

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 21 October 2015

Members

Mr Edward O’Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

Participating Members

Mr Gordon Rich-Phillips

Staff

Secretary: Ms Lilian Topic

Witnesses

Mr Alan Castleman, Chairman, and

Ms Rebecca Bartel, Chief Executive, Australian Centre for Health Research.

The CHAIR — I welcome Mr Alan Castleman and Ms Rebecca Bartel from the Australian Centre for Health Research. Thank you both very much for being here this evening.

Before I invite you to make some opening remarks, I just 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. Transcripts will ultimately be made public and posted on the committee's website.

We have allowed half an hour for our session tonight, so I invite you to make some opening remarks. Perhaps you could highlight some of the key points of your submission, and thereafter the committee will have questions.

Mr CASTLEMAN — Chairman, thank you. I will make some preliminary comments and our executive director, Rebecca, will go through the presentation that we have, fully, for you. And of course we are happy to have any discussion of questions.

The Australian Centre for Health Research, of which I am chairman — and in fact a foundation chairman — is a small centre supported by a number of health funds. The major ones supporting us are: Australian Unity Limited, out of which the whole organisation grew; Bupa Australia; we have Epworth hospital group and Cabrini as other very active members — their CEOs are on our board, for example; and we have a number of other smaller groups who contribute lesser sums of money to us. In addition to the membership formally of the organisation, we have partnerships with a number of medical groups — out of the Alfred, from Melbourne University, Monash University, Deakin University — and we build linkages into the public system more by that system than by having the public hospitals, in fact, as members.

We wanted to talk about end of life, which we have in fact been, as an organisation, talking about now for many years. Professor Bill Silvester I believe is the man behind the November activity that someone referred to. He really started this off. We had him speaking to us, and we took it on board as an issue that is very important. ACHR is focused on trying to find simple ways to make big impacts in the health system. There are a lot of people doing wonderful work medicinally in test tubes and research, but there is a great area of activity in health where simple things can be done which can have big impacts, and we are attempting to focus on that and to promote in that area. End of life is one of those areas.

We believe — and we cannot prove the stats on this, but — that having an effective end-of-life process through advance directives and other measures and with very well developed and effective palliative care systems can bring about two very important outcomes for our health system.

The first is a much better end of life for all those people who have a protracted period of dying. That is of enormous value, even though as a society we put no monetary value on it. It is of enormous importance that people are able to die in the way they would like to and not have done to them things that they would not want done to them in the end stages of life. We have had anecdotal suggestions from senior medical people, professors of medicine who work actively in the hospital world, to the effect that — and this is not my figure; it is anecdotal and I cannot prove it — something like 10 per cent of the national health budget is spent doing things to people that they do not want you to do in the last stages of life. If we can reduce these activities, there is a very great financial advantage to our system as well. As we all know, we want to spend whatever money we have in health in the most effective ways, not in the least effective ways. These are the things we are working with.

Cabrini is very focused on finding superior ways to handle palliative care and provide palliative care, and we think advance directives are a very desirable way to go. I will say a little more about that in a minute.

I want to just make a quick reference to euthanasia. We do not take a position on euthanasia, deliberately. It is a very divisive and very controversial subject in society, and we do not think that it is something we should get involved in. We do think, though, that if you can bring about much better end-of-life planning and very competent and adequate palliative care, the perceived need for euthanasia drops away immensely and you can diminish the issue that is represented in community divisiveness in that way.

I will say one more thing, and that is that we think we prefer non-binding advance directives. It is not that we would have any aversion to binding directives, other than that they become very controversial. We heard with the last speakers, and your questions about it, indications of the difficulties that arise when something is binding. People are reluctant to enter into it if it is binding. They are reluctant to hand it over. We think there is not a great deal of advantage in having it binding anyway. The major issue is that the family of the person who is dying understands what their loved one would want to have happen. That understanding is the most important thing. If they know that mum or dad would not want this done, they will be comfortable to say that to the hospital, and in most cases the hospital will be comfortable to go along with that. Most of these extensive procedures are undertaken because no-one is sure what mum or dad would want. So we are much happier just pressing for the discussions and the advance directives. Rebecca is going to say a lot more about that in a few moments. I think that is all I wanted to say at this point. Thanks.

The CHAIR — Thank you.

Ms BARTEL — Thank you for having us here. This is a fantastic undertaking. The Victorian government is doing a lot of great work in advance care planning and looking at end-of-life care, and it is great to see. You have got a little pack in front of you. This is our evidence-based document, and it is more or less a summary of what I am going to run through after that. You have a copy of the slides and a copy of the evidence document. This is a little bit ‘death by PowerPoint’, so at any stage if you want to interrupt and ask questions, please feel free to do so.

The CHAIR — I would ask: perhaps could we move through the PowerPoint reasonably quickly so there is time for questions as well?

Ms BARTEL — There are not many.

Visual presentation.

Ms BARTEL — Obviously a lot of people die in hospital unnecessarily, and sadly the majority of Australians do not want to be there. For patients and their loved ones no decisions are more profound than those made at the end of life, but they are not sharing them. Eight out of 10 Australians do not have an advance care plan in place, and if they do, 35 per cent of those cannot be found when the moment arises. Seven in 10 Australians have not even discussed end-of-life goals with their families. Good end-of-life care enables people to live in as much comfort as possible until they pass away and to make choices about their care.

We know there are real challenges to achieving choice in care, and I am sure you have heard all about that through these hearings over the last few months. There is increasing demand on the system; an ageing population; changing disease patterns; case mix changes — we are moving from an acute to a chronic state; rising expectations and patients actually making choices, and more informed choices; groups with diverse needs — dementia, CALD populations and Aboriginal populations who need entirely different kinds of care; residential aged care — there is a whole new growth in what palliative procedures should be occurring in residential care; and rocketing health expenditure, where we have now been asked to do much more with a lot less. Obviously things have got to change if we are going to achieve some choice.

We think there are 10 preconditions that underpin choice for end-of-life care: person-centred care, where the families and carers play a central role; needs-based care; integrated coordinated care; obviously advance care planning; equitable 24/7 access to palliative care; ensuring that everyone matters — making sure that everyone is covered; collaborative and case managed care; shared records; education and training for health professionals; and research and evidence to base a lot of these decisions on. That is not what I am going to talk about today, but we do see that these are critical to achieving choice in advance care planning and end-of-life care.

We think there is one thing, though, when we are going the simple route — when we talk about simple things — that can make a critical difference. That critical difference is conversation. We have got to start having a national conversation about end of life. We know from research and evidence already that conversation makes a significant difference. There is greater alignment between patient preferences and the care they receive; higher patient quality of life; improved satisfaction; less use of aggressive or non-beneficial life-sustaining interventions; greater use of hospice care; increased likelihood that people will die at home or at least in a comfortable setting of their choice; reduced family distress, anxiety and depression; reduced stress amongst doctors, nurses and other caregivers; and improved resource use and cost efficiencies.

This is an interesting study that was published in January 2008. Looking at you nodding, you have probably already seen it. This compares groups that had counselling about end-of-life care and those who did not have any counselling about end-of-life care. When you look at preferences and planning in the two groups, you can see that those who had counselling are more accepting of their illness. They value comfort over life extension. They are less likely to be in an ICU. They are more likely to complete a do not resuscitate order, but when you look at the last weeks of life — this is actually really significant — there are fewer ICU admissions and fewer interventions in general. This is one of those amazing trials that really shows when you engage with people and talk to people about end-of-life there are significant impacts not only for the person and their family but also in terms of resources.

The World Health Organisation recommends that some kind of shared approach is best when you are talking about and educating patients about end-of-life care — that it should be a conversation between patients and doctors. The problem is ultimately that doctors want patients to take the lead, and they just do not do it. So maybe 3 out of 10 patients — even when they are actively counselled to get on with this and get their affairs in order — will actually proceed down that path. There comes a tipping point when you are very advanced in your care or your illness that doctors will stop having that conversation and just start treating, no matter how many interventions or how painful it is for the patient. We are trying to get a grasp on what that tipping point is, but there is a point when it just stops.

Timing and triggers really matter when it comes to having these conversations about end-of-life care. This is a federal government document that looked at advance care directives and the consistency of advance care directives across the country. They said that of the people who tend to complete advance care directives through an advance care planning process, 60 per cent are actually well, 30 per cent are chronically ill and 10 per cent are near death. It really shows that if you can target that 60 per cent that are well, you are much more likely to get an educated patient and educated family by the time you have got to the terminal stage.

This was back in 2013: the Australian Centre for Health Research had a round table where we got a whole range of professors across Victorian hospitals and universities together to talk about end-of-life care. These were some of the trigger points they came up with at which some of these conversations and planning points should actually happen. There are a number here in primary care, acute care and aged care. You probably do not need me to go through them, but they are seen as key trigger points where this might occur. The problem with this ultimately is there are a lot of structural and financial disincentives currently at all these trigger points from this actually occurring.

We have spent quite a bit of time recently looking at how we can improve communication and community engagement on this topic. I hear constantly that the community does not want to talk about it and no-one really does, but I am starting to think the community really does want to talk about it and the people who actually do not want to talk about it are governments. We are looking at a range of new ways of engaging with the community, from citizen panels and a whole range of tools and techniques to try to get messages out to the public. It is interesting, even trying to do media releases, newspapers are not particularly interested in talking about this topic either — so PR is not the way to go.

We have been looking at some of the models. This is not a new phenomenon. Community engagement, social action and cultural change is a bit of a global phenomenon. The UK is doing a lot of work in this area, as is the US. Canada is also just starting, but the two most effective campaigns are one from the UK called Dying Matters and one from the US called the Conversation Project. The Conversation Project is funded by the Institute for Healthcare Improvement, and it is a very large organisation now — all volunteers, mostly contributed to by medical professionals. Dying Matters is a much more social welfare, social work-driven activity. The Dying Matters organisation claims to have 30 000 organisations supporting it and distributing its tools and communication methods.

This is a really interesting tool that is currently in the US. It claims to have had 100 000 meetings. It is called Death over Dinner. You literally invite your friends and family to dinner, and in advance of that dinner you are sent an invitation with some reading material, videos and things to consider, and you arrive at the dinner with some drinks and food. Everyone has to bring something; it is a shared evening event. You break bread, eat food, and you talk about death. It guides you through some questions and processes and prompts you at certain points. We have been working quite closely with these guys now for probably about the last four and a half weeks. We

are looking at bringing this to Australia, so it will be Death over Dinner Down Under. We are hoping we can really take this momentum and drive this forward in 2016.

When you show it to people everyone is a little bit put off by the name, but that is kind of the engaging part of it. It sort of stuns you into a bit of reality: 'Oh, I haven't thought about that. That's something I need to do'. We have been out doing some anecdotal market testing literally just on the streets, asking people, young and old, the whole spectrum, what are their feelings about the name and running through some of the screenshots and things like that. On a spectrum of 10 we get a really visceral response from 1 — horror, absolute horror. We get a group of 4 or 5 in the middle going, 'That's kind of interesting, I might do something like that'. Then there are a couple down the end who just love it. So we expect it to be quite controversial, but we think it is a really clever way to engage the public in conversations about end-of-life care.

The other thing that these guys are starting to do in the US that is also interesting is that it is now transformed into a tool for healthcare professionals to teach healthcare professionals how to have those conversations. So it takes the experience of the intimate conversation and starts helping healthcare professionals to do it. A number of HMOs in the US are now using this tool, and we would develop something very similar as well.

This is the Australian Conversation Project, which is what we are calling it. It will have the Death over Dinner function and the Difficult Conversations function, which is for healthcare professionals. We truly believe that this is a conversation that has to be had, because unless we can have this conversation, we are not going to have the uptake of advance care planning, we are not going to have the uptake of advance care directives. It is that critical first step. People just do not know about advance care directives and advance care planning, and that is why they are not doing them.

The other thing that we are currently lacking that the US has just now officially put in place is item numbers for advance care planning. We are working hard to lobby the federal government currently — we would love your support — to develop an item number specifically for having advance care planning conversations.

We really think that this is the elephant in the room. Having the conversation is the critical first step. By addressing that critical first step, I think we will start to see movement down the track.

That is the end of the presentation. There is a TEDMED. This is the guy who developed Death over Dinner, from the Conversation Project. I will leave that for you guys to look at as well later.

The CHAIR — Thank you both very much for your presentation and for your submission as well. I would just like to ask about one of the 10 preconditions you identified, the integrated coordinated care. We have heard from many healthcare professionals about the way medicine is specialised so much nowadays. How do you overcome that specialisation and get that integrated coordinated care for an individual?

Ms BARTEL — It is a right place, right time hard conversation. The silos in health are so ingrained now, and it is really hard to get that generalist view in the health sector. It is one of the great challenges with topics like end-of-life care, where you have got cardiologists as much as renal physicians as much as endocrinologists all experiencing this, but palliative care are the ones left with it, and they cannot cope with the burden. We have really got to start educating healthcare professionals about end-of-life care, just as much as we have got to educate the community, and make them realise that it is part of their chronic disease state and it needs to be managed. I think that will start to bridge some of the silo issues — forging bridges. But it is a challenging question, and I do not think there is a particularly easy answer.

Mr CASTLEMAN — I have an industrial background, and silos are very common in industry. It is a managerial challenge to break down silos and to stop them working. My experience of the health industry, where I have been close to it for 20-odd years, is that it is a similar issue. I do not think our management in health is strong enough. I think the challenge for the head of a big hospital group — Monash, the Alfred and others — is to have managers who are strong enough to persuade but also force if necessary the breakdown of these silos throughout the systems.

It is a big problem. Professional pride, professional protection of your flank and everything else is very strong. But mind you, that has happened in private industry as well. Big companies have nearly died because they allowed that to happen. In the private sector, when that happens you die and another one that is better takes you

over. We do not quite have that in the public sector, but I think it is a management challenge as well as of a challenge for the professions to break that down.

Ms SPRINGLE — Thank you very much. It was really informative and quite different from anything we have seen so far. You mentioned structural and financial disincentives for trigger points being acted upon. Can you unpack that a little bit?

Ms BARTEL — Yes, sure. Someone with advanced illness, they are more likely to be coming into an ICU or into a hospital in an emergency capacity, rather than coming through any other way. ICUs just are not made to be having end-of-life care discussions. It is all about getting people out of beds, moving them through, turning them around. No-one is rewarded in an ICU for having a 90-minute end-of-life conversation. At some point the doctors just stop having them, I think mostly because that is when the patient re-enters the system, coming through that ICU way. In terms of financial disincentives, it is a time thing. When there is a whole pile of things to look at for a patient, and doctors go into that fix-it mode, they would rather spend the time fixing rather than going down that pathway of the conversation, and there is no financial incentive for them to have that conversation anyway.

Ms SPRINGLE — I also note here in terms of the trigger, the percentages you have here, that you have named the 70-year age check-up and turning 75. We have heard from other people that perhaps even that is too late.

Ms BARTEL — Yes, it might be, too.

Ms SPRINGLE — I was just curious as to how you come to those figures.

Ms BARTEL — That was a round table that ACHR held in 2013 where we had a number of medical experts from across Victoria and university professors who came together and discussed the topic. That is the list that they came up with at the time.

Ms SPRINGLE — Going back to those disincentives, I hear the culture change stuff with the conversations, but structurally how are we able to overcome these barriers? It is not just about conversations, is it? There has to be some change in the system — in the way we are doing things.

Ms BARTEL — Yes, without a doubt. We are so uneducated about death that until you are actually going through it you do not even know what to expect. I have an example: my mum was diagnosed with acute myeloid leukaemia and had three months to live, and we were never told throughout that process what to expect at certain points. Suddenly if she is passing out because she does not have enough platelets, I am going, 'Oh, my God! I've got to get her to emergency!'. If I had have known that you maybe just waited a little bit longer, then you go in and have a transfusion, things like that would have kept us out of the process. Even just having an understanding and awareness of the trajectory of particular disease states and what to expect, I think, would stop a lot of that just turning up and some of those structural issues as well.

Ms SPRINGLE — Where does the responsibility lie for making sure that people have that information?

Ms BARTEL — I have to say it has got to come from the healthcare professionals ultimately, because they are the ones with the experience and the know-how about particular disease states. All too often the conversation that occurs about a terminal condition happens right at the beginning. It is never really talked about throughout the process again until it is right at the end. They just do not engage on it.

Ms SPRINGLE — So it comes back down to education for healthcare professionals. We have heard that a lot.

Ms BARTEL — Yes.

Mr MULINO — I was just going to make the general observation that there is a lot of really interesting material in here. I think a few people have made the observation that one of the big challenges is to get people to have conversations, and I think you have a lot of really interesting suggestions as to how to make that less daunting. All these trigger points are interesting — making it less formal and the dinner party idea. I think it is a really interesting contribution, so thanks.

Ms BARTEL — Great. Thank you.

Mrs PEULICH — Thank you for a good submission. I am not sure, Ms Bartel, that your enthusiasm about conversations about death would be shared by many people I mix with. I am specifically referring to multicultural communities. If I invited my mother over for a dinner party to talk about death, she would probably write me out of her will and kill me, or in the reverse order. I guess a lot of people who have come from difficult backgrounds where there has been conflict or authoritarian regimes where life is considered to be fairly precious, and there is also the influence of both culture and faith — and sometimes also a lack of education — there is a view that if you talk about death, you jinx it, you are actually going to bring it on, so they do not. In terms of your vox pops and your market testing, how many people from multicultural backgrounds would have formed part of your sample?

Ms BARTEL — Such a good question. Some of the richer cultures, the kinds of responses we are getting are, ‘We don’t need something like that; we already have a process and our own internal mechanisms for talking about it and dealing with it’. We have heard that quite a lot.

Mrs PEULICH — Any particular cultures?

Ms BARTEL — Indian communities, for example, have a really rich culture, and it just seems to be, ‘We don’t even need it!’ — more of that kind of response.

Mrs PEULICH — Because they believe in afterlife.

Ms BARTEL — Yes. Religious groups are some of the more enthusiastic ones — so Catholics, we have had really positive response from Jewish communities. The Jewish community are some of the most excited about this kind of process, which I found more interesting. This is very anecdotal; I have got no hard data, but that will be part of this process — making sure. In the US they certainly have a very mixed cultural environment, and this sits very nicely within that environment. They certainly have some negative bits and pieces that come out from time to time about their project in the US, but ultimately, if you do not want to do it, you do not engage.

Mrs PEULICH — No, I understand. That is why I appreciate Mr Castleman’s point about it not being compulsory; that it be voluntary.

Mr CASTLEMAN — I think your illustration is another reason why we do not make this process too rigid, but there is a great deal to be gained. Let us get what we can and not upset the system by being too directional.

Mrs PEULICH — Not overreach.

Ms PATTEN — Thank you, Mr Castleman and Ms Bartel. Mr Castleman, earlier you mentioned that you did not feel that advance care directives should be binding. We have had considerable discussion about that. A conversation I was having today was about doing an advance care directive and your family may well override it. When you are talking about binding, were you suggesting not binding to the doctor, or the doctor thinks that is the best thing but the family says, ‘Treat at all costs; we love our mother; we want to throw everything at her,’ and the mother is saying, ‘No’?

Mr CASTLEMAN — We feel that if you start to make it binding, you will get into a lot of debate — I mean, you will have parliamentary debates about the pros and cons of it being binding, what does binding mean, when can you ignore it — and you may finish up not getting the whole thing working at all. You may delay the implementation simply because of the debate and the disagreement that goes around detail, whereas a great deal of benefit can be taken even without being binding — and in fact I suspect as much without binding.

Rebecca talked about the conversations. We see the advance care directive as largely just putting down in writing what the conversation was about so that it is clear. One child might not be able to participate in the conversation, but if they see what Mother has written, they understand what Mother thought. I personally also would be hesitant to say, ‘If I reach these conditions, then stop feeding me’, because how do I know later whether something else will have cropped up? There are too many uncertainties in the future for you to think that you can at an advance earlier point define everything that is relevant about it. I think that is the problem.

I am sure that if we had many more people participating in this we would as a society find improved ways to do it over time and there will be progressive improvements. Not that we are opposed necessarily to try to make it

binding, but we just feel that that will not work as well and that it would work better if you put the conversation in writing, still as a conversation.

Ms PATTEN — One more question — it is quite sideways from this, but when you were mentioning some of your supporters or members being insurance companies, we have insurance companies offering us orthopaedic shoes, gym memberships or something. Have you had any conversation with insurance companies about advance care planning being an addition that an insurance company might offer or subsidise?

Mr CASTLEMAN — The members that we have have been quite positive about this. We do not call health funds insurance companies, and they are almost all mutual organisations whose responsibility is to help their members achieve healthy outcomes for things. They are health management organisations, even though that term is made to smell a bit in America. They are not really just insurance companies. They provide lots of services as well.

Ms PATTEN — I appreciate that, yes.

Mr CASTLEMAN — If the cost of care goes down, if there are less wasted moneys, obviously you would expect the health funds to say that that is an advantage, that your premiums can be lower and everything else, but their primary purpose is to have members feel that they are doing a good job, because they are not, in the main, profit-making outfits.

Ms PATTEN — No. I appreciate that, and I can see that an advance care plan and the conversation is obviously of benefit to the family but possibly of benefit to your members as well.

Mr CASTLEMAN — Yes. There is no doubt it could have a significant financial benefit to health funds if their members have a less expensive death, to be candid, but that is not the primary motivation because in all of this it is ultimately the members that pay in the premiums.

Ms BARTEL — On that note, one of the interesting conversations I have is when I go to Canberra and talk about end-of-life care. There is some really great work happening in Tasmania at the moment. It is an integrated palliative care program. It is like a hospice in a home. It is an extraordinary program. It has cost a lot of money. I do not think anyone appreciated how much it was actually going to cost. I think the pilot has been like \$60 million or something, but the reductions in hospitalisation have been absolutely huge. The conversation I now have in Canberra is that because care is moving ultimately with patient choice to the community, the burden of expenditure goes from the state government to the commonwealth, and so the commonwealth budgets increase and the state's decrease.

Ms PATTEN — Can you just explain that?

Ms BARTEL — Yes, because you are not getting patients in hospital you are getting patients who are being cared for in the community and ultimately — —

Ms PATTEN — And that is the commonwealth?

Mr CASTLEMAN — Yes.

Ms BARTEL — It is commonwealth funding. It is a really big issue about the federation and it is something that I know Nick Champion, for example, who is the shadow parliamentary secretary, is tearing his hair out looking at it. No doubt Fiona Nash is as well, who is responsible for palliative care. This cost shifting is a really big concern at the national level. Trying to get further and get more support without increasing the federal government budgets is key.

Ms PATTEN — That is really interesting.

The CHAIR — Yes, if you could provide any further information on that Tasmanian — —

Ms BARTEL — These are just sort of based on conversations. We have got some little bits and pieces written down about it, but nothing formal. I am happy to — —

The CHAIR — Even just a contact with the secretariat.

Mr CASTLEMAN — We could try to put something down.

Ms BARTEL — Yes, sure.

The CHAIR — That would be great for our information. Are there any more questions for the witnesses? Is anything else you would like to say to us before we conclude?

Mr CASTLEMAN — We wish you all the best and I hope you concentrate on those proposals that can be made to work.

The CHAIR — Yes. Thank you very much for your submission. There is a lot for us to digest and some very thoughtful proposals.

Mr CASTLEMAN — Thank you.

Ms BARTEL — Thank you.

Witnesses withdrew.