and I think this is really important, is we have our patient over here who has done some sort of advance care planning. The other thing we are doing at the Austin is that we have revamped our common-law advance care directive form — I do not know exactly what we are calling it right at the moment — and removed the treatment focus and got much more into the goals, values and beliefs of persons themselves. So our patient, family and whoever have worked through all of those issues, and we have helped them write things down in a way that is meaningful.

Then we have our doctor over here thinking, ‘Okay, I’ve got this person in. What treatment?’. They are thinking through what treatments are on offer, what treatments might be helpful and what might be the outcomes of the treatments. Then what we want to do is that we actually want to meet in the middle. The doctor we want to think about the treatment, the patients and their goals, values and beliefs and how they interact to develop a medical treatment plan. I think that is how this works. We cannot, I do not believe, expect the doctors to be the experts on the patients, and I do not think we can expect the patients to be experts on all the medical treatments. There has to be interaction and discussion.

In my view, this is where a lot of it falls down because everyone gets confused. The doctors think they just have to blindly follow what is written on the form or the patients think they have to be an expert on treatments. I think that yes, they can be experts on treatments, and some of them are, and that is fantastic, but I just think we need to think through how it works and how it is likely to work best for most people.

I have put this up — ‘Advance care planning where prognosis is uncertain’. That is where a lot of our staff have issues, and it comes back to some of the stuff Daryl was talking about as well — I often think that I do not have a problem with this, because in my view we are hoping for the best and planning for the rest. I often say to people, ‘We all have car insurance. When we actually took out our car insurance we weren’t planning on going and having an accident the next day, but if we did, at least we had a plan’. I think it is a lot about this. I also think it is a little bit like a bit of a rehearsal. You are thinking, ‘Okay, so if I get really sick and I’m in hospital, what am I going to do? What might I have to decide? How am I going to work it out?’. It is like a bit of a

practice run so that when the real thing happens you are a little bit more empowered, and I think it is for both the patient but also the people who are going to be making decisions, because this is really hard stuff. We need to make it important, and we need to help people work through it.

I just thought at the end that I would put this in real life. This is one of my patients. Again, it probably crosses a little bit over what Daryl has discussed as well, but he is a 62-year-old chap, five children, quite a supportive family, severe lung disease. He also has some heart disease. As part of our program he undertook advance care planning in December 2012. He appointed his 18-year-old son as his medical enduring power of attorney, and there was a lot of discussion around this because it was actually his youngest son and there was a bit of family dynamics, but it is what the patient wanted, and the son was happy, and there was a lot of discussion around that.

He completed an advance care plan, electing to have a trial of life-sustaining treatment. So he understood he had severe lung disease, he understood that at any point one of those dips might go really badly, but in between times his life was pretty good. So that was what he wanted to do. In 2013 he had three admissions, he came to the ward, he became quite unwell but he was managed on the ward, got better, went home. It was perhaps not always quite back to where he was, but he was getting on with his life. In early 2014, two further admissions. This is a fairly traditional trajectory and in hospitals we are seeing these types of patients much more often.

In September 2014 he came in again and he had a further exacerbation. He was managed on the ward, and we can do a lot of fairly aggressive management on the ward, including non-invasive ventilation, but he deteriorated. As per his plan, we got some help from intensive care, he was intubated and he went down to intensive care. He was there for a few days, and it became obvious to everybody — the doctors, the family and so on — that there was nothing reversible, that he was actually dying. So what then happened was that he was extubated, he was transferred back to the ward that he knew well and he died on the ward about a day or so later.

This was a good outcome for a number of reasons. It was a good outcome for the family. They had time to work through it. Even though it was really sad with what was happening, and that he was dying, they felt like if he had to die, he had done it in a way where he had some control, where it was thought through and everyone was respected. The staff felt really comfortable — they knew what to do. They did not have to think, ‘Oh, my gosh, what am I going to do when he gets into trouble and is it the right thing to do?’. Everybody knew. It actually took less time because everyone knew what the plan was. We did not need to keep having the discussion, and the staff were really happy because they knew that we were able to follow the patient’s wishes, and in a way the hospital was happy because we had a plan. He did not go to intensive care and spend weeks there with a tracheostomy and then rehabilitation, and finally realising he could not go home. This is what often happens in situations like this. Again, that is not to say that that is wrong, but it was not going to meet this fellow’s needs and we did not take too long to get there, so we could free up resources for the next person and help this gentleman achieve the outcome he wanted. So I think in many ways it is not perfect but it shows that it can work and it can work quite well.

In the last two slides I thought I might talk about some of the things that I see as barriers and facilitators to us getting this right. I think clinicians’ skills and confidence and competence is often a barrier. With all of those things it is a bit about skill and it is a little bit about confidence as well. It is a skill that needs to be learnt, you need to practice it, it can be taught. I think there is also often a lot of confusion around the law, both within Victoria but also within Australia and this worries health professionals. It is a very confusing area. Terminology as well gets quite confusing. A further barrier is around patient and community expectations — some people get it, but I think we need to be working in that space a little bit as well and help our population understand the limits of modern medicine and what can and cannot be achieved, and help them to then be able to make an informed decision about what is reasonable for them.

We work in fragmented health services. People move all over the place and come backwards and forwards and do not even go to the same emergency department in the same hospital, particularly in big, busy places like Melbourne but also they come from the country down to Melbourne and they come from interstate, so it is quite fragmented. Thus it is difficult to make sure advance care directives are available. We do not talk around the cost component of this, and I am not saying it is our foremost thing, but when we want to do something new in health care, we need to think about the best way to do it and how it can be funded. I think it is okay to look at

some outcomes that include cost so long as we keep front and centre the patient, the family, the outcomes we are trying to achieve.

Transferability is a little bit like what I showed you: a patient turning up at the right hospital with the alerts on the system — fantastic. If they came to a different hospital, so if they turned up to Eastern Health, for example, they would not have had some of those things. So the Victoria Health Department here is very interested at the moment in how we think we can make these more transferable. There are a couple of logical places to go there, like the eHealth record and potentially in some other ways linking up to other systems already in place. We have been exploring some options both within Australia and out of Australia as to how that might work, because if we get all the other bits right, if we cannot find the plans, we will still have some problems.

And funding priorities, we find it really difficult in this area to compete with all that hot, edgy, really exciting research that is life saving and all of those things that regularly attract health research funding. So when you go and say, ‘We want to do some funding in this area around this sort of stuff’, it is really difficult. Often people who decide about research funding do not quite understand what we are talking about, and I think that is one of the problems as well, and I think it is also sometimes hard to think about what are the outcomes we are trying to measure, but I think we need to be thinking a little bit more in these sorts of areas as well.

I think there are a lot of enablers as well, so we have the Victorian advance care planning strategy, and we are very fortunate to be in Victoria because, yes, there are some gaps and problems with it, but it is well thought out. It has had a lot of engagement. It has given structure to what we are trying to do, and I think many of the health services are finding that that is quite helpful.

We have the national quality and safety standards, and that has been an enormous enabler in terms of getting some buy-in from the hospitals, in terms of some systems in place and all sorts of other things. Those things are really helpful. There are efforts to work in the terminology space, and we are talking about advance care planning and advance care directives and substitute decision-maker and enduring guardians, and everyone gets a bit confused. I do think the current Victorian law — not to suggest that there may not be able to be some tweaks — is actually an enabler. We have a system to do some of these things around statute law. I think Australia-wide a lot of the advance care planning does happen in the common law space as well, and I think many people feel quite comfortable in that space as long as we are careful, so I think it is an enabler to a point.

I think there is a lot of state and commonwealth networking, and I think we are looking for an evidence base. Whatever we do in health care we need to have some idea of whether what we have done has been helpful to the people we are trying to help — that is, the population, the consumers, the patients, whatever group we are working with. We are fortunate in Australia because we have been able to be leaders in this space. There is some good work happening in a number of places overseas as well, but it has been an enabler, so despite some of the problems we have had, it has been quite positive as well. Thank you.

The CHAIR — Thank you, Dr Detering, for that presentation and thank you both for your expertise and skill and the presentations you have given us tonight. I have a number of questions. I will start with the first one and we will move around to other members. It is more about Victorian law, which, Dr Detering, you touched on at the end, but neither of you covered it in any detail, which is fair enough, but I would like to get your views on whether the current legal framework gives practitioners confidence and security, whether you see that is an area of reform or change or whether from your perspective it is stable and satisfactory.

Assoc. Prof. JONES — I think from my perspective the Medical Treatment Act particularly — the protection that we are not obliged to provide futile care — provides us with a lot of confidence. It is not something that we often have to call on. The vast majority of discussions with patients and their relatives end with a mutual compromise whereby there is an agreed plan and an agreed course of action subsequently. In a vast minority there is disagreement and patients and/or their relatives are insisting on therapies which, in the consensus decision of the clinicians, is not in the benefit of the patient and will not provide benefit. We do not want to not provide that because we are being nasty or paternalistic or arrogant, but we see the consequences of providing burdensome and uncomfortable therapies to patients who are actually going to suffer.

It is very distressing, particularly to junior medical and also to nursing staff, for them to have to witness that and for patients, particularly in the intensive care unit, where they are subjected, and I literally mean the word ‘subjected’, to therapies which can drag on for days, if not weeks, where we can literally prevent — —

I do not say keep a patient alive — we are preventing the patient from dying, and they are experiencing repeated aggressive, burdensome and uncomfortable therapies. It is the vast minority of cases where we have to do that, and to my understanding wherever that legal tenet has been challenged, it has always been upheld in the favour of the clinician. So I find a lot of comfort that we are not obliged to provide therapies that we do not believe are beneficial. What do you think?

Dr DETERING — I agree with what Daryl said, and I think the other thing in the area around the advance care planning, not necessarily saying the law is perfect, but I do think we can work with what we are doing very much within current law. If I was going to change some things, what would I do? There has been a little discussion around whether being able to appoint a substitute decision-maker, an alternate agent, is the best way, or should we have 2 or 3 or 10? I think it is hard sometimes and, having recently written an article on some stuff around Australian law, it is confusing. I think in some ways it is simple, it is relatively straightforward. It is really like appointing a spokesperson, but it does not mean other people cannot engage, so from that perspective I think that in my view as a doctor it works really well. In my view as a doctor it works well that it is separate to other powers of attorney as well, and I know there has been a lot of discussion around that.

The refusal of treatment certificate is often not filled in, as I pointed out, I think for a number of reasons. It is a very legalistic form and it is a bit scary for people I think. I think the word ‘refusal’ on it does not sit well. Patients are not refusing treatment, they are just declining to have a specific treatment. And I think the other limitation of that is that if you are just a frail, elderly person living in the community but have some very specific views about things — old age and various other things — the current condition does create some problems. So there may be some scope around that sort of area.

Other places in Australia have done all sorts of interesting things, and I am not sure it has necessarily facilitated what we are trying to do. As I mentioned, I think a lot of advance care planning works — maybe not the substitute decision-maker, but the rest of the planning — in the common-law areas, both within Australia and outside of Australia. I guess it is hard when there has not been a case in Victoria to actually be able to absolutely stand up and say, ‘This is what will happen’. I think we all get a bit scared around all of this, but when we think about if we know the wishes of the patient, they become paramount whether they are written down or not, and it is more around how we approach that and knowing the Medical Treatment Act and knowing how we work things I think that is helpful, but I am not a lawyer, and I am sure other people probably have different views.

Assoc. Prof. JONES — I think common sense comes into it on a lot of occasions. There are multiple situations where I have had to have discussions with patients’ relatives and they have not had a formal, documented advance care plan, as Dr Detering has alluded to, but the family has made their express wishes, and most importantly what level of disability they would find acceptable. So often the first point of difficult conversations I have with the family are, ‘Tell me about your mum when she is at her best. What is she like? What does she like doing? What is important to her? And what would not be acceptable as a state of functionality for her to get back to?’. Because if I cannot guarantee with a reasonable degree of certainty that I can get the relative back to that, or, more importantly, if I know for sure that they are not going to get back to that, then that is extremely important information for us. I think even though it is not written down, we can make those decisions in conjunction with patients’ relatives when the patients are not able to speak for themselves.

Ms SPRINGLE — My question I guess is similar but it pertains possibly more to the practical elements and perhaps the ethical elements. When you spoke about the patient’s wishes and that sometimes it is not possible for the physician to act on the wishes, or there is a disparity between what actually happens and the information that has been imparted by the patient about what they would like. Can you just go into that in a bit more detail?

Dr DETERING — I guess there are a couple of things in I think what you are asking. If we do not know what the patient’s wishes are — —

Ms SPRINGLE — Earlier in your presentation you talked about when their wishes are not — —

Assoc. Prof. JONES — Realistic?

Ms SPRINGLE — Yes.

Dr DETERING — Realistic. It is always easier when we know what the person's wishes are and we agree with them in terms of what we think. As the clinical ethicist, I spend a lot of time where it is often that the patient wants more treatment than the treating team feels is reasonable. In my view in those sorts of situations most of it is around sitting down and having communication with both sides: why is it that the patient and the family — it is often the families — want or are asking for us to treat in a particular way, and why is it that the doctors and the treating teams do not want to provide it?

It is very interesting when we nut through this, because it is often around patients' values and it is often around other things. I do not think it is easy to have a logical argument around this. Often what happens in those situations is that we will sit down and have an agreed negotiation period. It comes back very much to some of the stuff Daryl was talking about, so what do we believe the outcomes are likely to be? What do we think the person would accept as outcomes? We know from Charlie Corke's work and from some other work that probably around 3 per cent of the population want everything done no matter what, living is their first priority — like, being alive. That is great, and that is okay, and sometimes when you have those people it does not mean we will blindly follow. There is a period of negotiation, and our default usually is to treat while we work through that unless we believe significant harm is occurring. I would suggest that most of the time we can get to a gradually agreed process.

Often the people want a voice. They want to feel supported. They have not felt listened to. They have not understood. I would also suggest that most people understand that we are all going to die and that at some point things are going to happen along the way. Sometimes they just need a little bit of time to work through that. Touch wood, I have never ended up in a situation where we have been absolutely at clash at the end of it. Invariably, with some sensitive communication, things work through, but it is difficult. It is very difficult for the staff on the ground who might be at dispute with the patient and the family but at the same time are having to look after them. That is why having outsiders come in to support and help that can be really good.

We often get really worried about it, but it probably does not happen very commonly. However, interestingly, this week I had a call from a colleague at another hospital who has exactly this sort of situation and has sort of been asking, 'Can you come and give an opinion?'. I have given him some advice. I have not actually gone because I do not have authority to go into another hospital, although I have given him some support. One of the things I thought a few years ago related to clinical ethics services is whether hospitals should have them or whether Victoria should have some key people to come and resolve some of these issues, because they are often quite complicated. They are occasionally across, like between the children's hospital and the adult hospital who are deciding whether they will receive the patient for further care and a bunch of things. These really tough ethical things and really tough decisions do need something that is a little external to what is happening on the ground. That would be my view.

Ms SPRINGLE — A quick supplementary to that. Do you find that the reverse is common — that someone wants less treatment than what physicians are prepared to — —

Dr DETERING — That is extremely common. That is often the easiest situation to be in if we just talk to the patient, but occasionally we will get the doctor saying, 'I've operated on them' and, 'I've done'; and it is, 'Hang on a tick. Yes, you have and you have done a great job. Fantastic, now let's just get back to what the person would want, what outcome they would want'. We get around this a lot as well. It is not whether we should operate or not. It is very much back to — we often do things but we then need a bit of a plan. If things go well, great, and if they do not go well, how are we going to navigate through that? But a lot of my work is around giving the person and their family a voice and saying, 'Hang on a tick. They've said they don't want this; why are you doing X, Y and Z?'. They are much easier ones to resolve, but they are not always that easy because doctors and healthcare teams can be quite strong people sometimes too.

Assoc. Prof. JONES — But I have had different situations where patients have not been informed or they are not aware of therapies that will potentially benefit them. I cannot talk about specific cases obviously, but very recently I had a situation where a patient really did not want a therapy because they had a misunderstanding about the likelihood of success of that therapy. That person had a chronic illness and they had not been in hospital for four years, so they had an extremely good, functional quality of life and obtained a seasonal-related illness. I anticipated and the team anticipated that they would get back to a high level of function, so we talked the patient into a treatment. They were not declining it, but they were reluctant to receive

it. That patient almost certainly will make a full recovery and get back to a good level of function. It is about making sure that the patient and their family are adequately informed of the likelihood of a good outcome.

Mr MELHEM — On that point, I am just going to go through how informed Victorians are about their choices. You are talking about the point of the person who is already in hospital and you start talking about the choices, but generally speaking you are saying to me Victorians are not really that informed about their choices as far as end of life or care.

Dr DETERING — For the general population as a whole I think the answer would be no. Having said that, we have talked about a very specific component. There is a lot of work — in the community, in general practice, in all sorts of different things, work with the Health Issues Centre — to try and upskill people. Pockets of the population are very informed, but I think broadly speaking the population is not as informed as perhaps would be ideal. People do have access to a lot of information through technology and stuff as well. On the whole I see that as a good thing, and I encourage people to bring information they have found along so we can talk about it, but we do need to do some more work in this space.

As a community we do not talk about death and dying. We have all these other ways of vaguely talking about things. Now most people will go through life mostly without having much experience of that in their personal life and their family life. We see it all the time because that is where we hang out, but outside of that we do not. It is very different to perhaps a century or so ago where it was a very common thing. I think we have medicalised death — —

Assoc. Prof. JONES — And people died at home.

Dr DETERING — They did.

Assoc. Prof. JONES — People died at home, and even young children would see the process of dying, and there was no intervention to stop it because there was little that could be done. Now a significant amount of dying occurs in hospitals or institutions. I agree. It is a very medicalised process now.

Dr DETERING — Rather than a social and a life process. There are many things about death and dying. Part of it is the medical bit. There is a whole bunch of other stuff.

Mr MELHEM — What would you do to change that, do you think? TV campaigns, other education campaigns?

Dr DETERING — I think it is very much around raising public awareness around things. You would need to think about how you do it. For example, the department of health here has some little info clips. They are little character things that sort of remove the whole personal bit, and I understand that they have had some really positive feedback about it from a number of groups. We need to understand too that some people are very uncomfortable about envisaging their own death. They sort of get the death and dying thing, but they just need to remove themselves — some cultures, some taboos. I think there are ways around it, and it is probably a multifaceted thing. There is Death Over Dinner and a few of these sorts of programs popping up around, ‘Invite your friends to dinner and talk about death and dying’. I am not sure that is the most fun dinner party, but there all these various ways out there. I think it is just about normalising it. We are born, we live, we do all sorts of interesting things and we die. Everybody gets we are going to die, and it is not that by talking about it we are going to make it really bad.

I believe the baby boomer population is going to drive a lot of change. They do talk about these things. They have watched their elderly parents potentially have outcomes that are not ideal. I think they are the group that are very much going to drive a lot of change, but we need to make sure in their group driving change — —

A lot of my interest in this area is in the people who have less access to things, so the culturally and linguistically diverse population. They are interested in this; they just do not have the information that they can understand, and they do not have mechanisms to get that in an English-speaking hospital system.

Assoc. Prof. JONES — I agree. I think we just need to break down the taboos associated with talking about death and dying. You have to be careful in the context you put this because they are very linked, but I think the DonateLife program about, ‘You need to think about what your options are and talk about it with your relatives’. Discover, decide and discuss, I think it is. It was a very good program to promote discussions about

organ donation, and I think there needs to be something similar at a state and national level to get people to talk about death and dying.

Ms FITZHERBERT — Professor Jones, earlier when you were giving evidence you talked about a situation where people had been kept alive under your care or those of the doctors you work with, and they might be subjected to what you called burdensome therapies. Could you give me some examples of what you meant by that?

Assoc. Prof. JONES — For example, Dr Detering alluded to a patient who was short of breath on the ward. They had problems with their breathing and we could give them some medicines on the ward and we could put a mask that fits quite tightly on their face. If that fails, they would need to be put to sleep, as in anaesthetised or put into a medically induced coma, as you would probably hear on the TV, and have a breathing tube put down their windpipe. It is like when you go to anaesthesia. That is a very short, brief experience, and you are deeply anaesthetised while you have that breathing tube.

If you get a breathing tube because you cannot breathe, we do not want to completely put you to sleep, because you still need to breathe or your muscles will get weak, so patients will experience the discomfort of having a tube in their windpipe. They will have lines put into their neck, into their main vein, drips put into their artery, they may have tubes put into their chest in between their ribs to drain fluid or drain air. They may have operations if the cause of their breathing difficulty is related to a problem with their bowel or their intestine, so they may undergo a succession or a sequence of invasive and painful procedures. We obviously give pain relief, but they are nevertheless uncomfortable, and they are often protracted.

Dr DETERING — The other one that we see as well is tube feeding — tubes that go straight into the stomach that are used for various reasons around people who cannot maintain their nutrition, usually around a swallowing problem. They clearly have a very important place in modern medicine. Where they become problematic is in people perhaps with advanced dementia, perhaps with advanced cancer and other conditions where they are on a trajectory where the feeding is unable to offer them benefit. You might think that is okay. To put the tube in, there are a number of things we need to do. To keep the tube in — it sits in here; it can be irritated — we put fluid in there. People can what we call aspirate, where it comes up here and ends up in the lungs. People with dementia or confused people often repeatedly pull them out, so then we have to shackle them or we need to sedate them to keep it in. That is not to say it is always wrong. We need to think about what it is exactly that we are trying to achieve.

If we have got a young person who has had a motor vehicle accident who is likely to make a good recovery, of course we are going to do all of those things, because the anticipated benefit is huge. But if we have somebody who is unlikely to get any useful benefit out of what we are doing — that is, they are going to continue to deteriorate, they will not get out of hospital, they may be unconscious or confused or whatever.

The other thing too is when you cannot understand why something is being done. It is a little bit like a child. If we do something to a child, we do it because there is sense and benefit to it, but for somebody who is in a hospital, who is confused, who does not understand why we keep hurting them, it must be a horrifying experience. It is not so much about the treatment per se. Many of these treatments are very invasive, but it is when the net likely benefit is far outweighed by the burden. Nearly all treatments do have a degree of burden, even in somebody who is relatively sedated or unconscious.

Assoc. Prof. JONES — I agree. I often talk about with families about this. Where there is a chance of meaningful recovery, clinicians and the patient are willing to subject and be subjected to that, but where there is little or no chance of a meaningful recovery, we are providing harm where there is little chance of benefit. That is the area where I start to feel very uncomfortable. I once had a senior clinician — not at the hospital I work at — say, ‘What level of uncertainty are you willing to accept, Daryl? Is it a 1 in 100 chance of getting better, 1 in 1000 or 1 in 500?’. One of my other colleagues more recently has pointed out that it is fine to talk about that, but what about the other 999 patients who you have to harm in order potentially to get that one patient through? I think we really need to think about the number we need to harm in order to even remotely potentially get one patient through. That is something that I think we need to think about on a global perspective, not just on an individual patient perspective I guess.

Dr DETERING — I think the other harm we often do in this sort of area as well is false hope for relatives. I think as doctors we often run around talking about fixing things, and I sometimes wonder what it is exactly are

we fixing. Are we fixing a blood test result? Are we fixing a fluid balance chart, or are we actually fixing something or managing something in a way in a patient that will actually have an outcome? The relatives often get very confused — —

Assoc. Prof. JONES — Fixated.

Dr DETERING — Yes, they get fixated on it, and they end up running around doing a bunch of things that may or may not be helpful to them and to their family member. They will often say, ‘Now that we understand what’s going on, we can sit, we can spend time, we can take time off work and we can do various things to spend time with our dying relative’. I think often we do not mean to do it, but when we run around doing all of these things that are unhelpful, I think we do harm by offering false hope. Even if we do not actually say it, it is by our actions. I think again it is not always wrong, but we just need to think through what it is we are trying to do and how it is perceived. If we are concerned about it, we need to have the conversation. Nearly all of this is about communication. If we have sensible communication, we are nearly always able to bring people on whatever journey it is we are taking, whether it is for everything or bits and pieces along the way.

Assoc. Prof. JONES — I think that is why we came up with the acronym CLEARx decisions. I think the one thing that causes distress to patients, relatives and their families is when there is ambiguity, when there is disagreement between clinicians and there are attempts at aggressive therapy and then attempts at limits of therapy. It is very important for clinicians to get together and agree on a consensus plan and only after that is agreed upon go and convey it to the family. I think they find it very confusing when things are going from one extreme to another.

Ms SYMES — Thank you so much for coming tonight. It has been really good. Picking up on what you were saying about clear decisions — I had another question, but I am actually going to follow that through —

Assoc. Prof. JONES — That is okay

Ms SYMES — It is how it works in practice. I get the concepts — —

Assoc. Prof. JONES — The CLEARx decisions program?

Ms SYMES — Yes. For example — and I might be confusing two different issues — if you have a patient who has a terminal illness but it is a slow terminal illness, they are in their 80s, they have dementia, they are likely to develop pneumonia and they say, ‘I don’t want antibiotics’. I know you talked about several conditions at once, but in terms of a clear decision, if somebody says that that is what they do not want and they are a dementia patient and it comes to their authorised agent to try to put that wish forward, is that a complex case? Obviously every case is different.

Assoc. Prof. JONES — We would hopefully always have discussions with the patient when they are competent or their relative or their surrogate decision-maker, and we would provide information to allow the clinician and the decision-maker to come to a consensus. If antibiotics were not likely to provide a meaningful benefit, they would not be offered. In something like a simple chest infection, giving antibiotics will actually reduce distress because having a fever and an infection is uncomfortable. If they had some sort of quality of life, the administration of antibiotics is really not that burdensome. You might need a little drip, and that can be given under local. Once it is in it is usually not painful. Administration of antibiotics is usually not that distressing.

What would not be acceptable is if the patient deteriorated despite the antibiotics, some nasogastric feeds, some artificial nutrition, some oxygen therapy, physiotherapy from the physiotherapists, regular blood tests, tests to find what germ it is. If all that did not work — that is, optimal care — and if the patient continued to decline despite that, what would not be acceptable is putting a tight-fitting mask on the patient, which is going to cause distress, discomfort and again is just preventing death rather than prolonging life. What would definitely never be acceptable is jumping on their chest if they had a cardiac arrest, because the chance of getting them back to any meaningful existence is zero. They are probably going to die and suffer pain from the chest compressions. Even if they survive, they will probably fracture ribs and the sternum. Also to put a breathing tube down and put a patient on the breathing machine, like I alluded to before, because the likelihood of them providing any meaningful recovery is essentially zero, and they will provide immense distress to the patient.

Ms SYMES — So in terms of the CLEARx directions, you would need to have a fair bit of medical advice about where you are heading in order to make clear decisions.

Dr DETERING — When I teach my junior doctors particularly, it is about sitting back and putting the person in context. A 20-year-old with pneumonia and a 90-year-old with pneumonia are not the same. I will often talk in extremes because people get that. The 65-year-old with a few problems and pneumonia, where do they fit? It is about thinking through outcomes. The other bit is that I do not think we have to be absolutely certain. We do about some things. Obviously if we decide not to do something very significant, like if we do not provide a life-saving treatment — somebody cannot breathe and we do not ventilate them, they will die — in working through that, we do not need to be absolutely certain. I will often say, ‘We’re not sure exactly what the outcome is going to be, so let’s workshop it, if you like. Let’s think it through, and let’s think through the possible outcomes and have a discussion about it’. In that context you get opinions from the patient and the family around things that are important.

Some people will fight incredibly hard just to stay alive or just to have minimal function, something that many of the population would find intolerable. Sitting at home when their grandchildren come to visit and having a functional existence, some people will hold onto that unbelievably strongly, and that is completely fine. Other people find the concept of even walking in the door of a hospital or having to deal with doctors or machines or whatever very difficult. In the context of talking through the various possible outcomes we start to work it out. It is also where we talk about outcomes, values, beliefs, goals and things like that.

Another example is somebody who has got quite an advanced cancer who needs to have chemotherapy. There are various things you could do in that situation. You could give them the chemotherapy and they may or may not get an outcome in terms of some longer life or whatever, but the costs of that might be being in hospital, having blood tests and having a bunch of other things. Or the person might think, ‘Yeah, but what’s really important to me right now is that my daughter is going to have her 21st birthday’ or, ‘I want to go on a holiday to Queensland’, or whatever it is that people might want to do. They might prefer to have a bit of a trade-off and say, ‘Well, actually no, I’m feeling quite well right now. I don’t want medication that is going to make me feel sick and may or may not give me any useful thing. So I actually prefer how I am, and I’m prepared to take that risk a little bit and go and do something else’. So it is a trade-off, and you do not need to be certain.

That is why I talk a little bit about the car. People get the car insurance thing. I know it is very black and white and life is not like that, but it is about thinking through possibilities, it is planning for outcomes but things change and it is reassessing. We start treatment today, we go back and assess tomorrow. Did we achieve what we thought we would? If we did, we keep going. If we did not, we have another discussion and realign our plans. I think it is a very active, integrative sort of process.

Assoc. Prof. JONES — I think I may have caused confusion. I do not infer that CLEARx decisions means that the situation is black and white. Far from it. There is often immense uncertainty. The clinicians need to clearly articulate what they are thinking to the patient, the relative and their team, and everyone has to have a shared vision — a shared model — of where we are going. There needs to be an agreed-upon plan, and there needs to be an agreed-upon outcome of what we are trying to achieve. If things do not go right, we need to be clear about what the next step is. It may never eventuate exactly, but it should not be a surprise. If someone with lots of problems has a significant deterioration, they may actually get better. We would always try to get them better; that is what we do until the point when we cannot.

The thing I would emphasise and stress to my colleagues is that you need to talk about what happens if the patient does not get better. We do not want there to be a crisis, particularly out of hours, particularly when the patient’s relatives are not in the hospital and it is 3 o’clock in the morning and we are expecting people to make decisions under duress and uninformed, because the patient might get therapy that they may not have wanted and that is probably not going to benefit them.

That is what I guess I am talking about with CLEARx decisions: you need to be clear about what the therapy is, what you think the prognosis is — and there is always uncertainty — and what the contingencies are, because there is always going to be relative amounts of curative care and comfort care; it will just depend on where the patient is in the trajectory. Even if you come in with a simple problem like appendicitis, which you would always cure in a young person, you still give comfort care. You give analgesia, anti-nausea medication, you will give fluid to avoid the distressing symptoms of dehydration, but the aim there is 90 per cent cure and 10 per cent comfort.

Clearly, in other situations where patients are elderly and/or have significant functional impairment and lots of medical problems, the intent might be cure initially, but when cure is not working, there needs to be a greater emphasis on what we call switching to comfort care. You may actually continue to provide attempts at curative care whilst providing comfort care, but the emphasis needs to increase towards the comfort care as the patient is clearly demonstrating that they are not responding to what I call optimal therapy. I guess that is what I was trying to say about being clear.

Dr DETERING — I think the other thing is clinical leadership. In the middle of a crisis you need somebody to step up and start to take control. I think it is often what patients and families want. They will often have family members who will do that as well, but in the hospital setting we want senior doctors, senior nurses, senior clinicians to stand up and work the problem with the other staff and coordinate it and get the opinions and do various things, rather than say, 'It is not my problem. Ring this person, the most junior person, or the nurse or whatever'. It is very much about leadership as well — leadership and mentoring support, all of those things.

My role on the clinical ethics component of the hospital should become defunct if we can actually get these other things right, because they will be solved at local level. It is about getting colleagues, mentors, within the various places around the hospital, rather than having some assorted random outsider come in as well. A lot of the clear decisions are around the clinical leadership and the ownership, plus obviously the mentoring, plus also the discussions and all of that. When I was growing up in the hospital system, I got to see good role numbers, but I think in the modern hospital system it is very hard to find them, because no-one is in the same place. The consultant is here and the junior doctors elsewhere and here and somebody else is on another ward or clinic and it is somebody's afternoon off and it goes around in circles. In the middle of the night there is relatively little support. Nursing is marginally better structured, but again there is not a lot of staff readily available. They have to run around doing a lot of things too now. It is about getting senior significant support to help and support and mentor, and a little bit conduct things. Also for the patients and the families, they look to some sensible, controlled discussion and support as well.

Assoc. Prof. JONES — And simple discussions, avoiding excessive medical terminology and providing things in a clear and jargon-free manner as well.

Ms PATTEN — Thank you. Fantastic presentations and really informative. I just want to go back to the advance care planning. I was really interested in the work that the Austin is doing, and we have heard a lot about that from other people who visited. What struck me was — the process that you have got is fantastic, with the practitioner coming in — that I think in one of them it looked like only half the people actually took up that advance care planning response.

Mrs PEULICH — That was your trial. The percentages did not add up.

Dr DETERING — You were talking about the table? In the trial it was deliberate: half got it and half did not. But in the table — —

Ms PATTEN — Sorry, in this table?

Dr DETERING — Part of it is around resourcing. One of the really big difficulties we have is that we are actually shrinking in size, which is interesting in an area that is growing. It is not all bad. The Austin Hospital had something like 100 000 admissions a year — I am not sure the exact number — and this is how many people we see, which is the tip of the iceberg as well. The facilitated model works really well, but it is probably not sustainable either. We are doing a lot more work in skilling up lots of different people, including not just in the hospital, but if people come into the hospital with plans. They have done it in the community; they have maybe done it online themselves — they have used Charlie Corke's 'MyValues', they have done various other things. They have gone in the sort of places.

Mrs PEULICH — But the best numbers are about 65 per cent.

Dr DETERING — Sorry?

Mrs PEULICH — The best numbers — 19, 20 per cent, 2, 24, 23 — because there are still a large number who have not participated.

Dr DETERING — Advance care planning is about offering the discussion and having a conversation. Part of the point of this slide is that a percentage of them will go on and write things down, and sometimes we get so het up on what the piece of paper looks like, rather than actually offering and having the conversation. Again maybe coming back to the legal question before, I think underpinning what we do we are actually very well supported. Maybe we get a bit lost in the documents, and we can always change components of those, but much more about it is about other stuff. Because you are right, if we just counted documents, we are not doing very well. I think other work that other people around Victoria are doing, probably the hit rates are around about 50 to 70 per cent at best of people you offer to. Not everyone is going to write it down; they do not want to for lots of different reasons, and that is fine.

Ms PATTEN — Just following on from that, I appreciate that. Certainly what we have been hearing a lot is how useful a tool that conversation is. I understand getting the Death Over Dinner — we have done sex and politics, so now it is time to do death at dinner. We have talked about this with others. Do you think there are any positives to in some ways mandating advance care planning in conversations, whether it is entering into aged-care facilities or if it is a certain cohort of patients entering into ED or even ICU, where they are over 65 or they have got symptoms that one might imagine that they are on that declining trajectory?

Dr DETERING — My concern about mandating is that we will possibly cause more harm than good. Number one, people do not have to have this conversation, and if we decided that 75 per cent of people going into aged-care facilities needed to have a form, people will go up with the form and say, ‘Which box do you tick?’ and not have the conversation. My view is that we need to make it available and offer it and promote it and support it, and we do need to measure some outcomes. Part of why I then think things like this are really helpful is it gives us some idea of what is reasonable in terms of outcomes.

A while ago to go to a palliative care facility you had to be not for CPR. It was a really big sticking point — no exceptions, you have to be not for CPR. Often the first time somebody had a conversation about it is when the palliative care whatever said, ‘You are coming to our palliative care unit and you are not for CPR’. I do not necessarily know that mandating it solves it. I think supporting it, making structures and putting systems in place so that it can happen, for example, it does take some time. How does that get managed in a busy health system? Who pays for it? How do we manage that side of things? There have been some discussions I am sure around some of that sort of stuff as well.

Within the hospital, how do we actually do better than what we are doing and actually get it out there to many more of our population? In my view we should be targeting. Ideally, yes, it is for everyone, but we cannot do that, so let us target the high-risk groups. I think this is what the Victorian strategy has done quite well, very much targeted things. But part of the problem is we have not quite worked out how to do it in groups. I think the aged-care arena is better because it is at least a population we can define in some way, and we can offer and we can encourage and support and whatever, but we cannot mandate.

Chronic disease is our biggest headache in the health system, and advance care planning is linked to it. How do we find them? How do we promote it? How do we do it? Our hospital systems are not set up to manage the chronic disease sort of stuff. I think advance care planning is just one part of it, but it is all of this, so how do we do it? Do we ask the GPs to do it? Do we ask the physicians to do it? The answer is a lot of things, but we really need to be careful about mandating things I think.

Assoc. Prof. JONES — I tend to agree. I think if it was mandated, people would just do it and you would have quantitative results but very poor qualitative. I think it might actually be rushed and not done particularly well, and patients and their families might not be adequately informed. But I do agree that there are some groups where you could concentrate your energy to increase return on investment. I think entry to nursing home is a reasonable start, and the other one is patients who have multiple admissions within a defined period. They are clearly highlighting themselves to be on the trajectory of decline.

Mr MULINO — Thank you very much for your testimony and presentations tonight. It has been very interesting, and I also wanted to note that I found your randomised trial fascinating. I am one who believes that we need to use randomised controlled trials more generally across social policy. I think it is a really rigorous and interesting device, so I am really interested in this one.

I am going to ask you something slightly different: uncertainty was raised as a barrier to effective decision-making, and also it is underpinning a lot of medical practice. You raised it as a challenge, like what do

we do when someone is 1 in 1000 versus 1 in 100 versus 1 in 10? With improvements in medical practice, are medical practitioners getting better at accurately estimating what the actual likelihood of recovery or not being irreversible is, for different conditions?

Assoc. Prof. JONES — It depends on the condition.

Dr DETERING — I think it depends on the condition and it depends on the doctor. I think this will come very much out of some of the work through the end-of-life consensus statement and other things as well — they talk often about the ‘surprise question’. You may or may not have heard of this. It involves: ‘Would I be surprised if this person died in the next week, month, year or whatever?’. I find that a very interesting question because I find it very easy to answer but some of my junior staff have said, ‘Yes, but you are experienced. What is it exactly that you use?’. I think that is a fair comment. It is very much around developing tools and things to help people work this out. You still do not need to be exact, but there are a bunch of things that will help you. If you come to hospital more than twice in six months with something like the patient I described, you are unlikely to be alive in a year.

There is a lot of evidence around some of this stuff concerning if you are frail and elderly and your frailty scale. Age, per se, is predictive in some things, but it is more about the fact that you have just had longer to collect conditions, possibly. But there are some very elderly, very fit, very well people whom we all want to do everything we can possibly think of for as well. I think it is about helping to teach doctors what tools they can use. I do think we need to get some more objective measures around this surprise question, because what does it really mean? I think it just feels right, but I think we can put some objective things around it. I know Barwon Health has been doing a bit of work in this area as well.

The other thing I think we need to do is join forces and resources a bit better because there is not a lot of resourcing in this area. We need to network better, even though I have said it is an enabler, to work better to share what we are doing, encourage support and help and join forces to develop a lot of this stuff. It is also around getting stuff written and published as well getting it out there because that can be quite powerful, but it is not always the easiest thing to do for lots of reasons.

Assoc. Prof. JONES — I think if you are thinking more towards prognostic scores, if that is what you are looking at, prognostic scores work very well for a population. If you got a hundred patients with various degrees of organ dysfunction, age and functional impairment, you could develop a predictive score for them, but it does not actually work for an individual patient.

Mr MULINO — But you can take it back to risk factors and potentially — —

Assoc. Prof. JONES — You can risk-stratify a patient, but, for example, someone cannot be 20 per cent dead. So if you have a tool that predicts that you have an 80 per cent chance of dying from something, you cannot be 20 per cent dead. You are either dead or alive. All it can tell you is that you are in a higher group. For an individual patient, you cannot predict whether that patient is going to live or die, so usually we give a trial of therapy. We match up the risk of the patient responding to therapy with what their functional status is and what they actually would find to be acceptable.

If, for example, the patient is quite impaired and has reduced mobility and they come in with a fractured long bone or a major abdominal catastrophe, that patient’s likelihood of getting back to functional independence is extremely low. If they would not want to be functionally impaired, that is extremely important information. It is as important as the likelihood of the therapy saving their life because we can keep the patient alive but whether we actually get them back to a level of functional independence is something that I think is equally important to surviving.

As I alluded to earlier, the first question I ask relatives is: ‘What is mum like at her best?’. Firstly it shows that you actually care about the person and not the disease and you are trying to contextualise the disease and understand more about the human being and the person, but it also tells you where they are coming from. Because I am a good clinician but not a miracle worker, I am never going to get somebody back to potentially better than what they were, if they already had, on that trajectory, a functional decline. The best I am ever going to do is where they were. If they were struggling with the quality of their life and were unhappy with it, then I can honestly tell patients and their families, ‘The likelihood of me getting you back to that — that is the best I

can do — and the likelihood is you are going to actually be less able than you were'. That is important information to share with patients and their relatives.

Mr MULINO — Just a very quick follow up on this: I think that understanding these likelihoods is important. I know doctors are thinking about whether this is very unlikely or quite unlikely or a balance of probabilities situation, but then the additional challenge, I imagine, is trying to communicate some of these concepts to patients, which is probably even more difficult.

Dr DETERING — At the moment we are doing a cancer study with advance care planning, and we are offering prognosis. We have a validated formula around it, so we are recruiting patients whose median survival is 12 months, meaning at 12 months 50 per cent will be alive and 50 per cent will be dead. That is interesting, but how do we work that out? There is a formula around how we talk about it. We know, based on that, that the worst 10 per cent will live three months or less and the best 10 per cent will live 18 months or more, so we have developed a bit of a script around how we do that.

I think people need to have some idea. If you are expecting to live three years and you die in three months, we have a problem. We will often say that if we have 100 people, the 10 people who are going to do the worst will die within the next three months, and at least that gets people thinking, 'Okay, I could be in that. That is the worst scenario, so I need to do something about that', so they run around and do their will or whatever they want to do. At the same time we do not want them all running around doing that and spending all their money and living and thinking, 'Oh gosh, now what am I going to do?'. It is also about getting the idea that the best 10 people will live more than 18 months. That is not about quality, but it gives an idea. Again I think we have to get into talking about it.

The other thing I will do with my patients whom I am starting to get really concerned about is that I would talk a bit more generally and say, 'Look, right at the moment things are okay; I don't know exactly what's going to happen, but I think I'm talking in weeks, months or maybe a bit longer', and start to give them an idea that I am not exactly sure because we do not know. We might start talking about events. We might know when their birthday is or Christmas and start to give them an idea that life is looking pretty limited.

At the same time I have an 80-something-year-old guy who said, 'My parents were told I was going to die before I got to adulthood, and look how wrong they were!'. So we need to be a bit careful in the other direction too. I do think we need to offer what we know such that if people want to know — and they do not all want to know that — we can offer prognosis. People do not need to embark on that and they might not want to know, but if they do, we need to get better at talking about it in ways that are meaningful and let people engage if they want to.

Mrs PEULICH — I have two questions, if I may. I had lots, but fortunately most of them had been answered — so that is good. Of those who had an advance care plan, what is the incidence of that plan being changed by them, by the patient?

Dr DETERING — Actually that is a good question. It is a very dynamic plan. We have done some work around this, and people do change. I talk about, in a loose way, going down the food chain, moving down, so perhaps limiting more treatment with time. For example, someone might start on dialysis who is doing really well and living in the community and very functional. You might do some advance care planning, and they might be very keen to continue having everything on offer. Then they get a little bit sicker and various other things. Maybe they have some significant event happening like they go to hospital and maybe have a complication or whatever. They might then think, 'Okay, I am not as good as I was', and so they are reviewing things and maybe limiting treatment a bit and gradually moving on. It is also what we often do with doctors when we are doing the medical bit as well. We might start off by offering everything and then gradually limit it.

Mrs PEULICH — Is there an inverse situation?

Dr DETERING — There is an inverse situation, and I will give you two examples — one in the advance care planning area. There is an inverse situation, but it is uncommon. Most people hedge their bets a bit and sit in the middle with, 'Well, it depends on outcome'. Most people do not come along saying, 'I do not want treatment at all' or 'I want everything'. Most people sit in the middle, and sometimes people change. The couple of times I have seen it is where I do not necessarily believe we did advance care planning at the right time. For example, doing it as you are recovering in ICU, as you are about to get transferred to the ward, may not be the

best time because of all the things going on with a patient. They are often scared and frightened and sick, so if we do it then, we have to go back and review it. We might need to because maybe we do not know whether the person is going to get another opportunity.

The other thing on our treatment planning: we have done some research and had a look at where — so this is the doctor decision — doctors have limited treatment and then reversed it, and nearly all of the patients where treatment was reversed and the choice was for more aggressive treatments, actually died. Again we do not have a lot of detail. That is not to say they were all bad decisions or whatever, but invariably I think when there is a clear, well-thought-out decision, whether it be from patient or doctor, unless there is something unexpected and amazing — a miracle or a significant improvement we were not expecting — nearly always people review things and either keep them the same or limit treatment further.

I think there are rare occasions when intensive care clinicians will discharge a patient to the ward with significant limitations, even quite young people, on the proviso or the caveat that if that person were to improve, it would be reviewed. There have been half a dozen that I can think of in just the time that I have been at the Austin where that has been again upgraded and the patient has been readmitted because they were discharged from ICU profoundly impaired but under the caveat that if they do get better and go to rehabilitation, the limit of therapy that was adjudicated would actually be revoked.

Mrs PEULICH — Does mental health impact on an advance care plan that you may have subscribed to? For example, if you are in pain and you guys have managed that pain and alleviated that pain, the person may become more optimistic and perhaps look at a different advance care plan.

Dr DETERING — Yes. When we do advance care planning we make an assessment around the person's decision-making capacity, so it is around whether they are in pain, whether they are frightened, whether they are depressed or something else that might impair decision making. Depression can sometimes be a little complex because we clearly have people — in fact I can think of a number of quite significant circumstances here — where we may have even had suicide attempts or other quite significant things. Part of it is trying to work out whether the depression is impacting on the person's decision-making capacity, and we have a bunch of psychiatrists and psychologists who are very helpful at working through these processes quite well.

We have examples all of the time of where somebody has a severe chronic illness and becomes depressed as a consequence of it or maybe always had depression and whatever. We do not want to deny those people opportunities, but we do need to work through if the depression or the pain or whatever is impacting on their decision-making can be treated appropriately, will that then mean the person has improved and may make a different decision? We err very much on the side of trying to treat the problem before making an advance care plan.

I think it comes back to before: if we start mandating things, we are going to start doing some things in circumstances that perhaps are not ideal for the patient — recognising, of course, that chronic severe depression is also a chronic illness and it may have limitations for treatment as well. That is a whole different argument and obviously I am not an expert in it, but it is just about understanding how it impacts. We do get a lot of help. We have got quite a problem at the moment with a person who has had significant psychiatric illness, a young person, who wants to have a life-prolonging treatment withdrawn. We need to work through this. We believe she has capacity to make that decision and that it is her decision at whatever time, but we have done it with a lot of thought and support from people, including a couple of psychiatric opinions and a lot of other stuff.

Mrs PEULICH — Just one last question. Thank you for the very honest presentation and detailed, nuanced answers. Obviously there are a number of people with whom discussion is not possible. Communication may be a barrier. It may be that death may be taboo in their own culture, such as in culturally and linguistically diverse communities. For people who may have migrated to Australia from dictatorships or from life-threatening situations for whom life is precious, they want to extract every single last drop of life that they possibly can. There is also the baby boomer generation, for whom perhaps life is a bit like a styrofoam cup: if you are no longer productive, we are going to toss you away. Can you comment on all of those barriers? What are the characteristics of those people who do not want to engage in that conversation?

Dr DETERING — Actually, it is very variable. Lots of people do not plan — plan for whatever; it is not just about death — and it is completely fine. I used to get quite frustrated in terms of 'How do we engage the people who do not plan?'. I think it is very much about offering, but people do not need to do it, and the default

is that we have a whole system that errs on the side of getting everything. For me, a lot of it is about finding out where people sit and where their line in the sand is.

I think we do need to wear down the barriers. The language barrier is a quite significant one and that is some of the work we are doing. But interestingly, in working with the groups that work with the people — you know, the Italian and Greek-speaking communities particularly — there is a lot written saying, ‘They’re not interested’. They do not know about it so they do not know whether they are interested or not, and our work would suggest that if we provide appropriate information in an appropriate context that is fine. But it does not matter what we do, not everybody wants to plan. People cannot, will not, do not. Again it is why where we need to be careful about forcing people to do something. We offer; they can say yes or no. We come back, but we do not harass them either, and I think it is okay.

I think the other thing for me is we make advance care planning available in as many ways as we can. You can do it yourself on the computer at home. You can do it with a clinician in the hospital. You can do it with your GP. You can do it with your spiritual adviser, your cultural support person or whoever. We need to think really broadly about how we do it. It still does not mean everyone will, but at least people will get opportunities if they want to.

Assoc. Prof. JONES — Despite the change in public perception, in interaction and in ownership of their own health, there are still a lot of patients who say, ‘I’m leaving it up to you, Doctor’, and they actually place the decision in the doctor’s hands.

Mrs PEULICH — It is frightening.

Ms SYMES — I understand it, yes.

Assoc. Prof. JONES — Except you give them information about what you honestly think and you consult with your colleagues.

Mrs PEULICH — How about the surrogate decision-maker, the adult child who may not necessarily fancy being burdened with a frail parent or a parent who is lingering? Is that an issue?

Dr DETERING — It is generally not an issue, but you do need to question them and it is partly motivation. There are systems in place already where we can go somewhere else if we do not believe that the decision-maker is actually acting in the person’s best interest. It is one of the reasons why I am a bit of a fan of keeping the medical and the financial decisions separate, because I think they are different. I think for lots of different reasons the financial stuff is more complicated. I think the individual that is giving somebody financial power of attorney needs to be a lot more competent, probably, than with the medical stuff because the medical stuff works in a different way and most people have had a lot more experience and it is perhaps a little less open to abuse — it is not to say it cannot happen — but I think there are some safeguards already and we do occasionally use them, not often, to again protect our patient.

The CHAIR — We are nearly out of time. I know Ms Patten has some questions.

Ms PATTEN — This has been a very interesting inquiry, and it has been great looking at all aspects of it. We have received hundreds of submissions, as you would not be surprised to hear, and many of them are talking about the more proactive decision about ending their life, whether it is talking about very sad stories about a bad death and wanting to have that good death and that is being able to say goodbye at the time that they choose and at the point that they choose. Do you think there is room in where we are going that we can have those more proactive decisions in advance care so it is not just about refusing treatments but actually saying, ‘If I get to this level of disability, I’m not going to die from that disability but that is not the life that I want to lead’? Do you think we can take more proactive decisions?

Assoc. Prof. JONES — I just want to be clear: are you talking about euthanasia?

Ms PATTEN — I would be talking about physician-assisted dying in some form. Yes.

Assoc. Prof. JONES — Okay. I just wanted to be clear. In my experience, and I do not work in the community so I probably do not see these patients, in 20 years as a clinical practitioner, the number of patients I have seen who die to whom that applies is the overwhelming minority. So it is an important concept but just to

contextualise it, most patients die comfortably after either cessation of therapy or the commencement of comfort care, and with appropriate palliative care it is not often that patients need that. However, having said that, there are rare occasions. What is an example of a patient I have encountered? There was a young, incredibly intelligent female who had major physical disability, who described herself as a perfectionist in an imperfect body, to whom that applied.

I think there does need to be broader debate and discussion about it. I do not have enough experience professionally. The number of encounters with patients I have had of that type are very few and far between, but there potentially is scope for that. I think the people you need to speak to about that are primary care clinicians, so general practitioners; potentially palliative care clinicians; and clinicians who work with patients who have a lot of physically disabling conditions that do not have concurrent cognitive decline, I guess, so that they are actually aware and very frustrated and limited by them. If you want to get the perspective of those sorts of clinicians, I am definitely not the right person. Those people would never come to me.

Dr DETERING — I will just make two quick points. I agree with Daryl. Most people hang on to life and whatever; however, I completely understand that what we are talking about here may not meet everybody's needs. I have also had some experience with people who have looked at euthanasia, and some of it — not all of it, but some of it — is about regaining control. So I think there is a component of that. I am not saying it is the only thing, and I am not trying to downplay other reasons why people consider and think about other options.

The only other comment I would make is that there are places in the world where advance care planning, palliative care and physician-assisted suicide/euthanasia work very well alongside each other. Relatively small numbers of the population elect to pursue the euthanasia pathway, but perhaps you could look at some of their experiences. I have heard some of these people talk. I have seen some of the debates around it all. It often comes back to being around safeguards, and it probably fits in all of these areas. I am really just describing the situation in my world where these things have popped up. I would agree with Daryl as well that it is an important debate and people who have a lot more experience than we do in these areas clearly need to contribute to the debate.

I have seen some of the responses, including, I will say, written responses from a couple of people whose care I have had involvement. I can certainly appreciate that there are times and circumstances and illnesses where people are undergoing incredible suffering and do not have a treatment that can be withdrawn, or whatever, and they perhaps then consider how that sits. It becomes really important.

The final thing I would say is that we need to be careful about what we are talking about. There is a lot of confusion about withdrawal of treatment versus actively assisting death in some way. Again it gets confusing. It gets very confused in the media and I think that makes things difficult as well, so whatever comes out of it I just think we need to be very clear about what we are talking about so that we can convey it to the population.

Assoc. Prof. JONES — I will just add a couple of quick points. I think the safeguards are exceedingly important, and this I do not think can be the decision of a single clinician with a single patient. There has to be some sort of panel view. I am not talking about death panels like Sarah Palin talked about, but there needs to be a consensus. The patient needs to express it consistently on multiple occasions under multiple circumstances, including at times when they are not concurrently depressed either as a primary depressive illness or as a result of the burden from their disease, because these opinions fluctuate with patients who have chronic illness. Where yesterday potentially they would not have wanted to live, after they resume control of burdensome symptoms maybe their perspective is different. So I think it needs to be expressed serially under multiple circumstances, and one of the safeguards needs to be second and/or multiple opinions also from psychiatrists and psychologists, so that the decisions are not being unduly influenced by the patient's mental state.

Ms PATTEN — I think you are right. You look at some of those overseas countries where it is on offer and of the people who take it up, while they might go through that process, very few of them actually take the process to the end. It is having that process there.

Dr DETERING — Yes, so I think we can learn from their experience; it is not to say we are the same.

Ms PATTEN — Yes.

Mrs PEULICH — Then for those who are experiencing experiential pain who are proposing euthanasia, it would be even more complicated.

Dr DETERING — Yes.

Mrs PEULICH — Rather than for some physical incapacity.

Dr DETERING — Yes, it is about suffering, however that is defined. People define it differently and experience things differently — they are different challenges.

Assoc. Prof. JONES — But if patients have suffering due to mental illness, they will often achieve their end. No matter how hard we try to intervene, they will achieve what they are trying to achieve. One of the psychiatrists I work with, as a medical student, said we need to acknowledge that mental illness has an associated mortality, that there are some patients that we cannot treat, rightly or wrongly. Is that what you are saying?

Mrs PEULICH — In view of that, it is interesting that general practitioners do not often proactively direct their patients to mental health specialists or experts and do not devise plans at the early stages.

Assoc. Prof. JONES — That is out of my scope of practice.

Mrs PEULICH — It is my personal experience.

Assoc. Prof. JONES — Okay. I could not comment at all.

The CHAIR — Associate Professor Jones and Dr Detering, thank you both very much for your presentation tonight and for the considered, thoughtful responses to our questions. We very much appreciate it, and as I said in my introduction we will look forward to visiting the Austin in the coming weeks. Thanks again for that invitation.

Assoc. Prof. JONES — You will get to meet Dr Juli Moran, who is the director of palliative care. She is the other person involved, and maybe Dr Simon Judkins. He is a senior clinician in the emergency department. And maybe we will get some of the palliative care liaison nurses and intensive care liaison nurses and give you a multidisciplinary view — we are clearly both doctors. I think that other clinicians offer another perspective.

The CHAIR — Thank you both very much, and as I said the Hansard transcript will be with you in the coming days. I declare the meeting closed.

Committee adjourned.