

# **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  
TUESDAY, 27 FEBRUARY 2018**

**SESSION FIVE**

## **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 3.51 pm**

**Dr ANIL TANDON**

**Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, examined:**

**Dr MARY McNULTY**

**Palliative Care Medical Specialist, Silver Chain, examined:**

**The CHAIR:** Welcome this afternoon to Dr Mary McNulty and Dr Anil Tandon. 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 inquiry. I will introduce the committee. We have Simon Millman; Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; Reece Whitby; and Hon Robin Chapple.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices 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 that you might say outside of today's proceedings. I advise that the proceedings of today's hearing will be broadcast live within Parliament House and via the internet. Do you have any questions about your attendance here today?

**The WITNESSES:** No.

**The CHAIR:** Before we move on to our questions, would you like to make a brief opening statement?

**Dr TANDON:** Thank you. That would be excellent.

First of all, I would like to say thank you very much for the invitation to appear. It is really very good to be given this opportunity and I am glad you are interested in our opinions. By way of background, although I am here as the chairperson for the WA Palliative Medicine Specialist Group I am a clinician. So I do work full time in palliative care and have done so for the last 21 years since 1997. I am currently at Sir Charles Gairdner Hospital and as the visiting palliative care specialist at the goldfields, so principally Kalgoorlie and Esperance. I have previously worked in a number of sites in Perth as well as internationally, in particular in the United Kingdom. Also, I have previously been chairperson for the training committee for palliative care specialists. That is within the college of physicians and covers the training of palliative care specialists across Australia and New Zealand.

I do note the terms of reference, but I would like to make just a few general comments about palliative care in Western Australia. First of all, unfortunately access to specialist palliative care is limited. Just within metropolitan Western Australia specialist palliative care is not available in Joondalup Health Campus, Osborne Park Hospital, Midland Health Campus—public and private—Armadale hospital, Fremantle Hospital and Peel Health Campus. Yes, they have doctors with interest in palliative care, but not specialist palliative care. By way of example, Joondalup Health Campus is approximately the size of Sir Charles Gairdner. At Sir Charles Gairdner we receive around about 1 000 referrals per annum. My concern is if one of us had family members who were living in the catchment area for Joondalup or any of those other hospitals that I mentioned, where would our loved ones get palliative care input. I go to Kalgoorlie once a month and Esperance once every three months. There is a great team that I work with, but they are two nurses. I genuinely worry about what happens to the patients that I am looking after in between those one and three-monthly visits.

Finally, I extend a very warm welcome to any of you if you did want to come on a ward round with me. I have spoken to my head of department and the team, and they would all be very happy for you to come if you wanted to see what we do.

**The CHAIR:** Thank you.

**Dr McNULTY:** My name is Mary McNulty. I work for the Silver Chain hospice care service and I combine that with general practice. I bring to the committee today my experience. I have worked for 30 years in community palliative care and I have had the privilege of being involved in the care of many thousands of people, so I hope that the experience and knowledge that I have will be of use to the committee.

**The CHAIR:** We will just start with some questions around palliative care. Are palliative care interventions and issues able to be undertaken or considered by treating doctors who are not specialist palliative care physicians?

**Dr TANDON:** Absolutely, yes, but I think that the important thing is that in all fields of medicine we all practise within the limits of our knowledge and abilities. Just like I would treat a person with joint pain only up to my knowledge and then when it was beyond that I would refer to an orthopaedic surgeon, I would expect the same from any other primary doctor. They should have a basic level of knowledge, but then they should also know their limits.

**The CHAIR:** Should all treating doctors, such as GPs, have an understanding and experience with dealing with end-of-life care?

**Dr TANDON:** Absolutely, yes; particularly general practitioners. That is certainly something that we in our Palliative Medicine Specialist Group take very seriously. We do undertake a lot of training for both medical students but also doctors training to be specialists in other fields, whether they be general practitioners or training to be other specialists. Also, we conduct our own training for ourselves and our trainees.

**Dr McNULTY:** It is important to alert the committee to the fact that for the average GP they would probably see really only one or two palliative care patients a year, and that would be a GP working full time in an area where there was not such a young population. So even though people have an interest and a keenness, the ability to get experience is limited.

**Hon COLIN HOLT:** Would that be true for people working in regional areas; maybe potentially a single doctor in a town with a hospital attached? I would have thought a lot of their work would be palliative care in terms of supporting aged people in town.

**Dr McNULTY:** Yes, it would vary depending on your practice. Anil might have a better idea about country practice because he does visit rural communities.

**Dr TANDON:** Absolutely, yes. But I think that a lot of patients that we see, for example in Kalgoorlie, when patients are reaching end of life then they will be admitted to the hospital where the general practitioner may not have admitting rights. It does vary though.

**The CHAIR:** Is it correct to say that specialist palliative care physicians tend to provide care in the most complex cases and are also responsible for advising and educating other health professionals about palliative care medicine?

**Dr TANDON:** Yes, I think that is true. But also we are open to receiving referrals of any patient, regardless of their complexity. If they do not have complex needs but the patient or the family wants palliative care involvement, we will still be involved.

**Dr McNULTY:** In the community Silver Chain hospice care service, which is a specialist palliative care service, does care for people with simple palliative care needs and with very complex needs. We do

have palliative care specialist physicians who are able to assist the people with the most complex needs. Our model, as I think you know, involves a lot of GPs who have expertise in palliative care and experience, and they tend to deal with the less complex cases.

**The CHAIR:** In a recent report with a survey of around 1 800 patients, they found that in Australia people receiving care from palliative care services often experienced high levels of pain and other symptoms. In your experience and the findings of the survey, is it correct to say that only around one to two per cent of patients would have refractory symptoms around the end of life?

[4.00 pm]

**Dr TANDON:** I think we would always want to take any survey, any research, with a degree of caution. It may be that that study was unique for that particular population, and it may be that those patients had high levels of pain for reasons that are more complex. For example, it may be not necessarily that the treatment has not worked, but the patient has chosen to not take those pain medicines. Some patients will actually say to us, “I want to actually be in some level of pain so that I know whether my chemotherapy or radiotherapy is working”, strange as it may seem to us. Also, some people actually do not take medicines as prescribed because they are cautious of the side effects that they may experience. But absolutely no intervention in palliative care is 100 per cent effective, just like in any other field of medicine as well. There is always a balance between the benefit and the side effects.

**Dr McNULTY:** I think when people are ill and have palliative care needs but they are still active in the community, their levels of pain and the levels they are prepared to trade off against side effects and other effects of medication are different to the very last part of life. I think a figure of one to two per cent is quite accurate for the very last term or phase of life.

**The CHAIR:** Thank you.

**Dr TANDON:** It is interesting, if I can also add, this whole concept of refractory symptoms is evolving. If I think back to 20 years ago and the pain that our patients were in compared to now, it is different, and I would imagine also as time goes on that different treatments will develop and we will be able to use them better.

**Mr J.E. McGRATH:** Just one question on the point you raised about people who are receiving palliative care treatment and are still working. I did not realise that happened. Can you explain what circumstances this would be happening in and what kind of treatment that palliative care would take for someone who is still in the workforce but obviously has some issues?

**Dr McNULTY:** There is a bit of an idea that palliative care is the last post that you get to when everything else has failed and you are near death, but as palliative care has evolved we have become much more integrated and involved with people with illnesses that cannot be cured, but at the point that we are involved with those patients they are still having treatment and they are still leading an active life. The kind of contribution we can have is in symptom control, because we do have skills perhaps better than some of the other treating doctors on how to manage their pain and other symptoms. We also get involved with people around assisting with their decision-making. We get involved particularly in the community with people who might be having chemotherapy who are not sure whether the treatment is going to work or not work. People can continue to work during all of that time. The other thing is that palliative care specialists, particularly in the hospitals or consulting clinics, may get involved with the patient during one phase of their illness, when they are very unwell or in pain and things are not very well-controlled, but then that person will improve and the treatments that they have had—palliative chemotherapy or radiotherapy—may make them a lot better and they no longer need that input. Then they may become unwell again at another stage,

which might be a few months, or it could be a few years. So we come and go with people over a journey of their illness. It is not just a discipline that is applied at the very end of life.

**The CHAIR:** The WA Cancer and Palliative Care Network publishes evidence-based guidelines for adults in the terminal phase. Does the administration of these treatments require specialist palliative care expertise, or can GPs and specialists prescribe and administer these medications for patients at the end of their life?

**Dr TANDON:** The guidelines were primarily designed for primary healthcare doctors, so general practitioners, mainly. That is absolutely who they are intended for, to give them at least that degree of information.

**The CHAIR:** Thank you. We will move to the area of the doctrine of double effect —

**Hon NICKGOIRAN:** Sorry, before we move on I just wonder if we can have this table from yesterday made available to the witnesses?

**The CHAIR:** Yes.

**Hon NICK GOIRAN:** Doctors, what I am passing to you now is a document that was provided to the committee yesterday during one of the sessions. You can see there that the source is from a 2017 report, “Patient Outcomes and Palliative Care Results for Western Australia July–December 2016”. I appreciate that you are taking this completely without notice, but would you have seen this table or that publication before now?

**Dr TANDON:** I regularly receive reports from PCOC, but this specific table I cannot recall seeing before. But I am used to these reports.

**Hon NICK GOIRAN:** Okay. Are you happy to take questions about the table now?

**Dr TANDON:** Yes.

**Hon NICK GOIRAN:** Just looking at that data in front of you, it was suggested to us yesterday that this would indicate that the percentage of patients who have refractory symptoms would be between five and 10 per cent. It was not obvious to me how I could read that into that table, but if you have familiarity with it, can you just help us interpret the data?

**Dr TANDON:** No, I do not know how that figure of five to 10 per cent would be reached. I think at the outset—I am not sure if this was mentioned when this table was discussed yesterday—PCOC is open to some debate as to its role in specialist palliative care. It is a voluntary program and it is primarily used for two purposes—research, and benchmarking—so comparison between one service and another. Because it is voluntary, not every palliative care service in Western Australia uses it, and the tools that they use are open to a lot of debate as to whether they are actually valid and applicable across all palliative care services. Their definitions of terms are also open to discussion.

**Hon NICK GOIRAN:** Would you be willing to take this table on notice and return to the committee with a supplementary submission advising the committee what findings we can take from this information?

**The WITNESSES:** Yes.

**Hon NICK GOIRAN:** Thanks.

**Hon ROBIN CHAPPLE:** If I may, just on that, quite clearly, the figure—the weighted average at the very end of 2.2—follows very similarly the 2015 survey of 1 800 patients. Assuming that the 2.2 is equivalent to the 2015, and that is pain, you then actually look at fatigue and the other elements. What was put to us yesterday was that whilst the total number comes to 12 per cent, quite clearly

many people are going to have a number of issues at the same time, and that was why they sort of said somewhere between five and 10. They could not be more definitive than that. As we say, we want you to go away and have a think about this, but would you consider that if the overall figure was 12 per cent, somewhere between five and 10 per cent might be about right, assuming that these figures are correct?

**Dr TANDON:** Yes. I think that highlights the fact that, yes, we are not coming here to say that we can treat every person's pain so that they have no pain; medicine is not a perfect science and there will be some people who have uncontrolled pain. But also, it is not just the doctor who is responsible for the pain management; the patient is, and their families are also playing a role. There are other considerations as well.

**Dr McNULTY:** Often I think refractory pain and other symptoms do not always necessarily reflect a failure of the ability for our interventions to work, because especially —

**Hon ROBIN CHAPPLE:** No, I was not —

**Dr McNULTY:** In the community, some of the people that I have seen over the years who have had the hardest-to-control symptoms at the end of life are people who are really fearful of death. They are people who are fighting, who have not accepted that they are dying, and there are often a lot of unresolved issues to do with their relationships or their life. These are very complex psychosocial — we call it existential distress, and that can actually escalate people's pain. If you survey those people, it would look like a failure of our intervention, and hopefully as we get more sophisticated in our support of those people through psychological and spiritual support, we may be able to help them. It is a very complex issue, refractory symptoms at the end of life, because death is actually not easy, even for older people who know it is coming. It is hard and for some people it is something that they really have trouble accepting.

We see that all the time and that is what we are interacting with. So when we look at a symptom assessment scale, it does not tell you anything about the person who is suffering.

[4.10 pm]

**Hon ROBIN CHAPPLE:** I think I can say to allay your fears that we are all great supporters of palliative care.

**The CHAIR:** With regard to the doctrine of double effect, the committee has received evidence that doctors rely on the doctrine of double effect. Would you think it is fair to say that specialist palliative care physicians rely on the doctrine of double effect when administering pain-relieving or sedating medications to patients at the end of their life?

**Dr McNULTY:** We feel this is a really important question and a really important issue. I think that there is a lot of misunderstanding amongst the general public and also, unfortunately, amongst our own colleagues about the drugs that we use and their effect. Firstly, we only use drugs in the terminal phase when they are indicated. Last week I had a lady who was discharged from hospital to come home to die and she came home and she lived for about 48 hours. She had a very peaceful death and she required absolutely no medication at all.

I just thought as a little exercise to try to help you understand what we are treating, I was wondering if you could imagine the sickest that you have ever been in your life and that feeling that you have of absolute fatigue where all you want to do is just lie down in bed and you want everyone to leave you alone. You are longing for sleep but you have this inner restlessness and you cannot quite sleep, you cannot rest, you cannot eat because food just repulses you and you dream and sometimes you wake up and you are not quite sure where you are. That is actually a very mild form of delirium. What we are dealing with at the end of life when we treat with sedating medicines is we are treating

a delirium. We have lots of non-drug ways of treating delirium. We try to keep the lights low and have soft music and have a familiar environment and people around a patient whom they know. All those things can help, but they do not always help enough. This can be a very distressing situation. You might observe somebody who is tossing and turning and pulling off their clothes and trying to get out of bed and pushing away staff and not allowing people to clean them up. This is the sort of situation where we might want to use drugs to control it.

We are very certain that the drugs we use do not hasten death, which is why we do not believe that we need the principle of double effect, because we actually are not doing anything to hasten death. Just by way of some sort of example, the drugs that we use mostly are sedating drugs like benzodiazepines, like Valium or sleeping tablets. They are drugs that induce sleep; they are not drugs that stop you breathing. They are drugs that we use to treat delirium in people who have a reversible illness. You could go into Sir Charles Gairdner Hospital and there will be patients there with a delirium from something that is going to get better, and they have these same drugs in these same doses and they do not die from the drugs. We also know that the doses of the drugs we use are in keeping with their use in other circumstances. If you have ever been unfortunate to have a colonoscopy, you will get a drug called midazolam, which puts you to sleep for about 45 minutes or an hour. This is the commonest drug that we use. It is a very short acting drug and we use it in very similar doses to those doses that are used for sedation procedures. But our patients often need the drug more often, so we may want to give them that in a more regular way. I actually brought a pump because I think that you have talked about pumps a lot. What is a pump? I do not know whether anyone has ever seen a pump. This is a Silver Chain pump. It is basically just a little device that a syringe sits on and we put the medication in that and it just gently, gently, gently pushes the drug through into a little tube under the skin. It will do that over 24 hours, so that we can give an even dose of the drug rather than have people get distressed, have a drug, get distressed, have a drug. Over 24 hours, the doses that we use are also equivalent to the doses that would be used for any procedure. Also, there is some research evidence about the use of sedation at the end of life that Anil can tell you about.

**Dr TANDON:** I would like to submit just a collection of the latest studies compiling the research that has been done really over the last 20 years into the use of pain medicines and sedatives at the end of life, and these have demonstrated repeatedly that they do not hasten death. You may be aware as a committee of perhaps the most significant or landmark study which was published in 2010, which did demonstrate in a selected group of patients with lung cancer that their survival was actually longer with palliative care than without palliative care. So, if possible, I would like to just provide this.

**The CHAIR:** Yes, please; provide that to the staff and the committee will consider it as a supplementary submission.

**Dr TANDON:** Just to add on to what Mary was saying about the principle of double effect, what I spend probably most of my time in teaching doctors who come and work with me is this concept that what we do is not hastening their death and that these medicines, provided they are used for the appropriate patient in the appropriate dose, do not hasten death. I do not think I would be able to sleep at night if I was hastening their death on a daily basis with these medicines. I absolutely do hold those studies to be valid and that these medicines, provided that they are used appropriately, are safe.

**Hon ROBIN CHAPPLE:** We obviously are hearing lots about all sorts of things. We are getting people submitting to us about the dose of double effect. So you are really saying that you have never come across it?

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**Dr TANDON:** No. What I was trying to answer was: do specialist palliative doctors rely on the principle of double effect?

**Hon ROBIN CHAPPLE:** But the dose of double effect is utilised —

**Dr TANDON:** Double effect is utilised in many fields of medicine, yes.

**Dr McNULTY:** But the misunderstanding is, and often we spend a lot of time with our patients and their families to reassure them, that the medication we use is not hastening their death. We use them in our clinical judgement and knowledge of the drugs to use them in a dose that is effective but not fatal.

**The CHAIR:** So is there ever an incidence where you have a patient who is highly agitated and in a lot of pain in the very final stages and you require them to use significant doses of opioids? Can you clearly and confidently say that that would not hasten their death? It might make them comfortable but it would not bring forward their potential —

**Dr TANDON:** These are patients in the last hours to days of life, so it is very difficult to know and to say with the drugs and without the drugs when their death would be. But the studies that I have provided have been conducted in palliative care units with delirious patients, with patients in pain, in the last hours and days of life and they have compared the populations of those who did receive the drugs and those who did not, and their survival times were the same.

**Dr McNULTY:** For a drug to actually hasten your death, it has to have some pharmacological effect that causes death. For opiates, that effect is that it stops you breathing. We have all heard of the heroin addict who takes a fatal dose and dies. They die because their respiration is suppressed. The reason that happens in those people is that either they have had a period without their opiate drugs—so, they have had a period when they have not been able to get it—or they get a pure dose which is a much, much higher dose than they are used to. For our patients, they are usually on opiates, and when you have been on an opiate for a period of time—it is not that long; it is only a week or so—you develop what we call tolerance to the respiratory-depressant effects of opiates. So it is very difficult to stop someone breathing with an opiate drug if they have been on it for a period of time. It is also very difficult to stop them breathing if you build the dose up from a lower dose to a higher dose. This is one of the reasons why we are confident that these drugs, even in the doses that we use, do not hasten people's death, because there is no pharmacological mechanism for that.

**Hon ROBIN CHAPPLE:** Do you ever have patients who want to withdraw from nutrition and fluid, and how do you cope with that in terms of palliative care? You have obviously got to look after the person. I know that in some cases there are medical conditions which mean that people shut down and basically do not want any more fluid, but I am talking about those patients who may make an informed decision to remove sustenance and fluids. Do you come across that and how do you deal with it?

[4.20 pm]

**Dr McNULTY:** I would say I do not think I can remember ever doing that. The only time was when we had a patient referred to our service and the message we got was that this was an older lady with early dementia who had decided that she did not want to eat or drink anymore and that she had chosen to die that way. When my colleague went to visit her, she found a lady in a retirement village in a house with no food who said that she was really hungry, and she had to give her one of her apples out of her bag. That is the only time I have ever had a referral for a patient in that circumstance as a way of dying.

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**Dr TANDON:** This is for a person who is not connected to a drip and not connected to a feeding tube, but someone who is currently eating and drinking like all of us can. I have had probably only a couple of patients who have indicated that they wanted to stop eating and stop drinking because they wanted to die, and both of the patients that I can recall—this is over my 20-year career—were unable to do that. After a little while, they felt hungry and they started eating and drinking again. The loss of appetite and the withdrawal of food and fluid, like you have already mentioned, is very normal as part of the dying process. But as a conscious cessation, no.

**The CHAIR:** When it comes to the practice of terminal sedation and palliated sedation, would the assessment of whether symptoms are refractory be a matter for the patient or the doctor?

**Dr TANDON:** Before we do discuss this, can I just say that I am not at all familiar with the term “palliated sedation”, so maybe if we could just restrict this discussion to terminal sedation, unless you have a definition for palliated sedation?

**The CHAIR:** No, I am happy to.

**Dr TANDON:** Certainly, I would like to begin by saying palliated sedation is not part of my professional practice and nor is it the practice of other members of the Palliative Medicine Specialist Group.

**Dr McNULTY:** We make a distinction between using sedation for symptom relief at the end of life in a way that is appropriate, to actually taking a person and sedating them so that they die of sedation, which is not a legal practice.

**Hon NICK GOIRAN:** Can I just jump in here? I am just slightly confused. I heard Dr Tandon say that he was not going to deal with palliated sedation on this topic and just deal with terminal sedation.

**Dr TANDON:** It is more to say that I am not familiar with the term “palliated sedation”.

**Hon NICK GOIRAN:** Therefore, we are not discussing that at the moment; what you want to discuss is terminal sedation?

**Dr TANDON:** Terminal sedation, yes.

**Hon NICK GOIRAN:** Then in the next breath, I think you said that you do not practise palliated sedation?

**Dr TANDON:** Sorry; I meant to say terminal sedation.

**Hon NICK GOIRAN:** Okay.

**Dr McNULTY:** It is just the terminology. There are so many different ways of expressing these things, they get a bit mixed up.

**Hon NICK GOIRAN:** Maybe it would be just helpful to say, in your experience, does the practice of—now I am going to use the word terminal sedation; please feel free to use a different one if it is necessary—terminal sedation happen in Western Australia as far as you know; and, if it does, what is it?

**Dr TANDON:** In my opinion, it does not occur. A definition for terminal sedation has been provided under footnote 9. I agree with that definition. It may be helpful to give a real-life example of what that actually looks like. I am going to look at Mary. Mary has a brain tumour which is causing her severe headaches, and for those severe headaches, I am her doctor and I am not able to relieve them, but Mary is currently walking, talking, interacting with her family, eating and drinking. Every drug I try does not work. I get a second opinion. That other doctor is not able to then relieve Mary’s headache as well. We then decide that Mary, you are currently walking and talking—I am in discussion with Mary as a patient—we are going to give you a sedative and we are going to put you

to sleep. So we connect up a pump, we commence the sedatives, and we put her to sleep. She then no longer complains of that headache anymore. A week or so later, or a number of days later, she dies. That is what I understand to be terminal sedation. I do not practise that and I do not know other members of the Palliative Medicine Specialist Group who do. It is controversial for exactly I think the reasons that we are all suddenly thinking. Internationally, it is debated long and hard. Our specialty society—the Australian and New Zealand Society of Palliative Medicine, which covers palliative care specialists in Australia and New Zealand—last year tried to write a consensus statement and guidelines for the delivery of terminal sedation. They were not able to.

**Mr J.E. McGRATH:** Are you saying with that patient that you give her the sedation and she goes to sleep, and she dies a week later; but she is not sedated for a week, is she?

**Dr TANDON:** She is, yes.

**Mr J.E. McGRATH:** She is, so she does not recover from that? You just keep her sedated until she passes away?

**Dr TANDON:** Yes, and during that period of sedation, she is no longer complaining of that headache.

**Mr J.E. McGRATH:** She does not complain because she does not see anything; she is sedated.

**Dr TANDON:** Correct, yes.

**Hon NICK GOIRAN:** But the evidence is that that is not being practised.

**Dr McNULTY:** We do not do that, no.

**Mr J.E. McGRATH:** No.

**Dr McNULTY:** That person, if that was me—thanks very much, Anil!

**Dr TANDON:** Sorry!

**Dr McNULTY:** I am very glad to hear you are not going to do that to me! That person dies because they are asleep, they cannot eat or drink, and then they will develop the problems of getting pneumonia because they cough and choke. They do not die from the sedative drug; they die from the fact that they are in a sleep that prevents them from getting nutrition and fluids, and the complications of being asleep for a week or whatever. So we do not practise that.

**Hon COLIN HOLT:** Do they not die from the brain tumour?

**Dr McNULTY:** They do not die from the brain tumour on that occasion because the brain tumour on that occasion is not causing a fatal or terminal event.

**Hon COLIN HOLT:** So what will the death certificate say?

**Dr McNULTY:** Well, we would not do it—so that is right.

**Dr TANDON:** It is a very good question.

**Dr McNULTY:** It is a very good question, yes.

**The CHAIR:** Obviously you have said that members of your group do not practise it. Are you aware of it being practised in Western Australia? I am not asking you to incriminate anyone in particular, but in general?

**Dr McNULTY:** No, that is all right. I would think it would be quite difficult, because, for instance, you would have to be able to constantly administer a sedating drug, so you would actually need a pump or something like it. That is not something that is available to people who work outside of specialist palliative care service. It could happen in a hospital where people were able to be given drugs intermittently, but I would think it would be quite difficult to achieve.

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**The CHAIR:** So no other doctors practise this?

**Dr TANDON:** Not as far as I am aware, but it is certainly possible. I would also like to say, however, this is not to say that we do not use sedatives in people in the last hours and days of life. We definitely do, as Mary has already pointed out, in other situations when a person is dying within hours or days and they are distressed. But that is not terminal sedation.

**The CHAIR:** That brings me back to Mary. If Mary is still in chronic pain and you do not put her to sleep, what do you do?

**Dr TANDON:** We constantly try to work and adjust the pain medicines that we are currently giving. We will just keep on trying different treatments.

**Hon ROBIN CHAPPLE:** Could I just ask you, how many people in WA are palliative care specialists?

**Dr TANDON:** There are approximately, I think, 27 according to our written submission.

**Dr McNULTY:** And there are about 30 GPs who work for Silver Chain who are very experienced in palliative care. They are often people who have worked there for 20 years or more.

**Hon ROBIN CHAPPLE:** How many people are in the Western Australian Palliative Medicine Specialist Group?

**Dr TANDON:** Not all 27, because some of them are not actively practising in palliative care. I think it is approximately 20, but I do not have an exact figure for you.

**The CHAIR:** You have talked a bit about the pump and titration of opioids. The Department of Health guidelines for adults in the terminal phase recommend initiating opioids with a small dose and to increase the dose incrementally until pain is relieved. Are they the guidelines that your members follow?

**Dr McNULTY:** Sorry, my pages got mixed up when I printed this off; what question is it?

**The CHAIR:** It is 11(b).

**Dr TANDON:** I think all guidelines have their limitations and they have their lifespans. Generally in health care, guidelines are felt to be valid for roughly three years or so, so these are a little bit out of date, but I think that they are appropriate. However, I do not agree with the statement that opioids should begin with a small dose. We should commence the opioids at the appropriate dose for that patient, and similarly we should not increase the dose incrementally each day. The pain should be assessed every day, or at an appropriate interval, and either increased or decreased. There are many medicines, not just in palliative care, where it would be inappropriate to adjust the dose every day. We need to wait longer, because there may be just the natural fluctuations in a person's pain, or the changes I made today may not have taken effect until several days have passed.

[4.30 pm]

**Dr McNULTY:** Often, if someone is in very severe pain, we might adjust the dose every half an hour or an hour, and in the community, one of our nurses might be present when somebody's pain was really severe, and she may be there for several hours giving medication and slowly increasing it over that period of time. How quickly you escalate the dose and review how beneficial it is depends a lot on the clinical situation.

**The CHAIR:** In your view, should an instance of terminal sedation be formally noted in a patient's medical record, if that were to be practised?

**Dr TANDON:** If any medical practitioner did practise it, absolutely, and I think that is just like any other treatment. Every treatment should be noted in the medical record.

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**The CHAIR:** Under the Coroners Act, reportable death includes a death that occurs during an anaesthetic. Would you then view terminal sedation as a reportable death?

**Dr TANDON:** Once again, I do not practise terminal sedation. I have always found the coroner's office to be very, very helpful when I have been uncertain as to what to put on a death certificate. If I was in doubt, I would always ask them for advice, but if, in this situation, that fitted with the definition of an anaesthetic, then yes it should do.

**Dr McNULTY:** Yes, it should go in. It is a death through anaesthesia, which is reportable to the coroner.

**The CHAIR:** The committee has received evidence that some, at the end of life, elect to refuse all nutrition and hydration in an effort to hasten death. We have touched on that. During this process, they continue to receive palliation in the form of pain-relieving medications. Have your members ever raised concerns regarding palliative starvation?

**Dr TANDON:** It is not something that we have seen at all commonly. I can only think of one or two patients. It has been discussed in our group, and as a group we do not think that it is appropriate to be recommending to patients for them to refuse food and fluids. That would be very difficult.

**Dr McNULTY:** The truth is that most of the patients we look after have no interest in food. In the community, one of the things I spend a lot of time with is talking to families who are constantly preparing meals for their dying relative. They go to a lot of trouble to get them their most favourite food, and prepare all these elaborate things, and the person just does not want to eat. As I said before, if you think back yourself to when you were really sick, the idea of food is just repellent. This is what we deal with. Nearly all the patients that we deal with have no appetite, and they have no inclination to eat.

**The CHAIR:** In relation to the futility of medical treatment, doctors are not under an obligation to administer futile medical treatment. There is a reference here to a Canadian study that found there was extreme variability amongst ICU healthcare workers in the factors that were important in decisions to withdraw life. Do you think the outcome would be different if a similar survey was carried out in Western Australia?

**Dr TANDON:** I would like to perhaps begin my answer to that by saying that "futility" in the palliative care and medical literature is extremely difficult to define, and no-one, or no group, has been able to come up with an adequate definition. At a practical level, in my practice and in the teaching that I do, I find it most helpful to use the term "non-beneficial treatment". Definitely, a survey in one country is not always applicable to another country, and one group of professionals—in this case, intensive care workers—may well have a different response from another. If I can give an example of a case that I was involved with just peripherally last week, it was a patient who had respiratory failure from an infection. The patient, to live, needed admission to the intensive care unit, so it is very analogous to this situation. The ICU specialist thought the treatment was futile or non-beneficial and the chest specialist who was responsible for the patient's care thought that there was actually a chance of response. Who is correct in that situation? Clearly, there needs to then be a discussion between those two doctors, the patient, if they are able to, and the family, to work out an agreed plan forward. It is very difficult. In that situation, usually there will be a discussion about a time limit. A trial is the most common solution to that problem, so we will try intensive care for 72 hours or something like that, or maybe it might be that this person is not appropriate for our intensive care unit.

**Hon ROBIN CHAPPLE:** I am going back to my classic. When you are faced with DNR, how do you deal with that?

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**Dr McNULTY:** Faced with it in what way?

**Hon ROBIN CHAPPLE:** You have an instruction not to resuscitate. Do you not resuscitate?

**Dr McNULTY:** It depends how that DNR was obtained. If it is an order that has been obtained through discussion with the patient, then we would honour that, yes.

**Hon ROBIN CHAPPLE:** So a doctor has put on the bottom of the bed, “DNR”, so you would need to have confirmation from the patient that that was the patient’s wish?

**Dr McNULTY:** In that situation the patient would not be able to respond. We trust that the DNR, if it has been recorded, has been recorded in a manner that reflects the patient’s wishes.

**Hon ROBIN CHAPPLE:** Okay, so you would not intervene?

**Dr McNULTY:** No.

**Mr J.E. McGRATH:** What if the patient was at home?

**Dr McNULTY:** This is often an issue we have with community palliative care. We discuss it with our patients, because what can happen is that families sometimes panic. When somebody dies at home, when they have been looked after by us for quite a while, then the family knows that the death is expected, and when the patient has died, they call us and our nurse comes out and helps lay out the body, and it is all a very peaceful and dignified thing. But some families get quite distressed if somebody dies quickly or something suddenly happens, and even when the death is expected, they will call the ambulance, and when the ambulance comes to the home, the ambulance is obligated to perform resuscitation unless there is a not-for-resuscitation order. We, now, at Silver Chain, when we do an admission of a patient into our service, we have to discuss DNR with our patients, and record it. Surprisingly, even for people who get referred to a palliative care service, there are people who say that they still want to be resuscitated, and for those people we do not record a DNR; we leave it. But as time goes on, often, with some explanation about what resuscitation means and what it would mean for the ambulance to come and attempt resuscitation, people often then come to accept that that actually is not the way that they want to die; they want to die peacefully and quietly, not with four ambulance people thumping on their chest on their bedroom floor. We honour the order if it exists; and, if it does not exist, there is an obligation to resuscitate.

**Hon ROBIN CHAPPLE:** You talk about an order. What is that? Is it a written document? Is it a standard form?

**Dr McNULTY:** In our Silver Chain notes we have a place where we record—it just says that I decline resuscitation, and it is stated and assigned by the doctor.

**Hon ROBIN CHAPPLE:** And that applies across the board, not just to your group of palliative care specialists? Would any medical professional have the same form and order?

**Dr McNULTY:** No. Anil may talk to you about hospitals, but one of the issues that happens is that so often a person can be in hospital and a lot of work is done in talking to people about whether they want to be resuscitated, and it can be recorded in the hospital notes in whatever form that is, and it often does not get transferred to the community, or vice versa. So we could spend a lot of time talking to families about resuscitation at home, and when they go to hospital, that order does not get carried over, so there are issues. Perhaps Anil might talk a bit more about that.

[4.40 pm]

**Dr TANDON:** Absolutely, yes. We have identified at a statewide level that this was a major problem and there are huge risks for the patients when they move from one place of care to another. Within a hospital environment, every hospital in Perth uses a slightly different form, and so when a patient

moves from one site to another, what they had previously documented does not necessarily get carried across with them. I think one of the other witnesses who has appeared here is Keiron Bradley from the Cancer and Palliative Care Network. The network is currently working, together with the Department of Health, on a uniform statewide document, which is called the “Goals of Patient Care” form. That will allow the same form to be used across settings—for example, in an ambulance, in a nursing home and in a hospital. But also it will link in with the current IT systems that are used in health care just so there is an alert. It will not say what the order is, but it will say that there is a not-for-CPR discussion and now we need to find that form for that patient. It will hopefully greatly improve our patient care.

**Hon NICK GOIRAN:** Is the “Goals of Patient Care” something that has been trialled somewhere in WA?

**Dr TANDON:** Yes, in many sites. There has been a pilot process for that. It has been trialled or piloted in a number of public and private hospitals both within the metropolitan area and in regional WA. That was in 2017, and hopefully in 2018 the results of that pilot will be analysed and then the form as it currently stands may be amended according to that research and then a uniform statewide document will be available.

**The CHAIR:** Can you describe the distinction for the committee between withholding medical treatment for someone who is at the last stages of their life and someone who has requested voluntary assisted dying?

**Dr TANDON:** I think all fields of medicine are involved with patients. Many fields of medicine are involved in the end of life. A cardiologist, for example, who is treating someone with heart failure will eventually reach the point with their patient that they are unable to make the heart failure better and the patient will die. In that situation, the cardiologist will not be able to perform or refer the patient to a heart transplant. In that situation, that is very different from voluntary assisted dying —

**The CHAIR:** I should have clarified that—in the palliative care setting.

**Dr TANDON:** In the palliative —

**The CHAIR:** A “Do not resuscitate”, for example, so you are not going to resuscitate someone, versus someone who has requested voluntary assisted dying. What is the difference between those?

**Dr TANDON:** The main distinction, I think, in that situation is that the patient is making an informed decision to withdraw from treatment or the doctor is discussing it with the patient and their family that these treatments are no longer working, and so non-beneficial treatments are stopped. Then the natural processes will proceed, so the dying process will occur over a period of hours and days. In voluntary assisted dying, most commonly an act is performed by the patient or the doctor to end the life at that point.

**Dr McNULTY:** I think when we think about withdrawing treatment, it is really about people having a conversation with people about what are the benefits of the treatment and what are the burdens of the treatment; and burden rather than just risk. People make a decision about whether they want to have a treatment depending on the balance between those two things. That will vary from one person to another. Even in what seems like the same situation, two people might make quite different decisions. For example, if I am a 75-year-old man living in Esperance and I have a chance for some palliative chemotherapy that might work so that I live another three or four months, but it means I have to come to Perth to have it, I might make a decision that the burden of being away from my family and being away from my community is not worth it. The treatment and three months of my life is not worth that. I would rather have two months in Esperance than four months in Perth.

If I am a young mother and I have a treatment that might only keep me alive for a month, I might choose to have it because I want to see my first child have their first day at school. These decisions get made in evolution as people travel through their illness journey and their illness changes and the treatments that are tried are not working. Often, by the time you get to the last treatment, whatever that might be, it is most likely to be the least effective treatment. All the most effective treatments get used in the beginning. As you get sicker and people try more things, it is much more likely that they are not going to work. We have these discussions with people all the time about whether or not they want to have a treatment that involves maybe being in hospital or maybe having a drip or maybe travelling somewhere versus: Is it going to help me live for another week? Is it going to help my pain? What are the benefits of that treatment? What do you have to give up to have that treatment? It is not that someone sits down with a piece of paper and says, “We’re not going to give you this treatment” or, “I’m going to refuse this treatment”. It is a very complex decision that is made in discussion with the expert doctors who know what the treatments can do and the expert patient who knows what it is that they want.

**Hon COLIN HOLT:** The Esperance example, is that a real example? Do you have real examples of people making decisions based on the fact that they cannot get locally treated?

**Dr McNULTY:** Yes. We have a patient at the moment who comes from a farm in a wheatbelt town—it is one of those K towns, Cunderdin, Kojonup, something like that —

**Hon COLIN HOLT:** Kulin —

**Dr McNULTY:** Apologies to our rural members! He is actually declining expert palliative care because he has got some quite difficult symptoms to control. At the moment he is living up in Perth with his daughters. He just loves his farm and he loves his country community, and he wants to die there. That is more important to him than being here and having the 24-hour support of a palliative care service and the company of his family. That has caused quite a few difficulties for his daughters and also for us in trying to see if we can support him back in his community where there is no nurse and there is no doctor or after-hours service. People make those decisions all the time.

**Dr TANDON:** I have got a real Esperance patient at the moment. Myself and the oncologist involved with this man, we have treatment available for him but it would take him three weeks away from Esperance to be in Perth. The other option would be just one week here for a short course of treatment. We do not think that the long course of treatment is useful for him. We had the conversation with him and he chose the long course even though we did not think it was a good idea to be away from Esperance for so long. It was a discussion.

**Mr J.E. McGRATH:** On that point, I have met people who have said, “I’ve decided I’m not going to carry on with the chemo.” That is not about where they live or they do not want to come from the country; they make that decision that if it is going to shorten their life, they do not want to do it anymore. That leads to the question: with chemotherapy, will we ever get to the stage where we will find something better than chemo to help people with cancer issues?

**Dr McNULTY:** We hope so. In the last 10 years there has been a big shift in the way cancers are treated. There are a lot of new drugs called targeted therapies and immunotherapies that are not chemotherapies. They are having some really quite amazing benefits on cancers that we thought in the past were not treatable—for example, melanoma. I think you all know Jarryd Roughead, the Hawthorn footballer. Before these drugs were available, he would have probably died by now. There are a lot of changes. A lot of new things are happening. These drugs often are not as toxic and are not as debilitating as chemo drugs—some of them are. Things are constantly changing and improving. People have an idea that chemotherapy is always going to work, so when people say,

“I’m not going to have any more chemo”, they are often making a very sensible decision about a treatment that has long failed to give them any benefit.

**Mr R.R. WHITBY:** Going back to the start, Dr Tandon, and your comment about a lack of palliative care services, how critical is the issue and what do we actually need to do to address it? What are we talking about?

[5.00 pm]

**Dr TANDON:** I think it is very critical. I was previously the clinical lead for the Palliative Care Network. We had been trying to establish a specialist palliative care service at Joondalup with the closure of the cottage hospice in 2006. It still has not occurred, and it is 2018. That is just one example. I was involved in the writing of the contract between the health department and Midland Health Campus. Palliative care was originally included in that contract that it would be provided. It was removed from the contract. That was a tragedy. There are patients there at the moment who are missing out on this care. Unfortunately, money is required and I am very aware that our budget is not limitless. There is an opportunity cost for these sorts of decisions, which the minister and the director general will ultimately need to take.

**Mr R.R. WHITBY:** It is a question of funding in other places and that funding is not there. What is the alternative that happens now? What does happen? People are at home —

**Dr TANDON:** The primary teams in those hospitals do the best to the limit of their ability. They have access to an outreach telephone advice service where they can get put through to the phone of a palliative care specialist who is on call 24 hours a day, seven days a week to provide advice, or they are sometimes transferred and transferred inappropriately when they could have received that care in that hospital closer to home.

**Mr R.R. WHITBY:** What about home treatment?

**Dr TANDON:** Absolutely. Silver Chain: we have one of the best community palliative care services in Australia.

**Hon ROBIN CHAPPLE:** When you go to a hospital and you provide palliative care, other medical professionals are around. Do they learn from that process and do they then start mirroring your process?

**Dr McNULTY:** We hope for.

**Dr TANDON:** That is what we hope for, and it happens to a varying degree.

**Hon ROBIN CHAPPLE:** There are some other people out there providing, to use the word, “rudimentary” palliative care?

**Dr TANDON:** Or primary palliative care; definitely, yes.

**Dr McNULTY:** One of the problems in hospitals is that—I help down at one of the private hospitals for one of my colleagues occasionally—is that the care is very fragmented. Often people are in hospitals and no one doctor seems to take ultimate responsibility for their care. What they lack often is coordination in decision-making. Often a palliative care team comes in and creates that kind of coordination and enables that discussion. So when that is not there, if the treating doctor is not skilled in it, those people really miss out.

**Mr J.E. McGRATH:** I think Silver Chain is recognised throughout the state as a prime mover in this area and greatly respected. How are you funded? Have you got room for expansion? If there is need for more palliative care and a lot of people would prefer to stay at home, can you expand? Where do you get your funding from? What is the future ahead for Silver Chain?

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**Dr McNULTY:** The Silver Chain hospice care service is funded from the state government—the state health department. We are funded for—do not give me the exact numbers—about 420 people, but we provide service for over 650. We have actually created efficiencies where we are able to support a lot more people than we are formally funded for. Silver Chain has the capacity, obviously with more funding, to provide more care. One of the issues around the sort of service Silver Chain hospice service provides is that it is not always the best model for some community palliative care needs. There are people in the community who have needs that are not as easily met by the model that the hospice service has. That is particularly people who are frail and aged. To give you an example, our service gets referred a lot of people now who are frail-aged and who appear to have a terminal illness. They might get sick, have pneumonia, the family thinks is their last illness, we get referred, we go in, we put in a lot of equipment and we look after them but they actually get better. They do not die from that illness, but we then have someone who is a little bit more frail than they were before they got sick and a little less able to be independent. There is not anywhere for those people to get the kind of support they need. We are trialling at Silver Chain a new model for people who we know will probably die in the next 12 to 18 months to two years who do not need specialist palliative care service, but they do need a service that can respond to them when they become unwell and can respond to them in a manner that allows them to stay at home or at least be in that environment where they get palliative care. There are a lot of things more that we could do but we need the funding for it.

**Mr J.E. McGRATH:** Can anyone access Silver Chain or is there a means test?

**Dr McNULTY:** Silver Chain hospice service is by doctor referral. You have to be referred by a doctor, and that can be your GP or a hospital doctor. We have no waiting list. We never turn anyone away, so there is no block to the door. We assess everyone who gets referred to us within the first 12 to 24 hours, at least with a phone call. Sorry, what was the rest of your question?

**Mr J.E. McGRATH:** I just asked whether anyone can access —

**Dr McNULTY:** Anyone can access, yes.

**Mr J.E. McGRATH:** There is no means test?

**Dr McNULTY:** No; it is completely free. The doctors who work for Silver Chain agree to bulkbill Medicare for their services, so there is no fee for the patients or the doctors who visit or for the service.

**The CHAIR:** I am sorry to do this, but can I get back to Mary's brain tumour. In the instance that Mary still has another sort of week expected to live, if you like, or it is uncertain and you have exhausted your bag of tricks to get her neuropathic pain under control, what is the scenario for Mary?

**Dr TANDON:** If I estimate that currently Mary has less or about a week left to live, usually by that stage she is actually eating very little, drinking very little—literally maybe one or two mouthfuls or occasional sips of water. By this stage the person is actually bedbound, they are spending probably in the order of maybe 20 hours asleep during the week as it is, anyway. We are right on the cusp then of not being able to give the pain medicines by mouth, so we will often at that point need to move to a syringe driver because we are in the last days or week of life. A discussion will be made with the family about what doses we are going to put in, and then if those medicines do cause drowsiness or sedation we make sure the family is aware of that. If they say, "No, no; we want Mary to be awake for us as much as possible", then we will have a discussion, "Well, we need to remember that these are the last days of this person's life and maybe it's best just to ensure that she's more

comfortable”, and then an agreed plan will come into effect. That may include the use of sedatives in the last days or week of life.

**Dr McNULTY:** So she will sleep for the last days of life rather than be awake. The sedation will not take my life any more quickly; it is just that the nature of how I die will change.

**Dr TANDON:** In that example, on the death certificate it would be the brain tumour.

**Hon COLIN HOLT:** Frail care trial you talked about—has that got a name?

**Dr McNULTY:** Yes, Integrum.

**Hon NICK GOIRAN:** Doctors, thanks for your evidence today. I think the Chair has got through about half the questions we wanted to today. As best as the committee can, we try to estimate how long we want people to be here for. Some sessions have been 90 minutes and some have been 60 minutes. I think with hindsight, we probably needed 90 minutes with you. Is there capacity for either of you to come back in the future should the committee make such a resolution?

**Dr McNULTY:** Yes, definitely. We would be very happy to come back.

**The CHAIR:** A good question.

Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for corrections 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 the evidence cannot be altered. If you wish to provide clarifying information or to elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript. The committee will either write to you with the questions taken on notice, including the proposed questions we did not get to or invite you back for a second hearing if that is all right.

**Dr McNULTY:** Does that include this table?

**The CHAIR:** Yes. We will definitely write to you with those questions on notice from Hon Nick Goiran, and we will either send the questions or we will invite you back for another hearing, depending on the decision of the committee. Thank you both very much for this afternoon, very valuable.

**The WITNESSES:** Thank you.

**Hearing concluded at 4.59 pm**

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