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
MONDAY, 30 APRIL 2018

SESSION ONE

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

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Hearing commenced at 9.15 am

Dr BRIEN HENNESSY
Head of Anaesthesia Department, Sir Charles Gairdner Hospital, 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. We have Mr Simon Millman; Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; Mr Reece Whitby; and Hon Robin Chapple. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia and to highlight any gaps that may exist. It is important 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 may 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. The audiovisual recording will be available on the committee's website following the hearing.

Do you have any questions about your appearance here today?

Dr HENNESSY: No, I do not.

The CHAIR: Would you like to make an opening statement before we begin with questions?

Dr HENNESSY: I would like to. I have been invited to give evidence to this committee today as a service provider who deals directly with end-of-life care and the adequacy of the existing laws and resources for end-of-life care. I am the head of department of anaesthesia at Sir Charles Gairdner Hospital. Therefore, I will answer the questions from the viewpoint of this role from which I have been invited. I feel that there are two other pieces of information that are relevant to the hearing today. One is that I am the Western Australian representative on the Australian and New Zealand College of Anaesthetists Safety and Quality Committee. This is one of the committees that produced a response to the invitation by this committee, which I can see on the board there. Therefore, I am one of the members who contributed to creating this response, as we responded to the New South Wales and Victorian parliamentary queries as well.

The college of anaesthetists has chosen to not appear for this committee invitation. One of the main reasons it has chosen not to appear is that when the questions that were going to be asked of the ANZCA representative were presented to ANZCA, they felt that the terminal sedation questions were not really relevant for a college of anaesthetists. Like your Parliament, the college of anaesthetists is a large group of people—4 500 fellows—who have very disparate series of values and opinions and feelings around the questions that had been asked. Therefore, they felt that because those questions were not necessarily relevant to the current or existing practice of many anaesthetists, they chose not to appear.

The other point that I think is relevant is that one of my siblings happens to be Jill Hennessy, who is the Victorian Minister for Health, who was involved in voluntary assisted dying legislation and its passage through the Victorian Parliament late last year.

The CHAIR: Thank you. Was there anything else you wanted to add to your opening statement?

Dr HENNESSY: No. That is it.

The CHAIR: Thank you, Dr Hennessy. We will move through some of the questions, which I understand you have been given in advance. We may not get through all of them because there are quite a few, so we will move through some of those and members may have questions for you as well. Are you able to tell us in what ways anaesthetists and pain specialists are currently involved in end-of-life discussions and decisions?

Dr HENNESSY: Predominantly it occurs in two sets of circumstances. Anaesthetists generally are also pain physicians. Most pain physicians are anaesthetists. Generally, it occurs in these two circumstances. One, in a pre-operative phase where a patient who is booked to have surgery and that surgery may be futile and/or that patient may be at the end of life because of their various comorbidities. Then the anaesthetist is trying to discover what the post-operative course might be for that patient and, therefore, to try to determine what the best level of care for that person might be after their operation. In planning for that level of care, we need to give the patients an accurate representation of what to expect after that. If the patient does not realise they are at the end of their life, and in my experience that is often the case—more often the case than not, in fact—then end-of-life discussions need to be held at that point in time prior to an operation occurring so that it helps with their informed consent process. That is one situation.

The other situation is a patient comes in for quite an emergent procedure. The patient is not up for a conversation, too unwell to have a conversation and an emergent procedure needs to occur, but in the peri-operative setting, a discussion does need to be held with that person's next of kin or guardian regarding the expected outcome from that. Those end-of-life discussions can occur with those people whilst the patient themselves is not able to do that or once the initial operation has occurred and the person has regained consciousness and such, then the end-of-life discussions can occur and that is in a post-hoc situation.

The CHAIR: Are anaesthetists considered to have special knowledge of pain and symptom control at the end of life?

Dr HENNESSY: Yes. Anaesthetists do have special knowledge about pain and symptom control. Generally, though, that is in the peri-operative period rather than specifically for end-of-life matters. The peri-operative period, as I mentioned before, is often towards the end of life. It is a very high proportion of patients who have operations, particularly emergency operations in tertiary hospitals in Australia that—those patients are at the end of their life. Nearly 80 per cent of them are dead within a year. So, it is by that very nature that looking after that patient's pain and symptoms in their peri-operative period happens to be around towards the end of their life and trying to deal with their ongoing pain and symptom management in the period of time following the immediate peri-operative period. The question really is if patients who do understand they are near the end of their life are coming to have non-operative treatment, an anaesthetist ordinarily would not be consulted to try to manage that person's pain or symptoms. Similarly, for a pain physician, in some cases pain physicians are consulted to assist with that person's symptom management. Ordinarily, that would be in a procedural sense, rather than in an advice for medication sense, because that patient would ordinarily be looked after by a palliative care physician or a GP with palliative care expertise. Pain physician involvement at that particular point in time, when I say it is procedural, might be to insert catheters into that patient's nerve plexuses or central nervous system to run local anaesthetic and/or opioid infusions to help with their terminal pain management.

The CHAIR: We have had evidence to this committee that has stated that around anywhere between two and five per cent of patients at end of life experience unmanageable pain and symptoms. In your view, is that about right?

Dr HENNESSY: I think it is probably much higher than two per cent. The reason that I think it is much higher is because some of the pathologies that we die from can be particularly cruel. My wife is a radiation oncologist and I see a lot of her patients having particularly distressing symptoms. She looks after a lot of children as well, and that is very distressing for their parents. When we have pathologies that invade nerves and nerve plexuses and bone surfaces, they can be very particularly painful type of pathologies. If we were to look at opioids, for example, a morphine group of drugs, they have a maximum efficacy for severe pain management of between 30 and 40 per cent ordinarily. If we expertly manage other concomitant systemic analgesics, we may be able to get that more towards the 50 to 60 per cent efficacy. What that leaves critically is about 40 per cent underlying pain that is not managed by the most expert management with systemic analgesics. If that 40 per cent is something that is tolerable to that patient because the pathology is not a particularly bad one, then that person is not going to be experiencing intolerable pain and suffering. However, there are particularly quite large groups of patients in whom that 40 per cent will still result in quite intolerable amounts of pain and suffering.

The CHAIR: Does that group include malignancies as well as neurodegenerative diseases or would you distinguish between those two?

Dr HENNESSY: I try not to distinguish between those two because many malignancies are chronic illnesses now. Perhaps a decade ago I would have made a distinction, but not now. Many malignancies are chronic illnesses just as, for example, multiple sclerosis is or chronic degenerative cardiac conditions might be, in which case we have a number of large groups of our society who are living with chronic illnesses. Some of those chronic illnesses have pain associated with them that will definitely have at least a 40 per cent underlying untreatable pain that analgesics are unable to manage.

The CHAIR: You may not wish to answer this question, but if it is a lot higher than two per cent, would you put a rough figure on it?

Dr HENNESSY: I can only guess. My guess would be closer to 30 per cent.

Hon ROBIN CHAPPLE: You talk about untreatable pain. So, if one was to go into a sedated state, is that pain still there?

Dr HENNESSY: Pain is an individual experience, clearly. It is not nociception leads to pain. Nociception—I have a cancer. It is invading a nerve in my sacrum, for example, and, therefore, that is going to cause this amount of pain. That is not the case because there are so many other modifiers to that. It is a very complicated situation. If, for example, the patient is completely unconscious, then clearly that unconscious person cannot suffer pain. They can still have nociception. Let us take, for example, a person having a general anaesthetic. That person is unconscious. That person will not be experiencing pain. However, their body will still be experiencing the nociception of the actual surgery itself and the physiological response to that nociception.

The CHAIR: When you talk about pain, are you distinguishing between physical pain and psychological pain?

Dr HENNESSY: No, I think pain involves both of those things. I do not distinguish between those two. What we are distinguishing between is nociception, something that is causing inflammation and activating the pathways that would ordinarily result in pain versus the sensation of pain itself.

Mr J.E. McGRATH: Further to that, we have had some evidence from a medical practitioner that he had a patient who was very close to death and the family were there and it had been decided that they were going to give him as comfortable a passing as possible. He said he sedated him. He would

have done that himself or he would have called in a specialist to give the sedation. How would it happen, would you imagine, in that circumstance?

Dr HENNESSY: Sedation and unconsciousness are not necessarily the same thing. I think we need to understand that sedation again is a spectrum from awake to completely unconscious. Once a patient is completely unconscious, let us not call that a sedative state; let us call that unconscious. During this spectrum of sedation, a person can be either unaware or aware of what their surroundings are and what their feelings are.

Mr J.E. McGRATH: Just in a drowsy state—is that how you would describe it?

Dr HENNESSY: Yes, I would say that is correct. And that a drowsy state is a real spectrum. For example, during anaesthesia we monitor patients' EEG—their electroencephalograms—which has a mechanism by which we can ascertain the depth of their neurological anaesthetic state to try and judge where we want that person to be. To have EEG silence, for example, if I am going to work on their brain to take out a brain tumour, I do not want their brain to be active. Or I want them to have quite an active brain during that particular surgery but to be unconscious, or be actually conscious. And we use it to help determine the level of sedation during intravenous sedation.

[9.30 am]

Mr J.E. McGRATH: Most of the evidence that we have had has not mentioned anaesthesia with people where they are given assistance. What you are saying to us is that anaesthesia happens more when people are in the hospital prior to an operation or prior to surgery.

Dr HENNESSY: For inpatient care anaesthesia is provided so that a therapeutic intervention may occur. I think what you are trying to describe to me is terminal sedation, which is an intervention to try and make it so that therapeutic interventions are not required or are not occurring.

Mr J.E. McGRATH: To make it as comfortable as possible for that person at the end of life —

Dr HENNESSY: For that person to die of their illness.

Hon NICK GOIRAN: Further to that, I do not know if you are aware or not, Dr Hennessy, but the committee has had quite a bit of evidence on this issue of terminal sedation. My view at least—others might have a different view—is that there has not been consensus from the witnesses on the term.

Dr HENNESSY: Sedation.

Hon NICK GOIRAN: The term "terminal sedation". What is your definition of terminal sedation?

Dr HENNESSY: I must point out that in my course as an anaesthetist I do not conduct terminal sedation.

Hon NICK GOIRAN: You have never conducted it?

Dr HENNESSY: We do not conduct terminal sedation. That is not within our area of expertise and that is the principal reason why ANZCA is not represented here today.

Hon NICK GOIRAN: Sure. Are you still in a position to give a definition?

Dr HENNESSY: My definition that I would say would be that terminal sedation is that if a patient has chosen to be sedated for the end of our life, comments terminal sedation now, that is a situation where they would prefer their sedation to be turned up so that they become unconscious and unaware of their surroundings whilst they die.

Hon NICK GOIRAN: You drew a distinction earlier in your evidence between a person who is unconscious or sedated. Now the two terms are being used in the one definition.

Dr HENNESSY: Correct.

Hon NICK GOIRAN: To be clear, your view is that a person undergoing terminal sedation is unconscious.

Dr HENNESSY: I think that would be the endpoint that that person would have requested.

Hon NICK GOIRAN: When they are unconscious they would feel no pain?

Dr HENNESSY: So long as they are truly unconscious—yes.

Hon NICK GOIRAN: Can they be revived out of that state of unconsciousness?

Dr HENNESSY: If the agents used are reversible agents such as opioids and benzodiazepines, yes.

Hon NICK GOIRAN: In Western Australia, do we have any medications that are not reversible?

Dr HENNESSY: Many.

Hon NICK GOIRAN: Can you give us a list?

Dr HENNESSY: Looking at your question further down the track, there is a question regarding haloperidol, which is used for terminal sedation. Haloperidol is not a reversible agent.

Hon NICK GOIRAN: But is used in Western Australia?

Dr HENNESSY: Thiopentone is not a reversible agent. Pentobarbitone is not a reversible agent.

Hon NICK GOIRAN: Pentobarbitone—is that used in Western Australia for terminal sedation?

Dr HENNESSY: I do not know.

Hon NICK GOIRAN: Are any of the other medications referred to this morning used in terminal sedation in Western Australia?

Dr HENNESSY: Other medications such as?

The CHAIR: Haloperidol.

Hon NICK GOIRAN: The non-reversible ones.

Dr HENNESSY: Are they used?

Hon NICK GOIRAN: Yes.

Dr HENNESSY: I do not know because I do not conduct terminal sedation.

Hon NICK GOIRAN: Are the reversible ones used?

Dr HENNESSY: The reversible ones are used for many anaesthetic applications, but because I do not conduct terminal sedation I do not think I can give a truthful answer to your question.

Mr J.E. McGRATH: We had a witness who said that he brought someone back because the family members wanted to see this person. I think he used dexamethasone or something like that to bring them out of a sedated state.

Dr HENNESSY: Dexamethasone is a steroid that would not raise someone from —

Mr J.E. McGRATH: It could not do that?

Dr HENNESSY: Yes, maybe there was a different—naloxone would be a reversal agent for opioids.

Mr J.E. McGRATH: But he was able to do it.

Dr HENNESSY: Flumazenil would be a reversal agent for benzodiazepines. There are reversal agents for benzodiazepines and for opioids.

Hon NICK GOIRAN: If a patient was requesting terminal sedation, they would not request it of you because you do not practice in that area.

Dr HENNESSY: Correct.

Hon NICK GOIRAN: Whom would you refer them to at Sir Charles Gairdner Hospital?

Dr HENNESSY: I would refer them to the palliative care service.

Hon NICK GOIRAN: Who is the head of that service?

Dr HENNESSY: Dr Anil Tandon.

Hon ROBIN CHAPPLE: We also had evidence and—I am trying to remember who it was from—where a patient was sedated to try and alleviate the pain but the patient was still grimacing and clenching even though fully sedated. Would that person have been —

Dr HENNESSY: Sedated rather than unconscious.

Hon ROBIN CHAPPLE: They were concerned that any more sedation would cause the end-of-life. I am trying to work out —

Dr HENNESSY: Where that line lies.

Hon ROBIN CHAPPLE: Yes.

Dr HENNESSY: I am sure there are lots of people trying to work out where that line lies.

Hon Dr SALLY TALBOT: There are a couple of books on that.

The CHAIR: Can I put it another way? Does the practice of terminal sedation always leads to a state of unconsciousness?

Dr HENNESSY: Again, because I do not conduct terminal sedation, I do not know the answer to your question.

The CHAIR: But it could lead to sedation.

Dr HENNESSY: Yes.

The CHAIR: As a spectrum—as you say.

Dr HENNESSY: Sedation is a spectrum.

The CHAIR: As opposed to unconsciousness.

Hon ROBIN CHAPPLE: I think we need a pie chart.

The CHAIR: While we are on the topic of terminal sedation—I know that you do not practise it yourself but I am interested in your view. Do you think the practice of terminal sedation is well understood by medical practitioners?

Dr HENNESSY: No. I think the current legislation and the law around this issue, which is why we are all here, is unclear to many medical practitioners and patients alike. Such that, for example, there is media melodrama around this as well. When we have this whole realm where we are not really sure what we are talking about and we are not really sure what is going on, there is no clarity in it and I think that clarity needs to occur so that when patients do request terminal sedation, my own opinion is that I think those patients requests should be valid and they actually should be able to act upon that request and that those who are specialised to provide that service are given clarity about what it is that is acceptable to our society and what it is that would be unacceptable to our society.

The CHAIR: Can you describe the process of putting a patient into an induced coma as opposed to terminal sedation?

Dr HENNESSY: The term "induced coma" is a layman's terms for sedation whilst a patient is undergoing usually intensive-care treatment. For example, anaesthesia is the same sort of unconsciousness, but for an operative procedure. This is for a non-operative procedure. For example, in intensive care we will provide organ support, ventilation, renal replacement therapy, hepatic replacement therapy and treatment of the underlying primary pathology, which might be infection, where we are giving the patient antibiotics or something. Anaesthesia/sedation is for treatment, whereas I believe terminal sedation is different to that. Terminal sedation, as I have said before, I believe is sedation/unconsciousness so that we may not treat the underlying primary pathology, which may not be treatable.

The CHAIR: On the use of opioids, there have been a number of studies which have indicated that—obviously opioids are high risk and at times of underdosing patients. Do you think that doctors' uncertainty about the risks of opioids is leading to the underdosing of patients at the end of life potentially?

Dr HENNESSY: I think that the term underdosing is probably not a good one. With opioids there is an eightfold inter-individual variability in dose–response. That eightfold inter-individual variability, therefore means that the drug needs to be titrated, meaning that a dose needs to be given and its effect needs to be ascertained prior to more being given. In general, a basic rule of thumb is that with opioids you will go from peak analgesic effect to a significant side effect like sedation respiratory depression with a twofold plasma concentration rise. Bear in mind, a twofold plasma concentration rise will take the drug from peak analgesic effect to a big side-effect like unconsciousness but in the background we have not eightfold inter-individual variability. The maths does not add up, does it? Therefore, the drug must be titrated. For someone to say a patient was underdosed, does that mean they were underdosed to what? If the endpoint is analgesia, then that is a furry animal to try and nail down. How much analgesia you did you get? How much was that analgesic efficacy? And the best analgesic efficacy we are going to get out of the drug is a 40 per cent reduction. If the endpoint was not its maximum analgesic efficacy, but instead unconsciousness, that is a bit more black and white—a bit more but not entirely so. I do not think the term underdosed is a helpful one. I think it just describes a normal up-titration process of an imperfect drug with a variable effect.

[9.40 am]

The CHAIR: The scenario that you have just described with the two different potential effects—is that what you would describe as relying on the doctrine of double effect?

Dr HENNESSY: The doctrine of double effect is that the medical practitioner's intent is to provide symptom control and pain management. It is not necessarily to harm that person. If the doctor up-titrates quickly to get on top of the symptoms with a bigger loading doses and the patient suffers those of side effects, then I believe that in this particular circumstance the doctors who are doing this are relying on the doctrine of double effect. That is certainly not a circumstance in which an anaesthetist ordinarily finds themselves because we would never use one drug to anaesthetise someone—pretty much we would never use one drug to anaesthetise someone. Therefore, we rely on synergies, using lower doses of many drugs. It is not uncommon to have 15 drugs, for example, during a general anaesthetic. It is the lower doses of each of those that allow the synergies to have the overall effect of unconsciousness and unawareness but without getting any of the side effects of those drugs because they are such lower doses of the individual agent that we are not reaching anywhere near those kind of effects. It is only when we are reaching for a particular large dose of a particular one drug that becomes more of an issue.

Hon NICK GOIRAN: Could a patient die of an unexpected reaction from one of those 15 drugs?

Dr HENNESSY: Absolutely. Anaphylaxis is a big problem in the community in general. Western Australia is extremely lucky. There have been only two perioperative deaths from anaphylaxis in 36 years. That is not the case on the east coast of Australia. It is much higher on the east coast of Australia and much lower, in fact, in northern European countries where the sensitising pholcodine-type drugs are not available.

Hon NICK GOIRAN: If 15 drugs were used on a patient with their consent and there is an unexpected reaction that leads to the death of the person, the practitioner was not intending the death of the person. They were intending to provide good medical treatment in accordance with the informed consent of the patient. The death ensues and the practitioner then relies on the doctrine of double effect.

Dr HENNESSY: Meaning that they did not intend to harm that patient but the patient was harmed.

Hon NICK GOIRAN: Is that fair?

Dr HENNESSY: Yes, I would agree.

Hon COLIN HOLT: Why the difference between Western Australia and the eastern states—any thoughts?

Dr HENNESSY: In anaphylaxis?

Hon COLIN HOLT: Yes.

Dr HENNESSY: On the east coast, many non-anaesthetists provide anaesthesia services. Therefore the level of experience, training and ability to cope with intra-operative or intra-procedural anaphylaxis is markedly reduced.

Hon COLIN HOLT: Hon Nick Goiran just gave the example around the doctrine of double effect. In anaesthesia, with 15 potential drugs, the doctrine of double effect could apply. Also, are there indemnities that apply when people give their consent to an operation or procedure, rather than the doctrine of double effect, where there is a waiver?

Dr HENNESSY: Essentially, when a person consents to a procedure they are consenting to clinicians doing their best to help them. If those clinicians conduct themselves in accordance with accepted practice and intend to help that person but that person suffers an insult as a result of their good intentions, then that medical practitioner is ordinarily not held liable for that person's bad outcome. They did what they were trained to do with the best intentions, but because of that person's pathology, for example, or because that person might have had an anaphylaxis, which is a completely out of the blue event, it was not within the control of that medical practitioner.

Hon COLIN HOLT: Do they sign some sort of indemnity?

Dr HENNESSY: That is what is in the consent form. When we consent people for anaesthesia, the patient signs a separate consent form for that. That is the indemnity.

Hon NICK GOIRAN: But the indemnity does not remove negligence?

Dr HENNESSY: No. If the medical practitioner was criminally negligent, meaning that they intended to harm the patient, or just did something that was outside their scope of practice or something crazy like that, they would be held to account, as anyone else would be.

Mr R.R. WHITBY: You said that you do not practise terminal sedation. Are you able to tell us whether non-reversible sedatives are used in Western Australia?

Dr HENNESSY: Non-reversible sedatives are used in Western Australia. Are they used in terminal sedation? I do not know the answer to that question.

Mr R.R. WHITBY: If they were used, what would be the difference between a patient consenting to a doctor assisting with that non-reversible terminal sedation and an action of voluntary assisted dying?

Dr HENNESSY: That is an excellent question. If the patient has requested terminal sedation from a medical practitioner and that medical practitioner has agreed to provide them with that sedation, that is a pact between those two people. Is that voluntary assisted dying? I actually do not know the answer to that question.

Mr R.R. WHITBY: Particularly if it is non-reversible.

Dr HENNESSY: If you were to generalise that, you would say that we should not use non-reversible agents in any kind of sedation. That would then limit the amount of drugs available to sedationists and anaesthetists in general, and the quality of sedation and anaesthesia in general would be markedly reduced. That would not be a helpful track to go down.

Hon ROBIN CHAPPLE: Following on from that, I need to get it clear in my own mind. A process is started to provide comfort—sedation—to a person and you are using a non-reversible drug. So it is non-reversible, but if it is withdrawn, does the person come out of their sedation?

Dr HENNESSY: Yes.

Hon ROBIN CHAPPLE: I am trying to get the idea of what stage —

Dr HENNESSY: I can give you a little bit of a pharmacology lesson here.

Hon ROBIN CHAPPLE: That is fine.

[9.50 am]

Dr HENNESSY: If we are going to give a sedating-type drug to a person and we are going to give it either orally or intravenously—that does not matter—that drug will eventually get into that person's arterial circulation and eventually into that person's central nervous system, where it binds to the sorts of receptors that impair consciousness in that person. If the arterial concentration of that drug falls away, what will occur is that just as that drug is diffused into and bound to those receptors, when the concentration gradient falls the other way, that drug will unbind from those receptors and the falling concentration will go back into the arterial circulation and then that person might wake up. That is how ordinary anaesthesia and sedation works. If you have given a large dose of an opioid—not all opioids, but the majority of them—to a patient on a ward and that person was suffering side effects from that, such as unwanted unconsciousness, you can administer a reversal agent that will compete with that morphine, for example, and bind to those receptors more avidly than the primary morphine drug and not have the sedating effect, which would mean that the morphine effect would end instantaneously. This is how Narcan and naloxone works for people who have taken a heroin overdose, for example. It relies upon the arterial concentration falling. That arterial concentration will fall, assuming that the drug is cleared by that person because their liver and kidneys—the mechanisms by which that drug is ordinarily removed from the person—are still up and working and active.

Hon NICK GOIRAN: That is helpful.

Hon Dr SALLY TALBOT: I wonder if I could start by asking you to help clarify for us the area in which you work, which I understand from what you were saying is around the perioperative period?

Dr HENNESSY: Correct.

Hon Dr SALLY TALBOT: A substantial part of that work is pain control?

Dr HENNESSY: Yes.

Hon Dr SALLY TALBOT: Who manages pain control outside the perioperative period?

Dr HENNESSY: What I should say first is that mostly general practitioners will manage pain outside of the perioperative process. We do have a chronic pain service in Perth at least. That is run out of the tertiary hospitals at Charlies, Royal Perth, Joondalup and Fiona Stanley. It is a centralised state service. All of those practitioners are anaesthetists. That is predominantly an outpatient-based service.

Hon Dr SALLY TALBOT: Okay, so all pain specialists are anaesthetists?

Dr HENNESSY: Nearly all—all the ones in this state are, but they do not all have to be. Australia-wide, there are many physicians who are pain specialists. We are training a psychiatrist at the moment in pain management. It is a further subspecialty beyond anaesthesia, beyond psychiatry or beyond being a general physician.

Hon Dr SALLY TALBOT: Recognising that your professional work is in the perioperative period, which I think is what you said, can you make any observations about the use of anaesthetist pain specialists outside the perioperative period, particularly in relation to people who are receiving palliative care?

Dr HENNESSY: For example, at Sir Charles Gairdner we have an internal referral system between the pain services—that is, the acute pain service, the chronic pain service and the palliative service. For patients who have a known, declining condition that will foreseeably result in their death, such as metastatic cancer or end-stage cardiac or respiratory disease, then when we see patients in an acute or chronic pain setting we will generally refer that patient into the palliative care services. That is because the palliative care services have a bigger outreach into regional Western Australia and the outer suburbs of Perth itself to help manage that person's ongoing pain management, rather than the acute pain service, which is an entirely inpatient service, and the chronic pain service, which is an outpatient service but generally for patients who have nonterminal-type illnesses or nonterminal pain.

Hon Dr SALLY TALBOT: Anecdotally, the committee has heard that those services do not operate in a seamless way.

Dr HENNESSY: No, that is true.

Hon Dr SALLY TALBOT: We spent a couple of hours a few weeks ago at Charlies with the palliative care specialists, going around and visiting six patients that afternoon. Certainly their accounts did not suggest that pain management was being delivered particularly effectively. The palliative care specialist was expressing some degree of frustration.

Dr HENNESSY: Frustration, yes. Pain management could be a very large animal, but it is not. There is a very small number of pain physicians in Perth—a very small number. Therefore, they run a consultative-type service. Similarly, there is a relatively small number of palliative care physicians, and they run a consultative-type service with GPs. I believe what you are saying is absolutely correct; I think these services need to be better than they currently are. The internal referral system is robust, but the amount of work is not doable by the group that is there.

Hon Dr SALLY TALBOT: Can I also ask you to comment on the difference in the level of service that somebody might provide? I will describe what I see as two polar extremes. First, there is somebody in Charlies who has a terminal diagnosis—they may have metastasising cancer and they are clearly in the final phase of life. Everybody is on call, it is all working, and one of your colleagues, an anaesthetist who specialises in pain, turns up and makes them feel better. We can compare that with someone in Mt Barker who is being cared for either in the hospital at Mt Barker or at home, who is in the same circumstances, experiencing a similar level of pain. The answer is obvious, I suppose, in the way I phrased the question.

Dr HENNESSY: It is not even a city–regional difference. This is an intracity difference that happens across this country. It is not just in Perth. This happens in Melbourne. I helped my father's palliation a couple of months ago in Melbourne. He had quite different services offered to him between his two different primary care tertiary hospitals—vastly different services. This is a problem that the entire country is grappling with.

Hon Dr SALLY TALBOT: It seems appropriate to ask you some questions around the assessment of capacity, not necessarily in relation to end-of-life choices, but bearing in mind that you are one of the treating specialists who would have to do a constant assessment of capacity. Could you talk to us about the circumstance where you would have to make that assessment—for example, where somebody has dementia?

Dr HENNESSY: In practice, it is a lot less tricky than what it might seem. Speaking with patients and their support persons—their relatives, usually, when we are talking about something serious—you can usually get a pretty good sense of what that person understands by backing over the issues you are covering and seeing what they took on the first time and how they formed their opinions with regard to that. So their capacity to make decisions about what their care should be, particularly if they have a family member or support person with them, is actually relatively easy to make a judgement for. There can be some very tricky situations in people who have personality disorders. I am not a psychiatrist. I find that for those patients it is particularly difficult to judge what they understand and how they understand it, because they understand things differently to me. However, for the vast majority of our patients, even if they have some short-term memory loss or such, their value system has not changed.

[10.00 am]

Ordinarily you will be able to gain some sense of what that person's decision-making capacity is and whether or not they are able to make decisions that are in their own interests. In the small number of situations where I have no idea about what that person's comprehension is really like because they understand things differently to me and their learning systems are different, then we have an in-hospital psychiatric liaison who can help make that judgement. Similarly, the psychogeriatric service is really excellent in helping to sort that out for us. But in day-to-day practice, it is much less of a problem than what you might initially have thought, so I would not necessarily think that we would need to mandate some other specialty mental capacity assessment before we permit people to make judgements about their end-of-life choices.

Hon Dr SALLY TALBOT: Do you, as a person's anaesthetist, see an advance health directive if they have one?

Dr HENNESSY: Often we do not see them because if a patient has made one, sometimes they become unwell in a circumstance that does not permit them to bring it with them. The majority of people do not have one and have never had the conversation with their relatives. They do not realise they are sick; they do not realise they have come to the end of their life. I do not know if you have read my personal submission, but it is just shocking how elderly, sick people with so much wrong with them come to hospital with an intercurrent illness and when you say to that person, "You're dying", it is just a complete and utter shock to them, and to their relatives.

Mr J.E. McGRATH: Just one further question on that. I was interested in your comment when you said that health IT in this state is an absolute disgrace.

Dr HENNESSY: It is.

Mr J.E. McGRATH: Could you elaborate on that? How do we compare with other jurisdictions? What is it about this system that is not meeting the needs of —

Dr HENNESSY: It has just always been higgledy-piggledy and an added-on system from a primary system from the 1990s. It is built on a Windows platform from 1999 and has not been upgraded since. The logins change so frequently; you have to log in five times to find a patient's blood pathology results, their cardiology results, their X-ray results, to give you access to when they are going to come and have an operation. It is just so clunky in comparison with other systems that are used internationally where you can just walk into a patient's room and everything is just there and available on my own smartphone because it knows who I am and it knows I have walked into a particular patient's room and just loads all their stuff onto my phone and I can just look straight through it. There is no login required, nothing difficult. My wife commented that when she was at a hospital in New York recently she could just walk in there, look at all the patient's results, order the radiotherapy for that particular person and walk out in four minutes. She said that that would take her nearly six hours here. Why is there that difference? Because they value their clinicians' time there; it is worth something, whereas here it is not. It is terrible. The reason I made that comment was because I think that if we were to ask people to store their advance health directives, it should not be on some IT system that is not going to work when it is needed.

Hon Dr SALLY TALBOT: I just have one further question. You are of course at liberty not to answer this. I wonder if you could take your fraternal hat off; do you have any comments about the Victorian act, bearing in mind that it has not been evaluated yet? You have obviously had —

Dr HENNESSY: I was going to say, we are yet to find out. I think the Victorian act was put together with good consultation across many groups and I think the Victorian act was what society asked for and I think it will not be used very often.

Hon Dr SALLY TALBOT: Okay, thank you.

Hon ROBIN CHAPPLE: I just want to go back to the disastrous state; is that WA-specific or Australia-specific?

Dr HENNESSY: Particularly WA.

Hon ROBIN CHAPPLE: So it is worse here than it is in the other states?

Dr HENNESSY: Absolutely. My eldest sibling was the Serna Corp chief IT officer. He no longer is; he works for the hospitals now, getting their IT under control, but the programs and the IT that they put into hospitals in Victoria, Queensland and New South Wales are just so much better than what we have.

Hon ROBIN CHAPPLE: So is the system so bad because it is so diffuse and archaic that it could not be brought up and merged into a much better system?

Dr HENNESSY: I actually think that is the problem. I think the problem is that that has been our thinking for a long period of time: "We'll just take our existing platform and we'll just sort it out and make it work across the other platforms as they get introduced." I am not an IT expert; what I am is a clinician who knows completely clearly that any of the information I want is very hard to get. We are such a long way off with electronic medical records being working and functional here and it just does not need to be that hard.

Hon ROBIN CHAPPLE: Not putting words in your mouth, but if we continue down this path, is it only going to get worse?

Dr HENNESSY: Good money after bad, in my opinion.

Hon ROBIN CHAPPLE: Could we have a yes or no to that, please?

The CHAIR: For the record.

Dr HENNESSY: The answer is yes, it will get worse.

The CHAIR: Hansard does not quite interpret nods, unfortunately!

Hon ROBIN CHAPPLE: They try!

The CHAIR: They do very well!

I want to just go back to a question that Hon Dr Sally Talbot touched on around the voluntary assisted dying framework. In the Australian and New Zealand College of Anaesthetists submission you say that safeguards need to be meaningful if a VAD is introduced. What kind of safeguards do you envisage as being meaningful?

Dr HENNESSY: The ANZCA document is talking about the safeguards for practitioners at that particular point in time; meaningful rather than administrative or bureaucratic. Those safeguards need to be that, I think that people need to choose; medical practitioners need to choose to be involved or not be involved, and their decision needs to be unqualified. There is no, "I don't want to do that because, what's your reason because?" I think that needs to be a closed statement: "I do not want to be involved in that." I think that is important. I think the medical practitioners should be permitted to be present when a patient self-administers medication, along with anyone else that that person chooses to be present, be that a death doula, a family member, or whomever they want.

I also think the medical practitioners who are involved in this need to be involved in a significant way, meaning that that is something that they do in a specialised way rather than something that they just do every now and again.

Mr J.E. McGRATH: Further to that, I personally have a problem with self-administration if there is not a professional person there. That is my personal view, and I am pleased that you agree with that, but is that in the Victorian legislation? I do not think it is.

Dr HENNESSY: The Victorian legislation permits the medical practitioner to be there but it does not compel them to be there, so yes.

Mr J.E. McGRATH: But your view is that it would be a better system if a medical practitioner was —

Dr HENNESSY: No, I actually think the people who are present, it should be the patient's wishes— who that person wants to be there. If they want the medical practitioner or death doula to be there, so be it, but I think one of the issues around this is looking at it from the other side. If a medical practitioner is there when this person takes it, is that medical practitioner then under some suspicion of having coerced that person to take that medication?

The CHAIR: On that topic, we have had some submissions from people, mostly doctors, concerned about the involvement of intentionally killing their patients, compromising the patient–doctor relationship. Do you have a view or opinion on that?

Dr HENNESSY: I think in the vast majority of circumstances in which this occurs we have an open and trusting relationship between the patient and the doctor that has probably developed over some time, even in circumstances where that person has had a relatively short period of time to come to terms with their terminal illness. Most people, in fact, realise they are terminal only just before they die. I think that relationship is not one where trust is a big issue, so I actually do not think that is a problem. I think that is a non-issue. The people who will become involved in this will become involved in this because they want to be involved in this. You do not become a palliative care physician if you want to be, I do not know, a cardiothoracic surgeon. They are two different specialties altogether. They require people with different mindsets, different values, different skills. I actually do not think that would be a real issue.

The CHAIR: The Victorian legislation actually prohibits doctors from raising the issue of voluntary assisted dying at any point in their care. Do you have an opinion on that?

Dr HENNESSY: My opinion is that doctors should be able to raise it with the patient, but the Victorian legislation was never going to get through two houses of Parliament without that phrase, so I think that was political pragmatism.

Hon NICK GOIRAN: Dr Hennessy, you commented a bit on the so-called safeguards in the Victorian legislation. Have you had an opportunity to look at the Northern Territory legislation?

Dr HENNESSY: No, I have not. I have looked at the New South Wales proposals and the Victorian proposals, but I have not seen the Northern Territory legislation.

Hon ROBIN CHAPPLE: When you talk about a doctor being present, is there a thought behind that that says, "If a doctor is present and something goes wrong with that self-administration, that doctor is there, available to assist"; and, if so, in what capacity?

Dr HENNESSY: That is a good question. I think that would need to be completely outlined between the patient and the doctor beforehand, and what that doctor is happy to do and what they are not happy to do, because if the doctor was then going to administer a lethal medication, that would need to be known a priori and it would have to be present and there and available at that time, which it probably would not be. Victoria still does not even have the medications it needs for this, so just around lethal medication safety and authorisation, who is an authorised person to handle it, who is an authorised person to store it, how is it not going to fall into the wrong hands by mistake or whatever, they are very significant issues. We cannot have lethal doses of medication just lying around, maybe being taken by someone, maybe not. I think we are going to learn a lot about this over the next couple of decades.

Hon ROBIN CHAPPLE: So it is that doctor oversight which is that professional structure that you see —

Dr HENNESSY: I think that is important because the existing oral medications are not easy to take. Many people would not be able to take that.

The CHAIR: We are nearly out of time, Dr Hennessy, but I want to just go back to something you raised in your opening statement around futility of treatment and ask you to elaborate on that. Do you think there is a consistent understanding from treating doctors at end of life around futility of treatment and having those conversations with patients?

Dr HENNESSY: I think that those conversations are not had enough at this particular point in time. I feel that a societal shift is somewhat required for this to occur more elaborately than it currently does. As I alluded to in my submission, we see many people who come to hospital with an end-of-life terminal illness that they never realised that they had or did not realise how unwell they were, so if they then come to have their, for example, broken hip fixed, we do this operation all the time.

I have someone with a terminal illness, who did not realise they were terminal, come to hospital with a broken hip and we say, "Yes, I'm going to fix your hip because that's the best pain relief I can give you. If we don't fix your hip, you will be in agony until you die. So, we're going to do that, but I think you may die during the operation, because it is a life-threatening operation to have when you're frail and sick." We have these end-of-life conversations with the patient and their family at that particular point in time. That one is really easy to see because we know that if you break a hip, 30 per cent of you are going to be dead in a month.

The data is not so clear with many of the other things that we do. If you come with a bowel obstruction, for example, and you have end-stage cardiac failure and we have, "Is this is a futile

operation we are going to do for you or are we going to do nothing?" This is the issue where the patient and their relatives see life and death as a binary outcome, which of course it is not. Death is one outcome, but life is not. Returning to your normal life as you experienced it yesterday, that is probably unlikely to happen. If you survive this, you will survive it in some sort of diminished state and how diminished is that going to be? I cannot tell exactly how diminished that is going to be, so are you then going to proceed with this course of treatment, which is probably not going to get you back to your normal life circumstances, or are you not? Those conversations need to be had. Interestingly, these conversations—end-of-life discussions or goals-of-care discussions—are had more frequently in other jurisdictions, even within Australia, so if you go to the emergency department, you are given forms for advance health care directives: these are my values, these are the things I enjoy doing, this is something that I would determine that my life would not be worth living if this happened to me, if I was in this particular state. At least some very basic values are put down on paper when they come to hospital. We do not do that yet, but I think that that does need to occur.

The CHAIR: Do you have an opinion as to why people come to hospital in a very end-of-life position or end-of-life state and be unaware?

Dr HENNESSY: People do not realise how close they are to death in their normal community, in their normal life. They just do not know.

The CHAIR: Do you think that is because their health practitioners are not having the conversation or they are not willing to accept?

Dr HENNESSY: People have a general decline, they get an intercurrent illness which just knocks them off the cliff and it happens very quickly and mercifully, often.

The CHAIR: Thank you very much, Dr Hennessy, for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of transcription 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 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. We will write to you with questions during the hearing that we did not get to. I want to particularly thank you this morning for your evidence. It is very, very helpful for us.

Dr HENNESSY: Thank you.

Hearing concluded at 10.18 am

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