

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 ALBANY
WEDNESDAY, 7 MARCH 2018**

SESSION THREE

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 1.36 pm**Mrs IRENE MONTEFIORE****Co-Convenor, Death Cafe, examined:****Ms TRACY MAY ENDERSBY****Nurse, examined:**

The CHAIR: Welcome, both of you, and thank very much for taking the time to come and speak to us today. On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am the Chair of the joint select committee. We have Hon Nick Goiran; Mr John McGrath; Hon Colin Holt; Mr Reece Whitby; Dr Jeannine Purdy, our principal research officer; Hon Robin Chapple; Hon Dr Sally Talbot; Mr Simon Millman; and we have Hansard recording the proceedings today for the parliamentary transcript. 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. Please be advised the committee may decide to go into closed session, depending on the nature of your evidence, and you are welcome to request to provide closed evidence at any stage.

Before we begin our questions, do you have any questions about your attendance here today?

The WITNESSES: No.

The CHAIR: We have allowed about 30 minutes for your hearing today. Did you want to start by making an opening statement?

Mrs MONTEFIORE: I am happy to make a start. I am here primarily as a result of having been a co-convenor of Death Cafe, Albany, over the last four and a bit years. I am not sure whether the committee is familiar with the workings of Death Cafe. The reason that we started it in Albany was just that feeling that death is so often seen as something that should not be talked about and people, therefore, are left to struggle on through dealing with impending death, bereavement, on their own, and that it would be a good idea to give people somewhere where they could talk freely, share their thoughts, their fears, their ideas, ask their questions and it is not affiliated with any faith or group or whatever. There is no agenda. It is just entirely participant led. The only thing is that the conversation is about death and that we have coffee and cake.

So, over the course of the four and a bit years where we have been meeting every month, once a month, we have had very broad-ranging topics but we have had some topics that have come up repeatedly. I personally think that that is probably something to do with the age group of the majority—not all, but the majority of people who participate—most of the people who come along are in their 50s, 60s, 70s. Loosely you could call them baby boomers. Baby boomers have always been people who want to make their own decisions. So, the topics that tend to come up fairly frequently are funerals. So, what is allowed? What is not allowed? Why does it have to be that way? Can I organise my own funeral in advance? Do I have to use a funeral director? Those sorts of topics, so fairly practical stuff. But the biggest by far is about advance health directives and how do I make sure that the choices for the kind of care I want at the end of my life is the kind of care that I am going to get and that those choices will be honoured. In amongst that is a lot of discussion about: Where can we get the best palliative care? Is palliative care good enough? Is it sufficiently

widespread? Mostly in Albany we are very, very fortunate; we acknowledge this. What about if palliative care is not enough? What happens then? What about the situation where pain relief simply is not relieving pain and how do we make sure that we get the appropriate care in that situation?

[1.40 pm]

From that, I have come to my own position, along with a lot of reading and a lot of discussion, that it seems to me that having the option, with all appropriate safeguards, of deciding when enough is enough and when it is time to end one's own life in the face of un-relievable suffering and where there is no prospect of recovery is something that should be allowed for. That is pretty much where I am coming from.

The CHAIR: Thank you. Ms Endersby, did you have an opening statement?

Ms ENDERSBY: I did not do an opening statement. Basically, I am a registered nurse with quite a number of years of palliative care experience. I have been to the Death Cafe only on two occasions and I, basically, just wrote a little thing to read out. I was not very clear with the information I was given whether it would be a question and answer and I am also a little bit croaky.

The CHAIR: I am happy for you to read a prepared statement.

Ms ENDERSBY: I have only about 10 minutes of writing.

The CHAIR: That is fine and then we can ask you any questions afterwards.

Ms ENDERSBY: Did you want to speak more?

Mrs MONTEFIORE: No, that is fine.

Ms ENDERSBY: You are much better off the cuff than I am. Okay. I am sorry; I have got a terrible accent, but I have also got a croaky voice.

Thank you for the opportunity to speak with you today. I commend this committee for addressing this vital issue. I am a proud Australian citizen of 32 years, so the majority of my working life has been across Australia. My objective is to provide feedback and that this be helpful in the committee's remit. My name is Tracy Endersby. I am a registered nurse with nearly 34 years' experience in nursing. My core values have always embodied advocacy and holistic care even before I was aware of the meaning of these words. I have worked in palliative care for approximately 16 years and have completed several postgraduate studies in this area. I have worked in various settings from hospital inpatient units, a freestanding hospice, an international unit and in a rural area in New South Wales under a Medicare incentive package and in community nursing services, to name but a few. I have regularly experienced other nursing positions, as I believe we cannot exist in silos of specialty. So, I have worked in HIV–AIDS, infectious diseases, Aboriginal health, as a practice nurse and in an adolescent unit. All these various roles have utilised the skill base I have honed in palliative care and provided mutual benefits to those other organisations.

During my practice in designated palliative care roles, I have been asked on average twice a year to end a patient's life. I have been privileged to work in gold-standard palliative care teams, so these requests were not related to gaps in service. This provides sufficient evidence that we, as a society, must consider this very, very seriously. In fact, my last request was only in January of this year from a dying 54-year-old. I shared my love of dogs with a patient in the metro area and we had both had to euthanase a beloved family dog, and her agitation around her end-of-life experience was increased because she had no end-of-life options, unlike her dog. This recent experience raised in the back roads of my mind: do I believe people should have end-of-life choices? To be honest, I have to say yes, yes, yes. For all the people working at the coalface and accompanying people on their

end-of-life journey, whether that is a carer to someone with MND—motor neurone disease—in a palliative care team or in a doctor’s surgery, we can and must advance our response to this issue.

I consider it a great privilege to have had the opportunity to act as a representative on their behalf. I have kept this presentation brief in case it has prompted a response in the way of questions and look forward to reading the committee’s report.

The CHAIR: Thank you, Ms Endersby. So, you have spent quite a bit of time in palliative care.

Ms ENDERSBY: Yes; approximately 16 years. I have not quite added it all up, because it has been a long nursing career.

The CHAIR: Is that in regional areas as well as metropolitan?

Ms ENDERSBY: I have. I worked in an inpatient unit in Hollywood hospital, which was then the palliative care unit, with Dr Rosalie Shaw, who went on to work for the WHO. I have worked in the freestanding hospice, the Cottage Hospice that closed in Shenton Park. I have worked in Deniliquin for a Medicare incentive package probably in 1990 as a young vibrant nurse in a rural setting—just myself, a syringe driver and a car—to cover a regional service. I have worked in a HIV ward. I have worked in Silver Chain.

The CHAIR: You have pretty broad experience. Do you think the current palliative care provision adequately covers people’s end-of-life pain and suffering?

Ms ENDERSBY: My personal experience is that even with the best palliative care service in the world, there is still going to be a certain percentage of patients whose—and this is going back right to 1988. Certainly, we did not have the tools that we have now like advance care directive and things like—I welcome them—the Death Cafe, Dying to Know Day. All of those initiatives are wonderful. I still think there is a huge gap for people who want to make informed choices. I do believe I have never acted on the request to end somebody’s life. I do not believe that is my place, but I do believe that we need to advance the dialogue into end-of-life choices and do it with proper criteria.

The CHAIR: As a health professional, do you think health and medical professionals rely on the doctrine of double effect when administering opiates at the very, very end of life?

Ms ENDERSBY: In my experience, when I worked in country New South Wales, I had a patient whose GP escalated their morphine dose by 100 milligrams a visit until it was 1 000 milligrams a day, I believe in an attempt to euthanase this patient. We are going back a long time, before palliative care education was commonplace for GPs. This did not cause the patient to die, but, in fact, they prolonged their suffering in terms of their emotional suffering. This was a patient who had actually pulled a gun at my first consultation and said—he was a farmer—“This is what I am going to do at my end”, but, unfortunately, he collapsed and was then hospitalised. That was an awful scenario to see because, in all conscience, the GP thought that if he gave him enough opioids, it would kill the patient. That did not transpire, but trying to educate and support the patient and his family do the right thing legally was very troublesome.

[1.50 pm]

Hon ROBIN CHAPPLE: Supplementary to that, the doctor in this case was, what I call, escalating?

Ms ENDERSBY: Absolutely.

Hon ROBIN CHAPPLE: He was pushing up. Do you think, from your observation as somebody in palliative care, if he had not just escalated at 100 milligrams per session and he had escalated to a significantly higher portion, that would have resolved the situation?

Ms ENDERSBY: No, it did not. Over a course of three days, this gentleman went from 100 milligrams to 1 000 milligrams and he still was not unconscious or at end of life then. He was extremely distressed. What I did was contact my clinical lead, which was basically touch base with my old clinical nurse consultant who worked with Rosalie Shaw, and got some support for the GP to look at some sedatives to deal with this gentleman's emotional distress, but at no point were they trying to end his life. I just think back in those days, which was 1990, there was a belief amongst laymen and GPs that if you gave enough opioids, somebody would die as a result.

Mr J.E. McGRATH: But that dosage might have ended the life of someone else.

Ms ENDERSBY: I think it would have shortened their life. I think, yes, opioids do depress people's respiratory function, so you have to be very clear about the symptom control you provide. As a nurse, you are constantly educating people because there is a perception that "That nurse gave a needle of morphine and mum died two hours later." So, you need an awful lot of time to educate families and staff about using opioids, but you are not doing it in a conscious effort to hasten anybody's death. You are purely doing it for symptom control.

Mr J.E. McGRATH: At a session this morning, it was indicated to us that that all cases are different.

Ms ENDERSBY: They are.

Mr J.E. McGRATH: A dosage of 100 milligrams might have a different effect on one person as opposed to that gentleman you were talking about.

Ms ENDERSBY: Yes. Everybody who receives pain medication has to be individually titrated, so if they are opioid naive, which means they have never taken strong painkillers before, that is taken into account. It is a constant review, which can be more difficult if somebody lives in an outlying area, for example, and there is no community service that can go out to them. But I myself have nursed three people who were not even given a paracetamol and still went into a normal dying process, for want of a better expression. I think there is not enough education around what a normal dying process is, that people cannot tolerate food or IV fluids, that sort of thing. I guess, for me, I am lucky because I have worked in the area long enough to have seen the beginnings of lots of education and research et cetera. I do not know if that answered your question, sorry.

Mr J.E. McGRATH: Do you think in modern medicine today, the way the laws are constructed in our state, doctors are under more and more pressure now in this area?

Ms ENDERSBY: In terms of requests or —

Mr J.E. McGRATH: In terms of how far they can go to ease someone's pain in the latter stages of someone's life.

Ms ENDERSBY: I think 90 per cent of the time they do a really good job of easing someone's physical pain. I think it is very hard to relieve somebody of emotional or spiritual pain. I also think that it really comes down to what people's tolerance is for their quality of life. I already have an advance care directive. I am only 55, but I have had one, or at least instructions, for a number of years. People do not want to think about their end-of-life care and usually it only happens if they get a diagnosis or they are not prepared for someone to be killed in a car accident, for example. But I think advance care directives are good. I am not sure that GPs have the time or get recompensed enough to actually help people right through that process. I think you have to be very clear about how you educate people about advance care directives. Most people do not realise that, for example, if they are resuscitated after a heart attack, if you look at some of the studies, only 15 per cent of people actually gain another week of life, and you could argue that if more people were educated, they would opt not to be resuscitated. But we are such a death-denying culture that —

The CHAIR: I do want to go into advance health directives. I just want to take you back to your opening statement. I think you have said that since you have been practising, you have had around two requests a year.

Ms ENDERSBY: I have. That is approximately. I have been practising since 1989 in palliative care, so obviously I have gone off and done other things as well.

The CHAIR: What percentage of those people had decision-making capacity when they made that request?

Ms ENDERSBY: I would say approximately at least 60 to 70 per cent of them still had capacity. I think the relationship you build up when you are caring for somebody, whether it is as a family carer or a caregiver in a doctor's surgery, I think people start to want answers to questions and, really, the advance of advance care directives has been a great step in the right direction. I am not saying we do not need them. I think we passionately need them and we need Death Cafes and Dying to Know Day; we need all of that sort of education. But I think for people who are facing, for example, motor neurone disease, there is a lot of conversation around people with the same disease process who talk amongst themselves. If people are offered more choices, perhaps less people would take the choice, but just the fact that they know they have the choice relieves a lot of anxiety and stress. I do not know if that is clear enough. I am sorry.

The CHAIR: It is, yes.

Hon ROBIN CHAPPLE: Yes, thank you.

Ms ENDERSBY: I am a bit fluey so I am a bit foggy.

Hon ROBIN CHAPPLE: We are glad you are sitting over that side of the table!

Ms ENDERSBY: I am not catching. It is okay.

Hon ROBIN CHAPPLE: Thank you. Irene, I just want to go back to something you said. You talked about appropriate safeguards. What do you think those appropriate safeguards are? I might be fishing here.

Mrs MONTEFIORE: I am not sure what you might be fishing for.

Hon ROBIN CHAPPLE: No, just generally your thoughts.

Mrs MONTEFIORE: Appropriate safeguards, I would have thought, are the fact that people have perhaps had counselling prior to getting to that point; that the person still has capacity; ideally that they have had an advance care directive or an advance health directive put together previously, stating coolly and calmly their position, and that they have had an opportunity to talk that through with their GP as well as, hopefully, with their family members. So I think those sorts of things and the fact that it should be more than one medical practitioner making the final call. Having been with a few people as they have got very close to death, I think it is probably not realistic to say that they need then to be able to sign something if they are in their last few days and in excruciating pain, but it should have been discussed previously. From my perspective, I think at least in the first instance this should be for people with a terminal or life-limiting illness where pain cannot be relieved. I am not talking about the broader catch net of people with depression or mental illness or whatever. It is a very specific sort of set of circumstances.

Hon ROBIN CHAPPLE: Thank you. It really helps us build a picture and we are obviously hearing from a lot of people. Everyone's input is of immense value.

[2.00 pm]

The CHAIR: What do you think are the biggest hurdles to people taking up advance health directives? I will start with Ms Montefiore.

Mrs MONTEFIORE: I think it is partly just lack of awareness. So, a lot of people just do not know that there is such a thing. As Tracy said, we are in a death-denying culture, which I think, mercifully, is beginning to change, but for such a long time it has not been a nice thing to talk about. I cannot get my kids to talk about it: “Are you morbid, or what?” I think there is a lot of that gut reaction where the cultural norm is not to talk about it; therefore, you are tempting something by talking about it. I think we are fortunate in this area because of the work that is being done on advance health directives and we can have some confidence that advance health directives are going to be registered and are going to be seen, for example, at the local hospital. But on a broader front, I think there just has not been the education and the GPs are not necessarily raising. So, everybody’s input is of immense value.

[Interruption due to audio malfunction.]

A lot of that is to do with education, so people can come to their own perspective of what they think they will want at a particular stage in their life. They can always change it and have an advance directive at any point, so they can change it as many times as they like along the way. It is important that GPs are trained and recompensed to spend time with people preparing an advance health directive to make sure that people understand what the implications might be.

Mr J.E. McGRATH: Further to that, we have also been told that GPs are fairly busy with big numbers of patients, but if they had someone in the practice who could sit down with people, because it could take an hour to go through each one, that could be another service. That could be funded through the commonwealth government or state government.

Mrs MONTEFIORE: As I understand it, the bigger practices where they have a practice nurse are using that position when people have an older person’s check at age 70, or whatever age that might happen. That is really too late. If we can gradually change the culture so that it becomes the norm—so you go for a pre-employment health check or just a general kind of blokes over 40 check, whatever the check might be, a normal part of that, as well as having your blood pressure checked, is that you will be spoken to by someone, as you say, a practice nurse or someone with some empathy, who can ask questions about whether people have an advance health directive and what sort of assistance they might need to put it together. That, to me, would help because it becomes like a snowball. It will grow as it becomes more of a cultural norm that you have one and people talk about it and it becomes more accepted.

Ms ENDERSBY: I have worked as a practice nurse and usually the only opportunity you get to raise it is when you are doing an over-75 annual health check and it is part of the Medicare rebate questions that you ask people. You ask a range of questions from incontinence to—you also do a mini mental screen, so that is looking at capacity too. So, that is currently happening, but it is at age 75 and that is almost waiting too late. It is a good tool, but it takes time. That is almost waiting too long. There are lots of other things, like Parkinson’s WA do education. The Neurological Council, MSWA—all those support groups—do education around them and I think that is really good, but we say we do need more and I think we need to normalise it more too.

The CHAIR: We have had a lot of evidence from health providers and health practitioners that they prefer healthcare plans, rather than advance health directives. Why do you think that is?

Mrs MONTEFIORE: I am not sure from a medical practitioner perspective, but I think I would speculate that it is to do with the final sort of control and an advance health directive at this stage is a legally binding document; an advance care plan or a care plan is not.

The CHAIR: Do you think there is a lot of knowledge from consumers about the difference?

Mrs MONTEFIORE: No, I think the fact is that there is a contingent in our community who want to know, but they have to go looking for it. So Death Cafe last year ran a Dying to Know Day, where we had speakers on palliative care, on hospices locally and the various documentation, so advance care plans, power of guardianship, those sorts of things. We were fully subscribed. We could only fit 50 in the hall and we had 50. There are people who are wanting to know. There are people who are trying to find out. But until people get to that stage where something sparks them to try and find out, they have not got a clue about that kind of information. We need to make it, I think, more mainstream so that people do realise that this is part of what you do. You have your plan, and I believe there is some suggestion that the terminology is going to change from advance health directive to bring Western Australia in line with other jurisdictions. I am not entirely sure about that, but to bring together the idea of care planning and advance health directives.

Ms ENDERSBY: Certainly, I feel that we spend time looking after—we have regular meetings with midwives and women are very aware of their options from a water birth to a caesarean. We do not put that level of support into end-of-life care. It would be very worthwhile earlier in the piece.

Mrs MONTEFIORE: Can I add something a little bit tangential? As part of my own attempts to educate myself on this, I have been involved over the last couple of years with tweet chats—I never thought I would see the day—with palliative care physicians, and I have been really surprised with this group, from all over Australia and in some cases internationally, and what they say about the difficulty they have in raising the topic of end-of-life care and planning for end-of-life care for people who do not already have that. That would have to suggest some lack of training with doctors right from the word go, but in particular when people are moving to those sorts of areas that they should become familiar with and consider speaking to people about what their choices are likely to be when they get to the pointy end.

Hon Dr SALLY TALBOT: Albany hospital told us yesterday that they have a computerised system with the AHDs logged, so I presume if you are admitted, they look you up and if you have got one, that is put into action.

Mrs MONTEFIORE: That is the theory.

Hon Dr SALLY TALBOT: Do you think there should be a central repository? You could have an advance health directive, but if you end up on a gurney in a hospital, no-one knows you have one.

Mrs MONTEFIORE: I think there should be a central repository. I believe with the My Health Record—or whatever it is called now; the names change—with that system, there is a spot on that for putting that you have an advance health directive, but how far into that system they would go if you were taken into hospital in Coolgardie or Kalgoorlie, for example, I do not know. So, I think there needs to be a clearer system. I simply said when I eventually get around to registering my directive, I am going to get a medical bracelet, something like that—something practical that people can have that refers to the fact that they have an AHD and that there is then an obligation on medical practitioners to look that up and to find out what the person wants wherever they happen to be.

Mr S.A. MILLMAN: Ms Montefiore, in your capacity as one of the co-convenors of Death Cafe, can you reflect for us some of the conversations that were precipitated by two things: first, people becoming aware that this committee had convened to investigate this issue; and, second, the passage of the Victorian laws from the Death Cafe perspective?

Mrs MONTEFIORE: I am not sure that there has been a solid reaction to the fact that this committee had convened. We certainly knew that you were coming here, because we meet monthly and the word has been spread around the group that you were coming. I know because I spread it! But I am

not sure that people had picked that up generally. The Victorian decision was, I think, very well received. There is always in every group people who—I am not suggesting that everyone who goes to Death Cafe is absolutely in favour of assisted dying, because there are people who first and foremost believe that palliative care should be clearly and properly available to anyone and everyone where they are when they need it. I certainly would not argue with that. Then there are some people, for reasons of faith or ethics, who believe that it should not be considered. It is not the case that everyone in Death Cafe is rooting for assisted dying, but I certainly think that it was seen within the group as sort of a breakthrough, an achievement that change is being effected, albeit in small steps and albeit at that stage not in our jurisdiction, but that there was movement happening.

Mr S.A. MILLMAN: In terms of something both of you have touched upon in terms of the narrative around it and breaking down the stigma and the taboo, both of these things go to that as well, the committee and the Victorian legislation.

Mrs MONTEFIORE: It certainly does. I had a phone call today from the local ABC saying, “We’ve heard, but we can’t send somebody. Can you tell us what’s happening?”

Hon ROBIN CHAPPLE: That is the state of the ABC, unfortunately!

Mrs MONTEFIORE: So I am being interviewed on *Breakfast* tomorrow morning. Yes, it does. That does get the word out. I suppose that is what it is. It gets people thinking, people talking, people sharing their thoughts with each other.

Ms ENDERSBY: I certainly stay electronically in touch with Palliative Care WA, Dying with Dignity in the UK, all those things, but I only heard about your committee meeting from Irene. But I was aware about Victoria, and I see great things happening elsewhere.

[Interruption due to audio malfunction.]

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. To elaborate on your evidence, please provide an email for consideration by the committee. Thank you both very much for your evidence this afternoon. We appreciate you taking the time to talk to us.

Hearing concluded at 2.14 pm
