

JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
WEDNESDAY, 28 FEBRUARY 2018**

SESSION FOUR

Members

**Ms A. Sanderson, MLA (Chair)
Hon Colin Holt, MLC (Deputy Chair)
Hon Robin Chapple, MLC
Hon Nick Goiran, MLC
Mr J.E. McGrath, MLA
Mr S.A. Millman, MLA
Hon Dr Sally Talbot, MLC
Mr R.R. Whitby, MLA**

Hearing commenced at 2.01 pm**Mr CHAD EDWARDS–SMITH****Head of Medical Defence Services, Avant Mutual, examined:****Ms GEORGIE HAYSOM****Head of Research, Education and Advocacy, Avant Mutual, examined:**

The CHAIR: Good afternoon and thank you both for joining us this afternoon. On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson and I am the chair of the joint select committee. I will introduce the other committee members. We have Simon Millman; Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; Reece Whitby; and Hon Robin Chapple. The purpose of today's hearing is to discuss current arrangements for end-of-life-choices in Western Australia and to highlight any gaps that may exist. It is important that you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege. This privilege does not apply to anything you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet.

Do either of you have any questions about your appearance here today?

The WITNESSES: No.

Hon NICK GOIRAN: Madam Chair, before we get started, I just want to acknowledge that we are in a public hearing today and declare what I have already declared to the committee previously—that Ms Haysom and I have co-authored an article on a completely unrelated topic, and that we have not conferred in respect of today's evidence.

The CHAIR: Thank you. Before we begin with our questions, did either of you want to make an opening statement?

Ms HAYSOM: Just briefly, and we will share that, if that is all right.

The CHAIR: Sure.

Mr EDWARDS–SMITH: We have done our introductions, so just by way of background, Avant is a medical indemnity organisation and we offer a range of insurance products, legal advice and assistance to medical and allied health practitioners and students around Australia, as well as, obviously, here in Western Australia. What we bring today is the perspective of a national organisation assisting members across Australia within all the states and territories and a local presence here within WA. Our office assists members in providing medico-legal advice and education on a range of issues including end-of-life, advance care directives and substituted decision-making. We assist our members in responding to complaints and notifications by regulators such as AHPRA, and the WA Medical Board through AHPRA, and assisting our members with employment matters, medical negligence litigation, and, relevantly, coronial investigations, so a whole range of medico-legal issues.

The number of requests for assistance in this area, whether calls to our medico-legal advisory service, which is essentially our hotline for giving medico-legal advice, or requests in relation to claims and coronial matters, are very small in terms of the numbers of what we see, but as the committee would no doubt understand, they are particularly complex issues that we have to grapple

with from time to time. Calls often relate to who is the appropriate substituted decision-maker when a patient lacks capacity and there are several family members in often very highly charged circumstances with which we are dealing with our members in advising them.

We also have calls about how to proceed in the face of an advance care directive where it conflicts with the doctor's clinical judgement and where there is conflict within the family. Again, they can be very difficult areas. There are some examples in the paper attached to our submissions that you will have seen. Our doctors really ultimately are looking at what is in the patient's best interests at the end of the day. They want to do so within the framework—a good, clear, logical legal framework—and what is in their patient's best interests. That is why we are here before you today.

The CHAIR: Thank you.

Ms HAYSOM: What we find in our experience is that our practitioners are uncertain about their legal obligations and they are often challenged by the implications of advance care directives. Sometimes they feel concerned about relying on a refusal of treatment. On the other hand, they express concern about providing increasing pain relief and sedation in the terminal phase of terminal illnesses because of the concern that they might be subject to prosecution, and that then, of course can lead to the potential for under-treatment of people's pain and symptoms. I think doctors' concerns about being subject to prosecution and complaint has been heightened in recent times by the UK case that has been in the media recently about Dr Bawa-Gaba. I do not know if the committee is aware of that case, but it was about a young doctor. It was not an end-of-life case, but it was a young doctor who was convicted of manslaughter by gross negligence, and she has been struck off the medical register for life as a consequence of that. That is causing a lot of concern amongst doctors and they are fearful about the potential implications of getting decisions wrong and being prosecuted and complained about.

The other concern we have is about the lack of national consistency in the legislative framework and that is compounded by the lack of awareness and understanding of doctors and other health practitioners in this area. It makes it harder for practitioners moving between jurisdictions and, of course, we know that doctors and other health practitioners move a lot around the country. We think the answer is that we need to have consistency of terminology and of the legislative framework, or at least harmonisation of the legislation in this area. Emotive language, certainly, should be avoided in the terminology. Practitioners need to understand the implications of advance care directives. Some practitioners still do not understand that they should comply with a valid advance care directive and the patient's wishes in that regard. The literature confirms that doctors play an important legal role at the end of life and in end-of-life decision-making. They have to determine who the correct substitute decision-maker is, they have to decide on whether or not an advance health directive might be valid, but if they do not know or understand the law, how can they ensure that the patient's wishes are properly respected? We think there needs to be better education also of doctors. That will help practitioners to have better conversations with patients at the end of life about death and dying.

The other contentious issue, of course, is voluntary assisted dying. That, of course, challenges many doctors, as I am sure you are aware. As a membership organisation and as we mentioned in our submission, we know that our members have a range of views on this issue, so we have deliberately abstained from taking a position on that, but what we are keen to ensure is that any legislative framework that is implemented is clear and unambiguous, outlines the obligations of practitioners and, importantly, provides protections for practitioners whether they choose to participate or not. Ultimately, the decision about whether or not it should be legalised is a policy decision for government.

We are very grateful for the opportunity to give evidence today. We see this committee's investigation as an excellent opportunity to improve the experience of practitioners and of patients at the end of life, and we hope that the findings and recommendations will contribute to a nationally consistent and clear framework in this area.

The CHAIR: Thank you for that. You have raised a lot in that opening statement. I will go straight to the legal issues that you reflected on and the doctrine of double effect. You said in your submission that the doctrine of double effect is not well understood by doctors. Do you think the current law in WA adequately protects medical practitioners who rely on the doctrine?

[2.10 pm]

Ms HAYSOM: In WA the common law is what applies in relation to the doctrine of double effect. I guess before I answer the question, it does assume that administering sedation or pain relief may hasten death. Our understanding is that that is not necessarily the case. Our internal medical advisers have informed us that in managing patients at the end of life, the doctors' focus is, of course, on patient wellbeing and comfort, but doses of medication such as morphine are administered with the goal of relieving symptoms of pain and suffering and distressing agitation and then titrated so that no more is administered than is necessary to relieve the symptoms. Of course, it can be difficult because of tolerance effects, so increasing doses of medication can be required to produce the desired effect. There is a contentious issue around whether or not something hastens death. Let us assume that it does, then the doctrine of double effect is there to protect doctors as a legal protection against criminal responsibility. It is a difficult one. Legislation can provide reassurance to practitioners who are concerned about whether or not they will be protected, but it depends on the wording of the legislation. It is one that we have tossed up a lot in our organisation about whether or not you should have legislation or leave things to the common law. Ultimately, I think, education is the important thing. If people are educated about the contentious issue about whether or not medication leads to death, and also understand their ethical and legal obligations, that will probably go a long way to reassuring them. Certainly, a legislative provision could provide some reassurance to doctors.

The CHAIR: Any more questions on the double effect?

Mr S.A. MILLMAN: Does section 259 of the Criminal Code not provide that legislative protection? That is the provision that says you are not criminally responsible for administering, in good faith or with reasonable care and skill, medical treatment.

Ms HAYSOM: That is there; that is there in the Criminal Code.

Mr S.A. MILLMAN: When you have a look at the Victorian inquiry and the submissions from the Victorian inquiry, particularly from the AMA, the AMA made exactly the point that you made, but Victoria is not a criminal code jurisdiction and it did not have any equivalent provision to 259. But I think in WA, at least as far as the criminal liability is concerned, this provides it.

Mr EDWARDS-SMITH: Yes.

Mr S.A. MILLMAN: Far be it for me to say it, but would you accept if I said that this provides adequate protection in regards to the doctrine of double effect when it comes to criminal liability?

Ms HAYSOM: It would seem to—apart from the drafting, which has double negatives in there. That goes to our clarity point. The interesting thing about this provision of the legislation is that it is actually quite difficult to find if you are someone looking for it. It is not in the consolidated version of the legislation. When we looked at it, we had to go to the amendment act to find it. In terms of doctors understanding this and knowing where it is and finding it—but in terms of legislative provisions, there is that provision; that is true.

The CHAIR: It is an interesting point. We had some evidence from the AMA today and we put the same question and certainly—my colleagues will correct me if I am wrong—the response was, yes, they understand the doctrine, they rely on it regularly and they think the law covers them adequately.

Ms HAYSOM: Yes. I appreciate that and that is coming from the AMA. Our experience is that the doctors who we deal with often do not understand it. That is just a different experience.

The CHAIR: In Western Australia?

Mr EDWARDS–SMITH: Yes, absolutely, and I think it probably stems from the fact that we are getting calls from doctors at the pointy end of a case, grappling with the notion as to prescribing medication that perhaps is going to hasten death and am I adequately protected and, I think, as Georgie has pointed out, the provision is difficult to find and doctors often do not understand that very well so there is a little bit of confusion around that.

Hon ROBIN CHAPPLE: The AMA were actually saying we understand it; not a problem.

Mr R.R. WHITBY: Perhaps the ones who are calling you are the ones who are in doubt.

Ms HAYSOM: Well, that is it. That might be why they are calling us.

Mr EDWARDS–SMITH: I think that is a fair comment, member. I think, ultimately, we get the calls from the people who are confused. Our advisory line necessarily by definition is people who are grappling with not understanding what my legal position is and what I need to do. Perhaps there is a whole heap of people who the AMA represent that are out there understanding the doctrine and applying it every day.

Hon NICK GOIRAN: The issue of the doctrine of double effect touches on a couple of areas that we have been looking at in our inquiry—one is intent and the other one is complications. I just want to speak for the moment on complications because in evidence given by previous witnesses last year and this week, no-one seems to have data for us on the complication rate for medical practitioners. Being an indemnity insurer, I am wondering: do you have that kind of data at your disposal either today or to provide us?

Ms HAYSOM: Specifically in relation to end-of-life care?

Hon NICK GOIRAN: If it can be drilled down to that level of detail, yes, but otherwise just complication rate with regard to doctors in general, if needs be.

Mr EDWARDS–SMITH: We certainly have data in relation to medical litigation claims, and disciplinary proceedings against doctors that arise from complications sometimes, but I am not sure that that necessarily answers what you are looking for. I suppose our focus really is on the end result of the complication and where that goes, be it those various jurisdictions that we engage with, rather than the complication itself. It sounds like, perhaps, that is more of a hospital issue as to the complications they are seeing from a quality assurance point of view.

Mr S.A. MILLMAN: Following on from Nick's question, your policy presumably has a notifiable event provision where the people who are covered by the policy need to notify you if particular things happen. In terms of the data that you are able to supply, if possible, just general stats, I think, is what Nick is after. I would be interested in end-of-life or palliative care practitioners who have come through—not names obviously, but just numbers—in terms of notifiable events for palliative care specialists, gerontologist, GPs dealing with end of life.

Ms HAYSOM: I think we can give you some general comments in that regard. The numbers are not huge. More of our experience is in the telephone calls that we get from doctors who do not understand their obligations and also in giving presentations on this area in various forums. That is

where our experience comes from. It has always struck me as interesting that there are not a whole heap of cases on this and there are not a lot of disciplinary matters on it. There is the odd one here and there, but in the scheme of things there is not a great deal of litigation or professional conduct matters in this area. I am not sure whether that means doctors are doing it well or they are not doing it well. I am not really sure.

Mr J.E. McGRATH: With insurance, a lot of us like to double-check our insurance. These guys might understand, but they are just double-checking that you are going to cover their backs if something goes wrong. That is what I would think. I would think most doctors would understand it will fairly well.

Hon COLIN HOLT: What about some stats around misdiagnosis and litigation? I know of examples where some people have been diagnosed with motor neurone disease and it has been said, “Go get your affairs in order quickly”, and of course they have been misdiagnosed as some other form of motor neurone disease, for want of a better word. Are there any stats around that sort of occurrence that comes through for you guys as an organisation?

Mr EDWARDS–SMITH: We code notifications obviously in respect of the primary driver of what it is about, and one of those is indeed misdiagnosis across a range of specialties and the like. We are really trying to get a handle on where risks are for doctors and how we can help to improve that. It is not specifically in relation to end-of-life issues, but misdiagnosis as a broad category is something certainly that we have some insights into as an organisation.

Hon COLIN HOLT: I would assume that it would be of interest to the committee. A misdiagnosis in the situations we are talking about would have wideranging effects potentially.

Ms HAYSOM: Most of the data around diagnostic error—that is the way we phrase it—is about a delay in diagnosis or errors in diagnosis so that someone is not diagnosed with something rather than a misdiagnosis of something. Yes, we have that.

Hon NICK GOIRAN: Would it be possible to get data from you, preferably from Western Australia, on the diagnostic error for, let us say, the last five years? Is that something you would code and be able to provide?

Ms HAYSOM: We do not have the past five years’ worth of data coded in accordance with our current coding. We have the last two years of coded data, so we could do that.

The CHAIR: We will take what we can get!

Ms HAYSOM: Again, as Chad said, we are only seeing a subset of adverse events. We only see the ones where someone has decided to bring a complaint or a claim in our data against a doctor, not adverse events overall.

[2.20 pm]

Hon NICK GOIRAN: That data that you will provide in due course, will it be triggered by a complaint or a notification? Putting to one side that you actually have to have somebody in a position to complain in the first instance in order for this to even reach your organisation, are you in a position then to indicate what the outcomes of those notifications were? For example, the claim made against the practitioner might be withdrawn. It might be settled and a judgement might have ensued. Would you have the level of detail to also indicate if the person was subject to disciplinary proceedings and what the outcome of that was?

Ms HAYSOM: Yes, for the closed claims.

Hon ROBIN CHAPPLE: Touching on that again, we have been drilling down the nature of the issues that were subject to complaint or litigation; that is, was it a misdiagnosis or was it an inappropriate

operation and that sort of thing. I think if we keep it all together we do not actually drill down and get what we are after. Can you provide that level?

Ms HAYSOM: We have some levels. I am not entirely sure that we could get right to the really detailed level without looking at the individual files, and there are some privacy issues around that, actually. We could probably look at it from an aggregated level with some high level things, but I am not sure we can really get to the detailed level that I am sure the community is interested to see.

Hon ROBIN CHAPPLE: No, I just want it separated out a little bit.

The CHAIR: Just stepping back to the doctrine of double effect, in cases where the doctrine is relied upon, would you expect a reference to the medication to be recorded as a cause if not a contributing factor to the death on the death certificate?

Mr EDWARDS–SMITH: No, not necessarily. Ultimately, the death certificate is looking to identify the cause of death and, at times, the cause of death will be multifactorial. But in the general course it is that practitioners would be identifying what the underlying cause of death is rather than going into, perhaps, the mode or the manner in which it ultimately got to this, so, no.

The CHAIR: In relation to terminal sedation and palliated starvation, we have heard a bit of evidence regarding these practices. Have your members ever raised concerns regarding either of these practices?

Ms HAYSOM: No, we have not. We have asked our medico-legal advisers and we have searched our database on that but it has not actually come up. But it may be a language thing too. The terminology—terminal sedation and palliated starvation—is quite emotive language and I am not sure whether that is used in common parlance amongst practitioners or palliative care specialists.

The CHAIR: Sedation in the terminal phases of life—let us call it that—do your members raise any concerns around the use of sedation in the terminal phases of life?

Ms HAYSOM: We have not seen that, actually.

The CHAIR: In relation to voluntary assisted dying legislation, you have said that it should provide a clear framework. What is your view of the Victorian legislation? Do you think it is sufficiently clear and unambiguous; and, if not, what would you improve?

Ms HAYSOM: I think overall it is well-drafted. It is really clear. It sets out the requirements quite clearly. It remains to be seen, I suppose, how that applies in practice because it has not started yet. Of course, implementation of legislation sometimes produces unintended consequences, so it remains to be seen about that. The two areas that look at clinical judgement, which I think was one of the questions, are the sections on decision-making capacity and on determining patient eligibility. They are reasonably broad, but provide a framework in which those decisions can be made. As a lawyer looking at that legislation, I think it is reasonably well-drafted.

The CHAIR: In your view, could a statutory advance health directive be relied on to enable an incompetent individual to access VAD?

Ms HAYSOM: Ultimately, that is a policy decision for government. As I said, we do not take a position on voluntary assisted dying as to whether or not that should be legalised. Similarly, we would not take a position on whether or not an advance care directive could be used for that.

The CHAIR: For competency?

Ms HAYSOM: Yes.

The CHAIR: You also indicated that VAD legislation should not prescribe referral in the case of conscientious objection. What is provided for in current guidelines?

Ms HAYSOM: The Medical Board of Australia’s code of conduct called, “Good medical practice”, has a couple of provisions relating to end-of-life care. The main one in relation to conscientious objection—actually there are two. There is section 2.4.6 and 2.4.7. It says in 2.4.6 that —

Good medical practice involves:

...

6. Being aware of your right to not provide or directly participate in treatments to which you conscientiously object, informing your patients and, if relevant, colleagues, of your objection, and not using your objection to impede access to treatments that are legal.

And 2.4.7 says —

Good medical practice involves:

...

7. Not allowing your moral or religious views to deny patients access to medical care, recognising that you are free to decline to personally provide or participate in that care.

The CHAIR: Can you give us the name of that document?

Ms HAYSOM: It is called, “Good medical practice: a code of conduct for doctors in Australia”. It is produced by the Medical Board of Australia. That is the code of ethics, essentially, that all doctors are required to abide by.

Hon ROBIN CHAPPLE: It is a code?

Ms HAYSOM: Yes.

Hon ROBIN CHAPPLE: A regulatory code?

Ms HAYSOM: Yes.

Hon ROBIN CHAPPLE: And it actually has legal effect?

Ms HAYSOM: It is produced under national law and if a doctor does not comply with the code then they can be subject to disciplinary action by the board, yes.

Mr R.R. WHITBY: Is there a conflict in what it suggests about a referral to other—by doctors?

The CHAIR: Can you just go back and read those two sections again?

Ms HAYSOM: Sure, I said them quite quickly. I will read it more slowly. It says —

Your decisions about patients’ access to medical care need to be free from bias and discrimination. Good medical practice involves:

And there are a bunch of things, but the particular ones are 2.4.6 —

Being aware of your right to not provide or directly participate in treatments to which you conscientiously object, informing your patients and, if relevant, colleagues, of your objection, and not using your objection to impede access to treatments that are legal.

And 2.4.7 —

Not allowing your moral or religious views to deny patients access to medical care, recognising that you are free to decline to personally provide or participate in that care.

That is the ethical—enactment is the wrong word—statement of a doctor’s right to conscientiously object to participate in treatment they do not morally agree with.

Hon ROBIN CHAPPLE: So you can object, you can decline, but, I would assume, that you have to refer.

Ms HAYSOM: No, you just have to not impede patient's access to treatment.

Hon ROBIN CHAPPLE: Can you explain what that actually means?

Ms HAYSOM: There is probably a fine line between how impeding access is defined in that regard. I certainly know that doctors who have a moral objection to certain things such as termination of pregnancy, for example, and this happened in Victoria with their abortion legislation, feel very strongly that taking a step to refer someone for that treatment is being complicit in something that they consider to be morally reprehensible. That is the issue with referral. This comment in this regard came up because there was discussion in the Victorian legislation about whether or not there should be a positive duty to refer someone for voluntary assisted dying if you did not morally agree with it. We used the Victorian example of the Abortion Law Reform Act and pointed out that that caused a lot of difficulty for doctors in Victoria who morally objected to termination of pregnancy and, therefore, it should not also apply in Victorian legislation around voluntary assisted dying. We would say that the provisions of the code of conduct are sufficient to guide doctors' behaviour in that regard.

Hon ROBIN CHAPPLE: Were they enshrined in the Victorian legislation?

Ms HAYSOM: In the Abortion Law Reform Act, yes. There is a positive duty to refer. There is not in the Victorian voluntary assisted dying legislation.

The CHAIR: So there is the ability for doctors to refrain but not organisations, is that right?

Ms HAYSOM: In the —

The CHAIR: In the Victorian assisted dying legislation.

[2.30 pm]

Ms HAYSOM: I would have to have a look at the legislation. I am not sure about that.

Mr S.A. MILLMAN: The way the code operates is that if a complaint is made against a practitioner to AHPRA, the conduct will be measured amongst other things, but in part it will be measured against this.

Ms HAYSOM: Yes.

Mr S.A. MILLMAN: Are you aware of or have there been any complaints made to AHPRA against practitioners who have not referred patients who are seeking access to abortion, as an analogy?

Mr EDWARDS-SMITH: I am not aware of any particular cases, but I would suspect that there probably are.

Ms HAYSOM: Yes. I think there were some in Victoria actually, not in WA.

Mr S.A. MILLMAN: Yes, I accept that.

The CHAIR: Would they also need to let the patient know that the services are available?

Mr EDWARDS-SMITH: I suppose that comes within the auspices of not impeding the patient's access to that treatment. I think, arguably, perhaps, yes, "I do not agree with this particular approach; however, there are other practitioners." Of course, I think the code actually steps in to not compel the doctor, or to allow the doctor to not do the onward referral, but I think, at the end of the day, there is some scope for making sure the doctor does not get in the way of the patient actually receiving the service that they object to.

Hon NICK GOIRAN: So getting in the way would be if a practitioner specifically said to somebody that it was not lawful to do something that is lawful?

Mr EDWARDS–SMITH: Absolutely, or “Nobody I know does this; you’re not going to get that service here in WA” for instance, as opposed to “I’m a conscientious objector in relation to this treatment; you will need to go and see another practitioner” but then obviously not going as far as facilitating the referral off to a service, for instance, to actually have that done. It is a very fine line, but I think it is a very important one for practitioners to allow them, with respect, to conscientiously object and to not be tarred with having to be involved in something that they are opposed to.

Hon COLIN HOLT: Have you had any complaints in that sense?

Mr EDWARDS–SMITH: From patients in relation to doctors who conscientiously object? I am not aware of any.

Ms HAYSOM: I have had a few over the years, yes.

Hon COLIN HOLT: Can you walk me through an example?

Ms HAYSOM: I am sure I have had some in relation to termination of pregnancy. I have certainly had some in relation to sexuality issues where there is an allegation at least that the doctor did not treat the patient properly in regards to their sexuality and was asking inappropriate questions and that sort of thing. The complaint was that the doctor was alleged to have said that they did not agree with homosexuality and therefore would not treat the patient. That was the allegation. There was a dispute about the facts of that case, but certainly there have been cases like that.

The CHAIR: I just want to go back to the legal framework. You said in your submission WA should consider harmonisation of laws with other states. Given the discrepancy between the laws, is there a state that stands out as particularly good in this area?

Ms HAYSOM: I have been asked that question before and I do not have a good answer to it. My pipedream —

Mr EDWARDS–SMITH: Hopefully, she can say WA in due course!

Ms HAYSOM: Yes, that is it—harmonise legislation. The difficulty is that Victoria has had new legislation about the Medical Treatment Planning and Decisions Act and it has a new regime for advance care directives and it has new terminology—values directives, instructional directives. New South Wales is looking at their Guardianship Act. You may have seen the New South Wales Law Reform Commission’s report on that, and they are suggesting another lot of terminology which is for end-of-life and guardianship-type things, which is an enduring representation agreement to replace guardianship and powers of attorney. I think it probably is a pipedream, but that would be the ideal, because doctors find it really difficult. They do not understand the terminology; and, then, if they are travelling around, they have to work out in this jurisdiction, is it a guardian; in this jurisdiction, is it a power of attorney or an enduring representative; and is it an advance health directive or an advance care directive or a statutory health attorney or what have you. It gets very confusing.

The CHAIR: On advance healthcare planning and those instruments, what is the general view of your members of advance health directives?

Ms HAYSOM: I think there is a range of views about them. There is misunderstanding, as I mentioned before I think, about whether or not you need to comply with them. I was at a training session for some junior doctors a couple of weeks ago and asked the question “What do you do in an advance care directive; do you have to follow a valid advance care directive?”, and more than one person said no. Actually, the law is quite clear that if you have a valid advance care directive

that applies to the circumstances, you need to follow it as an expression of the patient's wishes and an exercise of their autonomy. There are those sorts of things that come up from time to time where they have a misunderstanding about the validity and legality of advance care directives.

The CHAIR: If and until the harmonisation of laws does occur in Australia, do you think it would be useful if there was a central electronic registry in Western Australia for the storage of advance health directives?

Mr EDWARDS–SMITH: Yes. Ultimately, I think the first issue in relation to complying with an advance care directive is actually knowing it exists and, secondly, being able to find it. It would be useful to have some mechanism by which practitioners can access them fairly quickly. I will note that there is provision for that to occur in the national My Health Record system. Obviously, if that was taken up, there would not be the need for a separate WA standalone provision for that. I think that would be the ideal—that they were all housed in one particular spot that doctors knew where to look. As we have already pointed out, these are highly stressful, tense situations that we are talking about. To the extent that we can make it easier in making laws and setting up systems for doctors to make good decisions and access resources, that is what we should be doing.

Hon COLIN HOLT: We have heard some evidence that the take-up rate of advance healthcare directives is very, very low. Do you have any views on why that is? From a legal practitioner's viewpoint probably, it would be interesting. What do you think of them actually? That would be good.

Ms HAYSOM: I think there is an increase in understanding and awareness of advance care directives and there has been an increase over the last few years. There are various organisations that are trying to push for people to be involved in advance care planning as a process, with the advance care directives being the end result. My understanding is that there is a push for that and that is increasing. The effectiveness of them depends on how well they are drafted and what they say. So, having a broad expression that someone does not want extraordinary measures at the end of life is not particularly helpful from a clinical perspective, because what does that mean when someone is in the ICU or the emergency department with a cardiac arrest or something? Their usefulness depends on how they are drafted.

The CHAIR: We have actually heard some evidence that, rather than health care directives being the end process of the planning, health care plans are an alternative to health care directives. Have you got any views on that or why that might be the case?

Ms HAYSOM: I think the notion of advance care planning is to have a whole process and a holistic process that outlines the patient's wishes, desires and beliefs and general values which can help guide decision-making. I think there is a school of thought that that is a better thing than having a form that just lists various treatments that may or may not apply in the circumstances, because it is more holistic and it can be shared with patients, their families and clinical teams—assuming you can find it. It would be a much better guide to what the patient actually wants to happen at the end of life.

Mr EDWARDS–SMITH: I think, ultimately, it is important to get to a point that the patient's intention is able to be conveyed to the practitioner in a reasonably clear way. I think the care planning is a better process for actually creating a better picture, but you do need to get to a point that it is actually clear enough for the practitioner to use at the end of the day. I think that is an important point. I suppose the care planning is a really good process to get to the point of whether it is a care directive or whether it is something else to make it clear enough. The difficulty would be that you have a care plan that is quite flowery and has lots of information in there and lots of thought

processes, but ultimately does not help the practitioner, at the pointy end of making a decision, come to a conclusion as to what the patient wants. That would be my concern.

The CHAIR: Would you consider a care plan legally binding?

Ms HAYSOM: I think it is a guide. Again, it depends on how it is worded. A plan in itself will not be binding, I do not think. I think a directive that has a clear statement of the treatment they do and do not want to have, and that can be part of the care plan, is most likely to be binding. But the good thing about a care plan is that where you have a substitute decision-maker making the decision, then they have an understanding of the patient's desires and wishes, and can make decisions to respect that.

[2.40 pm]

The CHAIR: What do you think can be done to improve medical practitioners' understanding of healthcare directives and enduring powers of guardianship?

Ms HAYSOM: Education.

The CHAIR: Can you elaborate on that? Who do you think is the best place to do that?

Mr EDWARDS–SMITH: We have, I suppose, talked about this long and hard and I would like to say that we have come up with some easy-to-apply template that you can just adopt. I think, ultimately, it is about the scope of the practitioner's career and getting practitioners fairly early and talking about end-of-life stuff, making it part of the curriculum. I do think that the starting point necessarily has to be having very clear laws that are well understood by practitioners and then having centralised resources. Practitioners need to know where they can access this information if they are at all confused about what the legal position is. The other point is that for some practitioners, this is bread and butter; this is stuff that they deal with every day if they are working within palliative care. But for a lot of practitioners, this is stuff that they are going to see infrequently, and so, like anything that we do, if you are seeing it infrequently, you need to be able to pull something out and get to the bottom of it. I think you need to incorporate all of that into an awareness campaign with good, centralised, clear resources and good laws.

Ms HAYSOM: The Public Advocate has good resources in Western Australia that we refer our members to.

Mr EDWARDS–SMITH: Absolutely.

Ms HAYSOM: So that is one place to start, as well as universities. I know there is some work being done in some of the universities—the Queensland University of Technology—on some education materials for doctors at the end of life, and that is a good start, too.

Hon ROBIN CHAPPLE: I have a couple of questions, if I may. You said that there were 75 000 doctors in Australia which your organisation sort of represents. How many are in WA?

Mr EDWARDS–SMITH: Goodness me; I do not have those figures exactly off the top of my head, member. There is quite a significant number. We are not the largest MDO within WA. We are the largest medical defence organisation Australia-wide, so we have a very large presence on the eastern seaboard, and less of a presence here in WA.

Hon ROBIN CHAPPLE: How many organisations are there?

Mr EDWARDS–SMITH: There are five medical defence organisations. We are the second biggest here in WA. I do not have the exact number of members off the top of my head. I would have to take that question on notice.

Hon ROBIN CHAPPLE: That would be useful. Could you also identify for us—I assume we do not actually know—the other medical defence organisations?

Mr EDWARDS–SMITH: The other medical defence organisations are MDA National —

Hon NICK GOIRAN: They are the largest in WA.

Mr EDWARDS–SMITH: They are the largest in WA. There is ourselves. There is MIGA, which is an organisation that is similar to us. There is MIPS. Then the last one is commercial; they are not a doctor-owned mutual. They are a commercial organisation known as Tego. That is your five medical indemnity insurers in the space.

Hon ROBIN CHAPPLE: It might be useful to find out from our perspective how many people are covered by each one, which might give us some sort of broader information as well.

Mr EDWARDS–SMITH: Of course.

Hon ROBIN CHAPPLE: Thank you for that. My colleagues know what I am going to ask about now! It is becoming a joke. Do not resuscitate. What is your legal view on the definition of “do not resuscitate” that is applied to patients, maybe unknowingly, by medical staff and/or families?

Ms HAYSOM: When applied unknown to families and to patients —

Hon ROBIN CHAPPLE: Not necessarily unknown to families, but unknown to the patient.

Ms HAYSOM: Unknown to the patient, for competent patients?

Hon ROBIN CHAPPLE: Yes, but I suppose you —

Ms HAYSOM: Sorry; clearly a “do not resuscitate” means they are not going to be competent, are they? But is it a decision taken by the family for an incompetent patient?

Hon ROBIN CHAPPLE: Yes, in that regard, but also the doctor in consultation, “Aunt Mabel is not going to survive if we do this too many times; my recommendation is that we put on a DNR.”

Ms HAYSOM: Yes. Sorry; I beg your pardon—the question was?

Hon ROBIN CHAPPLE: I am trying to work out the potential legal ramifications of that decision in a court of law. Say one family group and the doctor decides to put on a DNR and Aunt Mabel’s husband finds out this has gone on and he wants to challenge it. What is the legal status of the DNR?

Ms HAYSOM: A “do not resuscitate” order is like any other treatment decision, to my mind. To give you a little bit of the history, traditionally I think “do not resuscitate” orders or “not for resuscitation” orders were orders that were imposed on people by the medical staff way back. I think that caused a lot of concern. There has been a move away from that sort of paternalistic approach over the last 30 or 40 years to more shared decision-making and respecting patients’ autonomy. Certainly in New South Wales, the current guidelines around “not for resuscitation” orders are that they should be part of the advance care planning process and they should be as part of a shared decision-making process with the patient beforehand, as I said, as part of the advance care planning process. It should be one of the instructions that is given. If the patient is not competent, then it should be dealt with by the family, again as a shared decision-making process with the correct substitute decision-maker making the decision together with the medical practitioners, within the framework of whether or not it is going to be beneficial or futile treatment.

Hon ROBIN CHAPPLE: The next point arising from that is: what evaluation does the medical professional take in ensuring that the wishes of the relatives are not for other purposes?

Ms HAYSOM: I think you would have to ask medical professionals who are involved in these decisions that question.

Hon NICK GOIRAN: He has!

Hon ROBIN CHAPPLE: We have!

Ms HAYSOM: I do not think we can comment on that as an insurer, because we are not involved in those decisions.

Hon ROBIN CHAPPLE: It is obviously not common, but Aunt Mabel just won Lotto last week. I am sorry I keep on talking about Aunt Mabel!

The CHAIR: She has been resuscitated many times!

Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via y these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript. The committee will write to you with the questions taken on notice during the hearing. Thank you both very much for making time to be with us this afternoon.

Hearing concluded at 2.47 pm
