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
FRIDAY, 2 MARCH 2018

SESSION TWO

Members

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

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Hearing commenced at 10.06 am

Mr ANDREW HIRST
Executive Officer, Motor Neurone Disease Association Western Australia, examined:

Mrs KAREN SMART
Chairperson, Motor Neurone Disease Association Western Australia, examined:

Professor SAMAR AOUN
Vice President, Motor Neurone Disease Association Western Australia/Palliative Care Researcher, examined:

Ms JANICE KAYE TAYLOR
Past Carer/Secretary, Motor Neurone Disease Association Western Australia, examined:

Dr ROBERT EDIS
Neurologist, Sir Charles Gairdner Hospital/Perron Institute Motor Neuron Disease Clinics, examined:

The CHAIR: On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am the Chair of the joint select committee. I will introduce the other committee members. We have 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 that you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything that you might say outside today's proceedings. I advise that the proceedings of today's hearing will be broadcast within Parliament House and via the internet.

Would you please introduce yourself for the record?

Dr EDIS: I am Dr Rob Edis I am a neurologist who heads, obviously, a motor neurone disease clinic at Charles Gairdner and the Perron Institute, one of three of those multidisciplinary clinical teams. I have a long association with the Motor Neurone Disease Association of WA and the motor neurone disease advisers are an integral part of our teams.

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

The WITNESSES: No.

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

Prof. AOUN: Yes, thank you for that. Being a palliative care researcher, I may say that we have hard copies of our submissions. All our questions that we have answered, they are all typed and we have given some copies to —

I just felt that it is really important to emphasise the difference between palliative care and the palliative approach to care, because we know that in the developed world now we are equating palliative care really towards end-of-life care, and it really should be from diagnosis. The problem is

that it is quite costly; we do not have the resources to have our palliative care services here attend to everyone's needs right from the diagnosis—that is, for all life-limiting illnesses. I just wanted to emphasise from the start that we have always advocated for a palliative approach to care right from the start and that means general palliative care. Everybody who is in contact with MND or other life-limiting illness should be really skilled in how to approach a person with a life-limiting illness. We are talking about the GPs, we are talking about the nurses at the hospitals and we are talking about our motor neurone disease care advisers who go to the home. The responsibility does not really sit only with the specialist palliative care services. They are doing a fantastic job, particularly in this state here, but not enough for what our clients, and we are talking for the Motor Neurone Disease Association, not enough for what they really need. Until this moment we have not had enough education and training for all the general service providers to be able to know what to do right from the start, particularly for MND, which is a really complex disease and quite brutal right from the start. There is no cure and there is no effective treatment. This is where it is really important to have palliative care right from the start, because it is for the whole family, it is not just for the patient. We know from my research and other research how much the family carers suffer from not having the right information at the right time and the support that they need. This is what I wanted to say right from the start, because I know for most of you, the questions you have got there are about specialist palliative care, and we have sort of responded to them from that angle. I just want you to know that there is another option that is more part of life that we need to embrace and start working with that palliative approach to all life-limiting illnesses and particularly MND.

Hon COLIN HOLT: This is a question without notice. As an example, you say in your submission —

> Motor Neurone Disease … is the name given to the group of diseases in which the motor neurones undergo degeneration and die. Amyotrophic Lateral Sclerosis … Progressive Muscular Atrophy … Progressive Bulbar Palsy … and Primary Lateral Sclerosis … are all subtypes of motor neurone disease.

Do they all have the same prognosis of imminent death or death in a certain time frame?

Dr EDIS: No, they do not. It is not one disease. It is a whole spectrum where the motor neurones to voluntary muscles are affected and so there are different phenotypes; there are different common presentations. The most common form is ALS, so amyotrophic lateral sclerosis. That is a pathological term that comes from the late nineteenth century when this was first defined, when this disease was first identified, in France. Amyotrophy refers to muscle wasting; lateral sclerosis refers to a hardening of the tissues in the spinal cord, the descending motor pathways.

About 80 per cent of people who have a working diagnosis of motor neurone disease would have that mixture of upper motor neurone and lower motor neurone stiffness, spasticity, weakness occurring. It has been used as a synonym. The English term "motor neurone disease" was first introduced in about the 1940s or so by a neurologist in Britain called Lord Brain, which is his real name—Russell Brain. In English-based medicine, motor neurone disease embraces the whole spectrum of those diseases where ALS is the dominant phenotype—the common pattern—whereas in the United States and some other places, ALS is used in the same way as a general rubric for motor neurone disease. There would be 20 per cent or so of people who have other forms, which would refer to primary muscular atrophy—a predominant lower motor neurone presentation with a slower progression; flail limb—flail arms and legs—again, a slower progression with different male and female ratios; primary lateral sclerosis, only about three per cent of people with motor neurone disease where there is predominant spasticity. They do have different prognoses, but the common prognosis of about 70 per cent of people with MND dying within three to five years of symptom onset is the ALS phenotype—the 80 per cent common presentation.

Hon COLIN HOLT: Thank you. It is important for me because I am curious about misdiagnosis across the spectrum. How often does it occur? This is something you might need to take on notice. How often does it occur when maybe someone has been diagnosed with ALS, but actually they have one of the less progressive forms? How often does that occur? You might have to go and do some research, but even just in WA.

Dr EDIS: No, not often at all now because of modern imaging.

Hon COLIN HOLT: But it does occur?

Dr EDIS: With people who present with a weakness of a hand muscle, for instance, or a foot drop or something as the initial presentation, such as a musician I saw recently who could not use his finger properly on the flute, so if it is a lower motor neurone weakness, wasting, final cable system down to the limb muscle being affected, and an investigation showed that it is not something in the spinal cord, it is not in the periphery through electrical tests and whatever, we can find that it is a probable case of MND. So then it requires a period of observation to document progression and to make sure that it is not anything else. Misdiagnoses these days are very rare because of modern imaging and modern electrical techniques.

Hon COLIN HOLT: I do come from some knowledge because I know someone who has been and was told to go home and get their affairs in order.

Dr EDIS: It depends on the diagnostic skill of the people you see.

Hon COLIN HOLT: Sure, but that is the whole point, is it not?

Dr EDIS: Yes. We have a registry of over 2 000 people who we have followed from diagnosis to death now in Australia. It is called the Australian Motor Neurone Disease Registry—AMNDR. Within that, from confirmed diagnosis—definite diagnosis—of motor neurone disease, the median time to confirm diagnosis is 11 to 12 months. There is quite often a long period of limbo where there is a degree of uncertainty. There may be a working diagnosis that it is probable motor neurone disease, but it may turn out to be a motor neuropathy—something slightly different and slower in progression and not one of the conventional types of motor neurone disease.

Hon COLIN HOLT: That is really useful evidence as well—the fact that there is that time lag between probable and definite diagnosis.

Dr EDIS: Sometimes you can make a diagnosis immediately. There is a set of symptoms and signs and imaging and whatever which clearly indicate that this is ALS; there is just no doubt about it. So one can make the diagnosis on first presentation sometimes, particularly if the person has been through an ENT surgeon or someone else with a foot drop and had a back operation because they thought it was a disk but it was not or some other thing. You can make a diagnosis sometimes confidently right at the beginning, but there are others who will require quite a period of observation to be sure that that is what the nature of the problem is, even though it is the working diagnosis.

Hon COLIN HOLT: Do you have any data around that, because that may be useful?

Dr EDIS: Yes.

Prof. AOUN: Yes. That is what I was going to tell you. Rob and I did a national survey on breaking bad news and breaking the motor neurone disease news from the neurologist's perspective, the patients and their carers. Again, a lot of people are so distressed until they know what their diagnosis is, and they have been told, "You've got a psychiatric problem" or it is about ageing, "You're too frail" or "Your denture is not working" when they start not talking well. So we have got that; I will send it to you.

The CHAIR: Thank you. While we are on the question around diagnosis, can you give us an example—I know every example is probably different, but a general example—of the trajectory of an individual who has been diagnosed with MND?

Dr EDIS: The common variety ALS—the 80 per cent of patient presentation—is usually inexorably progressive to death within three to five years. It depends on how the person presents. The common presentation would be with a hand weakness, like Neale Daniher, for instance. He would not mind me telling you that, because he has told everybody else. It was the weakness of the handshake that gave it away initially. He would shake hands and they would say, "What's the matter with your hand?" and he would say, "I don't know; it's something not quite right." Or someone pegging out clothing who cannot do the peg properly, so a weakness, or a foot drop or trouble with speech or swallowing. It depends on how it presents. Then it spreads—that area that is affected gets worse and it tends to spread in that limb and then the adjacent limb. Then it may go from the legs to the arms or the arms to the legs, and then the trunk and then breathing muscles and then speech and swallowing. But it may present with trouble with speech and swallowing, where limb muscles are well preserved for another six or nine months or a year. Very rarely, I have seen patients present in respiratory distress where it has affected breathing muscles and diaphragm at onset, and their presentation is with dyspnoea—with breathlessness. The pattern varies from one to another, but there is an inexorable progression and it is usually relatively linear. You see a difference every six to eight weeks to three months in the progression of the spread of the disease and the weakness and disability that occurs. Most people die through respiratory insufficiency—they die a respiratory death.

[10.20 am]

The CHAIR: Can you describe that? What is that final six months like for the experience of that person?

Dr EDIS: It is that final three months to six months which is the most distressing. From initial diagnosis of a hand weakness or a foot weakness, you are not incommoded all that much necessarily and you carry on. As Samar said, at our clinics we follow a palliative approach, emphasising patient-centred consultations and supportive of quality of life, with a multidisciplinary team to help with OTs and physios and others, then teaming with respiratory physicians and then with gastroenterologists if there is going to be gastrostomy feeding required or not. For a period of the disease for people coming to terms with the diagnosis, there is tremendous help from the Motor Neurone Disease Association of WA. The MNDAWA is just key to best management of people with motor neurone disease as part of our team or outside of our team. But if one gets to a point of being very dependent or totally dependent on hoist transfers, that is where the difficulty comes in the last six to eight weeks or so. That is where we engage the specialist palliative care services, particularly Silver Chain. We work with the hospices as well and with public hospital palliative care teams. That is where someone may end up with a gastrostomy for feeding; some people refuse them. The rate-limiting thing in motor neurone disease is the breathing, not the swallowing side of things in most people or the nutritional side of things. That is where there is the distressing symptom of losing your cough; thick sputum gets in the back of your throat and you cannot get it out. It is very distressing; one of the worst symptoms in motor neurone disease. Fortunately, we now have what are called cough-assist machines that we often provide for people. It is a little electric machine with a mask which we can give a positive impulse into the lungs and then a negative extraction of the stuff from the back of the throat. There are ways of dealing with these distressing symptoms, which quite often give good relief, but sometimes cannot give complete relief. That period of time at the end with relative immobility, loss of autonomy, loss of enjoyment of life, often difficulties with

communication, or if there is cognitive impairment, that is where the difficulty comes in towards the end of life with MND and where the distress comes from in particular.

The CHAIR: Would it be fair to say that there are amongst the witnesses people who have had family members experience that end of life with MND?

Ms TAYLOR: Yes. My husband was diagnosed with motor neurone disease in April 2004 and he passed away in November 2005, so it was 17 months. He had all the symptoms that Dr Edis was explaining—the wasting away of muscle and foot drop. He actually maintained the ability to speak for quite a long time. I think at the stage he was diagnosed—we did have to wait six months, I will say, for that diagnosis—but he obviously was quite advanced, not that we knew at the time. He managed to keep his job and keep going to work in his electric wheelchair and everything else up until about seven months before he passed away. We kept him at home the whole time. The progression of the disease was so fast that every week, something new had to be dealt with at home. We had to get some new piece of equipment or we had to get someone else in to do something else. We had a little mini ward at home because we had people coming from Silver Chain to do the showering and all of that. We had hoists. We had an electric bed.

I had got in touch with the Motor Neurone Disease Association of WA right from the start, because I had no idea what this disease was and I wanted to look it up on the internet. I found we had our own association here, which was a godsend. They helped me every step of the way and I knew what was coming. We had a big initial consultation with one of the care advisers, my husband and me. It sounded horrific and scary when she told us how the stages go and what the end result will be but I remembered all that. It was interesting that, as scary as it was, I retained that information. So I would ring them up and say, "Oh, I think we need that electric wheelchair now" or, "I think we need this now" and "I think we might need something to help him breathe"—that sort of thing. It was a very full-on, stressful time for me and my children, and our friends and family, but we did our best to keep him at home because he did not want to go into care.

We had a schedule of duties and medications that he had to have every day, and we kept a little clipboard in the room, just like you do at a hospital. Everyone had to make sure he had his anxiety treatment. Towards the end, he had to have morphine. We had diazepam, temazepam; I do not know—all these pams! It seemed like every day he was having all this stuff. He did have a PEG tube. He could not eat enough food, orally, to support his body so the PEG tube feeding did give him a bit of extra nourishment and gave him a decent appearance. He looked quite well most of the time, but he could do nothing. In the end, I would say the last eight or nine weeks, he could do nothing at all. He had to be lifted out of bed by the hoist. He had to be taken into the shower still attached to his assisted breathing machine, so we had this extra-long transparent tube that was hooked up to the machine. He would get hoisted up with this mask on to go into the shower. It was not nice. So many things happened. Different staff would come from Silver Chain on different days—maybe someone was sick or something. That would stress him right out. In saying that, it was full-on. It was very hard to deal with—emotionally draining. He was a very intelligent man, so at a point in time, he called us all into our little bedroom that was turned into his little hospital room. We all got called in, immediate family: me, his twin sister, his younger sister, our two beautiful girls and he told us, "One day, I might say to you that I want this machine turned off." He said, "I want you to know that when I do that, I really want it turned off and I want you to arrange it. Do not be sad; I will only say that when I think I cannot stand this any longer and cannot put up with this life any longer." I can tell you, he had no quality of life. He did pass away in his sleep, which we were all grateful for, but he could do absolutely nothing for himself. He could not even hold a book up, could not do anything. He could not drink. He was like a trapped, beautiful, intelligent brain in a useless body.

The CHAIR: So he had capacity?

Ms TAYLOR: He had capacity, yes.

The CHAIR: Did he experience the respiratory problems?

Ms TAYLOR: Yes, and the saliva. We had to use suction for the saliva. As Dr Edis was saying, there is more advanced technology and equipment now to what we had then, but we had to do everything for him: clean his teeth, suction his throat, help with everything, toileting. He could not do anything. It is a devastating thing to see someone end up like that.

Mr R.R. WHITBY: I understand this is a hereditary disease, is it?

Dr EDIS: No. Probably about 10 percentage of cases have a definite family history of motor neurone disease or frontotemporal dementia—the connection between the two with one of the genes. There are probably other genes that contribute to it, for sure. It is usually autosomal dominant, usually evident within the family. One of the genes that was early recognised is appropriately called SOD1—superoxide dismutase. We made a major contribution to that in 1992 because we had a family with about 38 members that were able to be characterised on their blood and whatever through several generations with motor neurone disease. In about 90 per cent of people, it is sporadic without any definite family history.

[10.30 am]

Mr R.R. WHITBY: I guess the point I was making is that there is sometimes a family history, so there is an awareness, when a family member is diagnosed, because there might have been a history previously. In your experience, doctor, how common is the example of Jan's husband, where the patient does request that end-of-life option to be a possibility?

Dr EDIS: I am sure it comes into just about everybody's mind who has the disease, and in terms of it being discussed and articulated with us, probably about 50 per cent of people would overtly want to discuss their options and what is going to happen from early on in the disease, or in the mid-term of the disease. In terms of the final part of the disease, where things are becoming more difficult and a request for assistance for end-of-life, it does come up fairly frequently. Options are discussed, and some people say, "I wish I lived in Victoria" or "I wish I had an option like in Oregon or elsewhere", because they belong to Exit. They look on the internet, of course, with regard to all of these things. There is a definite interest and discussion in that. We try and reassure them about the quality of palliative care services that we have here, which are excellent, but, again, not every symptom can be relieved by palliative care.

Beyond that, there are all these existential things. If you live alone, it is a problem. If you get motor neurone disease, the best thing to do is to have a competent carer, or family. If you live alone, and you are estranged from your family, you are in trouble. If you go into a high dependency care, you are in trouble. One of my patients emailed me from a nursing home saying, "Get me out of here!" He said, "No-one should be in a nursing home with motor neurone disease, because at night time the staff ratio is one nurse for 60 patients. If you ring the bell, they disconnect the bell." You are ringing because you have got a problem, and you need to be turned or something, they will disconnect the bell, because they are just not staffed adequately. If you have got a competent carer, and you are at home and you are well looked after with support services, yes, that is fine, but if you live alone, you are in trouble. Some people living alone realise what they are up against, and what they are going to be facing. I have one person at the moment, who has been a very strong man, and who is a member of Exit, and he is planning his death. I have had a number of people suicide because they just did not want to face those difficulties at the end, particularly without support.

Mr R.R. WHITBY: How often does suicide occur?

Dr EDIS: Not all that often. I can think of three people in the last year that I am aware of who we think suicided, one overtly, and two who we think did suicide.

Mr R.R. WHITBY: Can you relate some of the details, to illustrate what sort of trauma was involved?

Dr EDIS: In terms of the suicide? Two of them I know were related to medication down a PEG tube, where they took excessive medication of various kinds and were able to kill themselves that way. The other, really, was just someone who was not that far advanced to be totally dependent, but just voluntarily decided to stop eating and drinking—deliberate terminal dehydration and malnutrition—and died that way.

Mr R.R. WHITBY: One last question: you mentioned earlier that it is not always possible to relieve symptoms. We have heard evidence from other doctors at this hearing that virtually all—close to all symptoms can be relieved. Is this something unique to motor neurone disease, or do you believe that it is true that —

Dr EDIS: Well, no, I think it would probably apply to other situations as well—malignant pain cannot be necessarily totally relieved, I am sure. Pain and discomfort can be part of motor neurone disease, but pain is usually not a major problem. It is really musculoskeletal pain usually, from sitting on your bottom all day and you cannot move or transition to a different position or whatever, or pain from frozen shoulder—you cannot move your hips unless someone moves you, and your shoulder moves a bit more and, ouch, pain occurs—pain from immobility and musculoskeletal causes. But then there is the distressing thing of losing your cough. The most distressing thing is thick mucus at the back of your throat, which you cannot clear, and the cough-assist machine—$15 000 a machine—will not necessarily work for you, or the impulse and then the extraction is distressing so you do not use it. Or the breathlessness—extreme breathlessness. Not everyone will use mask ventilation. Only about 15 per cent of people end up on assisted non-invasive ventilation, because they cannot deal with the claustrophobia, or they cannot deal with the requirements of ventilation. So persistent breathlessness, where morphine is the only thing you can use to reduce the breathlessness. So breathlessness and mucus at the back of the throat. The palliative care organisations themselves, on their websites, admit that they cannot relieve every symptom, so if they say that they can, that is not true. They have overtly stated that. The Australian palliative care websites will say that. It is well known that that is the case. Palliative care has been very good, and is very good for our patients—tremendous, really, particularly Silver Chain home care, and the hospices are superb, but there are some symptoms that can be very resistant.

On top of that, of course, is existential mental and emotional things where people just cannot stand the loss of autonomy. Particularly with baby boomers, this is going to become more and more common, I think. We are used to control of our lives; we do not want to be totally dependent. And carer burden—the anxiety and worry about what it does to the family. It drains families if it goes on for six months, a year or a couple of years, and people want out. Some people are very strong about that.

Prof. AOUN: Certainly the most common reason, from research, that people wish to die is that loss of dignity, and it is very strong in motor neuron disease. That is internationally recognised.

Dr EDIS: It is not necessarily the symptoms. Most of the time people do not feel ill; they are not feeling ill, just weak and dependent. They do not feel sick, nauseated vertiginous or headachy, most of the time. It is just a loss of dependency, the loss of social connection, the loss of enjoyment of life, loss of independence and worry about carer burden. Those are the things that concern them most.

Mr R.R. WHITBY: I will wrap up. A lot of the argument put forward for consideration of voluntary assisted dying has been based on unbearable pain, and being unable to relieve pain. Are you saying that there is a valid argument for consideration of this option for other reasons that you have just mentioned?

Dr EDIS: When they surveyed people in Oregon who have died, since their Dying with Dignity Act in 1997, and they have been very well plotted, the top three things that people say about contracting their deaths are loss of autonomy, decreasing ability to participate in an enjoyable activity and loss of dignity. Those are the three things that come top. Then come symptoms—breathlessness, pain, immobility; those sorts of things. Certainly, in motor neurone disease symptoms can be pretty distressing and pretty difficult for people. Drowning in your own saliva and stuff, when cough assist machines and suckers do not work very well, that is the thing that gets me, as is breathlessness. I have seen people readmitted time after time with terminal breathlessness, where the respiratory physicians and the palliative care people do not have a decent management plan for that, which annoys me a lot. It distresses me about that.

The CHAIR: I want to drill down on that a little bit. What would be the approach to someone who has that extreme breathlessness, is it the increasing —

[10.40 am]

Dr EDIS: It has to be better palliative care. Of course, in palliative care, particularly Silver Chain, people with motor neurone disease is a very small percentage of their work. Ninety per cent of their work is with cancer and heart disease and emphysema and things like that. There are only about 160 or 170 people in WA carrying the diagnosis of motor neurone disease, and about 1 400 in Australia. The palliative care nurse teams are nurse teams. They have GP doctors associated with most of the teams, but not all of them; they are all nurse-run teams, the Silver Chain palliative care teams in the community. Some are more experienced than others; some are more confident; and some of them will make brilliant care plans; others will not. So an education process is required, and we are involved in that, and we have interchange with Sarah Pickstock, who is the chief palliative care physician associated with Silver Chain. So there are problems with which Silver Chain team is looking after you, and their competency.

The CHAIR: Is terminal sedation a practice used for MN patients at the end of their lives to manage some of those symptoms, like breathlessness?

Dr EDIS: Yes, certainly. The use of syringe drivers with morphine and midazolam and other things as a terminal sedation solution would be commonly used, in agreement with the patient and the family and everybody else when it is clear that the person is near to death. It would only be used in the last days to a week of the person's illness I would think, most often.

The CHAIR: But they would obviously have those symptoms for a lot longer?

Dr EDIS: Yes, absolutely. So when it is really obvious to everybody that there is a struggle going on and there is distress, and where one may drive secretions, they may put the person into a sleepy state, that that is the best thing to do for them.

The CHAIR: You mentioned a more recent case where a patient experienced palliated starvation of their own accord.

Dr EDIS: Yes.

The CHAIR: Are you able to elaborate on that case? Was it also in conjunction with sedation?

Dr EDIS: Yes. This is Melanie. She is the lawyer. She used to be a lawyer to the Attorney-General of Australia, actually. She developed motor neurone disease. Her marriage broke up, so she ended up

being a single woman, with a disabled child. In any event, she got to a point where she became totally dependent and could not live at home any longer and went into a nursing home. She is the one who emailed me to get her out of there. She actually called an ambulance on three occasions from the nursing home to get her out of the nursing home. She had only been there a week. She had gone into Bethesda hospice, actually, but she had outlived her stay, because the care in the hospice was so good, as it usually is, so some people actually improve. It would surprise you—it surprised me—but you think you go into a hospice like Bethesda and 80 or 90 per cent of people are going to die in the hospice. They do not. They have about a 50 per cent discharge rate, and they get discharged home or they get discharged to a high-care facility, because there is a funding problem. You can only stay in a hospice for a maximum of about four weeks. So she was discharged to what was considered a very good nursing home, the high-dependency unit. She was there five days and then the staffing ratios, and her needs were so high, that she said, "Look, I just can't cope with this discomfort a lot of the time. Get me out of here." She called the ambulance from Fiona Stanley Hospital, and they came and said, "What are you doing? You're in a nursing home. We can't take you to hospital." She called them three times, and in the end they did. She was then transferred to Fremantle Hospital, a the holding ward there, where we saw her, where she said, "Well, how can I end my life? I will not go back to a nursing home. I refuse." We said, "Well, you have to. There isn't anywhere else you can go." So she said, "What can I do?", and I said, "Well, there is this thing called terminal dehydration, stopping nutrition, and we can do that, and I will negotiate with the hospice to get you there, and you will die within eight to 14 days, but we will cover your symptoms. We will cover the distress of thirst in the first day or two and anything else, and when you are ready to go, you let us know, and I am sure I can get the palliative care people to turn it on."

So I rang the Bethesda head and she said, "If she comes back here, I'll have nurses going on sick leave. We can't take her back." So I said, "All right; I'll try Hollywood palliative care, because she has got private health cover." One of the good things about private health cover is that there is a majority of palliative care beds in WA that are under private health care only. If you have private health care, it gets you a palliative care bed, so it is very good to keep your private health cover up. I had an interview with the palliative care physician at Hollywood, who was very supportive, and she talked to her team about it and said, "We've got this young woman who is in distress. She's in the terminal phase of her motor neurone disease. She wishes to end her life in this way. Will you agree to participate?" The nursing staff all agreed. If anyone disagrees, they can opt out of the team. The palliative care people do it that way. She came over. She then died under those circumstances. It was a very peaceful death.

Mr R.R. WHITBY: Thank you for that, doctor. The process that you have described to me, and I wonder if you agree, doctors and people have told us here that assisted dying does not happen; it is illegal. What you have described to me sounds pretty much like voluntary assisted dying. Do you think it happens in a de facto form in this state?

Dr EDIS: Yes, sure, all the time. I think so, yes.

Mr R.R. WHITBY: Do you think that is an example? Is Melanie's case an example?

Dr EDIS: Yes. That would be a rare situation. Terminal dehydration, the key to it is not taking any fluids at all. The key to it is not the nutrition, it is the fluids—the acid-base creates imbalance problems within your bloodstream very quickly, and then it puts you into a sleepy, semi-comatose state, and then you die. The longest time would be within 14 days, but usually in five to seven days. This is not a common practice. This is an uncommon practice, terminal dehydration, because the palliative care people do not like doing it and the hospice people do not like doing it. But when

people become aware of it, some people do take up the option. When this option was surveyed from nurses in Oregon, as part of that practice, they said that it seemed a comfortable death in about 90 per cent of cases. So the thing is to cover the thirst and any distress within the first day or two with the use of medication, and then the person goes into a sleepy state. With Melanie, she said all her goodbyes to her family and to her previous husband, and then within four days of being in the hospice they started the process, and she died after about four to five days.

Mr R.R. WHITBY: As her doctor, what was your intent out of that process?

Dr EDIS: My intent was to help her out of her distress. She was adamant she did not want to go back to a nursing home. She had had that experience. She was a very intelligent young woman, from a big professional background. The loss of autonomy; the loss of dignity. She claimed that she had been sexually abused in the nursing home, and I said, "Melanie, that's a terrible story, but I can't go there." The palliative care person took it up. She sent me an email: "Thank God some doctor is taking me seriously." But it did not progress further, actually, with the nursing home. That was one of her complaints, and I believe—I suspect—it probably did happen.

Mr R.R. WHITBY: On the question of intent, so it was your intent, was it, to help her to die?

Dr EDIS: Yes, definitely, but under controlled circumstances, and with the assistance of a very skilled and compassionate and empathetic palliative physician and her team in Hollywood.

[10.50 am]

The CHAIR: Would you say that it was difficult to provide the circumstances to allow her to carry out her wish? You say that you went to Bethesda first and they said no —

Dr EDIS: I should not have said that really. She was such an amazing person. The difficulties we had with her over nine months were massive in terms of our team and her wish for independence. She drove us to distraction trying to keep her at home. But on the other side of that was an admiration for her ability to fight.

The degree of difficulty? I think if you present the case, the palliative care teams will listen and will often participate. Her case, out of my experience of many years with patients with MND, she is the only one in recent years where we have deliberately gone this way, and just because I had been reading about it lately. When she brought it up and said, "What can I do?", I said, "This is what you can do." No-one had explained that option to her.

Hon NICK GOIRAN: I am interested in the access to the hospice issue. In Western Australia, Silver Chain is free. Any patient who is in need of Silver Chain can access it.

Dr EDIS: Silver Chain home hospice service, so home support, yes. But that is home support. The hospice as a physical facility is different.

Hon NICK GOIRAN: Absolutely. You mentioned with regard to the hospice that there is a funding problem—you can only get the first four weeks. Is that under the public system? Any patient in Western Australia, irrespective of a public —

Dr EDIS: If you look at the average length of stay in a hospice, nine to 10 days is the median time. It is on the web. You can look up the hospice statistics for the whole of Australia. It is amazing—I was just amazed by that. They will sometimes allow people to stay four to six weeks, occasionally two months, but usually under four weeks.

Hon NICK GOIRAN: I appreciate that; that is not the question. The question is: Who funds that? What I want to know is, in Western Australia, in order to get into a hospice, can any Western Australian access a hospice?

Dr EDIS: Yes.

Hon NICK GOIRAN: With the potential for it being up to four weeks?

Dr EDIS: Yes.

Hon NICK GOIRAN: After that, they are on their own?

Dr EDIS: No, it depends on the particular person's circumstances. Sometimes they will stay longer if it looks like they are about to die and it goes to six to eight weeks, for instance.

Hon NICK GOIRAN: Who funds that, Dr Edis?

Dr EDIS: There are a certain number of public palliative care beds, particularly in Bethesda. There is a crying need for a hospice in Joondalup in the northern suburbs because there are not any. Bethesda services the northern suburbs, Joondalup as well. I think the government is looking into that. The health department is looking into that, which is definitely required. There are a number of privately funded beds at Bethesda and in Hollywood and Glengarry and a number of other places. There is Murdoch hospice of course as well. There are quite a number of public hospital beds. It depends on whether there is a vacancy at the time, of course.

Hon NICK GOIRAN: I just need to get clarity around this: you can get funding up to four weeks?

Dr EDIS: Yes.

Hon NICK GOIRAN: Then there is a possibility to have that extended?

Dr EDIS: Yes.

Hon NICK GOIRAN: Still under the public system?

Dr EDIS: Yes, definitely.

Hon NICK GOIRAN: But in the case of that particular patient, that was not available to extend —

Dr EDIS: The problem was, and that is the difficulty with motor neurone disease, sometimes it is not entirely predictable when the person is going to die. They can hang in there for a while; it is just totally unexpected. Professor David Blacker and I, when we saw Melanie, we admitted her to Sir Charles Gairdner with a significant chest infection. She would have died if we had not treated it. She did not have an advance health directive because she would not participate with it at that stage. We kept her alive, but she was in respiratory distress. We thought, "She's going to die for sure. Let's get her over to Bethesda. That will be terrific. She will die in there. That will be fine." She got to Bethesda, got rehydrated and antibiotics; she picked up. She was ready for discharge at six weeks, because they could not really keep her any longer because she was hanging in there quite well. Then of course she went to the nursing home and then the rest of it happened. Sometimes there is an unpredictability about that.

Hon NICK GOIRAN: If you are out in the regions—rural or regional Western Australia—as I understand it, for a lot of regional Western Australia, Silver Chain is not operating. What is the hospice situation like out in the regions?

Dr EDIS: The palliative care services in Albany, Bunbury and Geraldton, even in Broome, are good. The local health service—everyone bands together. Esperance. Our experience of the country areas, is that they all muck in together. Quite often in the country towns, you can use the local hospital. The nurse in charge will then provide help for the person, and they may die. If they live in a farming community, they may go to Katanning Hospital or something and there will be a palliative care component to their beds.

Hon NICK GOIRAN: Just quickly, on the issue of what is available to patients with motor neurone disease undertaking palliative care, is anyone in a position to advise of the prevalence of dignity therapy in the practice of palliative care for such people?

Prof. AOUN: We have conducted a research project with motor neurone disease clients. Do you remember when Professor Harvey Chochinov came? It is great for them to have their legacy remembered. That is the whole issue of dignity therapy—to leave behind. Of course, Dr Chochinov has showed that it reduced the distress of cancer patients. Because we had a small group here who took part, it did not show. We did not have a big enough sample size to show whether it reduced any distress for them, plus we had to do it early enough because they need to communicate—they will not at the later stage of their disease—for them to show there is any difference in that, because it is like a series of questions they have to answer about their life and their wishes for the future. We were hoping it would be taken up by our association, but it was an expensive one to actually be done by a small association because you have to train all the interviewers to go and then do all the editing for the documents and present it. As a research project, it was great, but the practicality of it on the ground we could not do it here. I know Barwon Health, there is a social worker there who is now doing it on a regular basis for their clients, if they wish to do it. But I would not believe they are looking at the outcomes that it has had because they just think it is a nice thing to have for people to leave behind what they were like as important people in their life before they became to that state.

Mr J.E. McGRATH: One further question, doctor: getting back to Melanie, what was the cause of death on the death certificate?

Dr EDIS: I do not know. I mean, I was not there. It would have been respiratory. I think it would have been probably pneumonia. I do not know; it is a palliative care question, really.

Hon COLIN HOLT: Does the association keep any data around that, of what is written on a death certificate?

Prof. AOUN: No.

Dr EDIS: MNDAWA has a brilliant database. But within it—I have discussed this with the care advisers—I really wanted to have a field put in which has "place of death" because we do not even know that. It is about 50 per cent at home, we think, of our patients. We do not have place of death documented. We do not have whether it was poor, good or a problem. I wanted to get a feel for this. We have talked about that, Karen, but we should be documenting that. We do not know. We know of bad deaths and we know of very good deaths.

Hon Dr SALLY TALBOT: It is interesting you made that point about the death certificate because presumably on a significant number of cases it would not say "MND" on the death certificate. That is the crucial part of the data collection, is it not?

Dr EDIS: There would be two phases—so the immediate cause of death, usually pneumonia—and contributing causes; MND, one would think.

Hon Dr SALLY TALBOT: I see. I just noticed that part of your submission where you say the statistics are based on the death certificate. That actually was not my question. I have a couple of questions around refusal of treatment. I am not a medical doctor but it does not sound to me as if you are describing a situation where very many motor neurone disease sufferers would refuse the treatment that you are offering in order to die. Would that be right? I understand what you are saying about their wish to die but —

[11.00 am]

Dr EDIS: Not many, no. There have been some people who have become dependent on the mask ventilation. The mask ventilation has become so effective now. People would use it initially at night because our breathing is not as good at night—we become desaturated and get headaches and drowsiness when you wake in the morning and whatever. But if you use mask ventilation during sleep, you get better oxygenation, you get more energy in the morning and you do not get headaches and stuff like that. Then people begin to use it during the day for relief of breathlessness or other symptoms. A few people have become totally dependent on the mask and the machine, at home or attached to an electric wheelchair when they are out and about using the machine, where if they were not on it, they would die through build-up of carbon dioxide, lack of oxygen, drowsiness—then you die. In some situations they have said, "I've had enough of this, and I'm withdrawing from the mask ventilation." Dr Sarah Pickstock and the out-of-care team have documented about five cases now where she has gone into the home and, with everyone's acquiescence—it is all organised—the person will say goodbye. They will be given sedation and the mask will be removed under sedation and the person will die, usually within three to four hours later. Again, that is a rare occurrence. There may be about three cases I can think of where that has happened. We do that because if you just remove the mask there is a risk that you will end up being very short of breath and extremely distressed prior to death. That has been tested in the UK, so the withdrawal of any medical assistance is considered ethical. Some people would say that you are deliberately killing that person by doing that, but certainly in terms of the courts in the UK the ethics of withdrawing any medical assistance, such as a feeding tube or mask ventilation, is considered ethical.

Hon Dr SALLY TALBOT: I have another question about capacity. Your account of your husband's death, Mrs Taylor, was very moving. You talked about retaining capacity right until the moment he died.

Ms TAYLOR: He did.

Hon Dr SALLY TALBOT: Dr Edis, you mentioned that some MND sufferers suffer from a form of dementia.

Dr EDIS: Yes.

Hon Dr SALLY TALBOT: Can you just talk about that?

Dr EDIS: Yes. Probably about 15 per cent of people have what is called frontotemporal dementia. There is a particular gene where you can either get this form of dementia or motor neurone disease or both. If you cognitively test 100 people with motor neurone disease of different varieties, up to 50 per cent will show some form of cognitive deficit, particularly frontal lobe decision-making and certain executive functions. But overt dementia is probably about 10 per cent of people, I suppose. We recognise that that is beginning to happen through testimony from family members that they are behaving in a peculiar way—personality change, memory problems. If they will participate in tests to prove that there is a problem with executive function, that is where we get onto the advance health directive as soon as possible while there is the capacity to have that discussion and to get a medical guardianship in place, so that there is a medical guardian who is then given the capacity to make the decisions when the person loses competence. Not always does that happen. There are difficult situations where the person does not have competency and one is faced with what you do about decisions about gastrostomy or other things. Usually, the person will make it pretty clear because they just will not participate. You cannot force them to have certain things because they just will not participate, in which case you go, "All right, well they're not going to participate, we're not going to do it". The specialist palliative care approach will then be enacted.

Hon Dr SALLY TALBOT: Thank you.

The CHAIR: In relation to a voluntary assisted dying framework, your submission states that "We believe it's time to support their right to choose." Does that mean that MNDAWA supports a voluntary assisted dying framework?

Mrs SMART: I would suggest that we support self-determination, so people have the ability to choose in a legal framework.

The CHAIR: If a framework were to be introduced, what protections would you like to see and are there any features of the proposed legislation that would be required to enable people dying of MND to access VAD?

Mrs SMART: I have read only some of the Victorian legislation and it would seem that that would be suitably placed in Western Australia as well to allow people the ability to have access to choose. As Dr Edis referred to earlier, we have a large population of baby boomers who are accustomed to autonomous decision-making, so they would perhaps consider that their right. It is certainly not going to be compulsory; rather, that people can have the ability for self-determination.

The CHAIR: Would one of the features in any framework to allow people with MND to access it be the ability for someone else to administer, given their lack of physical capacity?

Mrs SMART: That is for legislators to decide.

Hon Dr SALLY TALBOT: What about the question of the time period? The Victorian legislation stipulates the expectation of dying within 12 months. Is that appropriate for a disease like MND?

Dr EDIS: I would have thought so, yes. I would have thought the Victorian legislation would be very well thought through. I can remember one person who committed suicide within weeks of diagnosis, but he was a physical fitness fanatic. He hung himself. He could not bear the thought of going onto disability and to be dependant, and he hung himself within the first six weeks of diagnosis. Diagnostic uncertainty; the palliative-care approach to treatment. In the old days you were on your own. These days, we have plotted some people about the new people they meet after diagnosis of motor neurone disease—how many new interactions with health professionals and others. It is like 80 from diagnosis to death. It is a very intrusive disease in terms of the number of people you start to come into contact with, particularly if you a private person. I am sorry, what was it again?

Hon Dr SALLY TALBOT: We were talking about the time period.

Dr EDIS: I would think within the last 12 months. In Oregon it is the last six months, but within 12 months I would have thought. It is pretty clear when you have turned the corner and where quality of life is very much less, and where the person is expressing that their degree of dependency is becoming more severe. Where the trajectory of the course of the disease is pretty clear is from the last six to nine months; you can be reasonably sure they are in the last 12 months of their disease, and that is where most of the distressing symptoms occur.

Hon Dr SALLY TALBOT: You would not be talking to someone about VAD at the point of diagnosis?

Dr EDIS: No. Well, I would if they asked in terms of saying, "What is going to happen in the future and what options have I got"; yes, but not straight off, no. I certainly would not be supporting anyone who wanted to end their life just at the point of diagnosis, no.

Hon COLIN HOLT: This is a really important point. It is suggested 12 months in Victoria got amended down to six.

Hon Dr SALLY TALBOT: Oregon is six.

Dr EDIS: As far as I know it has not, has it?

Hon COLIN HOLT: They split the time frames for different diseases. This is a question that will come up. In terms of motor neurone disease, what would be too short a time frame to consider—the lower limit? A toughie?

The CHAIR: You can take this on notice.

Dr EDIS: Certainly at diagnosis, yes, definitely, and early in the disease. The breathing is the key to it. The greatest prognostic factor in terms of predicting death is what is happening to your respiratory reserve and whether you can cope with non-invasive ventilation or not. That would be a very big prognostic factor in terms of trying to determine a likely time of death. I would have thought six to 12 months would be the right time frame—maybe six months, but six to 12 would be a good period of time I would have thought, personally, from my experience of people who do get distressed and who do take this up more seriously.

[11.10 am]

Hon NICK GOIRAN: In terms of diagnosis, is there any data about the age range or the average age of someone being diagnosed with MND?

Dr EDIS: It is not like Alzheimer's; it is not like the older you get, the more likely you are going to get it, so if we all live to 120, we are all going to get Alzheimer's disease. It is between 40 to 60, 40 to 70 years of age, is the most prevalent time. We have diagnosed people 18 years of age with motor neurone disease; in their 20s. For some people, the onset is in their 80s—but 40 to 60, I guess.

Prof. AOUN: Yes, so in most productive years, really, when they still have families to support. Motor Neurone Disease Australia commissioned a report, done by Deloitte, about the impact of the disease financially, psychologically and all that stuff. I will pass it on as well. It describes really well, for a disease that 2 000 people in Australia have got, what is the scope or basically how much it is costing in terms of so many agencies involved. It is such a high-maintenance disease that it is costing, per person, far more than any other disease, basically, in that category, let alone the carer's burden that is happening.

I just wanted to say something on the positive side in palliative care. It is not like, you know, things are not happening—they are improving—for people to live with some quality of life while they are living, because we keep saying that until there is a cure, there is care. This is where our association is, basically, doing a fantastic job. We do satisfaction surveys every year and we rate in the 80 per cent of people—this is patients and carers—having the emotional and practical support that they are needing. Of course, everybody can do better. But, reflecting on the case of Melanie, having to be in a nursing home with no carer. This is so important how carers are valuable in sustaining the patient, and sustaining their health as well in the process. We do have an intervention. It is called the "carer support needs assessment tool". We trialled it with Silver Chain and it has reduced the carer strain and distress at the time that they are doing all that caregiving, and it showed that it has benefited them as well after bereavement because they were so well supported looking after this. We trialled it in motor neurone disease; it had the same effect as well. This is the frustration of researchers. We come up with so many good interventions based on evidence, but the resources are not there to actually build them into practice and policy.

The other one is about the staff in general. General staff freak out when they see an MND patient in any ward or nursing home. First of all, they cannot communicate with them, so this is a problem. You know, when you do not know what are the patient's fears and wants—are they happy or sad—it is really a problem for them. That is why we sought National Health and Medical Research Council funding back in 2008, I think, when we rolled out the program—an education program for all the service providers who might come in touch with MND. Again, the evaluation showed that they are

feeling much more confident, they are able to care for that person, and then we would not have this problem that is happening in the nursing home for Melanie, feeling like she is really trapped in a place—they do not know how to care for her. Again, this is a program that our association runs every year for all sorts of multidisciplinary people who come to this. But, again, it needs to go into policy so that we have more of this happening to everybody. I mean, the latest research I have done on the quality of palliative care that we have in this state and also in other states, it is really good; but less so good in nursing homes, people are saying. Again, all that is in the written submission. I have put in a lot of statistics, and the articles are also there.

The CHAIR: I think that it is fair to say we have covered a lot of the ground today and that there is probably a lot more ground to cover. It may be that if the committee thinks it is appropriate, we will make contact to call you back, or, perhaps, if you would be able to assist, talk to people who have been diagnosed with MND as well. Did you say that you have provided written responses?

Prof. AOUN: Yes.

The CHAIR: Thank you, because we did not get to nearly all those questions.

Hon NICK GOIRAN: To the witnesses, you indicated that you provided some written responses. Thank you for that. If the committee is minded to make those responses public, is there any objection to that?

Prof. AOUN: We are happy with that.

Dr EDIS: Perhaps not my comment about Bethesda.

Hon NICK GOIRAN: Dr Edis, can I just stop you there. We are in public session at the moment, and broadcasting, so what you have said is already out there.

Dr EDIS: I apologise for that. I should not have said that privileged information.

Prof. AOUN: Just to show what a passionate and caring physician he is.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript. We will write to you with the questions and information we have requested on notice. I want to especially thank you all very much for your evidence today, in particular Dr Edis.

Hearing concluded at 11.15 am

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