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 TWO

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 10.58 am

Dr OMAR KHORSHID

President, Australian Medical Association, examined:

Dr KATHARINE NOONAN

Policy and Research Lead (Clinical), Australian Medical Association, examined:

The CHAIR: 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. 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 the current arrangements for end-of-life choices and identify 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. However, 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. Could you both please introduce yourselves for the record?

The CHAIR: Do either of you have any questions about your attendance here today?

Dr KHORSHID: No.

The CHAIR: Before we move to our questions, did you want to make an opening statement?

Dr KHORSHID: I would like to. Thank you very much.

I would like to thank the committee for the opportunity to present here today and to answer questions on behalf of the AMA and the medical profession in Western Australia. The AMA in WA, as you know, is the state's peak medical body and the only independent organisation representing WA doctors as a whole. The role of the doctor is to provide care and support for patients in every stage of life—in health, in illness, and in death. We do this every day and in most circumstances we are able to make a meaningful difference to our patient's quality of life. We acknowledge and agree that there is a need, both within the medical profession and in the community, for an open and frank discussion around death and dying, including palliative care, end-of-life choices, approaches to futile treatment and bereavement. We support debate around end-of-life choices. Our main role, as we see it, is to ensure that it is an informed debate which includes all of the issues around end-of-life care, not just a narrower discussion around euthanasia. We, in our opinion, must not move towards euthanasia as a cheaper or easier alternative to proper end-of-life care.

The medical profession over the last several generations has made huge advances in technology, medicines and care, such that life expectancy has increased enormously and so has quality of life for people living with chronic diseases. This has been achieved whilst following our strict code of ethics, most famously laid down by Hippocrates. That concept, primum non nocere, or first do no harm, is ingrained into our profession—into our psyche—and remains a key concept in the current declaration that every young doctor makes on joining the medical profession. This Declaration of Geneva states that doctors will have the utmost respect for human life. Whilst it may be debated about what that actually means, medical ethics and the law have created a clear line between ethical and unethical conduct, between legal and illegal conduct. This ethical framework has protected our patients for the entire history of medicine and explains the medical profession's general reluctance

to be involved in the deliberate ending of a patient's life, even when it seems to be the right thing to do and in the interest of a patient, and even when there is significant public support for that sort of change. The reality, though, is that it is not a clear line. It is grey—maybe wobbly—and many doctors would agree that there are circumstances where voluntary euthanasia or assisted suicide is both ethical and in the interest of the patient. However, many other doctors are concerned about the implications of crossing that line. What does it do to our society? What will it do to our profession—our ethics? How do we protect the vulnerable in the community? Do I have the right to ask someone else to end my life? How much will I harm that other person in making that request? These are key questions that in our opinion need to be considered. The AMA has made a couple of submissions already including the federal AMA's policy on euthanasia and physician-assisted suicide that I am sure you have all read. That came out of a long process of engagement with our members nationally and a lot of debate within the AMA itself. We also provided a brief submission subsequent to that proposing our general approach as a Western Australian AMA. For the information of the committee, we are also holding a symposium of our members in early May. We hope to be able to share the detailed outcomes of that symposium with the committee in due course. As I have mentioned, this is a very emotive and difficult discussion within the medical profession. We feel it is important that our members have the opportunity to be heard and to inform the general debate. At the end of the day it is not the role of the medical profession to dictate the answers in this debate. We want to be involved in the conversation to ensure that all the issues are addressed and to continue our key roles of caring and supporting our patients in all stages of their lives and protecting the vulnerable in the community.

The CHAIR: We will move to some questions around palliative care. I understand that you have had some prior notice of some of the questions. In which ways do you think palliative care could be better integrated across the WA health services?

Dr KHORSHID: Palliative care is something that occurs right throughout medicine. It is not a defined specialty that only occurs with palliative care physicians in palliative care settings. It is a concept that occurs in my practice of orthopaedics, in general practice, in hospitals, in cancer care—everywhere. It is integrated in that it is a part of our everyday life. However, the reality is that there are varying levels of skill and levels of understanding of palliative care issues amongst doctors. Access to palliative care specialists and palliative care teams variable in different sectors of the community and in particular in different geographic areas. The preliminary information we have had back from our members is that that variation does occur on a geographic basis. It is harder to access in rural areas, as you might expect. No great surprise there. It is harder to access for certain patients than others. Cancer patients have a formalised access to palliative care. Patients with other end-of-life conditions may have less obvious mechanisms of accessing appropriate palliative care. There is, of course, as is always the case in medicine, the public/private divide and the different funders which sometimes makes it complicated as to how patients can access care and how care is communicated between the different sectors.

We are aware that palliative care in Western Australia is generally better than the other states—is the feeling that comes back and the feedback we get from our members. The Silver Chain service in particular is a high-quality service and well supported by our members who are involved in the sector. We have had feedback that communication and involvement of general practitioners with palliative care services delivered through Silver Chain could be better. That is, again, not a special situation. As we know, with all sorts of specialist care it is often hard to involve general practitioners adequately in that care because of the way our complex health system is organised. Losing a patient to the oncologist and to the big tertiary hospital that a general practitioner might experience continues to some extent as a patient moves into the formal palliative care realm. We believe that

there is a big place for general practice in palliative care service delivery and if that can be integrated better into what our hospitals do, what our hospices do and what Silver Chain does, then we would have a better palliative care system.

Dr NOONAN: With the involvement of general practitioners, that better communication would, in terms of it being better, prevent unnecessary admissions at the end of life as well as investigations and things that may be distressing to patients at the end of that journey. That is the end goal of better communication, I think.

Mr J.E. McGRATH: Further to that question, we are also told that GPs at the moment are stretched to the limit. Would they have the time to take on more palliative care work, given the fact that a lot of people cannot even get into see some GPs. They are full up.

Dr KHORSHID: Some GPs are full up, but evidence that we are aware of suggests that there is a lot of access to general practice—unfilled appointments and things—but it is probably not with the kinds of doctors who are actively involved in palliative care. Those, what you might call good doctors, that have that holistic view and follow a patient all the way through their life including a to palliative care—they are very popular doctors and they are booked out. Yes, there is a challenge in service delivery there. We just heard in the sustainable health review interim report yesterday that WA has low numbers of general practitioners per head of population and we need to both increase the size and upskill our general practice workforce in order to address this and the other chronic disease challenges that are ahead of us.

The CHAIR: Are you able to provide some examples of where that lack of communication between specialists and GPs would result in a less ideal outcome for a patient?

Dr NOONAN: I have an anecdote I have been discussing quite a lot with different general practitioners who have an interest in palliative care. Her example was that one of her patients was diagnosed with cancer and then referred to an oncologist. She is regional in Rockingham so, obviously, a lot of the specialist treatment was happening in Perth. It was quite difficult to know what was happening with that patient and the patient basically assumed that the GP was being kept informed by the oncologist. At the very end of that story that patient subsequently passed away and she heard from a family member that that patient had died. There was not any communication there. That is one aspect that is obviously an extreme breakdown of communication.

Dr KHORSHID: Sometimes GPs have mentioned to us too that they may not be aware of the goals of care. Sometimes the way that some specialists communicate—they communicate in their own jargon and do not necessarily go back to the broad goals of treatment. We hope a good doctor would always step back to the patient and say, "What do you want out of this treatment?"

Sometimes it is not adequately communicated to GPs. They may not be aware of whether a patient is in an active treatment phase or progressing into a palliative phase and may then inappropriately refer the patient back to acute services when, in fact, that should not occur. It is a common problem in our split and complex health system that what occurs in our institutions is not easily communicated back to the GPs out in the regions who are closer to the patients.

[11.10 am]

The CHAIR: Would there be examples of perhaps tensions between other specialists—obviously, we have just talked about the GP specialists—treating that patient that may interfere with palliative outcomes?

Dr KHORSHID: Health care is team-based these days, and particularly in areas like cancer, where these discussions are commonly had, there are formal discussions around treatment options, around goals and around integrating palliative options into, for instance, cancer care. Will the

practitioners always agree and always communicate properly? Probably not. The reality is that we have a complex system; everyone is very busy; in particular, cancer services are stretched. So, I am sure there are examples, and you have probably heard them in your submissions so far, of people who have experienced conflict between their doctors or poor communication over goals of care. But on the whole I think it is fair to say that all doctors—in particular those doctors who work in areas where these discussions are had frequently, like oncologists, palliative care doctors—are experienced at team-based care. They understand that there will be differences of opinion. At the end of the day, these decisions are for patients to make in conjunction with their doctors; it is not for doctors to make on behalf of patients.

Hon ROBIN CHAPPLE: Just on palliative care again, we heard that there are somewhere between 40 and 60 what we call specialist care specialists and they are associated with palliative care organisations and also the Catholic Church. We have heard that a number of other people are providing palliative care services. Do you actually have any data around who is providing palliative care services in a broader sense, as opposed to the specialists?

Dr KHORSHID: Correct me if I am wrong here, Katherine, but I do not believe we have data. We do not have a mechanism to capture that. But we can say confidently that palliative care issues come up in almost every specialty. They come up in my specialty of orthopaedics, where you would think it would not come up much. But, in fact, if we see a 90-year-old who has broken their hip, we perform a palliative operation in order to reduce their symptoms for their last period of life and improve their quality of life. These discussions are right across every sphere of medicine and particularly general practice. They come up in paediatrics, cardiology and respiratory medicine all the time. One of the issues that we would like to see promoted is that discussions around goals of care and around death and dying are more easily had and that doctors are better skilled at having those discussions at the appropriate time—not leaving it until it is too late or the patient is no longer competent to make decisions before you have a broad discussion around what the patient's wishes are or what theirs goals of care are.

The CHAIR: We have seen a survey in 2015 of around 1 800 patients that identified that around one to two per cent of patients have refractory symptoms around the end of life that are unmanageable. In your view, is that about right, or do you have access to other data?

Dr KHORSHID: We do not have access to other data, but it is clear with every medical treatment that they do not always work, as I am sure everyone in the community has experienced. We have treatments; they have effects, they have side effects and they have failure rates. That applies to palliative care as well. We cannot absolutely guarantee that every single patient will have the end of life experience that they want. It is just not the reality of life. End of life can be a fantastic experience for a family. It can be awful. That is the reality. We do our best with the tools that we have to alleviate suffering. That is one of those ethical principles that I mentioned at the start. Palliative care physicians and specialists are extremely skilled at that. But I think they would agree, and I am sure you have heard from experts already, that there are some patients for whom our treatments do not provide the level of symptom relief that they would like or that their families would like.

Hon NICK GOIRAN: Dr Khorshid, you mentioned at the outset that there is a need to increase the size of the cohort of GPs in Western Australia and also to upskill them. Is the AMA in a position to suggest any recommendations that the committee should make in respect to making that happen?

Dr KHORSHID: Yes. We would support increasing the training opportunities both in number and in quality for general practice, and in fact other specialties. We know we have 330-something interns starting in the system this year. We are soon going to have over 400 graduates from a medical school in Western Australia when the Curtin Medical School comes online. We have a supply of young

doctors and we need to turn them into highly skilled specialists whether it be in general practice or in all the other areas. The reality is that there are not enough quality training positions for those doctors, as we understand it—nowhere near enough. This is not just specific to palliative care, but in fact in general we need to make sure that those training opportunities are developed in time for these young doctors to be able to be turned into the care deliverers that we need in the community. That in particular applies to general practice. It is not easy as a state because it is a federally-run system, but whatever the committee can recommend to ensure that the number of GP training positions is increased is supported. Specific to this area, I think it is fair to say that there could be better teaching and integration of palliative care principles into all of the medical specialties. It is not explicitly taught in specialist training in many areas and it could be and should be. Speaking as an educator myself, having recently gone through a curriculum review process, we brought up end-of-life care in discussions but we have not probably done enough in terms of formal training in skills and discussions around end-of-life care.

Hon NICK GOIRAN: Just on the curriculum issue, is that something that is really for the medical schools to address, rather than government?

Dr KHORSHID: The government can make recommendations for the medical schools and for the specialist colleges to consider. I am sure there is teaching of palliative care at medical schools, but there is a long time lag from graduating from medical school and being a GP or a specialist in the community. It is that specialist training that I am talking about, the college-based training, that perhaps could focus a little bit more on end-of-life discussions and also skills in relieving symptoms. We do not want to rely on that small 40 to 60 people to deliver all palliative care. There is too much of it needed.

Hon NICK GOIRAN: That college training that you are talking about and the need for there to be more of these training positions, can you just talk us through that? What are these training positions? How did they come about? Is there something that the committee can recommend that can expediently create more training positions?

Dr KHORSHID: That is a very good question. The state system is responsible for a lot of medical specialist training. In most of the hospital-type specialties, that is entirely within the power of the state, because they control the public hospitals where the majority of training happens, and by collaborating with colleges, new training positions can relatively easily be created, but they cost money. The health department produced a junior doctor business case some years ago, which was presented and supported by a previous government. But the cost of delivering that increase in medical training in order to provide the appropriate training for the graduates at medical schools is enormous. It is billions of dollars. So, it is not an easy thing to do. In general practice, it is probably a little bit harder for the state because you do not control employment and the size of the services. It is a private sector environment. But I am sure, again, by collaborating with the commonwealth government and the College of General Practitioners, if the state says, "We need to increase our supply of general practice graduates for our community", that could be achieved.

[11.20 am]

Hon NICK GOIRAN: Would a trainee potentially do some of their training in a GP practice?

Dr KHORSHID: Medical students do some training in a GP practice, and some other specialists do a little bit of training in general practice. But general practice training itself is mostly in general practice, so the trainees go out into general practice. They spend a little bit of time in hospitals, but they go out into general practice for most of their training and get on-the-job training with GPs. That environment and the cost of that is funded by the federal government.

Hon NICK GOIRAN: Right, so the general practice itself does not contribute towards the cost of that; they contribute the skill and the training?

Dr KHORSHID: They employ the doctors, the trainees. They deliver services through Medicare and private billing, as generally occurs, and there is some funding provided by the commonwealth to support that arrangement and to make sure the GP has time to adequately supervise and teach the GP registrar, because time is money and GPs are not in a position to reduce their practice throughput or their income without some compensation. The government does step up and help, but a lot of the cost of employment of the GP registrars is met by delivery of care through Medicare.

The CHAIR: I want to move on to the doctrine of double effect. In this instance, it is in relation to pain-relieving medications at end of life; I realise that it is applied throughout medicine. In your experience, do medical practitioners rely on the doctrine of double effect when administering pain relieving or sedating medications to patients at the end of their lives?

Dr KHORSHID: The short answer is yes. It is a common occurrence, remembering that according to our medical board's code of conduct—"Good Medical Practice: A Code of Conduct for Doctors in Australia"—our focus at the end of life is relieving symptoms. According to the doctrine of double effect, as you know, if a patient is at that end-of-life time and a treatment is provided in good faith to relieve symptoms and it may or may not reduce the length of life, the doctor is protected. Whilst this has been a topic of contention in the past, we are not aware of any doctors who have been prosecuted in Western Australia for doing that in good faith. So, we do not believe there is a problem with the laws as they stand, and we believe that doctors are able to provide adequate pain relief and symptom relief to patients at that phase of life under current rules.

The CHAIR: Okay; that was my next question. Do you think the current laws in Western Australia provide adequate protection for doctors relying on the doctrine of double effect? So, yes?

Dr KHORSHID: Yes.

The CHAIR: Where potentially double effect is relied upon, is there any reference to the medication recorded as the potential cause of death on the death certificate?

Dr KHORSHID: We do not have access to death certificates, so I cannot give you a black-and-white answer. I can give you an answer from my experience and in general using logic, which is no; it would very rarely, if ever, be recorded as contributing to the death, because it is the disease that led to the death. The medication was provided in order to relieve symptoms. You would never know whether the medication itself contributed to death or not, and it is really not that relevant. When you look at why we report deaths to the coroner and why we put information on a death certificate, there is a purpose behind that, and that purpose is not aided by saying, "We gave them morphine; that might've contributed". Similarly, when we get very young doctors who sometimes do not know the purpose behind death certificates, you will see as cause of death, "Cardiac arrest". Well, yes, sure, that is great, the heart has stopped, but actually that is not the cause of death. What we want to know is: was there a respiratory disease, was it cancer, was it trauma? What was the ultimate cause of death? That is what is needed to be recorded on a death certificate, not the method by which you got there and what happened along the way.

The CHAIR: Okay. In relation to the administration of opioids, there are differing views out there as to whether it does shorten life. Do you have a view on whether or not administering gradually titrated sedatives or opiates is likely to hasten death?

Dr KHORSHID: Opiates have variable but reasonably predictable effects on respiration and consciousness, and if given in adequate dose they will always cause death. However, we do not have any data to definitively answer whether the administration, as you have mentioned, of gradually titrated sedatives or opiates brings on death quicker than it would have or not; it will be extremely

dependent on the circumstances. In my view there would be circumstances where if a patient's symptoms are severe and high doses of opiates are needed to control those symptoms, then you are getting very close to that line where respiration ceases or becomes so slow that it cannot support the body's functions anymore. But that is part of dying, and we do not really believe it is that relevant to this conversation, as long as a patient is dying and is in those last hours or days of death with severe symptoms, whether the death is brought forward by an hour or a day. It is really not relevant. What is relevant is the patient's quality of life, how distressed they are, and how the family is able to be around the patient. Sometimes we may have a desire to keep someone going so that family can come in from overseas or interstate. It is a complex time and a very difficult and emotional time. The length of life and whether life was shortened or not is probably very low on the list of considerations at that time.

The CHAIR: Given the mixed views on opiates and whether they do shorten the process of death or not, do you think many doctors are under-dosing opiates at end of life?

Dr KHORSHID: We have no data, so this is very much an opinion. It is possible that some patients have refractory symptoms due to under-dosing, but we do not believe that is because doctors are afraid to deliver appropriate doses. Some doctors may have a philosophical issue with giving so much opiate that they believe they might be bringing forward death. There may be some doctors who are in that position. But it is very clear from our code of conduct under the Medical Board of Australia and for our ethics that our job is to support the patient and reduce their symptoms. In my view, it is highly unlikely that it is a common occurrence for doctors to under-dose patients deliberately in order to protect themselves. I think that is very unlikely.

The CHAIR: Okay. In relation to terminal sedation, we have received evidence regarding this practice. Do your members ever raise concerns regarding the practice of terminal sedation?

Dr KHORSHID: No, we have not received any member concerns around terminal sedation, and I have to say I had not even really heard of it as a label until this question came forward. As I understand it, in the extreme end of life with severe, severe symptoms, it appears that what is being discussed is the use of agents to cease those symptoms but also bring about unconsciousness. I believe that is what you are talking about. Again, the purpose of that is to relieve suffering. Really, you are at the very, very end of life, so we would not consider that to be an anaesthetic; we would not consider that to be an inappropriate treatment. That is a doctor, in consultation with patient and family, trying to do their best to relieve suffering, which is what we are there for.

The CHAIR: Can you describe the difference between sedation at the very terminal end of life to relieve that suffering and a patient who has requested voluntary assistance to die?

Dr KHORSHID: Sorry, can you repeat the question?

The CHAIR: Can you describe your position on the scenario where someone at the very terminal end of their illness is sedated to make them comfortable, and a patient who has requested voluntary assistance to die at the very terminal end?

Dr KHORSHID: The terminal sedation occurs when a patient is dying. In our view, a discussion around voluntary assisted dying or assisted suicide in any of its forms is not really about that group of patients who are dying, in their last day or couple of days of life, because they are going to die anyway and we have the choice of do we relieve their suffering or not, and of course we do. In our view, terminal sedation is completely different to somebody who is not in imminent danger of dying who requests assistance with dying in one form or another. We would not consider terminal sedation to be voluntary assisted dying; it is relieving symptoms at the very, very end of life.

[11.30 am]

Hon ROBIN CHAPPLE: Just on that, if you have a patient who, towards the end of their life, determines that they do not want to have any more sustenance or hydration and they request that be removed, you then would most probably sedate that person to alleviate the suffering. Is that the case?

Dr KHORSHID: If it is necessary. It is really a common occurrence for patients at the end of life to cease eating and potentially cease drinking. That is part of dying, depending on the cause. If in the course of that they then become symptomatic in some way, which is often the case, then, yes, symptom relief will be provided, and in rare cases that might include sedation. But I do not think it is a common practice to say, "Ok, we're in the terminal phase here; let's crank up the sedation and end their life quicker." That is not common practice. It may occur in isolated examples where it is the opinion of everybody that it is the right thing to do for the patient, but it is about relieving symptoms, and if they develop severe symptoms, you have to do whatever you can in order to help them.

Hon ROBIN CHAPPLE: When you have a family who say, in consultation with the relevant doctor, "Jimmy's got no chance left; do whatever you can to make the passing as quick and comfortable as possible", would that be a conversation that occurs?

Dr KHORSHID: That is a conversation that occurs. The difficulty is around the "quick". We would consider that if you are in a terminal situation, it is nature taking its course. We may intervene to alter that outcome very slightly in terms of the length of life or the quality of life, but it is nature taking its course. Some doctors might struggle with the idea, "Ok, it's terminal; I want it to be quick". That is something that some doctors may feel comfortable with because it is a logical thing to want—if you perceive there is some suffering going on, you want that suffering to be as brief as possible—but the majority of our members in my opinion would be seeking to relieve symptoms and not too worried about whether that meant they live an hour or a day or a week. But as long as you are relieving their symptoms and there is no overt sign of distress, then nature can take its course. That is entirely legal, ethical and appropriate.

Hon ROBIN CHAPPLE: Following on from that, when you may have that consultation at the end of life with family members about the process of enhanced dying, should we say—I am trying to use a word that covers it all—do you evaluate the motivation of the family members: "Aunt Mable's got a lot of money, we want to get there quick"?

Dr KHORSHID: I think this question is not so much around the very end of life because you cannot alter the outcome—it is the end of life and it is happening in the next couple of days or hours or whatever. Where that comes up is with advance care directives, guardianship orders, with decisions around end of life happening a little earlier, where we know, unfortunately, that in rare circumstances families do have different motivations to each other. The different family members may be in conflict and the wellbeing of the patient may not be the number one factor in rare circumstances. We do our best to evaluate that in helping a family make a decision where there is conflict. Thankfully, that is rare. The majority of families, they may have different views around the approach to palliative care or whether intervention should occur or not—should the 90-year-old patient with cancer have an operation to cure the cancer or not? That is something that the different family members will have different views on. If the patient is unable to make the decision due to their cognitive state or being unwell, then the doctors are in a position where they have to balance what they perceive to be the motivations and try to make the correct decision with the family. But it is probably more at that time and not at the very end of life, where it really makes no difference.

The CHAIR: With regards to palliated starvation, which is where a competent person at the end of their life chooses to refuse all nutrition but continues to receive pain relief and medications, have your members ever raised concerns regarding this practice?

Dr KHORSHID: Not to my knowledge. As I stated before, the practice of a patient choosing not to eat or drink is common. The withdrawal of sustenance by a family or by the doctors when someone is unable to make a decision—for instance, someone has had a massive stroke and cannot safely eat or drink—is a difficult decision because we can prolong people's lives by undertaking invasive medical treatments for a long time. But is that appropriate? That is a complex decision, and that is where advance planning and discussions well ahead of that occurrence are so important so that you are not stuck in a position with family members who have different views and a doctor saying, "Should we put a tube directly into the stomach and provide feeding or not?", because clearly if you do not, that patient will die. Do our members come to us worried about that? No. I think they feel they are doing the right things. They have these conversations on a regular basis. It would be in very, very rare circumstances that it comes to major conflict.

The CHAIR: In the circumstance where that were the case and the patient died, what would be recorded on the death certificate?

Dr KHORSHID: It probably depends on the context. The death certificate has to record what is legally required on a death certificate—the ultimate cause of death. In the example I gave, the cause of death would be stroke. Whether the doctor would put starvation on there, I do not think they would, because the cause of death was the stroke and you are letting nature take its course. We are failing to intervene, on discussion with the family, but we are not causing that patient to not eat. I do not believe it would be recorded. There may be circumstances where the course of the disease is much longer and where a decision by a patient is taken not to eat—you mentioned an example here—and in that case you may well put it on the death certificate because the cause of death was not the original pathology; it was starvation.

Hon ROBIN CHAPPLE: We heard a quote previously about the "activity of dying". I am trying to work out the time line for the activity of dying. It was identified that it could be an hour. We do not get the idea that as a doctor you can say that this person is going to die in three and a half days, or whatever. Is there some way of determining what may or may not be the activity of dying? You have a pulse rate reducing and this sort of thing happening. What are the time lines around that?

Dr KHORSHID: That is a very difficult question and I do not know quite how to answer it. I think dying is extremely different depending on the cause of the dying. People's causes are different and the patient and their relatives may have different perceptions about when the dying occurs. We do not have a definition that I am aware of of "dying". There is no pulse rate or respiratory rate or oxygen saturation number that says that you are now dying. We are measuring a complex set of variables and using our experience and knowledge to predict the future. But sometimes those predictions are wrong. Sometimes you will have a doctor who will say, "You've got a day to live; sort out your affairs", and the patient is still going a year later. We make mistakes, and that is one of the complexities in this area. Somebody thinks they have got a certain period of time but that could be completely wrong—the diagnosis can be wrong, the prognosis can be wrong and strange things happen. That is the reality of dealing with people. I certainly cannot provide you with a clear hard and fast, black and white definition of when dying starts. I can tell you when it finishes—that is a little easier.

Hon ROBIN CHAPPLE: Actually, explain that!

The CHAIR: We will move to futility. Doctors are not under an obligation to administer medical treatment, including life-sustaining treatment, for a patient in their care if on the exercise of good faith and competent clinical judgement they consider that the medical treatment would be futile. A Canadian study found that there was a lot of confusion around doctors, particularly in the ICU, around what would be futile treatment. Do you think we would find a similar result in Western Australia?

Dr KHORSHID: Yes. There is a significant variation in everything in life. We are in a very unstable world and it is absolutely true that it is impossible to come up with a completely concrete and universally agreed definition of "futility". Different doctors will have different opinions about when a treatment is futile or not. That might come from their own ethical framework, it might come from optimism that is unfounded, or it might come from personal experiences and so on. Doctors are people, and these decisions are made in consultation with families.

[11.40 am]

I think that is the key. What we are doing as a doctor is not saying we are going to do this or we are not going to do that, we say, "Look, these are the treatment options. We can't tell you for sure, but these are the likely outcomes." At the end of the day, it is for families and doctors together to make appropriate decisions. Sometimes families have unrealistic expectations and doctors may override those and say, "Look, we understand where you're coming from but this treatment has a zero per cent chance of working. We are under no obligation to provide it." Sometimes it is provided because it seems to be on balance the best thing to do, even though the doctor knows the treatment is futile, but because it will make that family or that patient happier. There are lots of examples I can think of where individual doctors disagree. You might have a surgeon who thinks that a life-saving procedure on a very elderly patient is absolutely necessary and must happen now. You might have an anaesthetist or an intensivist who says, "Hang on a minute. This patient is 95. What's their predicted outcome here? What's going to happen?" Sometimes there is a discussion that goes on and a different decision is made. The patient is removed from the waiting list, the doctors go and talk to the family and change the treatment decision because there might have been an overly optimistic surgeon. That is one example, and it is actually quite a common example. But the key is for the doctors to communicate. No one of us is the arbiter of what is futile and what is not, and it is a conversation that has to happen between the patient, if they are competent; if they are not competent, then with the appropriate family members or guardians and in the treating team.

The CHAIR: We have had some submissions and some evidence before the committee that indicate that the assessment of futility of medical treatment is quite a fraught issue for aged people and people with severe disability. Can you suggest any ways by which we can improve that experience for those people and their families? We had some evidence yesterday from a woman whose daughter had Rett syndrome and had lived a relatively long life. She was 41 by the time she passed away and had been admitted a number of times to hospital and was offered the option of not providing antibiotics for an infection, for example. We also had some evidence from people with disability that going to hospital settings is quite fraught, in encountering the medical community. What do you think can be done to improve that experience for those people?

Dr KHORSHID: That is another difficult question. I think there are a couple of factors. One is that the conversations around the progression of disease and the likely outcomes are had with patients and families early so that they understand. For instance, with neuromuscular-type disorders pneumonia is a common cause of death—what is it called? The "old people's friend" or something, pneumonia. It is a common way that as your body systems start to shut down, infection sets in in the lungs and it is a rapidly terminal event. That is the future for some people with some of these horrible diseases that we cannot adequately treat. You do not want to be morbid, but that conversation needs to happen at some point so that when it does happen the families are already understanding that they may be at the very end of life. You could still treat and potentially cure that particular issue but it is going to happen again and again, or you may say, "Okay, now's the time." If you have already had a chance to process and think about it, then coming into the hospital setting where everything is so intense and so pressured, you do not have time. We do not have the beds for patients to think about how they want to be treated for days and days and days. We need to treat or not treat and get you

out again because the next patient has to come in. These conversations are best had before, in conjunction with treating teams, general practitioners and family. Can we do better as a hospital system to respect patients' wishes? Yes, we absolutely can. I hope that as we move through a bit of a reform process in the health system that we are able to measure our ability to deliver the care that patients want and expect, rather than what we think or what the government thinks is an appropriate output from the health system. At the end of the day we are there to deliver care, not a certain number of weighted activity units of activity.

Dr NOONAN: May I add quickly to that. Building on that, we need to go back to what "futility" actually means, which is that any intervention will not give a meaningful prolongation of life. That is probably what you are alluding to with people with disabilities or the elderly; obviously, what is meaningful is so subjective. I think that is why it is so important to have conversations with people early about what is important to them, what would having a meaningful life mean to them, and what they are willing to sacrifice or not before coming into hospital, and therefore not facing any judgement by a clinician because their life is not "meaningful". That would be a suggestion as well.

Mr S.A. MILLMAN: One of the things that I am struggling to get my head around is the dynamic nature of the relationship that exists between doctor and patient in circumstances where you have increasing cognitive impairment. You have patients who enter into a conversation with their clinician at the start who have full capacity about how they would like to see things unfold and as that capacity deteriorates, on the part of the clinicians that conversation is necessarily ongoing. To what extent are doctors able to weigh the change in time between what the patient with cognitive capacity said at the start with what the patient at the end is saying in part of that conversation? That is the first part of the question.

The second part of the question is that a lot of witnesses have talked about how important it is to involve the family and carers and everybody else in the decision-making process. My concern around that is patient autonomy. It is a difficult question because it raises all sorts of philosophical issues, but I would like to get a handle on how —

Dr KHORSHID: It is another one of those difficult areas. Clearly, it would be great if the patient and family could have a conversation when they have the cognitive capacity to do so, lay down their wishes and that those wishes would not change. But the reality is that they do change. What you perceive might be the impact of a certain illness on you may be different to actually having the illness and realising. I have certainly in my experience seen patients who say, "I never want that to be done to me." Then it gets done to them anyway and they say, "Thank you for doing that to me. That's really good and I'm glad I'm still here." That is hard to process because you do not necessarily know what it means to be sick or to be in a certain circumstance until you are there. Once you have cognitive impairment that gets much, much harder, and at what point does the patient lose the capacity to make that decision and lose legal competence? That is a grey area and it is why these conversations need to be ongoing and people and doctors need to understand the law and do their best to inform families and patients of that so that you do not end up in a situation where wills are being changed by someone who is significantly demented and looking after one child and not the other one. We unfortunately do see this a little bit. Obviously that applies to their end-of-life choices as well, that once you reach severe dementia you are not capable of making those decisions and your families have to step in for you. If you have made those wishes clear, then hopefully for the family there will be less conflict and everyone will be on the same page as to what to do. If you have not had that conversation as an ongoing conversation, then it is the personal views of family members which may be influenced by other factors.

Autonomy is an absolutely crystal clear; one of those ethical principles that underpin the practice of medicine. We are increasingly recognising that doctors do not know everything and that the sort of

paternalistic approach to medicine is changing over the decades as we change as a society. We want to provide patients with as much autonomy as they can have, but there are limits on that when you have limits to capacity and laws that get in the way of what a patient might actually want.

Hon NICK GOIRAN: Dr Khorshid, I think I heard you say that the point a patient loses cognitive capacity is a grey area. Can you tell the committee what qualifications you say a practitioner should hold in order to make an assessment on capacity?

[11.50 am]

Dr KHORSHID: That is a guestion that I do not think I can answer in detail.

Hon NICK GOIRAN: I should hasten to add that there have been a couple of times this morning where you have said it is a difficult question and so on and so forth. I want you to assure you that it is perfectly acceptable to indicate that you would like to take the question on notice and come back to us, also appreciating that you are representing a very large body of specialists and you have your own specialty as well.

Dr KHORSHID: This is one of the questions that we are going to put to our symposium. When we run the symposium, we want to talk a little bit about ethics and so on, but really we want to also talk about what are the safeguards that if legislative change occurs, how do we protect the community and how do we make sure that we have no unintended consequences, no slippery slopes, no vulnerable patients either being harmed or being subjected to pressure to end their life when it is not what they really deep down want. One of those areas where we need to protect the vulnerable is questions around capacity and legal competence. So we will be having experts speak to us. We are having a debate on that, and perhaps that is a question that we can come back to you on with the AMA's formed view after the symposium.

Hon NICK GOIRAN: On that point, when is the symposium?

Dr KHORSHID: On 5 May.

Hon NICK GOIRAN: Is it a symposium of which attendance is restricted to members of the AMA?

Dr KHORSHID: That is correct. Not every speaker will be a member of the AMA. We are actually seeking some international experiences from jurisdictions that have gone in the different ways in this area, but it is a members' forum.

Hon NICK GOIRAN: Sure, and there may be capacity after that forum for you to come back to the committee and report on some of those outcomes.

Dr KHORSHID: That is the purpose of the symposium. We had hoped to have it earlier in the year, but it is very hard to schedule things and bring people together, so 5 May is as early as we could do it.

Hon NICK GOIRAN: In which case, I might hold my questions around capacity for that later time.

The CHAIR: In relation to forming a view, the AMA has indicated it does not support voluntary assisted dying. I know that the WA branch is holding this symposium. Can you just elaborate on how the AMA arrived at that position?

Dr KHORSHID: Yes. That was a position of the federal AMA. The federal AMA has an ethics committee that decided to take on this question. In the first instance, it surveyed the membership and received—I cannot remember the exact number, but quite a number of responses from members —

Dr NOONAN: About 5 000 nationally.

Dr KHORSHID: Five thousand responses from members. The committee had a range of experts, some ethicists, some senior doctors and some people, and they used the information from the

survey, plus an analysis of what had gone on in other jurisdictions, in order to come up with a draft policy that then went to the AMA's federal council, which is its ultimate decision-making body where all states and the majority of professions are represented, and that policy was signed off. It is reflective of the broad views of our members. There are doctors on the very ends of the spectrum and a lot of doctors are actually in the middle. It may seem a little conservative, but that is the nature of the medical profession. We are here to protect people and we do not want to take risks where we do not think it is necessary, and we want to protect the good things about what we do in terms of delivering care to the community. I think the position statement makes it very clear that although we may have a view, our view is one view. We think we are big stakeholders in this area, but we do not seek to dictate to the community what it should be doing. But we do want to make sure that the community is aware of all the other issues in this space, that it is highly complex and that there are some risks in going down this pathway.

Hon COLIN HOLT: Relating to that, it sounds like a fairly rigorous process you went through to me, not knowing the ins and outs of it. I would say it is fair to say there are mixed views amongst your association, would there not be? You made a statement around "We have got some people on the extremes and some people in the middle." What exactly do you mean by that? What are the extreme views and what are the middle views?

Dr KHORSHID: There are doctors—members—who write to me who believe that we should have made a decision to legalise active voluntary euthanasia decades ago, and they are highly supportive.

Hon COLIN HOLT: So that is one extreme.

Dr KHORSHID: Yes. The other extreme is people who have an ethical and religious objection to even talking about the topic, which is a commonly held view in the community as well and amongst our members. We have a lot of doctors who work in this area all the time and they have a mixture of views in the middle. It is probably a normal distribution, like so many other things. Even those who may have no major ethical objection to change are worried about the practical implications—the risks, the dangers that may occur. It is not always, from what I can gather—this is my personal analysis of where the profession is at-necessarily ethics: "These are the rules. We must stick by them; otherwise, we are not a doctor anymore." A lot of us are pretty practical. We are utilitarians. We deal with a lot of difficult discussions all the time and we may just worry about where it leads to and what it does. As we have said in the submission and in the public statements by the federal AMA, 50 per cent of doctors are effectively opposed, but that ranges from a little bit opposed to very opposed, and less than that number are for and there are some that do not know. But when it comes to the question of "Would I be involved?", it is a lower number. One of the key questions that need to be answered is: what participation from the medical and other professions will you get if you change the law; how many people are going to be involved or say, "That's all fine, but I'm not part of this"? We need to be careful that this becomes an inclusive process and not one that puts doctors offside.

Mr J.E. McGRATH: Just on that, we are told of surveys out there in the public where the figure is around 70 per cent of people are in favour of euthanasia.

Hon ROBIN CHAPPLE: Ninety-four per cent in WA. That was the Morgan poll.

Mr J.E. McGRATH: In the Kimberley!

Are you saying that maybe a lot of people just answer those surveys and say, "Yes, I'm in favour" without really knowing the practical implications and understanding enough about where this might take us?

Dr KHORSHID: Yes. With all surveys, it really does depend on the question. I do not believe that everyone in the community is fully informed about even what we mean by assisted suicide,

voluntary assisted dying and euthanasia—what these terms mean. If you ask an individual, "Do I want the choice to be able to determine how I die?", everyone is going to say yes, absolutely. But they are not necessarily thinking of the impact on other people, on society or on the vulnerable. They might also be confusing appropriate end-of-life care and double effect and all the things that we already do with euthanasia. They might be thinking, "Do I want unnecessary treatments? Do I want to go to ICU when I am dying? Do I want some invasive surgical procedure so I spend my last days plugged into machines?" Nobody wants that and the vast, vast majority of patients I come across say, "If anything happens, let me go, please." That is a really common view and that may be, again, merging a little bit with this concept of euthanasia. However, we do understand that the community views have moved from what they used to be. We are less religious. We are more—I do not know what the right word is —

Hon NICK GOIRAN: Secular?

Dr KHORSHID: Yes, secular but I think — **Dr NOONAN**: Autonomy is important.

Dr KHORSHID: Yes, autonomy has become more and more important and we are less worried about what someone else tells us to do as a society. We are more focused on the individual, me—what is good for me, rather than what is good for everybody else, or should I do what I am told? That is just a change that is happening. Although we would not accept that 95 per cent of people, fully informed, would support euthanasia—we do not believe it is anywhere near that high—we do accept that there is general community support for the concept. But as a medical profession, our job is to make sure that any change that happens is as a result of a robust process, which this certainly appears to be, and that there is no confusion. Sometimes when you see the media and some things that happen in other states or where these discussions happen, you see emotive stories and people's personal experience that is used as a demonstration of the need for change when in fact that patient could have been well looked after with current legislative processes. You do not need change to look after people properly in most circumstances, but we recognise there are circumstances where we, as a medical profession, do not provide the answers that our patients are looking for.

[12 noon]

Mr S.A. MILLMAN: Dr Khorshid, that was an excellent answer in respect of what you believe the factors are behind the high level of support for voluntary assisted dying amongst the general community. Can you give us some factors around why you think it might be lower amongst the medical profession?

Dr KHORSHID: I can. Really that comes back to my opening statement. We abide by our code of ethics and what makes us doctors. We think that is special and we think it underpins the success of the medical profession in changing the face of illness in the world over the last few centuries—certainly the last hundred or so years. We make those declarations. We are taught it right from the very start. It is part of who we are as doctors and why we do altruistic and selfless things quite a lot. It is part of our make-up and it is not easily dispensed with. But doctors are also sharing end-of-life journeys with their patients regularly. They observe people going through very, very difficult times. Doctors will be sitting there in the room with patients who have those horrible deaths that you hear about and there are doctors who probably feel helpless looking after a patient with a terminal disease who wants to end their life but is not able to. That is the mix of experiences within our profession. I think it is really easily understood why we are less supportive of change than the general community; at the end of the day, it comes down to protecting our patients. That is our primary reason for doing what we do.

Hon NICK GOIRAN: I agree that the response you gave with regard to surveys and polls and the like was incredibly insightful. Part of what you said there was around the use of language. The original question that was posed to you was that the AMA has indicated that it does not support voluntary assisted dying. So that we are all talking about the same thing, can you just indicate to us what you understand voluntary assisted dying is?

Dr KHORSHID: What the AMA's statement says, just to be clear, is that the AMA does not support—I hope I get these words right—activities whose prime intention is the ending a patient's life. We would use terms like "active voluntary euthanasia" which is where a doctor administers a life-ending treatment in a capacity where the patient has made that decision and has been demonstrated to be competent, or various forms of assisted suicide where another party assists a patient in ending their life—whether that be a family member or a doctor, in which case it is physician-assisted suicide. Voluntary assisted dying seems to be a mixture of those things but what the AMA is talking about is our participation as a profession in activities that end a patient's life as their primary intention rather, I guess, as a side effect of treatment that is intended to relieve suffering.

Hon NICK GOIRAN: That is quite helpful. We have a witness coming before us shortly who has actually appeared before us previously; it is the Chief Psychiatrist. He last appeared before us on 14 December last year at a public hearing. In response to a comment from my friend here Mr Whitby, Dr Gibson said, for the benefit of my colleagues and Hansard, I am quietly confident that I am quoting from the corrected version of *Hansard*, I quote —

Can I just say that, like the college of psychiatrists, I do not support physician-assisted suicide, but that is a different kettle of fish to voluntary-assisted dying.

Dr KHORSHID: Yes. You can define voluntary assisted dying how you like. What we have said in our submission is that we do not support doctors being involved in the way that we have just described. Suicide is legal. Should assisted suicide be legalised is a question for the Parliament to answer. If a doctor prescribes a treatment or is involved in the delivery of that treatment, then that is variable levels of physician assistance. Again, it is probably semantics as to where you draw that line and it is a question for you to consider. Our reservation—our line as our members have asked us to put it, and where we have put it in our position statement—is where the doctor is involved in a treatment whose primary intention is the ending of a patient's life. That would include prescribing and administering treatments. Different doctors, for themselves, will have different levels of willingness to be involved. Some doctors might say, "Okay, you have reached this process; it is legal. I might participate but only to the point that I will prescribe it. I am not actually going to end your life. But I will give you the mechanism—I will give you the tools—and if you, at some point, decide to utilise those tools, that is up to you. That is suicide and I am comfortable, ethically, with that level of involvement if it is legal." Others may not or others may say, "Look, I am quite happy to administer the treatment; what is the difference between prescribing it and administering it? There is not a lot of difference." Again, there will be different views on that.

One important point I would like to make—do not know if we are going to make it later—is that we strongly believe that if there is any move in this direction, if doctors are going to be involved and it is going to legal, then it should be an opt-in type system. Any doctor that is involved should be identified, appropriately trained, aware of the complexities and the laws and able to deliver the treatment in a way that is reliable and safe and so on. It would be potentially much more dangerous if any doctor was able to do this and then may blunder into it with good intentions but in breach of the law or in breach of good ethics. We strongly believe that if it goes in this direction, that opt-in an appropriate training are really key.

Hon NICK GOIRAN: Further to that, you said "appropriately trained". How does one appropriately train to participate in assisted suicide?

Dr KHORSHID: That would be training around the legal environment and training around competence, so depending on what the legal framework was, the doctor administering treatment might be one of the ones that helps the patient make the decision I am. I am not sure where that is going to go. It is knowing what the law is and what the steps are and being able to guide patients. This is really fraught stuff and from what we understand, a lot of patients who sort of sign up to the concept never actually go through with the act. Being able to counsel the patient appropriately is not a skill that all doctors are automatically going to have, so being trained in how to help a patient on that journey would be very important. When it comes to the act itself, making sure that is achieved in a way that is reliable and effective, and minimises suffering and does not result in a deviation of drugs. For instance, if you had a little packet of "suicide pills"—I hesitate to use that word—but if you had access to a treatment and you took it home and put it in the cupboard, then that needs to be protected. You cannot just have that kind of stuff lying around in the community. So, there is a whole lot of legal and practical things that would needed to be included in any training along with the counselling skills to make sure that the patients are properly informed of their rights and obligations.

Dr NOONAN: Something just to quickly add as well, we have been discussing this with clinicians and lawyers in Canada and technically, it is not a difficult thing to do in terms of prescribing a drug or administering a drug, but the doctors who have decided to take part have had extensive counselling for themselves and implications for their own wellbeing and consciences, I suppose, going forward. That actually was a more in-depth process than saying, "This is how you sign this form." That is really important for any doctors taking part.

Mr R.R. WHITBY: Dr Khorshid, would the AMA, do you think, continue to allow its members to opt in?

Dr KHORSHID: The AMA does not dictate to members. I think it is reasonably clear from our federal AMA position statement that if the law has changed in Victoria and if it changes again in various other jurisdictions and doctors participate within the law, they would not be in breach of our code of ethics. That is not to say we support it, but members who are doing something that is legal and consistent with good medical practice would not jeopardise their membership with the AMA.

Hon Dr SALLY TALBOT: I just wanted to take you, if I could, to the section that starts on the screen there. I am just trying to get a bit more of an accurate insight into the way the AMA works. That statement up there says that the AMA does not support interventions whereby a doctor has as their primary intention to end a person's life. That sounds awfully much to a layperson like the AMA taking a position, but you did just say that the AMA does not take positions.

[12.10 pm]

Dr KHORSHID: No, it does not direct its members. We do not tell them how to deliver medical care; that is not appropriate. We are a professional organisation that supports and represents. We do not dictate. The Medical Board dictates, and if you breach standards of good medical practice, then then your registration as a doctor—they are the regulator. We are a membership organisation—a professional organisation. Although we have a position, as clearly stated there, that is a position supported by 50 per cent of our members, so it is not a black and white rule that would jeopardise the membership of our association.

Hon Dr SALLY TALBOT: If it is 50 per cent of your members, how did you make the decision to make that your position statement?

Dr KHORSHID: I think I described that process pretty clearly before. It went through a full consultation process, a committee with experts and good people on it. It came to the AMA's federal council. I think it actually went back to the ethics committee and then came again to the AMA's

federal council. The federal council has 35-odd—something like that—members who represent our doctors broadly across all states and territories and across the majority of the large professions. That is about as robust a process as you can have on a contentious issue, and I have to say that since it was released there has been almost universally positive feedback from members. Even though they have different views, our members have given us very positive feedback about this position statement, which they do not always do.

Hon Dr SALLY TALBOT: Yes, I know. I realise that it is an ongoing process, so can I just take you now to the second paragraph where you talk about a 2016 survey that said that 62 per cent of your members say they would not provide physician-assisted suicide if it were to become lawful, and 25 per cent said that they would. How does your organisation work in terms of that proportion of your membership that says that they do want to be involved; they would be actively involved? Is that the training that you were just talking about; you would make services available to them in training and awareness?

Dr KHORSHID: I am not sure exactly what the question is. The AMA, as I said, does not control its members.

Hon Dr SALLY TALBOT: You are not binding organisation.

Dr KHORSHID: No.

Hon Dr SALLY TALBOT: You do not make a decision and then —

Hon NICK GOIRAN: They are not a union.

Hon Dr SALLY TALBOT: I was not going to use that word!

Dr KHORSHID: In areas where we have a role in education we provide education, so we as an organisation provide training to doctors and to their staff and things around certain areas. But our role here is advocacy, both for the profession and for our patients and the community. It is not a regulatory, or even formally a training role. If the laws change and if there is work to be done, then we will have a look at how we can value-add to that. If legislation is proposed that we do not think provides adequate safeguards, then we will advocate very strongly against it. If legislation is proposed that is consistent with good medical practice but not supported by the majority of the members, then we will take a more nuanced approach. It really depends what happens as to what our next steps will be.

Hon Dr SALLY TALBOT: Finally, can I just ask you—we are talking specifically now about voluntary assisted—a form of euthanasia. Whatever name you want to give it. Presuming there are other issues on which your members would not be in agreement—things like abortion, sterilisation and IVF—you have got mechanisms in place, presumably, to continue to accommodate those varying views.

Dr KHORSHID: Absolutely. Our members have varying views on almost every topic. If you get a group of doctors together you will have more views than you have heads in the room.

Hon Dr SALLY TALBOT: We are quite familiar with that!

Dr KHORSHID: As a membership organisation we have to deal with that. Our policies are reviewed regularly. This position statement will be reviewed at an appropriate time as the situation changes around the country, and if legislative changes are occurring across the country and it brings up other issues, then they will be included into our advocacy and our position statements. We are used to working together with differing views, as we have. I think the last time the abortion debate was divisive in the medical community was 20 years ago. The president of the AMA at that time said he was pretty scarred by that experience, and he felt sorry for me being the president now while this discussion is going on. But I hope that we can make it a positive discussion rather than have

members sniping at each other. I think if we handle it poorly it can be an extremely divisive discussion—this topic—extremely divisive. But if everybody acts in good faith and if we are able to come together as a community, properly informed, and make good decisions, what is there for anybody to complain about?

Mr J.E. McGRATH: Getting back to that same subject, I was just going to ask, doctor, the question: I am concerned a bit about privacy with these things. If you have doctors that are going to opt in, how will people know which of the doctors are opting in? Will it become known in the local area that if you want to end your life, this is the doctor you need to go to? Do you have any views on how—if it does happen—it could be best managed?

Dr KHORSHID: I guess we have got some opinions. We understand, from some recent research on what is going on in Canada, that there is actually a phone number you can ring to find out, or a doctor can ring to find out who are the appropriate providers in an area. There are a couple of hundred doctors who are registered with the group that agreed to provide this service, and I presume they provide the training et cetera for the practice. We do not want individual doctors to be the kind of "Dr Death" in that part of the community. I think that would be unfortunate. But the reality is that the majority of doctors, as we stand at the moment, will not be comfortable in participating in any form of physician-assisted dying, and therefore if it is to become available to the community some kind of information will need to be available as to how to access those services. We do not believe that there should be a compulsion for doctors with a conscientious objection to refer, as is the case in other contentious areas, particularly where there is a religious basis for those convictions, but information must be available to the consumer if it is going to be an effective option for them, and there needs to be an appropriate mechanism that protects the doctors and protects the patients.

Hon COLIN HOLT: We are kind of talking before the fact here, but we have got an after-the-fact in Victoria and I presume the AMA has got a Victorian branch. Did they have a similar attitude from those surveys as the AMA in WA has had; and what sort of adjustments have they made as an industry or an association now that the laws have come in—not quite in yet, but the legislation has passed? Do you have any insights into how they have handled it?

Dr KHORSHID: If you require a detailed answer to that question I would need to take it on notice. It is fair to say that the AMA's advocacy into what was a very contentious discussion in Victoria was not supported by all of its members, and the AMA brand there has actually suffered because of that. It was a difficult discussion, and some members felt the AMA was not appropriately positioned in the debate. I cannot answer as to how the AMA has reacted there since the decision. I have just seen some basic commentary on the legislation. Obviously there is no experience with it, as yet. What we would hope here is that if legislative change occurs, it is similarly restrictive and appropriately targeted at the very small group of patients for whom we do not have the answers, because it is a small group, and that any legislative change does not upset anything else that goes on; that we do not damage the doctrine of double effect or good medical care in order to achieve another outcome. Obviously, we just do not have the experience yet from what has happened in Victoria as to whether that has occurred.

Hon ROBIN CHAPPLE: I have got four questions, but I will try to make them very brief. Are all doctors covered by the AMA?

[12.20 pm]

Dr KHORSHID: The AMA Western Australia has approximately 50 per cent membership penetration.

Hon ROBIN CHAPPLE: You actually said in your submission—I was intrigued by this—under "Implication in any proposed legislation", "AHDs should not be involved in the process." Yet we have

had some submissions saying that AHDs should be involved in the process. Why do you have that view?

Dr KHORSHID: Advance healthcare directives are directives. They are legally binding documents set at a particular point in time. We believe that decisions around end-of-life care are much more fluid; that patients change their minds as they go through a disease process. At some points in a disease process they can be wanting to end their life and then they can come out of that a week later as symptoms resolve et cetera. It is a very fluid process. Having a direction to end someone's life in a legally binding document is very, very dangerous in our view. The patient at the time of the act would potentially not be competent and that is getting awfully close—in our view it is crossing the line into active euthanasia; into doctors choosing to end someone's life. We would be very strongly opposed to that.

Hon Dr SALLY TALBOT: I just want to follow that up with you, if I could, please. It is not clear to me how an AHD could do what you have just suggested it would do and direct a doctor to end someone's life. An AHD is basically about consent. It only has two sections to it, has it not? Are we talking about the same document?

Dr KHORSHID: I think we are talking about the same document.

Hon Dr SALLY TALBOT: My understanding is it has only got two sections. The first one is the circumstance and the second one is about the treatment. I just want to dig down a little bit further. Surely, if you have got a patient who is not consenting to treatment, you have to respect that, do you not?

Dr KHORSHID: Absolutely. I think what we were saying, though, is that an AHD should not be modified to allow a patient to say, "If, in the event I am no longer competent—I've entered a nursing home, for instance—I wish to have my life ended."

Hon Dr SALLY TALBOT: They would say, "In the following circumstances I refuse consent to the following treatment."

Dr KHORSHID: That is allowed under current rules. What we are saying is that the rules should not be changed to allow euthanasia to occur—to be directed by the AHD.

Hon Dr SALLY TALBOT: Thank you.

Hon ROBIN CHAPPLE: That clarifies it. Thank you for that.

DNRs—do not resuscitate—the process of establishing a DNR is made by a doctor in conjunction with a patient in most cases or in conjunction with the family. It has been quite difficult to try to establish how DNRs are actually ascribed and the validity of a DNR.

Dr KHORSHID: A couple of things: I think DNRs have improved a lot over the last 20 years. That is my personal experience—I have been a doctor for 20 years. They were a rare event and often an afterthought in the past, and now they are an explicitly discussed item, sometimes on admission to hospital, which is entirely appropriate. They are important because they cause a conversation to happen between the treating team and the patient and all the family. That will depend on circumstance as to what their views are and what our views are around what should be done in certain events. It is not just about resuscitation, it is also potentially about certain life-saving treatments. As I understand it, we do not require a patient's consent to not resuscitate them. Because of the futility argument, if a clearly fatal event has occurred or if it is clearly inappropriate to resuscitate, we do not resuscitate—we do not have to. But the problem is that is very hard to work out at the last minute. For many, many years we resuscitate first and ask questions later, but then it is too late—the patient may be resuscitated and may have suffered further harm as a result of the cardiac arrest that occurred. It is about predicting those things. For many, many patients who

come into a hospital, if they deteriorate to an extent where their heart stops, resuscitation is not going to alter their outcome. Whereas say a patient has said, "I don't want to be resuscitated if I die", if their potassium level goes very, very low during an operation and they have an arrhythmia that might cause cardiac arrest, that is easily and quickly treatable, and gone—cured. It is all in context. And a death under anaesthetic, for instance, or an arrest under anaesthetic—in most circumstances that patient will be resuscitated because it has been caused by something that we have done and we can quickly fix it. It is not quite the same as a patient getting sicker and sicker and sicker and dying.

The other time when DNR orders are important is the sudden cardiac death that can occur when people are very, very sick and we know that successful resuscitation—departing hospital after one of those is pretty rare. It is entirely appropriate for the majority of elderly patients or sick patients that if a sudden death like that occurred just on the ward, that it would be inappropriate to resuscitate. The DNR order allows that conversation to happen and for it to be documented. It is somewhat binding but I do not think it is entirely binding because the law does not refer to DNR orders; it refers to futility or it refers to us, our job as doctors, to look after patients. That is our ethical obligation and we would certainly do that.

Hon ROBIN CHAPPLE: You have a particular form at the moment. We heard from a previous witness that there is a review going on. Are you involved in that review?

Dr KHORSHID: I am not aware of a review into DNR orders. It could be happening.

Hon ROBIN CHAPPLE: That was from the previous—they were looking at restructuring the form.

The CHAIR: It was a range—it was consistent care forms.

Hon NICK GOIRAN: I think the "Goals of Patient Care" is being trialled.

Dr KHORSHID: One of the things we would really like to come out of this conversation that is going on is for doctors and patients to be talking about goals of care right at the start; an episode of care. That might start in general practice. Certainly when you come into hospital, "What are we trying to achieve here?" Stepping back for a moment and saying, "What is a good outcome for you?" Sometimes the doctor might realise that the patient's goal of care is different from what they thought it was. We would certainly support that and —

Hon ROBIN CHAPPLE: You are involved in that process?

Dr KHORSHID: We are not formally involved in any review of the DNR forms in any particular hospital, but we are certainly supportive of the general direction.

The CHAIR: I am conscious of the time. We have a lot more questions for you. I want to put one more to you and I think we have indicated that we would very much like to invite you back after the symposium because I think a lot of our questions would be probably better answered then. There is a reference here to a survey. Professor Magnusson, in 2003, outlined —

At the empirical level, the existence of a euthanasia underground is difficult to deny.

He points to a survey and said —

It is about how best to regulate what doctors have always done, and what they will probably always do. The choice is not between having euthanasia, and not having it, but letting it stay underground, and trying to make it visible.

Would it be in the community's best interests or would they be better served in having a regulated assisted dying regime as opposed to more covert practices that appear to be going on at the moment?

Dr KHORSHID: We would not accept the notion that there is widespread breaking of the law by doctors. I think the evidence for that is extremely limited. There are potentially isolated cases but we believe that the doctrine of double effect covers the majority of the times where doctors are involved in the potential for hastening someone's death and it would be extremely unusual for any doctor to be taking the steps that he is suggesting there of crossing the line into voluntary euthanasia in a covert manner. We do not accept that notion that it is better to regulate than to have it underground—we do not believe it is happening. The question of whether to move towards a framework for voluntary assisted dying is more around those patients who cannot access it who want it and for whom we cannot provide adequate symptom relief. As I have stated before, we believe that a very small number of patients are in that situation. For the majority of people who support the concept of euthanasia, they are thinking about their last days and weeks of life; they are not necessarily thinking about the small number of progressive conditions where there is a lot of pain, there is a lot of severe impairment of quality of life but without a rapidly terminal prognosis. That is where the Victorian legislation is poignant. That is a small number of people, but that is a real number and we accept that.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for the correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days of 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 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 of evidence. The committee will write to you with questions taken on notice during the hearing and we will include any proposed questions we were unable to address, but we will, I expect, be inviting you back very shortly after your symposium, if that is all right with you. Thank you.

Hearing concluded at 12.30 pm