

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Subcommittee

### Inquiry into end-of-life choices

Melbourne — 15 October 2015

#### Members

Mr Edward O’Donohue — Chair

Mrs Inga Peulich

Mr Daniel Mulino

Ms Nina Springle

Ms Fiona Patten

#### Staff

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#### Witness

Associate Professor Peter Hunter, Chair, Victorian Clinical Leadership Group on Care of Older People in Hospital.

**The CHAIR** — I would now like to welcome Associate Professor Peter Hunter, geriatrician and director of aged care, from Alfred Health. Welcome. I just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and is further subject to the provisions of the Legislative Council's 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, and transcripts will ultimately be made public and posted on the committee's website. We have allowed 45 minutes for our session this afternoon. I would like to again thank you for being here, and we look forward to hearing what you have to say.

**Assoc. Prof. HUNTER** — Good, and thank you for giving me the opportunity to speak. I am actually speaking, I guess, on behalf of the clinical leadership group on the care of older people, which I chair as one of the most senior geriatricians in Victoria. If you are not aware of that group, that is a group that was facilitated by the Department of Health several years ago, and it really is made up of senior clinicians, academics, health administrators and consumers who sort of have a burning passion about improving the care of older people in the health system. That has been the driving force in terms of the work we are doing, and we thought it was important that we put a collective view forward to this committee.

As you said, I am a geriatrician. I am the head of aged care at Alfred Health, and just by the by, end of life is something that all health services are very focused on at the moment. In fact I am chairing a working group of the most senior clinicians at Alfred Health, and we are looking at developing a much more strategic approach to dealing with end-of-life issues for all the people who come in contact with Alfred Health. I know many a health service are doing the same work, so I am hoping that what you are doing sort of dovetails with some of the thinking that is evolving in terms of what is best practice around end-of-life care.

I guess where I am coming from is that whilst there is a focus on physician-assisted suicide, to my mind the focus on that is actually a symptom of, I think, some broader issues that need to be addressed. I think that is the challenge for all of you in terms of thinking of things a little bit more broadly around improving end-of-life care. In my work as a geriatrician I am dedicated and focused on providing optimal quality of life for older Victorians, and one thing I see, and many geriatricians see, is that older people are very concerned around issues around end of life. They worry and have fear in the last days of their life that they will still suffer, that they will be tortured by doctors and by the healthcare system and that their death will be institutionalised. Very much that is the sort of thing we need to protect against.

Many of us are influenced by a very influential article in the *British Medical Journal* from 2000 on what actually constitutes a good death. I think that is a very good point of reference in terms of the way clinicians ought to be thinking about end of life, and that is that people ought to have control, they need to be symptom-free and they need to have the right to die in the right environment with the right people around them and have all their needs met, physical and spiritual.

I guess one of the important things is that we in society think of death as being a bit of a surprise, but it is seldom a surprise. In this day and age most people actually die in the setting of a trajectory of illness in terms of whether it is a chronic degenerative disease or whether it is a chronic disease which is continuing to progress. So most people die with a context of ill health before them — not all people, but many people do. In fact there is evidence that if you were to ask the question of doctors of their patients, 'Would you be surprised if this patient died in the next 12 months?', that is actually a remarkably valid tool to predict that person's death. What that tells us: it does not tell us that we ought to be therapeutic and nihilistic about these patients, nor to be ageist, but it tells us that there is opportunity with 12 to 18 months to start to have the right sort of conversations with people so they can prepare for what lies ahead of them. They have the opportunity to talk to their loved ones about what they want and what they do not want and to talk about their values and their preference, and that is a lost opportunity in the health system as it currently stands. If you look at the international literature, there are rays of hope, and I think we need to look to those in terms of what we do in hospitals, in health services and indeed across the Victorian community.

In our submission there are a couple of themes that come through: one is the importance of communication; secondly, the importance of community discussion; and thirdly, the fundamental and absolute importance of the adequate resourcing of palliative care in the healthcare system. In terms of communication, I think there are a couple of elements. No doubt you will have had some presentations around advance care planning, and there is

no doubt that that is absolutely pivotal and central to moving forward in terms of an approach to end-of-life care. But we do have a problem in this state despite having a very good strategy document, and that is that there is no consistency around advance care planning, and indeed patients are not central to that process.

In our mind advance care planning ought to be something that is patient controlled in some shape or form. There needs to be consistency with documents. We need doctors who work in different hospitals and different settings to actually understand advance care planning and to understand, if they have something in front of them, what that actually means. There is no way that happens at the moment, and doctors worry all the time about version control: 'Is this document one that was written yesterday, the day before, the day before that?'. We think having the patient control is actually central to solving that fundamental problem that worries many clinicians.

The second issue around communication is actually communication skills, because fundamentally there are many doctors who do not have skills around breaking bad news, about articulating appropriate care or indeed giving honest prognostication, and that is a fundamental skill that is not taught in medical school and not really taught in hospital in terms of training. To my mind it is almost like advanced life support or CPR training — it is something that doctors, nurses and other clinicians ought to be doing on a regular basis. It is a core competence that in this day and age all clinicians should have.

The third thing around communication for us is the fundamental importance of medical enduring power of attorney. In some respects we have got some of the legislation there. We had a long discussion around this as a clinical leadership group, and it is our belief that a hospital admission is a fantastic opportunity to put in place a medical enduring power of an attorney if that is not there. We would go so far as to argue that it is almost a key performance indicator of hospitals around end-of-life care to ask and ensure that patients have appropriate medical enduring power of attorney.

The last thing around communication that we think is important is communication in the community. I think there needs to be more discussion in the community about what we realistically want out of the health system. There are lots of myths around what health can do. We are driven by watching all the sexy medical dramas on television — and everyone who has a cardiac arrest survives that — and that is not the reality in the real world. People have unrealistic expectations about what health can provide, and we need to actually address that.

But perhaps more fundamentally — and this is where I really like to push you all — is that there are some models internationally which I think are some rays of hope. There is something called the Conversation Project in the US, which is not driven by government and not driven by hospitals or the health system but is a grassroots movement to allow people to normalise death and for there to be discussions in the community about what people want as they get towards the end of their life — so having discussions with Mum and Dad around the kitchen table. By having those sorts of discussions we can really avoid some of the sticky things we face when people come into hospital and think, 'Crikey, what the hell do we do now? We do not really know what this person would actually want'.

I guess the other key theme for us is around palliative care, and it really must be appropriate resourcing of palliative care. People want to die at home, but most people die in hospital. There are two sets of issues around that. One is that clinicians do not have the palliative care skills that they should. All clinicians should have fundamental skills in palliative care. As a geriatrician I say that most of the people in hospitals are old, so therefore people have to have geriatric medical skills. I would also argue that all clinicians need to have palliative care skills. Building upon that we really need to invest more heavily both in hospitals and in the community on palliative care. In fact I think we need to reimagine palliative care. Palliative care is often thought about as giving up, but actually palliative care is a form of escalation of care. It is as much of an escalation of care as someone going to intensive care. We know now that palliative care does not divorce someone from having active treatment at the same time, so this idea that palliative care is giving up is wrong. It is its own form of escalation, and by escalating people to appropriate care you get to relieve a lot of the worries that people have.

The view of the clinical leadership group is that if we were to adequately address people's issues, if we were to actually give people palliative care skills, then we can address almost all the issues people worry about in terms of the system torturing them towards the end of their lives. For that reason our group collectively were not supportive of physician-assisted suicide and thought that really the way forward is in actually understanding what people want, making sure that we actually increase and improve the quality of conversation of death in the

community, and skilling clinicians to be able to address the sorts of symptoms that people worry about that have not been adequately treated in the healthcare system as it currently stands.

**The CHAIR** — Thank you very much, Associate Professor. I will start the questioning just by asking more about the Conversation Project in the US. Can you give some detail about that? It sounds like an innovative —

**Assoc. Prof. HUNTER** — It is actually something that has sprung up in a number of states in the US. It was championed by a Pulitzer Prize-winning author whose mother died in fairly unpleasant circumstances. This author decided, ‘I cannot let other people go through what my mother went through’, so she started to think, ‘How do we actually address this?’. She spoke with other like-minded people, and the Conversation Project came out of that. The worry was that if this is driven by government, there is always the question of, ‘This is about resources’, or if it is driven by hospitals, ‘This is about resources’. Really, this has been a grassroots movement that is driven by people who are worried that they are not being listened to and that there has been no opportunity to have the sorts of conversations you need to have around end of life.

What is really clever in the States is that there has been a bottom-up and a top-down approach, so if we are going to allow people to have these conversations in the community and encourage people to have discussions around the dinner table, with Mum and Dad speaking with the kids about what they want as they approach the end of their life, we actually need a health system that responds to that. So the Institute for Healthcare Improvement has developed in parallel a program called Conversation Ready health services. If people have these conversations, they come into hospitals, and the hospitals and the health system need to be able to respond. You have had that conversation, and this is what you want. We understand that — we are going to make sure that your wishes are heard, and we are able to address those wishes in terms of what your preferences are around treatment.

**Ms SPRINGLE** — Thank you. That is fascinating. You talked about communication skills and the lack thereof within the health industry. We have heard that from a lot of people. What in your view is the block to rectifying that? Is it through education, through the degrees for people who are studying medicine? If it is such an acknowledged problem, why is it not being addressed?

**Assoc. Prof. HUNTER** — Universities move slowly, and they are, I guess, captured by vested interests about what needs to be covered off in medical schools, nursing schools and the various allied health schools, so it has never been a particular priority. The amount of teaching around palliative care, for example, at Melbourne and Monash is minuscule. When I taught at Melbourne University, there was a two-week block of palliative care training in five years of medical training, and it is one of the most fundamental issues. It has never been thought to be particularly important.

I have to say that things are starting to evolve now. It is better than it was. We still have a long way to go, and part of the problem is that the role models in hospitals are senior clinicians who have not gone through this, so it is all very well to train up the junior staff, but they actually then respond to the way they see their seniors acting, and some people are better than others. That is why I think medical schools, nursing schools and physio schools need to focus on this, but actually there is a responsibility for hospitals to do this sort of thing as well and develop communication packages that actually allow you to have some really difficult conversations with people. There are some pockets where that is happening well.

The Palliative Care Network, for example, had an advanced communication course that it ran on a regular basis. I did one of those in the past. It was a fantastic thing, and I encourage people to do it as well. At Alfred Health we have developed a package of training for junior medical staff, and our aim in the next 12 months is to have all our junior medical staff go through that training package. We get great evaluation in terms of feedback from the staff who have gone through that, and this is something that I am hoping that if we get it right at Alfred Health, it will roll out to other organisations as well.

This is not a one-off thing. It is a bit like advanced life support. You just cannot have a one-off training session on communication and tick that off as being done. It is something you have to work at and continue to work hard at. It is not an easy thing to do. It is quite labour-intensive to do this.

**Ms SPRINGLE** — In your opinion is there anything that could be done to hasten that sort of culture change within the industry?

**Assoc. Prof. HUNTER** — There are a couple of things happening at the moment. There is an end-of-life strategy that is coming out of the Department of Health and Human Services, which we very much support, but that sort of piggybacks on an approach that a number of health services are taking. The CEO at Alfred Health, Andrew Way, asked me to convene a group to think about how we can treat old people better towards the end of life, and communication has been a critical component of that.

Speaking to colleagues from other health services, they are all adopting a similar approach. In fact I have a meeting with like-minded clinicians right across Victorian hospitals. We are meeting in a week's time to do a bit of sharing around what we are doing. What I will be bringing to the table is, 'This is the communication course we have developed. We are happy to share what we have learnt and for you to be able to do that'. I do not think we ought to be too pessimistic. I think there are opportunities that lie ahead, and they lie in the support from the Department of Health and Human Services, and indeed from the national accreditation body, with draft 2 of the national standards around health. There is going to be something of a focus on end-of-life care, and by necessity communication will be part of that. So there is some cause for optimism, I think.

**Ms SPRINGLE** — On a different issue, you talked about advance care planning and the lack of consistency around that. We have heard from a number of people who are not supportive of something that is mandated. If it was not to be mandated, if advance care planning was not to be something that was compulsory, I suppose, how do you think it could be encouraged so that it becomes more of a standard practice for people before they get to that critical stage?

**Assoc. Prof. HUNTER** — It is the communication. It is actually normalising discussions around end of life. It is clinicians being attuned to the fact that someone is entering the last 18 months of their life and really having those difficult conversations. We actually have to talk about this. We cannot not talk about it. One of the things you can do is implement an advance care plan. We actually had a lot of discussion in our group around whether or not advance care plans should be mandated, and there was a strong feeling that they ought not be mandated. But everyone has to be given the opportunity to have an advance care plan. If people do not want to have one, that is absolutely fine, but we have not got to that base yet. Most people do not know about advance care plans. Most people are not offered them. We are a long way from being at the place we should be, I think.

**Ms PATTEN** — Thank you, Doctor. Just following on from Ms Springle's question, I noticed that Alfred Health made some recommendations about advance care planning and not necessarily mandating that they take place but making them somewhat binding in being respected. Would that be the position of your group as well?

**Assoc. Prof. HUNTER** — What we are trying to get to there is that I guess what we need to know is what the patient's perspective is, what their choices are, what their preferences are. You need that first up. Then we actually have to interpret that within the prism of what the clinical information is. Our view is that they ought to not be binding, but we ought to work towards implementing what that person wants, unless there are mitigating circumstances which actually call into question what has been put forward.

I guess there is lots of debate in health about how specific advance care plans are. I think we are increasingly of the view that the most useful advance care plans are not getting down to specifically, 'I do want this, I don't want that, I don't want an IV cannula in my left arm but I'll have it in my right arm, I'll have this tube but I won't have that tube'. That is not particularly helpful, because you can never cover every eventuality. But actually allowing people to articulate their values, their general preferences, what they want out of their life, that is actually very useful then in terms of determining what the next treatments might actually be. Certainly in my role as a clinician I find them very useful in terms of helping me guide treatment.

I have to say I was on ward service at Caulfield Hospital last weekend, and it was an absolute blessing when I was doing a round and I had a patient who said, 'Oh, by the way, I've got an advance care plan'. We sat there and we read it and it actually gave me absolute clarity about what should happen in the eventuality of X, Y and Z happening. It is extremely, extremely beneficial.

**Ms PATTEN** — And rare? Is it rare for that to happen?

**Assoc. Prof. HUNTER** — It is rare, but not as rare as it used to be. It is changing, but I think the opportunity there is to needle things to move it forward. As I said, I think that advance care planning's future lies in the patients having control of them and then being the holder of the true version, rather than the approach where individual hospitals have them in their records and, you know, 'Is this the current one? Would they have

changed their mind since then?’ I will know with confidence. If someone hands me something saying, ‘This is the advance care plan that I currently have’, that I can work on that. I will not be worrying, ‘Oh, it’s six months ago, have they changed their mind? Is there another one that I’m not aware of?’, et cetera.

**Mr MULINO** — Thanks very much for your submission and also for giving evidence today. I note you are arguing in part for increased resourcing for palliative care, both in the hospital environment but also in the community environment.

**Assoc. Prof. HUNTER** — The good thing is I do not actually come from palliative care, so I do not do this from a point of view of vested interest. It is really more that I see, sitting alongside the services that I am responsible for, this is the crying need.

**Mr MULINO** — I found your call for resourcing credible even before knowing that, so it is even more credible now.

**Assoc. Prof. HUNTER** — Good.

**Mr MULINO** — I guess I am also interested in your statement that palliative care is not about giving up but it is about an escalation of care, if anything. I suppose just knowing what the government’s task is, and it does not matter who is in power, the health budget is a very large part of overall expenditure, and it is under great strain. Clearly this is one of a number of areas where there is a very justifiable case for increased resources. It seems to me that that case might be able to be made quite compellingly if one looks at the overall, holistic costs of the system, particularly a lot of the things you talk about in relation to improved communication and discussion. A lot of people seem to be getting treatments which they do not necessarily want, which are often very resource intensive. Really a lot of what we are talking about, to my way of thinking, might be about shifting resources from one part of the system to another at the direction almost of patients, who we are not listening to necessarily enough at the moment.

**Assoc. Prof. HUNTER** — Absolutely. One of my mantras as a geriatrician is: the worst place for older people is in the hospital system. We actually do harm to older people when they come into hospital. Older people who come into hospital are at high risk of iatrogenesis. We give them hospital-acquired infections, they fall, they become confused, they develop urinary incontinence. The best place to treat people is not in hospitals but in an alternative setting. Home-based palliative care, hospice care, really is a much better way to treat people. What is more, it is actually much more cost effective.

I actually have just returned from the Institute for Healthcare Improvement’s international forum in Hong Kong, where Don Berwick spoke. He is the guru of safety and quality in the world. He had some very strong messages to make, and perhaps the strongest one is: we actually do not need more in health. We have got enough. We have just got to deal with the waste. In the US he calculates that there is 35 per cent waste in the system. To be honest that is probably, in truth, what happens in this country as well. There is a lot of waste because we do not direct our care the way we should. We have got the wrong models. Focusing on cheaper, person-centred models outside the hospital, which includes palliative care, is the way to move forward. If someone has got to come into hospital to die, that is a really bad outcome.

I will make it personal for a moment. I can relate the experiences of my wife’s family. Her father died with cancer, and he was in hospital. That was a sad affair in a major tertiary teaching hospital. We did not want that to happen. When my wife’s mother died she had Alzheimer’s, dementia, and she was in a nursing home, and there was a collective decision that we would treat her in the facility with the support of services. That was almost a life-affirming end to her life, surrounded by the people she loved in a quiet environment. There is the contrast, I suppose, and there is a lot we can do to ensure that we do better than having people in hospital when we have got better models that we can develop and implement.

**Mr MULINO** — Is there any evidence, whether it be case studies or other kinds of evidence — and again, whether it is here or from international experience — that might be relevant to our considerations, particularly in relation to better resourcing parts of the palliative care system?

**Assoc. Prof. HUNTER** — I know the literature around geriatric medicine, but in terms of specific palliative care, I could not give you the literature. It is certainly not something that I am particularly familiar with. I am sure my palliative care physicians have it up their sleeves.

**The CHAIR** — If I may, Associate Professor, you spoke before about a fear of institutionalised death, and further to Mr Mulino’s point and your response, is communication the key to perhaps delivering the outcomes for patients you described for your mum — giving them the options at an early juncture, explaining to them the choices and working towards their preferred outcome?

**Assoc. Prof. HUNTER** — Absolutely, and that is at the heart of it really: good communication, honest prognostication, not veering away from difficult conversations. No one likes to talk about death, and doctors do not like talking about death either. In fact, surprisingly, some of the groups that have the most difficulty with this are those where death is a by-product. So as we try and develop models at Alfred Health — and this is a reflection of what happens more broadly — some of the hardest groups to engage are actually the oncologists.

**Ms PATTEN** — I just have one quick question. I have noted that you talked about age discrimination, and sometimes that lead into underassessments and undertreatment. We have heard quite a bit about pain management, and I wondered if your group has had any conversations about pain management in your aged patients.

**Assoc. Prof. HUNTER** — Yes. Pain is a really important issue, and if you were to ask people what the sorts of things they worry about most of all are, it is actually pain management. We do know that in almost all patients, if we do a proper assessment and understand that the drugs are available, we can alleviate pain and we can do a good job of that. Every now and then, in terms of controlling pain, when people are in the terminal and dying phases, the consequences of adequately treating people’s symptoms will actually be death. There are many people tying themselves up in knots about that and saying that what you are actually trying to do is kill the patient by giving them too much morphine et cetera, but we do know that one of the consequences of end-of-life treatment and controlling the symptoms is death. You just have to be upfront with people about that. This is the milieu that we are actually working in.

I have never not been able to control anyone’s symptoms around pain once you have got them on the right treatment path, be it narcotic analgesia or infusion pumps et cetera, so I think that if anyone dies in pain, that is an absolute travesty because there is capacity to really manage that effectively in this day and age.

**The CHAIR** — Before we close, is there anything further that you would like to add to what we have discussed already?

**Assoc. Prof. HUNTER** — No, I do not think so. You have our submission, and I think I have had a fair hearing, so thank you very much.

**The CHAIR** — Okay, thank you very much for your attendance this afternoon. The transcript will be with you shortly.

**Committee adjourned.**