

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
THURSDAY, 5 APRIL 2018**

SESSION SIX

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 3.02 pm**Dr ALIDA LANCÉE****Medical practitioner, examined:**

The CHAIR: Thanks for coming back, Dr Lancée. You know the drill, so I will go straight into the opening statement.

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; and Hon Robin Chapple.

This is a closed hearing and Hansard will be making a transcript of today's session. The transcript will not be publicly available unless the committee or the Legislative Assembly resolves to authorise its release. 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 that you might say outside of today's proceedings.

Do you have any questions about your appearance today?

Dr LANCÉE: No. I am nervous, but that is fine.

The CHAIR: Do not be nervous! Before we begin with any of our questions, did you want to make a statement for the committee?

Dr LANCÉE: Yes, and I do have to apologise ahead of time; it is quite long. I have a lot to get off my chest.

The CHAIR: We have allocated about 45 minutes to an hour for the hearing, so we would like some time to ask some questions at the end.

Dr LANCÉE: Sure; there will be plenty of time for that.

The CHAIR: Okay, good.

Dr LANCÉE: I am not that longwinded! I will read it, because I am not good at ad-libbing, sorry—if you do not mind.

The CHAIR: That is absolutely fine; whatever is easiest for you.

Dr LANCÉE: I thank the committee for its commitment and tireless efforts to ensure that this inquiry is comprehensive and thorough, as it is no easy task and I feel privileged to be asked be a part of the process. I would like for my evidence to be made public, if possible, as the deceased patients' relatives that I will refer to have given their consent and I have nothing to hide.

My interest in palliative care was ignited through working with Dr Doug Bridge in Fremantle Hospital. I did further training in palliative care and attained a college of GP's fellowship. I worked in general practice in Byford for 25 years where I took care of nursing home resident inpatients at Armadale hospital and the dying in their homes with the help of Silver Chain Hospice Service. I have guided several hundred patients and families through the dying process through psychological, spiritual and medical support. The dying patient always had control over all their healthcare decisions after careful explanation of all their options. For a few, the decision included the option

of preventing a slow, lingering death. This greatly reduced their fear of dying so they could focus on living right to the end.

I chose to stop working in end-of-life care when a nurse threatened to call the police after I asked for an increased medication dose for a distressed, dying patient in a nursing home. The nurse interpreted this dose as an attempt to kill that woman. The end result was that the dose was left unchanged and the woman was left with uncontrolled distress before dying 24 hours later. On reflection, I felt I could no longer work in end-of-life care under the current legal framework. My open declaration of my help to stop the suffering of an elderly woman with end-stage lung disease was intended to challenge the current grey area in the law. Was it terminal sedation or was it voluntary assisted dying, which is currently called murder? I provided this lady with exactly the same treatment as palliative care doctors provided the sister of a colleague of mine, Dr Behan, and I have his permission to tell the story of his sister's passing.

He contacted me to ask for help some six months ago. He had read my story in the book *The Damage Done*, and I have a copy for each of the committee members if they would like to read that story. He described that his sister, Peggy, had suffered also from end-stage lung disease and was suffering severe breathlessness and had repeatedly requested him to help her to die. She still lived independently but was strong in her wish that she did not want to linger on to dependency. Peggy had asked for a respiratory specialist to help her to die. This specialist prescribed morphine tablets for her and told her that if she took them all, that would do it. Dr Behan asked me for advice and after talking to him, it was clear that his sister had not been provided with palliative care input. I told her not to take the morphine as it was almost certainly going to cause vomiting and may not have the desired effect. I advised her to ask her GP for a referral for palliative care.

Dr Behan informed me of the events that followed. The palliative care team admitted her to a Perth palliative care unit where she was given low-dose morphine. Over the several days later, she persisted in her wish to die. The family was told to come and say their goodbyes as they were going to provide terminal sedation and it was explained that this sedation may affect her breathing and cause her death. Peggy was told to remove her oxygen so the doctors could treat her increased distress from breathlessness with deep sedation. Hours after the infusion was started, Peggy passed away gently. Dr Behan told me that everyone was relieved and happy for her. A day prior, this lady had walked into the hospital and now she had died.

Was that good palliative medicine or was it voluntary assisted dying? I say that Peggy was very lucky and I say it was both. She would not have been given this care in a Catholic palliative care unit. An onlooker could have alerted the police. The law does not distinguish between Peggy's medical care and murder unless one can prove the doctrine of double effect in court. The only difference between my care and that of Peggy's doctors was that I did not ask my patient to remove her oxygen to create distress to justify providing terminal sedation. I call a spade a spade and I openly declare that I gave my patient medication with the understanding that it would significantly bring forward her death. I know that a frail old lady with severe lung disease will stop breathing when I sedate her. The aim was to stop suffering. The side effect was death and that was her wish.

Over the past 18 months, I have found myself in a unique position where many people have approached me and they trusted to talk to me about their pain and fear. Large numbers of people have contacted me and told me their stories of bad deaths of a loved one. One of the most memorable was a man who told me that his wife was dying in hospital. He had begged the doctors and nurses to increase her medication as she was suffering.

[3.10 pm]

He felt desperate and told the doctors that if they did not increase his wife's medication, he would go home, get his gun and shoot his wife and then himself. Imagine how distressed he must have felt to contemplate such a desperate measure and how awful to finalise a lifelong union like that. Many people with a terminal diagnosis have contacted me to request for help. Unfortunately, with a blue spotlight on me, I am not able to offer any direct help except to ensure they have expert palliative care. Most of those have since passed away, some likely in a way that none of us would find acceptable.

One lady I did agree to help was a lady with terminal [REDACTED] cancer. [REDACTED] all she wanted was a choice. Her husband encouraged her to tell her story to the committee, as she cannot do so herself. She first contacted me some 12 months ago. She was aware of her terminal illness and was petrified of dying like her mother, who had died a slow death over several months, and she asked for advice. I put her in contact with Dr Rodney Syme, who talked to her on several occasions from Melbourne. Six months later, she told me that she had been discharged from hospital with a limited prognosis of weeks to months. She asked me to come and meet with her and her husband. She was in a wheelchair, as she had lost the use of her legs but appeared in good spirits. She told me she was planning her death and asked me to get the Nembutal for her. I said, "I have no access to Nembutal." This caused a huge panic in her. She thought I had the stuff. I said that the only doctor I knew in Australia who had access to Nembutal was Dr Syme. In desperation, she started to talk about plans to travel to Melbourne and see Dr Syme to get it. I explained that she was not well enough to travel to Melbourne. Her fear was palpable. She now had no means to safeguard her from the slow, lingering death that she was dreading. She asked me what else she could take. I told her that no other oral medication was reliable enough. Then she asked me if I would give her an injection if she decided she had had enough. I felt torn in my fear of my legal situation and the need of a dying woman. Her need won. And I eventually agreed that I could come over and provide her with rapid deep sedation if her suffering became unbearable. Words are not enough to describe the relief that she showed. She cried with joy and relief, telling me how grateful she was. Over the following weeks, she and her family planned a huge party to celebrate her life and death and say her goodbyes. She called it her living funeral party. There was music and laughter.

Five weeks later, I got that dreaded phone call from her husband that she had asked for me to help her. My dread came from the potential legal ramifications, not the act itself, as that is a gift of beautiful relief for all involved. We had made detailed plans to safeguard the family and myself and were talking in code, as I did not know if my phone was still being bugged. I would come the next day. Early the next morning, her husband called me that she had died during the night and my help was no longer needed. I was so relieved. Over the previous 12 months, her repeated message had been, "I'm not suicidal; I love my life. I just want a choice about how and when my life ends." That was her message. I feel proud to have been able to provide this lady and her family with seven weeks of quality of life by removing her fear of dying and giving her her last wish to have that choice.

Many healthcare professionals have contacted me with support, including carers, nurses and practitioners. The most supportive are the nurses, who are at the coalface of end-of-life suffering. Their national representative body, the Australian Nursing Federation, is strongly supportive of law reform. For some reason, the leaders of the Western Australian branch have their own views on this issue and do not represent its members. I know many nurses who have contacted the Western Australian branch to ask its position about voluntary assisted dying and none have received a reply. Six other medical practitioners, including two palliative care specialists, as well as several nurses, have told me in private that they have also provided medication which they knew would hasten the death of the patient.

One thing I have learnt about my colleagues is that privately expressed views are much more honest than opinions expressed in public and can differ widely. For example, one palliative care doctor wrote a submission to the committee stating her opposition to law reform but privately she mentioned to me. “I know I kill people; it’s the right thing to do.” This same doctor ordered an opioid antidote, Narcan, after she had administered morphine to relieve the pain of a 90-year-old dying woman. The morphine had severely reduced this lady’s respiration and oxygen level, and could lead to her death if not reversed. But reversal could cause severe rebound pain. I asked her why she asked for the Narcan, as the patient was dying and needed pain relief. She told me that the family wanted to keep her alive for as long as possible and may cause trouble for her and the hospital if they found out the morphine dose preceded her death. She did not want to risk that. I asked: what about the patient?

Dr Bridge—whom I respect enormously and worked with in Fremantle Hospital—and I agree on many and most issues regarding end-of-life care problems. Healthcare professionals are really bad at talking to their patients about death and go into overdrive attempting to prolong life. For the patient, this creates false hope, futile traumatic medical interventions and no time of letting go prior to dying. One of my patients was obviously dying but her oncologist suggested one last chemo treatment. She was dead the next week. However, Dr Bridge and I do not agree when it comes to patients’ end of care. Doctors have no role in deciding which care options are morally right for their patients and should never try to steer them one way or another. He told me he does not provide any patient with terminal sedation as it makes him feel that he kills people that way and he does not like that feeling. He now only offers intermittent sedation to give patients a break from their suffering. He told me he feels that almost all requests for a hastened death are caused by psychological stress related to unresolved life issues. He said that when a person asks him to help them die quicker, he explores their emotional state and then they mostly change their mind.

I wonder how a suffering, dying patient feels when they get asked to express their emotions about traumatic life events when their bodies are failing and they experience pain and feel nauseous, feel exhausted or cannot breathe. Is that not patronising? I would not want to continue that conversation either. This is called directive counselling. The aim of the talk is to make the patient see the error in their ways according to the personal view of their doctor. Doctors are in a position of power and can direct their patient to express or withhold their views or fears. The desire for a hastened death may be there, but such thoughts are often kept secret by patients unless a doctor specifically asks and is non-judgmental and the notion that end-of-life suffering somehow can be a teaching tool for personal growth is abhorrent. Should the end of life be a time for a dying person’s last challenge or is a dying phase a time of letting go—a gentle surrender and open acceptance of the end?

Another question: Can voluntarily stopping eating and drinking be an alternative to medically assisted dying? Stopping eating and drinking is a way to bring forward death, but it can take weeks. The person would have to endure several days of hunger pains followed by the symptoms of metabolic effect of starvation, which is ketotic acidosis. This causes headaches, confusion, breathlessness, delirium, agitation, weakness, muscle cramps and eventual sedation. Medical support is required to ensure these symptoms are controlled. When this is available, the process can be similar to terminal sedation. It is not clear, however, if this medical support would qualify as assisting a suicide. According to a Dutch report by the KNMG, most people who choose to stop eating and drinking do so after they have had their request for voluntary assisted dying denied because they do not qualify.

[3.20 pm]

It is an option of last resort.

Last week, I talked to Dr Ellen Wiebe, who is a GP in Vancouver, Canada, with 30 years of experience in palliative care. She has provided over 100 patients with medical aid in dying, which is what they call it there, and has developed a training program for medical practitioners in Canada. She gives people who request voluntary assisted dying all the care options, including terminal sedation and voluntary stopping eating and drinking. She is yet to have a patient opt for the slow method, and most people prefer a doctor-provided injection rather than self-injection. She finds that the most common reason for a request is poor quality of life and loss of dignity. It is all about giving people all the options so they can decide for themselves how to manage their end-of-life journey.

I would now like to present a brief audio clip of a man with end-stage motor neurone disease. He is not able to move from his neck down. His words really say all that needs to be said. Sorry to be difficult, but I just thought the only people we are not hearing from are the people in that situation. He said —

I am feeling powerless in that process. We are not powerless. You know, for a person with ALS who has gone through the process of losing physical capacity and feeling powerless in that process and that there is nothing to be done, to be able to be offered the fact that you can live as you see yourself living until you can't, is tremendously empowering. I think all of us live a balance between our love for life and when life becomes all too much for us. So this balance, which I have been doing for the last four years, has suddenly showed how I might start to say that I don't want to live, that I love my life, but it is to say that the challenges of ALS at a certain point become so much that the question of quality of your life is a serious consideration. I think that for now, I still have the ability, the capability, of enjoying my friends and family, and yet if my physical or mental capacities were to be so compromised that I could not enjoy that, I could not have that sense of engagement with the people that I love, that my judgement of the quality would be much harsher than it is now, even though I am paralysed from the neck down. At night time when everyone is asleep, including the cats, and I am not able to move, I am not able to shift, not able to do the things that most of us would do just to get a little more comfortable, so what for most people would be a minor irritation over time grows into a very painful situation, and at those times, I would rate the pain up at the eight, nine, 10 area. It is interesting that we are focused on pain, because I think that is what most of us imagine would be the kind of thing that would be the tipping point. But I do not think that is really going to be the tipping point for me. I think the tipping point for me will have something to do with what I said before about feeling so powerless and so unable to engage with the life that I love that that life is just virtually impossible because of the loss of capacity.

His wife said —

I think the worst thing you can do is see somebody you love suffer. And as much as I want Bruce with me, I do not want to see that. I do not think I could bear to see unrelenting suffering. So as much as I hate to admit it, I would support his decision if he decides it's too much.

He went on to say —

By facing death and embracing death, you actually get to focus on life, and that to me is a tremendous gift. That is how I want to die. I want to die fully alive.

I would like just a few more minutes to talk about advance health directives, community palliative care and law reform, please.

The CHAIR: Yes.

Dr LANCÉE: Regarding advance health directives, there is one illustration I would like to put up. To improve full uptake, I have some suggestions that could be considered or could be included. The college of GPs presents each GP with a guide for preventative health activities. An advance health directive discussion could be added to that at a specific time or age to encourage GPs to initiate discussion. A public awareness campaign could also be used to improve our public awareness, something like “Help your doctor know your health priorities”. People could be sent a letter to invite them to prepare an advance health directive on a specific birthday, similar to the current breast and bowel cancer screening program.

I have noticed resistance from aged-care facilities. It took me 18 months of repeated requests to be allowed to discuss and implement advance health directives for my nursing home patients, as they said it was against their ethos to allow residents to refuse life-extending treatment. Mandating an advance health directive for all people entering assisted living facilities, and mandated adherence, could be a solution.

Another obstacle is the format of the Western Australian form itself. You can see that on page 2 there are very open-ended questions. This is the only page where people can put that in. So they need to decide for themselves under what circumstances they want what type of treatment. Most people have no idea how to fill that out. They really do not have a clue. Then, whatever they write down, how is a health care practitioner going to interpret that under a different circumstance? The New South Wales forms, on the other hand, if you have a look, are very user-friendly. Page 1 talks about the patient’s values, so what type of situation they would find acceptable or unbearable. On the next page, they are asked what their natural dying preferences would be. On the page after that, they are asked what interventions they would like or not like. My suggestion would be to implement a reform or a redrafting of the Western Australian forms to make them more user-friendly. I think that would definitely be good. People feel overwhelmed and do not have a clue what to write down on them.

Acute healthcare staff have low awareness of their priority to check for advance health directives prior to commencing medical interventions. A central registry of advance health directives, similar to the one in California, could be implemented. I think it should be a legal mandate to adhere to an advance health directive if there is knowledge of its existence. The next illustration shows my parents—my mum and dad—who carry with them a card like this and a tag on their neck whenever they go out in public, so that people know that there is an advance health directive in place that they do not wish to have a CP resuscitation, and they feel reassured by that.

Unfortunately, when you are in a specific hospital, it does not matter; they have their own ideas about what you want and what you do not want. My dad was admitted to a hospital and they did not want to have much of a look at advance health directives, because they had their own policies over CPR.

[3.30 pm]

The next issue I would like to talk about is the fact that dying at home is the wish for most of us. It has been a privilege to share this journey with many of my long-term patients and their families, and it was definitely heartbreaking when families had to admit that their capacity to care for their dying loved one had reached its limit and transfer to hospice was needed. Some hung on until a crisis ensued. An elderly couple living in Mundijong were patients of mine for 20 years. He was dying from prostate cancer. He was a proud man and could be very stubborn. He hated hospitals and absolutely insisted that he wanted to die at home. He became poorly mobile and often could not reach his commode on time, and he refused to wear a nappy. His wife spent most days washing his clothes and sheets and cleaning up after him. She had become exhausted and she one day rang me

up telling me in tears that he could not get out of bed and she could not clean him up. When I got there he was confused, drowsy and lying in his faeces across the bed, and she sat sobbing next to him. I helped clean up the mess and then she reluctantly relinquished him to hospice. He died there a few days later and she felt she had let him down. The limiting factor there was not medical care, not nursing care, but carer support. Increased funding for community palliative care services and, specifically, a carer support package would enable people to die at home more often.

Lastly, I will say a few words about law reform. We have the benefit of being able to learn from the experience of other jurisdictions over several decades. We can check the multitude of reports and reviews about the problems they faced and we can feel reassured that none of the dreaded fears of elder abuse, coercion, death-thirsty doctors, slippery slopes or degradation of palliative care have been realised in places where voluntary assisted dying is legal. In order of importance, firstly, an ideal law would provide ready access to an expedited death in a manner, time and place of their preference for those who suffer unbearably at the end of life. Secondly, there would be as little extra burden as possible and a guidance by a healthcare team for loved ones. Thirdly, there would be clarity and ease of interpretation and straightforward process, as well as legal protection and the ability to opt out for medical practitioners. Fourthly, there would be safeguards to prevent inappropriate use of the law and to ensure that those who do not wish to participate are not affected in our society.

The group Doctors for Assisted Dying Choices is preparing a review of the Victorian act, which has 142 sections and 130 pages. This compares to the 12 pages of the Oregon act. The group Doctors for Assisted Dying Choice is very keen to see a simplified less bureaucratic bill for Western Australia. I feel it is essential for patients and loved ones to have guidance and backup of a healthcare team. If Western Australians are ever lucky enough to be afforded the legal option to shorten their dying process whilst they are suffering, I would be very keen to implement a mobile end-of-life service. This team would include doctors, nurses, psychologists and social workers to provide guidance and support for the dying person and their loved ones through the process of a medically assisted death. I feel it is vital that medical care is at hand at the time of administration to assess the effect of medication, step in if needed and to guide people. I do not think people should ever feel abandoned by their healthcare team at this crucial time.

I can answer any questions and clarify issues.

The CHAIR: I have a couple of questions, particularly around a couple of things we have heard as evidence from the committee about aged-care facilities and that is the lack of specialist palliative care services provided in aged-care facilities and a lack of advance health directives, as opposed to what is termed as “my last wishes”. Firstly, I invite your comment on what you think the state of access to specialist palliative care services in aged-care facilities is.

Dr LANCÉE: Firstly, I must point out that the specialist palliative care service is only needed for a very small percentage of people who have difficult-to-control, complex symptomatology. The majority of palliative care is offered by general practitioners with the care of nurse practitioners as well, who work in palliative care, and there is now a mobile service that we can call if we have difficult-to-care-for people in nursing home facilities. But I think that is still an underserved area, particularly for people who are not very well vocalising their symptomatology or distress, and I think too many people in nursing homes are suffering physical pain as well as other symptoms without them being managed well enough.

The CHAIR: Would staffing be a factor and the scope of practice of staff?

Dr LANCÉE: Absolutely. My concern is that nursing homes are run as businesses. They are under the banner of so-called—they often have affiliation with religious groups and the like. It was always

terribly difficult to try to find resources for people. I often wanted to just simply have a woolly thing under their bed to try to prevent sores, and there was very little funding. Staffing, again, is very difficult, particularly qualified nursing staff at night-time—non-existent. That means that people get shipped off to hospital at the drop of a hat, which was a huge problem for me, and eventually I absolutely insisted, “Please, call me, day, night, any time, but don’t ship them off until I’ve assessed that they need it”, because people do not want that. It is very distressing for someone to be shipped off to hospital, particularly if they are mildly demented and then that shift can just send them into a real confusion state. So, staffing levels, nursing staffing levels in particular, I think are lacking in aged-care facilities.

The CHAIR: There is that level of fear, if you like, of the PCAs or the carers who are working in the facility that they do not want to be responsible for a death, even though people are actually at the end of their lives in aged-care facilities.

Dr LANCÉE: Yes, I do not know whether there are some protocols in place from higher up, but I find that the knee-jerk reaction is if someone falls out of the bed, they are off to hospital. Call me; have a look yourself first. Can they get up? Do they move? But no, it is straight to hospital, which is distressing and a waste of resources.

Hon Dr SALLY TALBOT: I have a couple of lines of questioning that I am interested to pursue with you. The first is about the advance health directives. I have to say that I was shocked when I saw the Western Australian form. I had not realised that it was so open-ended.

Dr LANCÉE: Yes. I used to photocopy the New South Wales one and stick it in and say, “See this”, but I do not know how legal that is. At least people felt they had some idea of what they were writing.

Hon Dr SALLY TALBOT: You get your parameters from the New South Wales form.

Dr LANCÉE: Yes.

Hon Dr SALLY TALBOT: If we are able to fix the bureaucratic end of the system, how do we then go about fixing what happens when somebody with an AHD—let us say we get the perfect form and we get some kind of register so that everybody can dial it up and know exactly what the person’s got. We have been hearing evidence consistently about the fact that you can go into hospital with a “do not resuscitate” or an advance health directive that is very specific, but the doctors will still say, “Our duty is to do our best.”

Dr LANCÉE: I guess you just need to write a law saying, “If you do not adhere, you are actually assaulting that individual if you instigate treatment against their wishes.” I cannot see any other way.

Hon NICK GOIRAN: Does that law not already exist?

Dr LANCÉE: I do not know. Professor Richard Lugg actually looked into that and in fact it is not binding. He told me that there is no legal mandate to adhere to it. It is a guide.

Hon NICK GOIRAN: You cannot assault a patient.

Dr LANCÉE: You can assault. If you treat a person against their wishes and you cause them some physical effect, then that is assault.

Hon NICK GOIRAN: That is right. You cannot do that by law in WA.

Hon Dr SALLY TALBOT: I think there is probably an extended debate we can have here, but I think we have heard clearly, and I seem to recall three reasons, that you can override an advance health directive, so I will take that point as it was made by the witness.

Hon ROBIN CHAPPLE: We have got a bit of a dialogue going on here, but I suppose in that context, is chest compression or that sort of CPR—is that an assault, or is an administration of a drug to get the heart going again an assault? I think that is where it gets really messy.

[3.40 pm]

Hon Dr SALLY TALBOT: What do you do about paramedics, because they are in a different situation, are they not?

Dr LANCÉE: Nowadays, with the ready access to internet everywhere, if mum has an advance health directive registry, and my mum drops on the floor and a paramedic comes over and sees her thingy all he has to do—there it is, do not resuscitate, leave her alone. If it says resuscitate, then go for it. I think that by the time they get there anyway, it would take a minute to check that. I do not see any limiting reason to not be able to get that information. The police can get who you are on your numberplate like that—you know.

Hon Dr SALLY TALBOT: So you would include paramedics and first responders.

Dr LANCÉE: Totally; that is essential, because once you rock up into hospital there is no stopping them.

Hon Dr SALLY TALBOT: Thank you for that. The other area I wanted to ask you to speak a bit more about is what happens outside the metropolitan area, or indeed outside regional centres. You have clearly been living with this issue for many years. You have got some very practical suggestions about how we might start to change both practice and culture. One of the things that has struck me during this inquiry is that, when you leave the metropolitan area and go to, say, Albany, as we did a couple of weeks ago, you find that in Albany you currently have access to exactly 50 per cent of the services in terms of in-home palliative care that you will get in the metropolitan area. When you drive 50 kays west to Denmark, you have a third of that. We are going from 24/7 to 12/7 to eight hours a day, Monday to Friday, and when you go another 50 kays to Mount Barker, you are on seven hours a week. Can you just talk us through how—if you were in charge for a day and you could implement all these changes, what do you envisage for somebody living in a community like Mount Barker?

Dr LANCÉE: Who wanted to die at home?

Hon Dr SALLY TALBOT: Yes.

Dr LANCÉE: Officially, I think, any GP who services Mount Barker has ready access to a web-based, high-quality palliative care resource, called Decision Assist, which is a national-based resource where practical palliative care medical problems are guided through. I do not think one needs to have access to specialist service to be able to be good at knowing what to do. So a GP could do that, but in terms of the actual home care, again it comes down to the carer support and the in-home availability of—they often need a hospital bed; they need commodes; they need all the aids put in. I do not have an answer to that. When I initially started palliative care, Silver Chain did not come down to Byford either, and it has gradually stretched further down, which is fantastic. Honestly, I cannot praise their service high enough. It is essential that we have that and we expand on that. But at the end of the day, this is why a lot of people who are elderly move back to the metro area or to places like Dunsborough, because the medical services there are better. I do not know how feasible it is to say you can live in Woop and you can have all the services there that you could get elsewhere. It is just not practical. I do not know.

Hon Dr SALLY TALBOT: Related to that question, if I may, just one last question. We have heard that there is likely to be serious under-reporting of palliative care patients, so patients who are in hospital receiving palliative care who do not show up on the data as receiving palliative care, and the

suggestion was made to us that that is because, to be admitted as a palliative care patient you must be under the care of a palliative care specialist.

Dr LANCÉE: I think this is, again, the tip of the iceberg. I think that if we look at who receives palliative care, it would be most people who are in fact entering their terminal phase of life. Whether that is by a specialist and it is called as such or not is another matter. Let us just say that the words “palliative care”, is really all about improving quality of life by managing people’s psychological, physical and other distress so they can have a quality of life. Whatever word you call it, the actions, I think, are happening around most people’s end-of-life path, whether they have specialist input or not.

Hon Dr SALLY TALBOT: Are you suggesting that the determination that somebody is in the palliative phase does not have to be made by a palliative care specialist?

Dr LANCÉE: Of course not—no. There is a framework that we work by, particularly in aged care residences where we use the surprise question, which means that if we have a patient under review, every year, or every six months as I used to do, in a review of that person’s health condition, we would ask, “Would you be surprised if this person died in the next 12 months?” If the answer is, “Yes, I would be surprised”, one would continue life-extending interventions, et cetera. If the answer would be “No”, then we would enter a more symptomatic approach to their care, which means a palliative approach, if you like. Certainly, I instigated palliative care measures, if you will, at the time of a potentially life-limiting illness, not when they are at their last. That is a concern that I share with my palliative care colleagues—that palliative care intervention is often delayed way down the track, and part of that is because, bless them, the oncologists or other people just want to keep people from feeling—no, we can extend your life. They are not being given an opportunity to say, “No, now we need to focus on quality of life and facing your impending death, and coming to terms with that in accepting it.” I think that there is a misconception there, I do not think amongst general practice as such, but certainly Dr Behan was not aware palliative care services were available for people who did not have cancer, and so when I advised him of that, that is how his sister was helped.

Hon Dr SALLY TALBOT: I just have one more question about AHDs that I forgot to ask you earlier. You talked about a nursing home that you had a connection with discouraging people from making AHDs, because they did not —

Dr LANCÉE: No, they just did not allow me to, because in a nursing home the patients do not tend—they are quite non-functional, if you will, so they do not tend to initiate things about their care so much, so it would be me who would be initiating the discussion with them, and they just would not let me start that. Even after I implemented this, I said, “What are your priorities to a certain person”, and I completed an advance health directive, they would not adhere to it. They would still be sending them to hospital.

Hon Dr SALLY TALBOT: Because they said it was not part of their brief to facilitate people refusing treatment?

Dr LANCÉE: They thought it was against their ethos. That is the word they used. It was a board of people who would need approve that that was something that could be implemented.

Hon Dr SALLY TALBOT: Was that a faith-based institution?

Dr LANCÉE: Yes, it was.

Hon ROBIN CHAPPLE: Slightly following on from that, and this comes from some of the evidence that we have heard, we certainly have evidence that older doctors who have been practising for a long time to actually have a relationship with the patients and in understanding all their palliative needs. We have also heard that in your training as a junior doctor, you only get one week of

exposure to palliative care. I am trying to put words in your mouth, I suppose. What should we do with junior doctors about end of life?

Dr LANCÉE: Firstly, when one finishes a medical degree, you have to go through several years of hospital training, and then you cannot practise independently unless you receive specialist training.

So in the general practice college GP program—it used to be a family medicine program—there is a significant amount of end-of-life care training. There is certainly more than a week where people are—that is a focus on a module there. So before you end up on an individual chair in a general practice, you have been exposed to more training. But when we are talking about doctors who are junior doctors in the hospital, they do not tend to make decisions. It is the senior doctors who supervise them who tend to make the decisions. The junior doctors tend to follow instructions and do the humdrum things.

[3.50 pm]

Hon ROBIN CHAPPLE: Okay. One that is quite a different question: you talked about the lack of availability of Nembutal as an obstacle. Now —

Dr LANCÉE: No, no, that was only for that particular lady because she thought I had it, and I do not.

Hon ROBIN CHAPPLE: I want to try to talk about Nembutal. What is Nembutal, where is it supplied and what is it used for under conventional means? We know people travel overseas to get it. So is it used for any other purposes? What is Nembutal?

Dr LANCÉE: I have had discussions with Dr Rodney Syme about this and he has told me where he gets it from, which will remain confidential. But the Nembutal was pentobarbital, which is a fast-acting barbiturate. We used to prescribe barbiturates regularly, up until about 20 years ago or so, as a sleeping aid. It was a sleeping tablet. However, because of its toxicity in overdose, it was restricted. Then, eventually, we made it unavailable for human use. Of course, it is widely used by veterinarians for euthanasing for their animals.

Hon ROBIN CHAPPLE: That I did not know.

Dr LANCÉE: Yes. So no other oral medication or combination has ever been proven or shown to be having the reliability of a gentle passing or death than the fast-acting barbiturate, and Nembutal is one of them. Secobarbital was another one. So Nembutal needs to be consumed in a liquid form; it is dissolved and it is very bitter. The secobarbital can be used in capsules. I think both of them are used in Oregon. When I talk to Dr Ellen Wiebe, who is the Canadian doctor who provides voluntary assisted dying for her patients, she has used it on two occasions only because all the other 105, I think, preferred the injection. I think in Canada they need to import it from the US, and at huge cost to the patient, so that was a huge limiting factor there. I have been told, but I cannot be certain, that Australia actually produces it for veterinarian use in its liquid form but it has a very short shelf life, so the palliative form is not available in Australia at all.

Hon ROBIN CHAPPLE: That cleared up a lot of things for me. I did not know any of that.

Hon NICK GOIRAN: There was a little discussion earlier about referrals to palliative care specialists. What criteria do you use to make such a referral?

Dr LANCÉE: I use the criteria when I feel that I have a problem or that a patient is suffering from symptoms or complex symptoms that I have difficulty in controlling, or I do not have specific guidelines about how to manage them that I feel comfortable with.

Hon NICK GOIRAN: So you might not refer someone to a palliative care specialist —

Dr LANCÉE: I have.

Hon NICK GOIRAN: Sure; I understand that you have. But you might not refer someone to a palliative care specialist, whilst another GP might refer the person to a specialist?

Dr LANCÉE: I think everyone has different levels of confidence and experience in a different field of medicine, yes.

Hon NICK GOIRAN: Okay.

Hon ROBIN CHAPPLE: So you have a patient, you have been prescribing the medication to keep them comfortable and everything else, and it goes a bit wrong. So you phone up the palliative care specialist and you will get information down the phone, or teleconference or whatever: “Well, now I sort of get an idea of what’s going on here, this person’s most probably got X, Y, Z. We would suggest adding this to the pump and that might do it.” So you are using that palliative care specialist as an advisory body to your function?

Dr LANCÉE: Absolutely, and that is what a specialist is. A specialist sees people who have specific needs, and they see them for a short assessment period.

Hon ROBIN CHAPPLE: Or maybe just provide the information to you over the phone?

Dr LANCÉE: Sometimes, yes. But they are consultants, meaning a consultant, a consultation-based—so they do not tend to follow the one patient up, unless they are admitted in their hospital under their care. Yes.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via 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. Thank you very much, Dr Lancée, for talking to us.

Dr LANCÉE: Thank you. Here are the books if you want them.

Hearing concluded at 3.56 pm
