

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Melbourne — 24 February 2016

#### Members

Mr Edward O’Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Mrs Inga Peulich

Mr Cesar Melhem

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

#### Witnesses

Professor Peter Hudson, Director,

Associate Professor Mark Boughey, Director, Palliative Medicine, and Co-Deputy Director, and

Associate Professor Jennifer Philip, Deputy Director, Palliative Medicine, and Co-Deputy Director, Centre for Palliative Care, St Vincent’s Hospital and Collaborative Centre of the University of Melbourne.

**The CHAIR** — I declare open the Legislative Council’s legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I welcome Professor Peter Hudson, director, Centre for Palliative Care; Associate Professor Mark Boughey, director, palliative medicine, and co-deputy director, Centre for Palliative Care; and Associate Professor Jennifer Philip, deputy director, palliative medicine, and co-deputy director, Centre for Palliative Care at St Vincent’s Hospital and Collaborative Centre of the University of Melbourne. Thank you to the three of you for making yourselves available at this time of the evening.

Before I invite you to make an opening statement, 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 in the next week, and transcripts will ultimately be made public and placed on the committee’s website.

I invite you to make an opening statement, and thereafter the committee will have questions. We have allowed approximately 45 minutes for this evening’s session. Again, thank you very much for being a part of it and being here tonight.

**Prof. HUDSON** — Thank you, and thanks very much for the opportunity to present this evening. My understanding is we will have up to about 15 minutes — is that right —

**The CHAIR** — Yes.

**Prof. HUDSON** — to present some information and recommendations from our behalf. Is that okay?

**The CHAIR** — Sounds great.

**Prof. HUDSON** — Maybe we should begin by introducing ourselves. I am Peter Hudson, the director of the Centre for Palliative Care. The centre is a statewide academic unit based at St Vincent’s here in Melbourne, but it is also a collaborative centre of the University of Melbourne. The focus is in two areas; one is in research in palliative care, and other is training multidisciplinary healthcare professionals in how to best provide palliative care. My background clinically, historically is in palliative care nursing, predominantly in home care.

**Assoc. Prof. BOUGHEY** — Mark Boughey. As you have already mentioned, I have a dual role as director of palliative medicine at St Vincent’s, and that is across the St Vincent’s network, including Caritas Christi in Kew, as well as we have a large consultation service across our hospital, public and private, and two inpatient palliative care units; and then co-deputy director of the Centre for Palliative Care. I take on the education and training portfolio, the breadth of training programs for specialist palliative medicine doctors in the state and as practitioner collaborative our university graduate courses and day courses and so forth. I am also chair of the Palliative Care Clinical Network for Victoria.

**Assoc. Prof. PHILIP** — I am Jenny Philip, co-deputy director of the centre and deputy director of the clinical services at St Vincent’s. My main clinical role is heading up the consultancy service, and we have a busy inpatient and outpatient service across the campuses. My role in the centre is to head up the research portfolio, and I am actively involved in research in doing that role.

**Prof. HUDSON** — By way of introduction I would like to acknowledge that we are by no means experts in law, and I think what we convey this evening and in our documentation is collective experience over several decades, experience in caring for hundreds of patients and families across multiple settings, whether it be at home or in the inpatient facility.

We also have experience in conducting research to get a sense of the experience of what it is like to have an advanced disease from both a patient perspective and also from a carer perspective during the time of looking after someone who needs palliative care and also during bereavement, and also collective experience relating to training doctors, nurses and allied healthcare professionals in best practice in palliative care. What I think we bring this evening is those collective experiences, and they are supported I think by the documentation that you have that we have provided in terms of our submission. We also have some additional documents. One is a paper that we co-wrote highlighting some of the pragmatic implications associated with potential legalisation of

euthanasia. We thought it was important to air those in the public arena. You have also got a handout of some of the points we would like to convey in our introduction.

We have got five recommendations we would like to go over fairly swiftly — due to the available time — as I said, with the handout to refer to as we talk to each of those recommendations. I might start with Mark to talk about some of the issues and recommendations associated with palliative care service delivery.

**Assoc. Prof. BOUGHEY** — Our first one is covering the status and provision of palliative care across the disease trajectories and end of life. I think the issues are that there is actually good evidence that you have most probably already heard that palliative care does provide something of a supportive layer to patient care at any stage in their disease trajectory, whether it be cancer or non-malignant or neurodegenerative disease, but it is that connection of the care earlier in the disease trajectory that seems to make the effective difference and also can contribute to increased longevity as well as good symptom management, supported care and a sense of completeness of the care that is being delivered.

People's expectation of palliative care is that it provides this level of service of multidisciplinary, interdisciplinary, good allied, nursing, medical therapies/therapists from all sorts of different directions, providing good support. But the reality most probably is that even though we know we can achieve those levels — and Australia does have a good kind of connection to and Victoria particularly has good services — the variability of those services and the way that are provided and brought together is quite variable. So what people conceptualise as palliative care does not always meet those expectations or needs, so when we see the words 'palliative care' in the press or see them written, the reality is very different for different people at different times in their illness trajectory.

At somewhere like St V's we have a very well developed capacity to connect to three non-malignant clinics. At disease diagnosis we connect to our cancer patients very early in their disease trajectory, so we get a quite coordinated approach, but that would be a rarity in the system at the moment. One of our top recommendations in the clinical setting is that the models of palliative care certainly need to be reviewed, regenerated and redeveloped on best evidence.

**The CHAIR** — Sorry to interrupt, would you mind just bringing the microphone a bit closer, just for the benefit of Hansard?

**Assoc. Prof. BOUGHEY** — Sorry, I can talk a bit louder. Again, the recommendation is that the modelling of palliative care needs to be looked at and on evidence we need to be able to provide the sort of palliative care that people expect from that sort of modelling and our experience and evidence.

The other thing is the administration of that and the actual services. At the moment there is a disconnect — there are community-based services, there are small NGOs, there are big tertiary hospital institutions. With the sort of structural administration of those services, even though we aim for seamlessness, there is a lot of overlap and issues to do with the way that service is being delivered for the patient. Often the patient does not realise the work that has to go into connecting all the dots together for the service to be provided, particularly back into the community if it is needed and when it is needed. I think that was my initial presentation on our views on service delivery.

I am going to put my education and training hat on and to really say that for many years now there has been great development in trying to grow the profession of palliative care, palliative medicine, so specialist professionals in nursing, medicine, allied health and many other areas, but the reality is that baseline training of most healthcare professionals is very limited in the ideals of what palliative care is about and the process of palliative care. Still other than in the medical field, there is very little in the actual competencies around the training of allied health nursing that is mandated as a normal part of practice and training, so there is great variation and variability in terms of the ability of somebody to practise what we would see as palliative care in the reality.

A lot of that training has to happen postgraduate at the moment rather than undergraduate or in those training areas. Really there is some need for some national or state-based competency and credentialing framework. We find that unfortunately the training colleges are often slow to adapt. Particularly the medical colleges are quite slow to adapt to these sort of new changes, so somehow there have to be other triggers and mechanisms to see that people do have these competencies as part of normal practice. You would expect healthcare professionals

to be able to know how to manage a diabetic patient, take blood pressure and talk to somebody about discharge planning, but to actually get healthcare professionals to be able to talk about palliation, palliative care or what palliative care represents is still quite difficult, so I think our recommendation is certainly around that competency sort of based framework.

**Assoc. Prof. PHILIP** — I am talking to the next little bit. I think that there is an opportunity to really enhance public awareness around what it is to live and to die in the 21st century at the moment, and I think there is quite a lot of lack of understanding and there is certainly a lot of misinformation around what palliative care is, and therefore that also translates — forgive my acronym — to healthcare professionals, which means that people often engage very late if at all, because there is quite a lot of fear around, for example, palliative care.

So I think we would certainly recommend a systematic approach to public engagement, promoting a public conversation about what it might be like to die now, here and now, what that can mean — are there choices and opportunities, and what are the limitations on those? I think that could potentially enable us to change and frame the language around palliative care so that it is not something to be feared or just for the special — that it is actually just part of quality care for people with advanced illness. And that potentially, if we really can engage on this level, we could bring about meaningful paradigm change about what we expect our care to look like, what we expect for ourselves and therefore what we can provide. I think that that would not be care necessarily in and out of the acute hospitals when we have got an advanced illness. It would be something quite different, and I think that to be able to promote that in the public sphere is a great opportunity.

The other point I wanted to make is around research and investment in research funding. We know that there is an important evidence base that needs to be enhanced to ensure that the care that we deliver is of very high quality. We are working very hard, but we are struggling with competing for what is a very small research dollar going to palliative care. In cancer that is less than 1 per cent. In other diseases it is much less than that again, yet many people will die from these illnesses, so we would really advocate a systematic and sustained approach to build research capacity in palliative care.

**Prof. HUDSON** — Our final recommendation relates to euthanasia, and in our journal article, which you have a copy of, we are fairly explicit in outlining some of the areas we think require further consideration at this point in time. Some of those are listed on your handout, so I will not go over those, but I would like to highlight one in particular, because we think it is particularly important. Our conception is that amongst the community perhaps there is a view that many people with advanced disease or terminal illness have a desire for euthanasia. We have been collecting data in two large teaching hospitals for about 15 years now, and it shows that less than 1 per cent of patients referred to the palliative care consultation service actually request euthanasia. So this is not a common issue in palliative care. That does not mean that these patients should not get best care, should not get compassion and should not get all the best care possible, but I think it is worth acknowledging that it does not seem to be commonplace in practice at present.

Our recommendation would be to fully resource palliative care — Mark has highlighted some of the issues currently that are occurring from a service perspective — coupled with a systematic public engagement strategy and awareness strategy and importantly formalising training for all healthcare professionals involved in looking after someone with advanced disease. Virtually all healthcare professionals will be required at some point to care for a dying patient and family, and our concern is currently they are not getting the training they require to meet even the fundamental aspects of palliative care provision. So we might conclude there in terms of our introduction and our key recommendations.

**The CHAIR** — I might ask the first question. Not to usurp Mr Mulino's line of questioning, but, Mark, I just want to take you up on the point of the duplication and overlap you referred to. We have heard that evidence from other witnesses. In a practical sense, how can that be challenged, how can that be addressed? Because there is significant growth that needs to be — —

**Assoc. Prof. BOUGHEY** — I think, as I mentioned, somehow reshaping the administrative way that the modelling of palliative care occurs. Somehow there is a kind of a way of moving in and out of the system or sort of taking away the boundaries and barriers that, say, a hospital builds to a community and a community builds to a hospital.

An example I can very easily give you is we had a young woman recently, quite disabled by a particular cancer, again desire to be at home. She was ready to go home. We needed to get some equipment in the house, and so

to connect to getting that equipment delivered we would normally contact the community palliative care service from a hospital setting. We contacted them. They said that the patient actually had to be home first before they could then go and consult to get that equipment in the house. So we are already in this catch 22. This was a metropolitan Melbourne service and a very supportive family and patient, so they were patient. We had to then go through the process of getting a private contractor to come in and get the equipment in for a week before the palliative care service would then come and see the patient to actually then deliver the equipment we needed for this person, who needed the equipment.

So you get in these ridiculous situations. For us it is ridiculous, but for the patient it is just barriers to effective care. They do not understand all these sorts of things. So I think it is having a more streamlined service so that somehow the point of assessment that sees the needs should be identified irrespective of whether that is community, hospital or wherever. Somehow that need should be taken seriously already — that the assessment has been done and the recommendation has been done. The connectors should happen much more seamlessly. That was just a very, very recent example.

**The CHAIR** — Just to take that example further, if I may, was that an example of a hospital and then a healthcare provider in the community? What was the barrier that generated that?

**Assoc. Prof. BOUGHEY** — The barrier was the way that maybe the community service set its structures up to then integrate to the patient care at point of entry into their system. We could have rung another service if they, say, lived in a different suburb and there was a different community palliative care service. They may have approached it completely differently, in a very different way. They would have said, ‘That’s okay. We’ll meet the patient at home. We’ll bring the equipment out already. We understand what you need’. The variability is there across the different regions, so again we have to sort of second-guess a little bit, but we get to know our community partners and they get to know us. So they kind of know how we need to work with those services, but sometimes the care is urgent and so the difficulty for this patient was that we knew it was urgent. There was a window of opportunity, so the reason we went down the path of the private contractor was because we knew it would solve the problem much more readily, but we should not have to be doing that sort of level of intervention when the two systems are not quite talking appropriately or working together.

**The CHAIR** — And presumably sometimes that situation of a private contractor is not available, for example, and the patient would stay in hospital.

**Assoc. Prof. BOUGHEY** — Yes, and again it is not all about beds. They were quite happy to stay. They were a supportive family. We were expecting a prognosis of maybe a couple of months or so, but really if the urgency is there, we then question it. This person may not have died at home when they expected to die at home. It would be constrained by the system. But again if they are in a different suburb, a different service, it may have actually been a very different outcome. It is almost like there are barriers in different services as to how that outcome is going to play its way through. We cannot guarantee that patient X in suburb Y is going to get exactly the same as the patient in the other suburb for the same situation or occurrence.

**The CHAIR** — Which makes it challenging for us to make recommendations that can address these issues.

**Assoc. Prof. BOUGHEY** — Yes.

**Assoc. Prof. PHILIP** — Could I perhaps chip in? At the moment a lot of this is around funding and how the equipment is funded based on different assessments and things. I am not the creative thinker in this way, but if there were some capacity for the funding to follow the patient in some way, then that would perhaps transgress some of these barriers. How that would look exactly I am not sure, but as a concept it seems to make a lot of sense.

**Mr MULINO** — I have a couple of questions. The first one relates to research, and you have noted the very small proportion of research that goes into palliative care as opposed to other areas of health service provision. I am just wondering, are you talking primarily there about, for example, peer-reviewed, cutting-edge health research to improve methodology, or are you also talking about social science research which might look at ways in which we can improve social awareness of palliative care in the community? Is it a bit of both, or is it primarily about the former?

**Prof. HUDSON** — It is both, ideally. We need to undertake the health service research to work out what are the best systems and models of care that should be implemented to ensure there is quality care for patients and families, and we also need the clinical trials to discern the best drugs and dosages of those drugs to ensure best symptom management as well, and we need the interventions that look at psychological and social support for the patient and family, and research that looks at interventions to ensure those patients and families who are at risk of poor psychological outcomes are picked up and cared for appropriately. In keeping with our recommendation around public health engagement, I think that should be coupled with an evaluation component to discern the kind of impact of that. So it is probably both and more. I do not know if you want to add to that, Jenny.

**Assoc. Prof. PHILIP** — No. I agree.

**Mr MULINO** — Are there countries where the funding for research is more balanced?

**Prof. HUDSON** — In terms of palliative care I would say that this is an international issue. My knowledge of palliative care spend proportional to cancer spend in the UK and the US is that it is similar to Australia — that is, less than 1 per cent. It seems illogical, because approximately one in three people will die of cancer, approximately, yet less than 1 per cent of the cancer research dollar is going to palliative care.

**Assoc. Prof. PHILIP** — Can I just add to that? We have come from a presentation where this exact issue was discussed, and one of the thoughts behind some of this is that people just do not see that dying is part of their purview. You go to the cancer funding institutes and, ‘Well, we’re not doing dying; we’re doing cure’, and you go to the cardiology funding institutes and, ‘That’s not our area’. It does not really belong anywhere, and perhaps it is around this notion of living well with the illness — and it comes back to that sort of public engagement thing that we were talking of — and how we can best promote that. Perhaps the research funding is also tied up with that.

**Assoc. Prof. BOUGHEY** — Again, we had a seminar yesterday — a big public forum yesterday — where we spoke about these issues of the public perception that palliative care is all about just the dying and is not about the one, two, three or whatever years that you connect with the patient along that trajectory. Someone like Jenny in her outpatient clinic in the cancer centre will see people for a number of years, sort of walking hand in hand, and so the assumption the public make is perceptible, which is understandable, but it was interesting to see the reaction in the audience when we were talking yesterday — a sort of palpable relief when they heard about some of the things that palliative care should be able to do and also that the research demonstrated some of these things. It was sort of agitating for a bit of public change — that they are the ones that need to drive the sort of change for us.

**Mr MULINO** — I have a question on your comments on euthanasia and assisted suicide. You have made the observation that a relatively small proportion of people actively request one of those outcomes, and I think that is in line with other professionals — not necessarily all professionals, but many of the professionals we have heard from in the sector. The fact that it is a small proportion, as you have observed, does not necessarily mean that reform is not worth exploring, but I guess I am just interested in your views on that small proportion. What are your views on the capacity for a well-funded palliative care system to provide symptom relief and, say, psychological support where that is an issue? Do you think that is strong even in that small proportion of cases? Is it improving? I am interested in your broad observations on that.

**Prof. HUDSON** — Currently I would say as a general statement that I am concerned, I think, if a particular person requests euthanasia and was linked in with a gold standard palliative care service that had a strong multidisciplinary team, that had an educated professional team involved in supporting them, then I think that would be the exception. We know that most Australians who qualify for palliative care, so to speak, are not getting access to the care that they need — the educated care that they require and should get. So I am concerned currently in the current system that that person may not necessarily get the compassionate, professional care that he or she deserves.

**Assoc. Prof. PHILIP** — I am not sure that perhaps behind your question is: if in the rolled gold palliative care service, would there still be that small proportion who request euthanasia? Is that what you are asking?

**Mr MULINO** — I suppose there has been a range of perspectives put to us, and there has been a thought from some that where somebody might have this request, in some instances there might be scope, with a

well-funded and multidisciplinary approach, to help them work through some of the issues that might have led to that request and that that capacity might be improving over time.

**Assoc. Prof. PHILIP** — I mean, I think that that is the case. I do not think that that would mean that there are no people who would request euthanasia because, as you would have heard, it is not necessarily around pain or symptoms or other things; there are often other sources of suffering that are perhaps not immediately amenable to what our traditional health systems offer and require much more of a community and societal response.

**Assoc. Prof. BOUGHEY** — Can I also add that I think when you do find services that seem to walk together, so you might have clinicians in their subspecialty group or their chronic disease group walk hand in hand with palliative care, you start to address many of the issues that percolate up. But when the referral process means there is a disconnect — the specialist does not see the value of palliative care; they just see it as kind of end-of-life at the dying time — there is a multiplicity of issues. And it is not just the issues of the patient dying; it is the issues of the carers, families, mentors. There are all sorts of things that come into play, and often people feel very isolated where they could have actually felt much more connected and their voice could have been heard. A lot of these issues are sort of walked through.

Even though you get delayed referrals, I think our clinicians — and I am speaking from the training doctors now — are getting a lot more buy-in for good communication skills training. We are starting to see hospitals take an interest in having a more systematic approach. You can see it, I think, in the quality of the trained doctors — that they are approaching patients in a new and different way — and I think that does make a difference. Then that needs to translate across the board. You can still take the opportunity to talk to people about the issues and burdens.

I was telling a little story just before we came in here. I do clinics out in Shepparton and Wangaratta, and the farmer guy did say to me he was really thinking seriously about ending his life by fixing his car up to the fumes and things. I just talked to him and had a very simple conversation about what was his sense of burden, what were his issues and some very simple, basic stuff that he wanted some reassurance around. He looked at me and just said, ‘Maybe I won’t turn the engine on today’, just after our conversation. That was a signal that he just wanted to be heard. It was very simple. It was not the best drug; it was not anything. It was just having an effective conversation at the right time.

**Prof. HUDSON** — I think, to add to that and following on from my remarks before, is the concern that if somebody raises those issues about potentially wanting to die sooner rather than later, if that happens in the context of specialist palliative care, well you have got a team who can respond and unpack that and try to discern what led to that request or that desire, because sometimes it might just be that that person is having a rotten day. It might be that they have got some intractable symptoms that need to be addressed, or it might be a legitimate request and this person has considered everything and still wants to go ahead and end his or her life sooner.

The worry is that if it is a patient who is not in a specialist palliative care system, then they are going to be looked after by somebody who does not have the fundamental communication skills in how to respond to an acknowledgement like that. A nurse, for example, might just say, ‘Oh, it’s illegal in Australia’, or avoid the conversation and not take it any further, and that is not good care. That is what we are really worried about — the lack of communication skills training in addition to broadening the skill base of symptom management and psychological and social support as well.

**Assoc. Prof. PHILIP** — I would agree. I would just add that such a request, either tentative or very firm, is a good opportunity to talk and to find out what the concerns are. There may be simple things that can be allayed in some way or there may be deeply sustained wishes to hasten death, and all of that needs to be on the table with one human being to another.

**Ms PATTEN** — It is a really interesting conversation. I read your paper with interest, and it was very thoughtful. But just following on from the notion that someone who is thinking about end of life and thinking about wanting to end their life for whatever those reasons are, you mentioned that you felt that it needed to be a palliative care specialist who should be having that conversation with them because they are able to provide more information about palliative care treatments. I guess some of the models that we have been looking at around physician-assisted dying would be around two doctors — in Oregon, for example. I know in your paper

you mention Oregon. To go back to my question: do you think that all doctors should have a competency level in palliative care, so that when you talk about a national competency and credentialing framework that is every single GP to the emergency nurse?

**Assoc. Prof. BOUGHEY** — I would say yes, it really is. It is really trying to get people to see that this should be a standard of care rather than a specialist care in a sense. The specialist network is there to support the more generalist kinds of people, but there really should be competency-based care in the medical field from the GP right up to the best physicians and so forth. We often talk about this: in the public hospital systems, where you have what we call scrutinised care, we are sort of judged by our peers and we converse and it has got a holistic sort of frame around it so these conversations can occur. But in the kind of unscrutinised care, where it might be a private practitioner or a solo GP or a nurse practitioner who is there, they need to have that competency built into their system already so they are aware of the appropriateness of those sorts of discussions and so forth.

**Ms PATTEN** — Just following on from that, because I think that is a really interesting recommendation and we have certainly talked in the past about people needing more training, particularly GPs in their practice, one of the other things we had heard is that if physician-assisted dying is on the table, so it is available, that enables the conversation. So when someone might want to talk about ending their life but we know that that is not legal in this country, do you have an opinion on that: if physician-assisted dying is on the table, that actually enables a more fulsome conversation with the patient at end of life?

**Assoc. Prof. PHILIP** — I would suggest not necessarily. I think that a good conversation can be held almost suspended from the parameters, and much of medicine takes place in the intimacy of the consultation. I think that in that sense really the law does not frame what one says, and a good conversation can occur and does occur in many ways without having to have a change in the legislative framework. I think, on the thing that Peter said around the issue about shutting down conversations because it is not legal, I think that those practitioners will probably shut down the conversations by some other mechanism anyway because it is uncomfortable. So I think that the piece of work that needs to be done is to facilitate clinicians to stay in that space — to be with that person and be willing to explore. It may be an uncomfortable thing, and you need to be able to explore with the person: what is it about their life at the moment that is causing this request?

**Assoc. Prof. BOUGHEY** — Can I just add as well that I worry personally that our health system at the moment has created an environment where intervention is seen as care, so interventional care is good care — treatment, chemotherapy, radiotherapy, disease intervention, surgery. Sometimes I wonder if a legislative framework that would allow assisted suicide just gives a clinician another intervention, so instead of the oncologist or whoever thinking, ‘We need to engage palliative care to bring in this supportive kind of framework or supportive care’, it is easier to offer another intervention, and the intervention is physician-assisted suicide. That is a concern from my perspective.

**Ms PATTEN** — Yes; it is just that I have never heard anyone say that before.

**Assoc. Prof. BOUGHEY** — Yes, but it is, because you often do see that, that there is this kind of — rather than having a difficult conversation, we will circumvent that by referring them to the gastroenterologist for a scope or we will refer them to the haematologist for — —

**Ms PATTEN** — Yes, I appreciate that.

**Assoc. Prof. BOUGHEY** — So that is a sort of overarching concern — that I think doctors may not take the challenge up of becoming better communicators; they may just see it as an easier pathway to just — —

**Assoc. Prof. PHILIP** — I think we are very focused on doing, and these are hard spaces to be in. I think that sometimes the hardest thing is to stop and have a conversation. Legislation or no, I do not think it would change that willingness to have a conversation, and that is what we need to change and that is why we need to empower people to say, ‘Actually, I want to talk about this; it is not good enough to send me off on another round or chemotherapy’ or just ‘do this’ or ‘do that’. It is actually something that we need to explore.

**The CHAIR** — I have a question following the piece you wrote. In the conclusion, if I could just quote it, it says:

The overwhelming majority of justifications for EAS focus on the individual who desires this pathway, while the potential impact on society, institutions and healthcare delivery have received far less attention ...

We have heard evidence from people who have made assertions that a voluntary euthanasia scheme, or however you describe it or however it is enacted, does have a corrosive effect on institutions and healthcare delivery and the health system and on the broader society. Did you have any evidence you could offer from other jurisdictions that points to that?

**Assoc. Prof. PHILIP** — Can I offer a personal anecdote — well, not a personal anecdote but I guess a lot of experience at the clinical coalface — which is that certainly a couple of times a week I would have a patient for whom the prescription of opioids carries great fear, and they will not take them or someone will not let them have them because this might well hasten their death. I am very concerned that if there is a sort of a change in the milieu in which I practise, that will be even greater, that concern. I think this is actually sort of an unspoken effect that clinicians are concerned about — that if euthanasia becomes legal and that baseline changes, this could mean that some people do not have access to medications which would otherwise be very helpful.

**The CHAIR** — I appreciate that, and I appreciate your coalface experience. But is there anywhere you can point to from other jurisdictions overseas that have actually had this, in fact as you referred to, ‘society, institutions and healthcare delivery’?

**Prof. HUDSON** — I think part of the, I suppose, subtext of that and the message we are trying to convey is that we think there needs to be wider public engagement about the pragmatic implications if we went down the pathway of legalisation and that some of the implications within hospitals, within the community and also within palliative care delivery as well do not seem to have been considered at length and some other questions seem to be unanswered — what is the impact on family, the longer term impact on family? What is the longer term impact on doctors, if they were to be involved, if we went down this pathway? So I think it was in reference to that that we were trying to convey that point, and perhaps it did not come across as clearly as we had hoped.

**Mr MULINO** — I have just one quick one. Just going back to education and training, and this has been an issue that has been raised a lot — the fact that it is patchy, as you say, and there are gaps in capacity and people’s competencies. Is what you are suggesting, in a practical sense, mandatory elements of undergraduate courses and also mandatory CPD requirements?

**Prof. HUDSON** — Correct.

**Mr MULINO** — Is it a combination of those two?

**Prof. HUDSON** — Yes, and credentialling. So as it stands at the moment for palliative care specialisation it is only possible in medicine and it is only mandated in medicine, so if you can become a specialist doctor, there is a pathway for that and a credentialling process. Yet we have got a lot of specialist palliative care providers in Australia, and many of the other workers may not necessarily have formal qualifications in palliative care. There is a national initiative trying to embed palliative care across curricula. That is a terrific initiative, but I do not think it addresses everything so there needs to be some postgraduate training as well. So it is trying to get the individual disciplines to credential palliative care, recognise it as a speciality and even consider having some fundamental training as being core to all healthcare professionals. That would be terrific so that people can have the capacity to have the appropriate conversations, they can treat basic symptoms, they can provide fundamental psychological and social support and refer on to specialist palliative care providers where necessary. We are not expecting everyone to have the advanced skills but just the fundamental skills in be able to care for a patient and family affected by an advanced disease.

**Ms PATTEN** — I suppose in reading your paper I was struck by that patient autonomy or the autonomy of the individual did not seem to come into it. Is there a point where a patient can say no and say, ‘Enough is enough’? Or do you think that they should let nature take its course and continue with palliation and continue with the great palliative services that are on offer? Is there a time when a person can say no?

**Assoc. Prof. PHILIP** — Say no to?

**Ms PATTEN** — Say no to — ‘No more treatment’ or even be more proactive than that and say, ‘Actually, I’d like to say my goodbyes now. I know that I can live comfortably for another three weeks or I know that I could live comfortably for another week, but I choose not to’?

**Assoc. Prof. PHILIP** — Yes, I guess people do — can say that, do say that. Not very often.

**Ms PATTEN** — No.

**Assoc. Prof. PHILIP** — So we often help people negotiate stopping life-prolonging treatments, helping them make decisions around things that may be burdensome or may be prolonging their life. And I understand that is not what you are asking.

**Ms PATTEN** — No — —

**Assoc. Prof. PHILIP** — But I think that is part of the bread and butter of thinking about, ‘What are my values, and what is important to me at the moment? And how can I best navigate the health system to serve that, to serve those values and achieve them?’. At some point, then, if someone does not want to live anymore, then we have the conversation that we talked about, and sometimes we sit with that. I think that clearly that person is not on their own, so their family and those people need to be engaged with, and sometimes it is not soluble. People have potentially spoken at this forum about sedation. I think it is very rare to use sedation, for example, in that situation because it is a very rare situation. I am not sure if the others want to comment on that but ultimately sometimes in medicine there is a limit to what one can do, and I guess the question of where that limit is drawn is ultimately up to the law and the practitioner and the patient.

**Ms PATTEN** — Yes.

**Assoc. Prof. BOUGHEY** — Sorry to interrupt, Jenny, but I think there is a responsibility for the majority of healthcare professionals and specialists. Cancer treatments have changed so much in the last 5 to 10 years that the trajectory for cancer and the evolution of the individual cancer a person has now really can become much more burdensome because the disease eventually progresses in a much greater way, into different organs, affecting the brain and so forth. Someone mentioned yesterday at the public forum getting on this cancer treadmill and they do not know how to get off it. So there are these expectations that you have to keep being treated when the patient inside is saying, ‘Maybe this is the time I should be starting to think about other things’, because the cancer doctor may not necessarily be having a conversation about the possibility of stopping. It is the expectation of continuing treatment.

So the person ends up in this very difficult, burdensome environment, down the track, maybe not by their decision-making, but maybe they could have decided to pull away from that sooner rather than later. So the decision-making is not just around the dying time; it should be around the whole continuity of care and what you are expecting to get out of that care. That is where the conversations get very difficult and very individualised. Sometimes we get feedback from our patients that maybe the other specialists are not giving them the ability to have those conversations.

**Ms PATTEN** — Yes. Just quickly following on from that, in recognising that St Vincent’s Hospital comes with certain values, very long-kept values, does that affect this conversation about patient autonomy and about physician-assisted dying within a structure such as St Vincent’s that has those deep-held values?

**Prof. HUDSON** — Being a Catholic institution, St Vincent’s position is quite clear. It does not condone euthanasia. I think it is important to acknowledge that even within the specialty of palliative care there are different viewpoints about euthanasia, so it is not palliative care versus euthanasia, which is how I think sometimes it is portrayed in the media.

**Ms PATTEN** — Yes, that is right. I would agree with you.

**Assoc. Prof. PHILIP** — I would also add that all of us have worked in secular hospitals or non-affiliated hospitals, and my practice is no different. The conversations are the same and are probably universal, I suspect.

**Assoc. Prof. BOUGHEY** — Yes, and I think, again, the diversity of where we work — regionally, rurally — it is the same work, the same conversations. I think certainly, if anything, the hospital at St Vincent’s highly prioritises palliative care, so it allows us to have a very strong palliative care team, whereas other

hospitals may not have such buy-in. So the benefit is not necessarily about not having euthanasia, but the benefit is that we are allowed to practice palliative care quite widely across our hospital.

**The CHAIR** — Unfortunately we had better leave it there. To Peter, Jennifer and Mark, I thank the three of you for your time, for your candour and the expertise you bring to the committee. We greatly appreciate it.

**Witnesses withdrew.**