

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 25 November 2015

Members

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Ms Georgie Haysom, Head of Advocacy, Avant Mutual Group.

The CHAIR — I welcome from Avant Mutual Group Ms Georgie Haysom, head of advocacy. Thank you very much for coming down from Sydney to provide evidence and for your submission. Before I invite you to make some opening remarks, I will 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 a proof version of the transcript in the next week or so. Transcripts will ultimately be made public and posted on the committee's website. Thank you again for being with us. We have your submission, but we would invite you to make some opening comments, and thereafter we will have questions.

Ms HAYSOM — I would like to thank you for the opportunity and the invitation to come down here and talk with you this evening. I understand that you have a copy of my bio, but just by way of background, I am the head of advocacy at Avant. I am legally trained, and I have been practising for over 20 years. Pretty much primarily during that time I have been assisting doctors and advising doctors on medico-legal issues. Avant is a medical indemnity organisation, and we provide a range of insurance products to medical practitioners, primarily professional indemnity. We also provide legal advice and assistance to medical and allied health practitioners and students around Australia. We have got about 68 000 members around the country, and 18 000 or so of those are in Victoria, so we do have a significant presence in this state.

Just to give you some background, our Victorian office does assist members in a wide range of medico-legal issues, including advising them on end-of-life issues. We assist our members also in responding to complaints that are made to regulators, such as AHPRA, the Victorian board of the Medical Board of Australia and the Office of the Health Services Commissioner, and we also assist our members in employment matters, medical negligence litigation, coronial inquests and the like. We have fairly broad experience in assisting practitioners in these areas. I guess what we bring is the perspective of a national organisation that has a presence in all states in Australia, but particularly a strong presence in Victoria.

This appearance at the inquiry is quite timely because we are just about to release a position paper that we have prepared on advance care planning and end-of-life decision-making. I have copies for the committee here. It does highlight some of the things that we mention in our submission on the approach around the country and our experience in assisting members dealing with the issues that arise. The numbers of calls or requests for assistance in this area — and often they are calls to our medico-legal advisory service; we have a service where our members can ring us any time for advice on medico-legal issues — are quite small, but they are always quite complex, as you would probably appreciate. Often calls will relate to who is the appropriate substitute decision-maker in a particular instance when a patient lacks capacity. Often there are several family members involved or there is conflict between the clinicians and family members about what is appropriate treatment. Sometimes it is about the conflict within a treatment team about what might be appropriate. We also have calls from practitioners who are unsure about what to do when they are faced with an advance care directive or some such document or expressed wish by a patient, and they are concerned that that might clash with their clinical judgement about how to proceed. I think essentially it is fair to say that doctors really worry about getting it wrong and often they ring us for reassurance that the approach that they wish to take might be appropriate or to discuss the issues that they might have.

I think it is fair to say — and I know the committee has heard from a lot of the legal academics and other practitioners — that they are uncertain about their legal obligations. That is certainly what we have found. Even though the numbers of calls we get are small, we also provide education to our members on a range of medico-legal issues, and end-of-life decision-making and advance care planning is one of those things. It is quite interesting that the same sorts of questions come up — and have for many years — about how to proceed where there is an advance care directive or an expressed wish from a patient.

I was actually recently in the audience of a hypothetical panel discussion about a month ago on an end-of-life decision-making topic and the patient had an advance care directive in this hypothetical. They said they were at home, they wanted to die at home and they did not want to go to hospital if they had a fall, a cardiac arrest or something like that. There was discussion amongst the clinicians about whether, if they were rung by the family members, they would call the ambulance. It was quite interesting because, despite several years of discussion around advance care directives and end-of-life decision-making, the practitioners were still really uncomfortable about not calling an ambulance in those circumstances and complying with the patient's wishes, because of

course their whole ethos is around trying to help patients and cure them, I suppose, ultimately. I think it is fair to say that doctors do feel very uncomfortable proceeding on the basis of refusal of treatment, and having some reassurance that they are not going to be prosecuted or have some sort of adverse implication would be of some comfort, and it also means that the patient's wishes are going to be respected, which is the most important thing, I think.

On the other hand, practitioners also expressed concern about the doctrine of double effect. I know you have heard from people about that. They do express concern about pain relief and they often have conflict with nursing staff about that too, so the nursing staff may be concerned about providing pain relief where they think it might hasten death and sometimes there is conflict between the nursing staff and the practitioners about whether that is appropriate or not. That does cause concern.

With regard to the legislative framework, I have mentioned in our submission the lack of national consistency and I am sure the committee has heard about that from others who have presented here. But it is quite interesting to see all the different terminology that is used around this country, which really is quite a small country, for the same thing. I have outlined in our paper there that we have directions in the Northern Territory, we have advance care directives in New South Wales and that is common law, we have refusal of treatment certificates in Victoria plus or minus advance care directives, and we have statutory health directives in Queensland. That does cause concern for practitioners. I am sure you are aware of the literature that says that doctors are unclear of their obligations. The lack of consistency, I think, causes concern to practitioners and, in a society where doctors are moving around, how they can come to grips with all of that — which is a legal framework and not something that they are taught routinely in medical school — I think is quite a challenge. We agree with the evidence of others that there is a lack of awareness and understanding about the existing legal framework in this area, and that is compounded, we say, by a lack of national consistency, and it means it is harder for practitioners moving between jurisdictions.

So what is the answer? We think it does lie in some consistency of terminology, as has been suggested in the national framework. It is good to see that there is some movement towards that. We have mentioned the South Australian legislation and, whilst we are not necessarily endorsing that is the framework that should be adopted, the fact that they are using terminology that is consistent with the national framework and is used in other jurisdictions is helpful to practitioners. We think the thorough investigation that the committee has been doing is an excellent opportunity to improve the experience of practitioners and, most importantly, the experience of patients in this area. We hope the findings and recommendations that you will make will contribute to a nationally consistent framework in this area.

The CHAIR — Thank you very much for those opening remarks. Taking you to the issue of uncertainty that you have flagged with doctors and medical practitioners not necessarily having a good understanding of the legal framework, do you think that is because of the framework itself or because medical practitioners will only be concerned about this issue and, for example, give your helpline a call when they are confronted with the situation?

Ms HAYSOM — Yes, I think it is a combination of the two. I think they may not necessarily confront it every day. I imagine if you are in the emergency department or ICU you will probably confront it more than if you are a general practitioner, perhaps, or an orthopaedic surgeon, for example. So yes, I think not having to deal with it every day might be an issue, but also the legal framework is, as you are aware, very complicated. Thinking about the three pieces of legislation that we are referring to in Victoria, there are different tests and different terminology, and when you look across the whole jurisdiction there are different tests, different terminology and different definitions, so 'capacity' in one piece of legislation and 'sound mind' in another piece of legislation. I think it is a combination of the two.

The CHAIR — On the jurisdictional comparison you mentioned South Australia, but is there a jurisdiction that you would point to as having the simplest, the clearest or the easiest to understand framework for practitioners and the broader community?

Ms HAYSOM — There are probably aspects of a number of them that might be helpful. It is hard to say because they are quite different. In New South Wales, which is where I come from, we do not have any legislation, so it is completely guidelines and the common law. Queensland has quite a different set of legislation. It is interesting that there seems to have been quite a few cases in the Queensland jurisdiction, QCAT, about the application of that legislation, so whether that means it is not clear or whether that is just a

process issue I do not know. As I said, the South Australian legislation is quite good and is reflective of the national framework, yet there are other aspects of that such as it must be in a particular format and, if it is not in that format, it is invalid. I cannot really say whether one or other would be necessarily any better.

The CHAIR — You alluded to this and we have heard quite a bit of evidence from different witnesses about patients. The typical example given is of an elderly patient going through emergency and receiving perhaps unwanted treatment, or treatment beyond what that patient would have expected or wanted at a particular time. One, is that something that you see through your members or your policyholders? Two, what do you think the cause of that is? Is that because we do not have a culture in our medical profession and with our doctors of having those communications, or does it get back to the legal uncertainty and the regulatory issues that are so complex?

Ms HAYSOM — I think this probably goes back to your previous question around whether the uncertainty is due to the legal framework or the application of it. I think there is a cultural piece. I still think that people, as I said, do feel uncomfortable. They may not think about the legal framework at all, or they might think about it only when they are facing the particular situation. I think there is something around culture, and I think that is the important part of the notion of advance care planning and all the movements around the country to incorporate and implement advance care planning into the medical profession, because I think that will go some way to overcoming some of these problems.

I think actually the advance care planning process is probably the key thing here. You can have a legal framework and people can be aware of it, but ultimately it comes down to having good discussions with your patients about what might be the expected outcome of the illness or what might happen in the future, and they can have a good open discussion about treatment options as their disease progresses. If we are getting to the stage where people are only thinking about it when they are at some sort of acute episode in hospital, it is a little bit late really and that is when the problems arise, I think.

The CHAIR — If we could just go back to the threshold point, do you think that, to use that example, there are a lot of people who are receiving treatment in hospital who come in in an emergency context and perhaps would not necessarily want that treatment?

Ms HAYSOM — It is anecdotal. It probably is happening, but that is an anecdotal thing rather than something that we have lots of experience dealing with as an insurer.

Ms SPRINGLE — You may well have answered this question already; I am not quite sure. Obviously this is a state-based inquiry, and when we are talking about a national framework, that becomes problematic because we are not the federal government.

Ms HAYSOM — Yes, that is right.

Ms SPRINGLE — How do we start this process of reform in terms of this area at a state level without there being a national consistent framework for us to fit within? How do you perceive the advance care planning process? As you said, it is the key thing. How does that impact on what we are doing and how we can raise the bar, I suppose?

Ms HAYSOM — In the first question, with regard to the framework, there is that national framework that has been produced by AHMAC, I think it was, which does set out some general principles around advance care planning. There was a recommendation that that be implemented. I think it arose out of a Senate committee report into palliative care, in 2011 perhaps. Because of our federal system and constitutional issues, it is of course going to be a state-based thing, but I do not think that negates having consistency of terminology. I think consistency of terminology is the thing. I do not think you necessarily need to have a commonwealth approach to that.

Ms SPRINGLE — Yes, it does. Is the framework that you referred to — I will be honest; I have not seen the framework — the one that you would suggest? Is it still a valid option?

Ms HAYSOM — Yes, I think so. It is quite detailed. It is here, some several pages, and is quite comprehensive.

Ms PATTEN — We have discussed double effect in various areas and from various angles, but we have not heard of much litigation around it. Are you aware of many cases that are either relevant to double effect or even relevant to end-of-life decision-making?

Ms HAYSOM — No, there are not many. It is kind of curious and interesting. I have reflected on that from time to time as to why that is the case. Certainly as far as I am aware, there has not been very much civil litigation in this area. In fact the civil litigation rates have dropped off significantly since the tort reforms that came in the early 2000s, so the civil litigation anyway has gone down against medical practitioners. Perhaps as a consequence of that, there has been an increase in professional conduct complaints and complaints to the regulator, such as AHPRA — a slightly side issue. There is one case that I am aware of in New South Wales, which involved some self-represented litigants who were at odds with their father's wishes about the treatment of their mother. That was a case called Lane, and that was around the conflict that happened, but other than that I am not aware of any cases, and it is curious.

On one view, you can say that doctors deal with it very well. When I have said that to doctors, they say, 'I don't think we necessarily deal with it very well', so it is curious. The cases that have been around have related more perhaps to who is the appropriate decision-maker when someone has lost capacity, or alternatively where a hospital is unsure about what their obligations are and feel that they need to go to the court for a declaration that withdrawing treatment or complying with a patient's wish to refuse treatment is an appropriate course to take because they are concerned that it does not have the court's sanction.

Ms PATTEN — Looking at the advance care directives, I can understand your pain in the variety, as we have heard as well, around the states. I am not certain — and maybe it is because it has been so many months — that we have talked about the national framework, which is really interesting. One of the things that has come up with us time and time again is that an advance care directive probably needs to be a living document. You might develop an advance care directive for yourself at age 40, and your ideals and aims might be very different when you are 60 or 70. Have you considered how a document like this could be living? One of the concerns that has been raised with us is: when do you know you have got the right version, which, if it is a living document, and it is a constantly evolving document, probably the best case is that it would be that?

Ms HAYSOM — Yes. I would agree with that, and that is why the process is so important. Like any chronic disease plan, I suppose, we are probably talking more about the role of general practitioners here, because they are going to have the ongoing relationship with the patient over that period of time. I think it does have to be a living thing, and it does need to have constant review. Much like any care plan, you need to review it depending on the medical condition that you have at the time. That is the problem with, I am sure you have heard about, the refusal of treatment certificate, which only relates to current conditions and does not give you the ability to have that perhaps living document and planning process. I think that does need to be built in somehow. The advance care planning process is about education and the implementation more than about the legal framework.

Ms PATTEN — It is interesting about the doctors not knowing whether to respect a patient's wishes when they think it is against their medical advice. I appreciate that. When we have been looking at advance care directives we have been looking at whether they should be binding. We have heard some evidence to say that they should not be binding and that the doctor should ultimately have the final say in every circumstance. From your perspective, would you suggest that a directive should be binding, and would that give your clients — your doctors — greater peace of mind?

Ms HAYSOM — There is a lot of philosophical argument about whether you can actually make an advance directive that applies to the circumstances. The problem that doctors face sometimes too is that they might have a document, and it might be a living document and might have been reviewed, but it does not necessarily apply to the circumstances that they are faced with at the time. In that case it will not be binding. Under common law it will not be binding. I think, though, if it is a valid directive, it does apply to the circumstances and the doctor makes a clinical judgment about that, then it probably should be binding. In that way you are respecting the patient's wishes. Again, it comes back to communication. You need to have a good conversation with your patients about what is going to happen and what sorts of interventions they might want. That communication piece and education piece is really important here.

Ms PATTEN — We have been hearing a lot about the difficulty of that, particularly for doctors, given the complexity of medical treatment these days. You will have an oncologist here, you will have a renal specialist here and you will have maybe someone who has met the patient longer than for a few minutes over there.

Understanding the patient's wishes at that time may be incredibly difficult without a document. I have been struggling throughout this process to see how that works to keep the doctors feeling that they are respecting wishes and not feeling uncomfortable with that decision.

Ms HAYSOM — That is right. It is interesting you talk about those disparate groups of people who might be involved in care. My GP colleagues with whom I would work would say, 'Make sure you call the GP', because quite often the GP is the one who has had those ongoing conversations with people, and they are the ones who know what the patient's wishes are. Sometimes that can be of assistance to the practitioners who might be coming in at a later and more acute phase of someone's illness.

I did want to mention something. I do not know whether you have seen or read the book by Atul Gawande called *Being Mortal*. He is an American doctor who is a writer, and he has written several books, including this one on end-of-life care and decision-making. It gives some really interesting insights into how he has approached end-of-life care — not only him but also some of his colleagues — and how they go through that planning process and discussion process with patients. He is a surgeon, so it is quite interesting to see his perspective. It is quite a good book and very easy to read.

Ms PATTEN — One of the other areas, obviously, is that we have had a lot of submissions around physician-assisted dying or voluntary euthanasia or varieties of that process. Are you aware of any insurance companies in other countries that may have grappled with dealing with something like that? We know that there is physician-assisted dying in numerous jurisdictions.

Ms HAYSOM — I am not, but I know there are insurance companies in America, for example, who would have presumably grappled with the issues that might arise in those jurisdictions, yes. Certainly it is something that we have not looked at. We have got a broad membership. We would have a range of views amongst our membership as to physician-assisted dying, so we do not formally have a position on that at all in our organisation.

The CHAIR — Can I take you back to the complaints to AHPRA. Are there any learnings from the themes that come out of complaints that come out of the end-of-life process?

Ms HAYSOM — Again, there is not that many, but they generally — the ones that I am aware of — relate to communication, that whole communication point again. I have certainly been involved in matters where the complaint is from a family member about their father or mother who may have died, and the family member did not understand the process and did not understand what was going to happen. I think a lot of those complaints relate to communication.

The CHAIR — Communication has been a constant issue that has come through in submissions and in evidence to the committee. Can you suggest any structural changes that are needed? We have heard a lot of emphasis on education and better forms of communication, but there seems to me to be some structural challenges, and Ms Patten referred to one with the complexity of medical treatment now and specialisation of medical treatment. Have you got any thoughts on how we actually deliver that in a practical sense?

Ms HAYSOM — It is a constant challenge to work out how to implement that, I have to say. One of our major points that we raise in our education to practitioners is around improving your communication. I do not know whether that is something that needs to be dealt with at medical school level to ensure that doctors are trained in communication skills, but certainly a lot of our complaints and claims relate to failures of communication, if you like — communication could have been better. I do not know whether that is a cultural change that needs to take place. I think doctors are probably getting better at communicating with their patients, but there is probably some more work that needs to be done. As for implementing ideas on that, that is a bit of a challenge.

The CHAIR — Can I just take you to the issue of palliative care in the home or in the community. Again we have heard a lot of evidence, and you would be aware of the stats around people who say they wish to die at home versus dying in hospital or in an acute situation. Are there any inhibitors from your perspective and a risk perspective to giving people that choice of dying in the home, or is it more just around service provision and resourcing?

Ms HAYSOM — Yes, I think it is more around service provision and resourcing, and again that whole communication piece with the general practitioner about what the patient wants and also family members. That is the most important thing. I know you will have heard stories of the patient who says, ‘I want to stay at home’; something happens and the family members think, ‘I’ve got to call the ambulance’, and they struggle with the same issues about whether or not to get them to hospital, even though the family member may have said that they want to stay at home. I think it is more around the communication, actually, with the general practitioner and the family.

The CHAIR — We have covered this a little bit, but I invite you to perhaps make more comment about the risk level that medical practitioners perceive they have when they are in this environment and perhaps how we as a committee can help to mitigate or reduce that, whether it is real or perceived.

Ms HAYSOM — Yes. If you look at the fact that there are not that many cases relating to it — I am not aware of much civil litigation, or there are only those few cases where hospitals have gone to get declarations to ensure that their approach is appropriate — I think probably it is more of a perception than a reality in terms of their risk of litigation or prosecution, for that matter. I know you have heard from the police department in relation to that and that prosecutions are very thin on the ground. I think that should give some comfort to practitioners, but still they are concerned about it.

Ms PATTEN — Just looking at those few AHPRA cases, were they about giving unwanted treatment, or was it a family’s feeling that not enough treatment was given?

Ms HAYSOM — The one I am particularly thinking of was more about families thinking that probably not enough treatment was given. You would need to get AHPRA’s statistics on those sorts of things, but again they are quite rare too.

The CHAIR — Is there anything else you would like to say to us? Are there any points we have not covered or any perspectives you can give from where you sit that can inform us in our deliberations?

Ms HAYSOM — I suppose the only thing is just with regard to the role of the law in these things, which is something I am quite interested in, there is that balance that needs to be reached between making something too prescriptive and having it too flexible. But we do not want the law to intrude into medical practice. The law really needs to enhance medical practice and facilitate good medical practice and quality patient care rather than becoming a compliance burden. I think a lot of doctors feel like the law — not necessarily in this area but generally speaking — does impact on their medical practice in a negative way and becomes a compliance burden, so that they are taken away from providing proper patient care and they are focusing too much on compliance issues. Any legislative framework that is set up needs to make sure that there is that appropriate balance and that it facilitates good practice rather than inhibits it.

The CHAIR — Thank you very much for your evidence tonight, and again thank you for coming down from Sydney. We really appreciate it.

Ms HAYSOM — Not a problem. Thank you.

Committee adjourned.