

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, 1 MARCH 2018**

SESSION FOUR

Members

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

Hearing commenced at 3.29 pm**Professor MICHAEL QUINLAN****Consultant General Physician, examined:**

The CHAIR: Professor Quinlan, thank you for joining us this afternoon. We have a couple of members who have been called out. They will be joining us during this session.

On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am the Chair of the joint select committee. I will introduce the other committee members: Hon Robin Chapple, Reece Whitby, Hon Nick Goiran, Hon Colin Holt—Dr Jeannine Purdy, our principal research officer—and John McGrath. Joining us shortly will be Hon Dr Sally Talbot and Simon Millman.

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 might 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 today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Would you please introduce yourself for the record.

Prof. QUINLAN: I have hearing aids. If you have trouble hearing me, just tell me to speak up. If you do not mind, if I have trouble hearing you, I will ask you to repeat the question.

The CHAIR: Please do.

Prof. QUINLAN: Thank you. Madam Chair, I would like to thank the committee for the opportunity of appearing before you all. My name is Michael Quinlan. I am a consultant general physician, if you know what that means. If you do not mind, I can make an opening statement.

The CHAIR: Yes, please do.

Prof. QUINLAN: In my submission to you I deliberately stated that I am not a palliative care physician, for several reasons: one to indicate that I do not have a vested interest in palliative care but, more importantly, to indicate that it is the responsibility of all medical practitioners to have knowledge of the dying process and the care of the dying. When I graduated at the end of 1961, there were no coronary care or intensive care units, only a primitive list of useful medications, closed-chest massage for resuscitation was a novelty, and the only available defibrillator we had was so dangerous that we used it with great temerity. Ultrasound, CAT scans, MRI and PET scans did not exist, oncology and immunology had not emerged, coronary angiography, bypass surgery, stenting, and transplantation surgery were all in the future, and the treatment of cancer was the province of the surgeon and the radiotherapist. As a medical student, I had an extensive course in forensic medicine but there was no discussion about dying. Ward rounds often bypassed the rooms of dying patients. Patients were often not given the full details of their illness in a sort of patriarchal way. Sometimes the only visitor to a dying patient in a hospital was the person who swept the floor or changed the flowers.

Cicely Saunders and Elisabeth Kübler-Ross, icons of the twentieth century hospice resurgence, had both just graduated in 1957. Cicely Saunders was to open St Christopher's Hospice in 1967 and Elisabeth Kübler-Ross published her book, *On Death & Dying*, in 1969. Dr Balfour Mount, a Canadian

neurologist, after a visit to Cicely Saunders, was the originator of the name “palliative care” in 1977. This was soon adopted worldwide; so the new entity of palliative care, if you like, is 41 years old this year. This resurgence has spread throughout the world to the benefit of many people in the last stage of life, no less so in Australia, which has been a leader in palliative care. This is not to gainsay that care was lacking or neglected previously—many dedicated individuals and groups had this at the heart of their endeavours. For example, the Sacred Heart Hospice at St Vincent’s in Sydney was opened in 1890, the Little Sisters of the Poor locally at Glendalough, and the famed St Joseph’s Hospice in London opened in 1905, plus many other examples over the centuries.

How things have changed. I have been privileged to witness the extraordinary advancement in medical knowledge and technology over the last 50-plus years, and as well as the parallel emergence of high-quality palliative care, yet the paradox of the preoccupation of the culture of death is sweeping the First World. I am concerned at my age, not for myself so much as for the practice of medicine, current and future medical and nursing students, and the unintended consequences that would flow inevitably from the change of our existing laws.

I am very happy to answer the questions you have put to me as succinctly and as free of euphemisms as I can. Madam Chair, if time is running short in answering the list of 21 questions you have given me, may I request that I have the opportunity of answering questions 20 and 21 on the list?

The CHAIR: Yes, we can accommodate that. We are also happy to send you any questions that we do not get to in the hearing, if you want to respond in writing.

Prof. QUINLAN: Thank you.

The CHAIR: That will be available to you as well.

Prof. QUINLAN: The first question on your list is: if you are acting out of conscience when administering pain-relieving medication, what role is played by exercising clinical judgement? That is a curious question. I am not quite sure how to interpret it. Clinical judgement, as you know, is the ability to make decisions in the patient’s best interests by either actively intervening in the phase of the illness or even withdrawing treatment at the appropriate time, or changing treatment, or not treating at all. It all combines into clinical judgement, which is really based on knowledge and experience.

In terms of conscience, I do not think you can separate conscience from clinical judgement. One controls and one influences the other. It is knowledge of the patient’s total situation—cause of distress; not just pain—contribution of psychological factors as well as physical factors all combined in terms of the clinical judgement decisions. That includes the knowledge of the pharmacological agents used to relieve distress. For example, knowing the right doses of drugs in order to achieve the end result rather than over-reaching is exceptionally important.

In terms of number 3 under “Palliative Care” —

The CHAIR: Professor, there are a number of surveys which demonstrate that around one to two per cent of patients in palliative care experience refractory symptoms. We have also had evidence from other practising doctors that that could be as high as up to five per cent. Would you say that is an accurate figure, from your experience?

Prof. QUINLAN: In conversation with my colleagues, particularly my palliative care colleagues, I think the figure of around one to two per cent is accurate; in other words it is quite rare. I think the improvements in palliative care over the decades have caused that figure to shrink from previously probably higher levels around five per cent that you alluded to. Things are improving all the time.

The CHAIR: Are you familiar with the PCOC assessments?

Prof. QUINLAN: No.

The CHAIR: The Palliative Care Outcomes Collaboration, which is a data collection from a range of palliative care providers. It is voluntary. Their assessment is: patients and clinicians each rate the severity of a patient's pain, while only clinicians rate the severity of a patient's psychological or spiritual problems. In your view, would the assessment of whether their symptoms are refractory be a matter for the patient or the doctor?

Prof. QUINLAN: The patient is the critical person to tell you how they are reacting to the care given to them. That information has to be interpreted properly. I think it underlies the score—the very important principle that care of the dying patient, let alone care of every patient, is related to good communication and listening.

The point is often made by experienced practitioners that doctors particularly do not listen enough and do not actively listen; in other words pursuing issues that may be seen to be black and white but they are not and unravelling all the other issues surrounding patients' illness. I cannot stress that enough; it is very much a listening process. Unfortunately, busy doctors often seem not to have time to listen. If that is the case, then they should go back and re-listen to the patient more than once.

[3.40 pm]

The CHAIR: The Department of Health guidelines provide indications for treatment of opioids. In your experience, do medical practitioners follow those guidelines?

Prof. QUINLAN: Guidelines are guidelines and, really, the use of opioids is related to the doctor's experience and the knowledge of the drugs, particularly the variety of opioids and the modes of administration that are available. I think in good clinical practice those guidelines are wittingly or unwittingly followed and that really reflects the long-term experience of the attending clinician. It is not just a decision made by the individual doctor; he or she must consult with the other carers looking after that patient, particularly the nursing staff and the relatives. It is a family situation.

The CHAIR: Would you say that the patient's level of distress should be the guiding factor of treatment; and, if not, what other factors would be considered?

Prof. QUINLAN: I think the obvious answer to that is yes, of course. The patient is the only one who can really indicate whether or not they are distressed, whatever that might be, or the features making up that stress are being accurately assessed and accurately looked at. I go back to Balfour Mount, who originally made the point: sitting with the patient and listening often unravels the distress and, in many cases, relieves it. We have a ceremony at Notre Dame University for our students of medicine and nursing and any other professions where there is legitimate ability to lay hands on people—that ability is getting less and less, unfortunately, in our day and age—it is a very privileged thing to lay hands on people and we regard that privilege as being part of the clinical process. There is something almost mystical about touching a patient. I always say to my students, "When you see a patient; each time you see them, you must touch them." That might be shaking of the hands; it might be taking of the blood pressure or physically examining them, but it is part of the interaction; it is part of building up the patient–doctor relationship, so it is very important. That should not be neglected in the day-to-day care of patients as well, including nursing staff. Nursing staff more often touch patients than medical staff, but they should not neglect the opportunity.

The CHAIR: Do you think the practice of terminal sedation is well understood by medical practitioners?

Prof. QUINLAN: No. I understand what it is and I think it is a crime. I think it is a felony because it implies deliberate sedation of patients to terminate their lives. I certainly would not advocate it and I certainly do not practice it.

The CHAIR: In your understanding does that practice take place in circumstances where nutrition and hydration are also withdrawn?

Prof. QUINLAN: I have never seen that.

Hon NICK GOIRAN: Professor Quinlan, during the course of this inquiry, this question with respect to terminal sedation has been asked of almost every witness and it seems that as many times as we ask the question there is a different definition. Clearly, in response to that question, you have understood terminal sedation to mean the terminating of a patient through a sedation process. There is another definition that has been put to us which is that at the end of life, particularly in the last few hours or days, there is a sedating process in certain rare cases. Is that something that you have seen?

Prof. QUINLAN: This brings up the whole question of euphemisms. Throughout the whole of palliative care, it is riddled with euphemisms. I regard there to be three separate forms of sedation. Sedation itself just means giving something to a patient to help them sleep and/or relieve anxiety. Palliative sedation is used by palliative care physicians to judiciously use sedation to relieve distress temporarily and reversibly; for example, if a patient for one reason or another has not slept for up to a week, you need to give them a good sleep in order to make them feel refreshed, like we all do after a good night's sleep. That is palliative sedation; it is reversible; it is not intended to make the patient comatose and terminal sedation is just that. You are deliberately sedating a patient into a deep coma to a point that their life will be shortened as a deliberate intent.

The CHAIR: Would you consider that a reportable death under the Coroners Act as a death under anaesthetic?

Prof. QUINLAN: If the intent was deliberately to kill the patient, yes.

Hon ROBIN CHAPPLE: If somebody who went through palliative sedation due to respiratory conditions during that process then passed, would that be reportable?

Prof. QUINLAN: If it comes back to intent again and the size of the dose, if that was out of the guidelines particularly, that comes down to conscience, very much so. It is usually because you have other staff around you—nursing staff and members of the family—a process that would happen very uncommonly but, again, it comes down to intent.

The CHAIR: In that instance are physicians relying on the doctrine of double effect?

Prof. QUINLAN: I am familiar with double effect. It is often misinterpreted and not understood.

The CHAIR: Can you give me your interpretation?

Prof. QUINLAN: It was very popular about 30 or 40 years ago to discuss the principle of double effect. This in part related to promulgation of the possibility of relieving patients' symptoms by the Pope of the day, Pope Pius XII. You may or may not have read about him. Double effect was then often talked about. I think that its application in day-to-day practice has become less and less an issue. The classic example is given of a woman who is pregnant and is found to have cancer of the uterus and the only way of treating that cancer is to do a hysterectomy with the undesired effect of the death of the foetus. That is an incredibly rare situation, but it is a striking example of where the principle of double effect can be legitimately applied. I make it clear that it is not a legal principle; it is an ethical principle and, consequently, with better knowledge, better scientific knowledge, better experience, the day-to-day application of double effect is not commonly done. I do understand what

it is. I do feel that not a lot of doctors understand clearly what the principles are, and it is bandied around as almost a legal defence. It is not, as I said, a matter of law; it is a matter of ethical principle.

The CHAIR: Do you think that doctors, particularly in end-of-life care, rely on the doctrine of double effect?

Prof. QUINLAN: Not actively, no. All the students at Notre Dame, for example, we try to give a background education in the benefits of a good education. They include mandatory subjects, philosophy, theology and ethics. In the case of medical and nursing students, it is guided towards bioethics particularly, so at least they have a grounding in the whole ethical principles.

Much to our delight, all students, or the vast majority, find these subjects, although they are a bit unusual for the average university student, very rewarding and interesting.

[3.50 pm]

The CHAIR: Given the discrepancy between the required opiate doses to manage pain, particularly where someone has been on opioids for a period of time, can you be certain that those dosages are not in any way hastening a patient's life at the terminal phase?

Prof. QUINLAN: Nothing is certain in this life, but I think that with knowledge of the pharmacology of the drugs, experience, consultation and careful use, that should not arise. I know that some doctors have not had experience of using opiates to a large degree, and their variety of use as well and their route of administration. For example, you have probably heard of fentanyl. Fentanyl is a sort of artificial opioid in a way and it has caused immense disasters in the United States, where tens of thousands of people are killed annually from the addictive use of fentanyl or the unwise prescription of the drug. I hope it does not reach Australia in similar proportions. But it has an extraordinary depressant effect on respiration compared to other opiates, so its use should be looked upon with great caution.

The CHAIR: On the converse of that position of overuse, do you think that because of the potentially dangerous side effects of those drugs, that there is the potential that people are being under-dosed?

Prof. QUINLAN: Sometimes, yes; very much so. Again, it comes down to experience, but I think that is true. I think it is possible through training, proper palliative training, to understand how to reach that proper dose of opiates. It should always be started at a fairly low dose and built up rapidly. The intravenous route, if you are familiar with how to use it, is a good way of achieving desired pain control or symptom control in a fairly short period of time—I am talking about hours, not days. There are techniques available that you can teach doctors to do that, but I agree with you that in many cases it is under-utilised.

The CHAIR: I am going to step back to where patients elect to refuse nutrition and hydration in circumstances where continued pain-relieving medication. Is this recognised as a common treatment or practice around the end of life?

Prof. QUINLAN: As a deliberate choice by a patient, not often—not in this country, although I am familiar with the experience in other countries, particularly in the Netherlands where it is commonly adopted by patients as a choice. But, as you well know, terminal illness of whatever sort often is associated with a loss of appetite, loss of a desire to eat. So there is a big difference between that and consciously saying, "I'm going to stop drinking and eating."

The CHAIR: Would you distinguish that decision from a suicide attempt?

Prof. QUINLAN: Of course; it is voluntary and it is reversible if the patient so chooses it. If you look at the proper literature on it, the actual process of self-withdrawing of fluids and food is not as gruesome and as grim as has been made out. It actually can be a moderately peaceful way to die as

long as good associated palliative care is also given, particularly with care of the mucous membranes of the mouth and throat—keeping them moist. But it can be a less uncomfortable and less onerous way of dying than you might imagine.

The CHAIR: We have read in a number of submissions and it has been stated that where the patient stops eating or drinking or is provided food, that mouth care is very important. What is the experience for the patient in that instance?

Prof. QUINLAN: Very much so.

The CHAIR: What are they experiencing in their mouth?

Prof. QUINLAN: Apart from water and water-based solutions, sometimes it is slightly oily-based solutions that do not cause quick evaporation, because the dryness of the mouth —

The CHAIR: It is the dryness of the mouth?

Prof. QUINLAN: Yes.

The CHAIR: And people find that unbearable?

Prof. QUINLAN: Some patients do, and in my reading some patients have abandoned their attempts at voluntary restriction of fluid and food for that reason—not a lot of them but a significant number.

The CHAIR: In your assessment, in light of the Brightwater Rossiter case, is the right to refusal of treatment, including those who are dependent on others for the necessities of life, now clear for medical practitioners?

Prof. QUINLAN: I think it was pretty clear before. I must declare an interest here, because Mr Rossiter and his mother were both patients of mine at one stage, so I cannot divulge any technical or real-life detail about them, but I do know it is public knowledge that after Chief Justice Martin delivered his findings, which were very explicit and very clear and restated what a lot of us knew anyway, Christian Rossiter decided not to starve and deprive himself of fluid, and died from natural causes.

Hon ROBIN CHAPPLE: We heard today some interesting anecdotal evidence that the use of PEGs, which used to be quite common in treating Huntington's disease was very, very common at one stage and is now virtually non-existent—where people are electing not to have PEGs. Is that something that you would have seen or experienced?

Prof. QUINLAN: I vividly remember the first time I recommended a PEG to someone many years ago. This poor man had myasthenia gravis, which you may not have heard of. It is a treatable condition of the neuromuscular junction which causes temporary paralysis and it is treatable with medication. Some patients are very resistant to the medication; you have to wait it out to see if it will come under control. This poor man was being fed by a nasogastric tube in Royal Perth Hospital under our care for six months and because we were waiting for his swallowing capacity to return under the influence of the drugs we had. I happened to have had my appendix out during that period of time and I woke up with a nasogastric tube in. It was the single-most uncomfortable thing I had had for some time. I wondered why and I was told why. It was not routine after an appendectomy. When I recovered sufficiently, I went back to this unfortunate man and I said, "Would you consider the use of a PEG?" I explained what that was to him and we did do one on him. He was extremely grateful because he did not have that uncomfortable tube down his throat anymore, and he eventually did recover. But, as you imply, I have seen other patients over the years in whom PEGs have gone wrong and they, of course, had local sepsis and local peritonitis and other problems. Yes, I think, the full implications of what a PEG may or may not do for a patient has to be clearly explained

and understood by the patient. PEGs, way back then, were not common so it was a learning phase. But like all these things you learn lots of things along the way—some good and some bad.

The CHAIR: Given the guidelines around opioids are to start at low doses and titrate upwards, is there a risk that given the very different trajectories of degenerative illnesses or terminal illnesses, that those guidelines would leave some patients in pain?

Prof. QUINLAN: You do not look up the guidelines actively every time you treat a patient, but I think that the answer to that is it depends exactly, as you say, on the individual patient, their age, size, associated features, other drugs that are being used and so on, in order to come to the appropriate dose.

The CHAIR: I want to turn to futility of medical treatment. We know that doctors are not under an obligation to administer futile medical treatment. How would you assess whether life-sustaining treatment would be futile?

[4.00 pm]

Prof. QUINLAN: Perhaps I can give you an example—two examples, if you do not mind. One is a young man, going by my standards, with a metastatic melanoma of the body, and I mean everywhere together, but not his brain. He was fully alert and conscious. His liver was so badly affected he was pretty bright yellow, so the liver was failing at the same time. He came to me for some advice on the advice he wanted was, “Should I fly to Germany on my own to seek out a cure for my metastatic liver?” He had read about it and he was grasping at something that might help him. Instead of just a blanket refusal, saying, “No, do not do it, it is a waste of time”, I sat down and talked to the man about it and said, “What are you hoping to achieve?” He said, “A bit of time.” I said, “Have you thought through the implications?” The implications were that he was travelling to a foreign country where he did not speak the native language, he was going on his own and he was not going to have his family or circle of friends around him to give him succour during that time. The treatment itself was of doubtful use and the airplane flight, let alone back the other way, would be a sufficient ordeal for him to think many times about doing it. Did he think he was going to be worth it from his own personal perspective, given the odds? Least of all was the cost. Cost is often not considered, but I think it also is an issue. For him in his circumstances cost was not an issue. In the end he went away and thought about and decided, no, he had to accept the fact that he was dying, this was a vain hope and he was not going to put himself, let alone the family, through the whole ordeal, particularly when he realised he might die over there and then the family were faced with another tragic set of circumstances.

The other example was a non-malignant situation of a 91-year-old man who a general practitioner asked me to look after in hospital. He was admitted with severe renal failure, which meant in his situation that the waste products his kidney could not excrete resulted in a semi-comatose situation, so he was unable to give a very coherent history. He had two sons and both of them were very intelligent young men totally devoted to their father and they wanted everything done for him. When you are faced with that sort of situation, the first thing you have got to decide is whether there is any reversibility for the situation of a realistic nature and a simple way of doing that is an ultrasound of the kidneys, which we did. The kidneys were very small, indicating that this was a process that had been going on for some time, a chronic process, and it had resulted in the kidney shrinking and there was no kidney substance left to give rise to useful function. The only thing that could be done for him was to put him on the dialysis program and this case a haemodialysis program where the blood was rinsed. There was no realistic hope that even this improved into a state of him waking up and being able to converse and carry on his daily life that a transplant would be available with someone aged 91. Having explained all this to the boys, they were still very determined that

something be done for their dad, so instead of just saying, “No, that is it”, I said, “All right, I will get a renal physician to see him and will have a think and get his thoughts and ideas about it.” Along the line, we tried to tell the boys what a dialysis life meant to anyone, let alone to a 91-year-old man. A haemodialysis life is no fun and it is no fun for a young person, let alone an elderly person. By spelling out the actual realities of that dialysis life, what it might mean to their dad, and after getting a renal physician to see him who agreed that it was a tricky decision, we sat down with the boys again and explained it all once more—several times more in fact. In the end, they accepted this was going to be imposing on dad a mode of living that was not going to help him in anyway whatsoever, in other words under the title of “futile”. So, I think it is a doctor’s responsibility to explain the nature of the illness and whether or not treatments are available and what the implications of these treatments are, what the outcome is likely to be and to be honest about it. In the end the boys said, “No, no, we understand what is happening”, and he died peacefully in a uraemic coma, and a uraemic coma, believe me, is quite a peaceful way to die.

It brought to mind as I was talking about the last example, if I may, a young doctor with a cerebral tumour who had been resected and as with primary cerebral tumours it recurred nine months later, which is about the average time. His family desperately wanted something done for him and they had heard that a surgeon in Sydney would operate on him and make him better. I tried to talk to family and say, “What is your intended outcome”, and I talk to the patient as well, who was still able to make his own decisions, mind you, with some family pressure. In the end, the decision was to fly to Sydney. He had his operation. The post-operative care was pretty sketchy, from what I can gather, and he came back physically much worse than he left; in other words, the operation did not really give him anything extra except a week or two of extra life. I could not say to them, “I am going to wipe my hands of this”, and just walk away. I would be there to support him when he came back as well. That sometimes these decisions about futility have to be explained more than once in order to come to a sensible conclusion. So, honesty and a good patient–doctor relationship and listening are the most important features in this whole exercise.

The CHAIR: A Canadian study that the committee has had access to that was provided to us found that there is a lot of variability amongst ICU care workers and in factors that are important in decisions to withdraw life support. Do you think a similar result would be found in Western Australia?

Prof. QUINLAN: Of course, and again, that comes back to experience and expectations. As a young graduate, you are often filled with a sense that everything might be possible and you have a go at it. That enthusiasm and that zeal should not be stamped on, but the other examples of experience must also be made clear to the young doctor. In some specialties, including management of malignancy, often with the patient’s request, rather futile treatments are given, which impart a terrible ordeal of suffering on the patient, and you cannot deny them the choice, but it also is professional integrity to tell them what the limitations of those treatments are and to give advice, for example, “Doctor, what would you do?”—sometimes you have to honestly say, “I would not go that route, because I do not think it is going to be of any benefit and more importantly it is going to make your life pretty miserable.” I think we have to educate young doctors to think about things more sincerely and more accurately if they go along and acquire their own learning experience, and there is no other real way of doing it. So, you will find differences of opinions, particularly in the acute setting of intensive care and coronary care.

The CHAIR: Do think the principle of futility compromises the patient–doctor relationship?

Prof. QUINLAN: Can do.

The CHAIR: Can you elaborate on it?

Prof. QUINLAN: Yes, it can work both ways, where a doctor thinks things are futile and they may not be all that futile or where the patient demands a lot of treatment when they think there is may be a very small hope of success, but “I am going to give it a go anyway.” The patient’s ability to cling on to life should never be underestimated. It is a bit like a mother’s protection for a child—never underestimate it. My father is an obstetrician and he told me when I was just a young boy, “Never underestimate the power of a mother’s affection for a child. If you do, you will be in trouble.”

Mr J.E. McGRATH: Professor Quinlan, on the subject, have you had patients say to you at any time, “Listen, doc, can you help me finish it? Just finish it for me. I don’t want to keep going.”

[4.10 pm]

Prof. QUINLAN: Yes, I have. That is where listening comes in. I think in my submission I gave an example of the old lady I was asked to look after with heart failure. She was very distressed with her breathlessness. She grabbed my arm when I went to see her on my own—no nurse, nothing. She said, “Doctor, give me that needle. No-one will know. I will slip away.” I said, “I cannot do that. You know I cannot do that. But I can make you feel a lot better.” I treated her with pretty standard treatment and she was that much better the next day she grabbed my arm and said, “Thank God you didn’t give me that needle.” It comes down to the patient’s perception of what the illness is doing to them. That is what I alluded to in the submission—what I call “illness behaviour”. In other words, patients may change from day to day depending upon what the nature of the illness is doing to their psychology and thought processes. That is something, as I also noted in the submission, nurses have got to understand because nurses spend more time with patients. If they get distressed by a patient’s behaviour and so on, you have to say, “Look, this may not be the patient. This could be the illness working through the patient.” If a nurse does not understand that, she can go mad and leave nursing if she is not educated to accept that sort of patient–nurse relationship problem.

The CHAIR: With relation to voluntary assisted dying, you have indicated that you are totally opposed to physician assisted dying. Are you also opposed to voluntary assisted dying?

Prof. QUINLAN: That is where euphemisms come in. Physician assisted dying, at face value could be good care of the dying. So could voluntary assisted dying—it could be good care of the dying. But if you strip the euphemisms away, patient assisted dying in my definition is medical homicide—a direct intention to kill the patient by an act carried out by the doctor. Voluntary assisted dying is voluntary assisted suicide, which is currently illegal. Again, that comes under the category, as far as I am concerned, of aiding and abetting a crime.

The CHAIR: If voluntary assisted dying or suicide became part of the law in Western Australia, what protections would be required for doctors?

Prof. QUINLAN: The glib and simplistic answer to that is do not change the law. That would be my attitude. I may expand a little bit on that, if I may. As we all know, the law has been passed in Victoria and will come to action as an active process in 2019, I understand, once they have worked out the protocols and procedures. In Victoria also there exists a situation of compulsory referral for termination of pregnancy, which was highlighted by a case several years ago of a doctor who insisted it was his right of conscience not to refer a patient for a termination. He was told that that was not so under the law. As you know, the Canadian law was changed about 18 months ago. The whole of Canada, not just Ontario, introduced voluntary assisted dying and patient assisted dying. Just as an aside, you have probably read that after 18 months the number of patient assisted dying is 1 029 and the number of voluntary assisted dying is one. So there have been 1 030 deaths and one voluntary assisted dying. That is just an aside. The law as it stood was challenged by a group in Ontario saying that the law as it stood contravened their conscience and contravened their right to religious freedom. On 31 January this year the three justices of the Superior Court of Ontario

unanimously said that the doctors' rights of conscience had been transgressed but in view of the need for public access to health matters that was overridden. The College of Physicians and Surgeons of Ontario's effective referral policy—that is the equivalent of our medical board—presents reasonable limits on religious freedom demonstrably justified in a free and democratic society. To me, that decision means that conscientiously objecting physicians no longer have an adequate conscientious objection under law and that civil conscription has become a reality. That decision will obviously be challenged, but I think it is a harbinger of what could come about.

That has influenced me by suggesting that perhaps the laws in Victoria and Canada would be not a blanket law that allows all doctors to kill people under the law and be protected by the law, but instead of doing that, let us reverse it 180 degrees. If such a law is passed it should contain provision for only those who voluntarily wanted to be involved in euthanasia—whether they be doctors or nurses, hospitals or hospices—should put their hands up to go on a registry. That registry can be kept by the state and freely and transparently made available to all members of the public, including health professionals, so that they can clearly know who to turn to when they want to have a voluntary euthanasia process fulfilled. In that way I think it would do away with all the issues related to conscientious objections and compulsory conscription. I think it is something to think about. I have not seen it in any other statute across the world, but I think it is such an important issue for the practice of medicine in the future.

Hon NICK GOIRAN: Professor Quinlan, curiously, earlier this week the committee asked witnesses about the validity of slippery slope arguments. You have not been asked that despite the fact that your submission notes the expansion of access to euthanasia, particularly in the European jurisdictions. Can you elaborate on the failings in overseas jurisdictions?

Prof. QUINLAN: In every jurisdiction where the law has been passed, subsequent changes to the law have occurred. I am reminded by some of your parliamentary colleagues who I have been talking to recently on both sides of the political spectrum, that laws made by politicians of the day can always be challenged by politicians of the future, not just challenged, but altered. Nothing can be set in stone. The experience in overseas countries, including Canada, has been just that. Already in Canada, for example, even after 18 months there has been application to include children in their law. In the Netherlands they are suggestion now that if you reach the golden age of 75 you can volunteer to have yourself euthanased even if there is nothing wrong with you. I fear for those people who are aged 74 years and 11 months if they have greedy children around them. I think the evidence for possible abuse is very clear. I have said many times, if you can think of anything that could happen in this situation, it has already happened somewhere else. Slippery slope is an emotive phrase but I think that things change and they will inevitably change once you change the law.

[4.20 pm]

Hon ROBIN CHAPPLE: Professor, you have been in the medical profession for quite a long time and I congratulate you for that. When were you aware that the issue of do not resuscitate became a practice to identify a patient should not be resuscitated and what was the original basis for those decisions?

Prof. QUINLAN: That will cast my memory back some decades, because it arose when I was a physician at Sir Charles Gairdner Hospital at the time. Efforts of resuscitation had improved so much technically that it was becoming quite popular. As you know, most hospitals have crash teams where the blue alert goes off and they thunder around the wards to resuscitate someone who is presumed to have had a cardiac arrest. A number of things came out of that era, which was in the 1970s and 1980s particularly, including the fact that your chance of being resuscitated, even in a hospital, were not all that good, and even if you were resuscitated, your chance of leaving hospital was about

10 per cent—10 per cent of those who were resuscitated. So it was often not a very good idea. If you happened to be in coronary care and you were recovering from a heart attack or in intensive care recovering from a serious illness, the circumstances were entirely appropriate to have a go if suddenly a cardiac arrest happened, although in some circumstances you did not because of the nature of the disease. Anecdotally, I can remember the senior sister at Fremantle Hospital, a woman of great experience, stopping the resuscitation team at the front door of the ward saying, “Stop. This patient has not had a cardiac arrest; he has just died.” In other words, do not try to resuscitate people who are going to die anyway. But it prompted me to have a symposium on just this issue about when to resuscitate and when not to resuscitate for the hospital staff—nurses, doctors. We had numerous questions from the audience about it all. But the significant issues at that time were if you had pre-existing disease, particularly of the heart and lungs, or severe malignancy, your chances of resuscitation were dictated by those pre-existing conditions. If you were 80 and had a cardiac arrest but had no particular history of those diseases, then resuscitation may be successful. So there were a lot of factors that guided the proper use of that resuscitation call. Things have improved, but there is still far more resuscitations that are attempted than really should be to put it that way.

Hon ROBIN CHAPPLE: Just on that going down further, you indicated the nurse standing at the door saying, “Do not resuscitate; this person has died.” She was making a deliberative statement about that person. I know that do not resuscitate has now changed and it has to be recorded in the notes. At what stage did that change, because it was originally doctors saying, “Do not resuscitate”?

Prof. QUINLAN: I think because of the uncertainty, that is when advance directives and so on became law and popular, and the law had to change to accommodate that. Incidentally, if the law is ever changed in Western Australia, a lot of those other laws will have to be changed as well because they do not talk about resisting treatment; they talk about not having treatment. It does not talk about euthanasia as an option, but that is an aside. I think it happened around about the 1980s and 1990s, and it became an issue that really required the law to act and put in place advance directives and the equivalent laws.

I am a bit suspicious of advance directives. You have got to be very careful about their wording because people change their minds. They may not, when they are perfectly healthy, have any illusion about how they want to be treated when they have got a severe illness maybe in some 10, 20 or 30 years’ time, but it does not stop them from changing their mind in 10, 20 or 30 years’ time. When interpreting an advance directive, if the patient is alert and conscious and able to mentally make a decision, it is worth revisiting. It becomes even more difficult for the relatives, if they are the appointed executor or attorney, to deal with their family members’ wishes. It is not easy and never will be easy.

Hon ROBIN CHAPPLE: Just one stage further and then I will finish up. If, hypothetically, you have got a patient in hospital who is in a very serious way and is not going to survive and you do not have relatives or guardians, do doctors actually still determine DNR—and there is no advance care health directive?

Prof. QUINLAN: I think almost certainly only after discussion between others—fellow professionals and the nursing staff. But it will certainly happen, yes. It comes down to futility.

The CHAIR: Professor Quinlan, is there anything else you would like to add today?

Prof. QUINLAN: No. As I said originally, I am worried about my young colleagues. Victorian nurses and medical students who have not signed up to do nursing or medicine yet but do so after 2019 will not know anything else, and that worries me. In other words, I think it is going to radically change the practice of medicine in this country or this state, and I do not like that. I have drawn up, if you

wish, a list of unintended consequences which I am happy to leave with one of the staff. You might want to read that.

The CHAIR: Thank you.

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 for your time today, Professor.

Prof. QUINLAN: Thank you for your courtesy.

Hearing concluded at 4.26 pm
