

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
MONDAY, 26 FEBRUARY 2018**

SESSION ONE

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 9.01**Mr PAUL COATES****Chief Executive Officer, Carers WA, examined:**

The CHAIR: Hello, welcome, Mr Coates. 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. I want to say a particular thankyou for your patience at the end of last year when we got caught up with another witness and for agreeing to come back today.

Mr COATES: No, you need to get it right. That is good.

The CHAIR: Yes, absolutely. The committee really appreciates your patience for that.

I am Amber-Jade Sanderson; I am the chair of the joint select committee. We have Simon Millman; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; Reece Whitby; and Hon Robin Chapple. We are just waiting for Hon Dr Sally Talbot, who will be joining us very shortly. The purpose of today's hearings is to discuss 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 you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet.

Do you have any questions about your attendance today?

Mr COATES: No.

The CHAIR: Before we begin with our questions, did you want to make a brief opening statement?

Mr COATES: Yes, I think the committee is probably aware, but certainly palliative care, if not the end-of-life element of it, is something that is becoming of great interest within the state. There has been a CEO round table of the interested organisations set up that now have periodic meetings with the health minister, Roger Cook. End-of-life palliative care are areas that are certainly on topic and need to be addressed by the state at the moment. From the perspective of my organisation, we advocate for family carers. These are people who care for family members with disability or aged-care issues, health issues, mental health issues or chronic health issues. WA was the first state or territory to have legislation supporting the recognition of carers. Family carers provide the majority of care. People go to GPs and have periods in hospital, but with long-term illness or disability or that sort of thing family members are generally the ones who provide the majority of that care, which is unpaid. Therefore, in any aspect of care, including end-of-life palliative care, that sort of area, they frequently have quite a significant role in that. Their needs should be noted and their interest, understanding and knowledge of the person they care for should be respected. They need support, particularly when you come to things like the end-of-life period.

The CHAIR: Thank you. You have seen the questions that were sent to you. Would you like to go topic by topic or question by question?

Mr COATES: Whatever suits the committee.

The CHAIR: We might address each topic if that is all right.

Mr COATES: Yes.

The CHAIR: I turn to advance care planning. Do you want to make any comments on advance care planning and the understanding of families and carers in terms of advance care plans?

Mr COATES: With advance care planning, it is the sort of topic—the questions are asking how well families know about advance care planning and whether they are aware of it. The answer is, like many things in health, disability and mental health fields, those in the know, know it and those who do not, do not. To say, for example, that the majority of people know and understand advance care planning would be wrong. It is something that will come into people's minds, heads and life if they are faced with a family situation, probably, when there is an individual with chronic illness. Many people may have heard it. There is certainly no research or statistics that I know of that can give an indication of the degree and extent of knowledge, but from my experience dealing with people who work in the sector—so you would expect them to understand and know about these things—it is even sporadic in that area. There is a lot of misunderstanding about advance care planning, what it means, what the rights are, certainly from your layperson. I even think there are a lot of grey areas in the medical profession when we get to advance care planning or advance health directives.

The CHAIR: Do you think there are systemic and individual barriers to advance care planning?

Mr COATES: I think there is a recognition that it is a valid process, but I think the understanding both in the trained professional area and in the area of families is mixed and certainly the understanding about what can be achieved through advance care planning and how once you have done an advance care plan that will be delivered—I think there is misunderstanding over that, because I think these things can be taken over by medical circumstances and sometimes people do not realise that.

The CHAIR: So, you mean in the instance with emergency treatment, people's advance care plans may not be necessarily honoured in that moment of emergency treatment being delivered?

Mr COATES: That is right, yes.

The CHAIR: Your submission indicates that families and carers need more training in advance care planning. Who do you think should provide that training?

Mr COATES: I have no firm views. I think it could be the Department of Health and there have been elements doing that. It could be not-for-profits like my own that can do that, or the Public Advocate. There are a number of potential people who can provide that—maybe all three different scenarios and situations.

The CHAIR: What types of supports do you think carers need in this area?

Mr COATES: In advance care planning?

The CHAIR: Yes.

Mr COATES: I think it is an understanding of what it means—when preparing an advance care plan, what it might look like, what its content might be, how far they can go with that and an understanding of what the legal limitations are from doing advance care planning, especially when you are dealing with end-of-life situations, as there are a lot of complex legal issues to be dealt with there, and an understanding that there are limitations. With the best will in the world, what you complete does not necessarily mean that that is what will end up being followed.

The CHAIR: No. Do you think they would be more effective if they were held in the central repository or database?

Mr COATES: I do. I think the challenge is to get awareness and understanding about advance care planning, and then once that has been gained by people if there is one place to go—not a solicitor, doctor or a family member—it has to make it easier.

The CHAIR: Do you think health professionals generally follow the wishes of patients as expressed in advance healthcare directives?

Mr COATES: I cannot answer that, honestly. I have seen no research or statistics on that. From my dealings with people in the medical profession, it generally is, yes. I expect they would if they are able to.

The CHAIR: In relation to appointed guardians and enduring guardians, do you think health professionals generally follow their wishes?

Mr COATES: Again, I do not know. I have no stats or research I can use to back that up, so it would be pure anecdotal and opinion.

Hon NICK GOIRAN: Are you able to advise the committee whether it is common for there to be confusion on whether somebody's advance health directive is the most current one for that person?

Mr COATES: I am not sure how common advance health directives are anyway. Again, I would guess I would refer back to the concept of a central repository, so if there is one place where it is and that would have a record of what the latest version is, that could clarify that. But I suspect they are a bit like wills, you know, there are a lot; there could be one or two versions around and no-one is quite clear which is the right one. But again I have no evidence or statistics. These are things that have not been studied. I talked about the CEOs and palliative care round table. One of the things that they have come up with is that there is a need for a lot more research and information in that area to understand, and this will be possibly an element of that.

[9.10 am]

Hon NICK GOIRAN: In terms of a central registry, is there anything that is currently available to carers in terms of a database or a system that all carers have access to that would be a useful repository for such a thing, or do we need to create something?

Mr COATES: No. We have a carers database, for example, but we only have about 20 000 members, whereas the amount of carers in WA is 300 000. How many tens of thousands of those would want such a thing, I do not know. Something like the Office of the Public Advocate or the health department would be a logical place for this to me. But I do not know of a database—an immediate one—which would solve the purpose.

Hon NICK GOIRAN: Would a carer need to have access to that database at the Office of the Public Advocate?

Mr COATES: Yes. I think IT systems can be set up to allow for passwords and all those sorts of things to enable access to happen, so they do not have to physically go to a location.

Hon NICK GOIRAN: Do you think it would be important for the carer to have access to that information?

Mr COATES: Yes, absolutely. Certainly, when you are coming to things like the end of life, they need to have a full understanding of what it is that has been documented, because the persons involved in that plan, when it was originally created, may not be around themselves. There might be other relatives involved who might not be aware of it or might not be aware of its content. I also think these things sound good—advance care planning—but medical circumstances change. You might have a very valid plan in 2008 and it might not be the right sort of thing in 2015.

Hon ROBIN CHAPPLE: My question follows on from that. When changes are made to an advance care health directive—obviously, you might have different service providers—how is that information moved through those different service providers?

Mr COATES: The problem is that we do not have a central repository. We do not have a system, really. People have lots in there. It is just something that needs to be noted. If there is a transfer of service providers, all sorts of information is transferred, including medical and patient information, and that should be an element of it. But I do not believe we have a system that would necessarily facilitate that. They would be focused on the patient and client information as they transfer services, and the medical history, but I am not sure about the stuff around there.

Hon ROBIN CHAPPLE: Obviously, a central repository would be great, but would there be—I was going to say “medallion”—some sort of device one could wear, a bit like a blood-type device, which would point people in the right direction?

Mr COATES: We can always have these things made, but there are none that I know of. And then, how many of these things do you end up with for all sorts of other things? It could be like something out of a disco in the 70s, with the medallions!

The CHAIR: We will move to palliative care. Do you think the role and availability of palliative care is well understood by the community in Western Australia?

Mr COATES: No, I do not.

The CHAIR: Why do you think that is?

Mr COATES: It is not a topic that is particularly attractive to people to address. People will not want to go out and find out about these things until they are in that situation. I think there is a need to probably improve palliative care. There is a reliance on a couple of organisations that provide a lot of that care in WA. I think it is very available. Probably, if you live in the metropolitan area, you have a better chance of getting a better service than if you are outside the metropolitan area, and that is a common thing with all services. There is a lot of education to do for the community, but perhaps it is not general education for the community all the time. Again, it is a bit like the medallion and a trigger point. There might be trigger points where those involved, who are not paid professionals—in other words, family members and that—are brought in to give them support and advice, which they do not have at the moment.

The CHAIR: Do you think palliative care services are adequate in Western Australia? I think you have touched a bit on the regional issues.

Mr COATES: Again, that group I mentioned—the CEO roundtable; the one that meets with Roger Cook—is led by Palliative Care WA. I think there is a need for more information and a lot more research to answer these questions in a meaningful and objective way.

The CHAIR: Okay. You have obviously mentioned that in regional areas there are significant shortfalls. Are there any other areas of shortfall that you can readily identify?

Mr COATES: No. I think there is a general need to improve the supports and education for palliative care. There are stats around about people getting their wishes and how much it costs to take someone through the process at home compared to a medical facility, but there is a lot more education and training that needs to be done in that. I have been in situations where I have moved from that to the end of life as a carer in England—three times in fact. Certainly the first time you do it, your average member of the public has no idea what this is. Some people do not know what palliative care means. When you talk about palliative care, they will not really understand until they do need it. With end of life there is a whole range of issues that need to be communicated appropriately to the family, or certain family members, because some tend to take more of a lead role on this and some like to sit back and do not want to know. They need to be educated through the whole process. For example, until a few years ago I had not sat with somebody and I did not realise the stages of dying. It is stuff like this that families need to know about and understand, or

certainly the lead carer might do and then be able to communicate that to family members to get that understanding. They can then recognise that this is what is actually happening and can prepare family members for that, as well as providing all the care and support that you do end up providing them.

The CHAIR: What obstacles do you think exist for patients being cared for and dying in their place of choice?

Mr COATES: I think there is an attempt, from what I have seen, to meet the wishes of people where they can, but it is dependent on what is available and what services are available. The theory is that the majority of people's place of choice is their home. Again, there are stats about what that costs compared to a facility. But these things do get overtaken by medical intervention. There are situations where there might be an individual who may not want a certain medical intervention or may have said, "If this happens, I no longer want this," but then the person gets taken into hospital, maybe for something not quite that but related, and the medical staff do not have an understanding of all these things and therefore they intervene because they are trained to save people and extend life, not to close off life.

The CHAIR: It is probably fair to say that where there is a clear documentation of people's wishes and where they are at in their medical treatment, there are far better outcomes for people in terms of palliative care.

Mr COATES: Yes, but it is easier said than done. For somebody who is in the situation of having a severe breathing asthma attack, which is sort of related but not necessarily the primary thing, and then they are taken to hospital, the hospital staff will do all they can to get that person comfortable and breathing again, and that may not have been the wishes in this plan. It is hard to expect people in clinical services, especially if they are dealing with something like an emergency, because that person has been admitted, to do nothing other than what they would do in any other situation. The first thing would not be to say, "Is there an advance care plan for this person that I need to take account of?" Then there are all the medical moral dilemmas that clinicians have to face as well.

The CHAIR: Do you think that palliative care services in WA meet the needs of the following groups, and for the purposes of the transcript I will list them: CALD communities; people living in aged-care facilities and disability residential care; people living in rural and remote areas; Aboriginal and Torres Strait Islanders; children and young people; patients suffering non-malignant, chronic illness; patients with intellectual and developmental disabilities; people with mental illness; and prisoners and others in detention?

[9.20 am]

Mr COATES: I do not know enough about it, to be categorical; it is anecdotal. For a number of those groups, the key issue is one of language and communication and getting an understanding. In some of those groups there are elements of culture in there and different ways of dealing with things like palliative care and end of life. It is very tempting nowadays to say, of all that list, you get that list in everything and everyone says, "Oh, you've got to have a specialist in this." But there are probably common things you can do in terms of communication and education of people to accept diversity, accept culture and education over stigma. You mentioned disability groups and other things. There is probably general education to improve people's attitudes to diversity. That is probably what is needed. But yes, certainly in what a difficult situation for palliative care end of life, if you have got further values of culture, language and stigma and other issues, then yes, it is going to add to the mix, so ensure the probably is not —

The CHAIR: Would you say cancer sufferers generally have better access to palliative care compared to patients with other chronic or life-threatening diseases?

Mr COATES: Yes. I mean, my three examples were not here, they were in the UK but they are all cancer related. I think they are more set up for this because this is what they do. It is what it is. They are more set up for that but, hopefully, they will be less set up as we find we will be able to address cancer and find more cures for it. They certainly deal with cancer better than something like late-stage dementia—that sort of thing.

Mr S.A. MILLMAN: When you say they are more set up for this, do you mean the sufferers or do you mean the clinicians?

Mr COATES: I mean the clinical services generally, because it is a certain element of what they are doing. In the example I went through in the UK, the district nurses were superb; they managed stuff I suspect they dealt with day in, day out; week in, week out. The way they were able to deal with families and communicate with families was very good and I think it is probably the same in a lot of areas in WA. It is just a more obvious part of the process. Dealing with things like dementia, which itself has an end-of-life process and in certain circumstances can do, I guess people are not focussing on that, are they? With cancer there is an expectation that the person, in many cases, is going to die. It obviously is not nowadays, but that is an expected pattern. With dementia, people do not really know and there are all sorts of other diseases where it is less certain, but there seems to be a time line often put on it with cancer patients.

Hon COLIN HOLT: Outside that cancer network, do you get feedback from your members or carers, generally, because it falls to the general doctor or your general GP or family GP to talk about palliative care and end-of-life options? Do you get any feedback from your members about the adequacy of that?

Mr COATES: No, I do not get a lot of feedback from, say, GPs and that. I think it is once you get your Silver Chain-type services is where those sorts of things seem to get more discussed. They are quite a significant provider of palliative care services. They do, from what I hear, a reasonable job—from the feedback I get as a whole. It is hard with feedback because it is a very difficult time. People could be doing a really good job, professionally, but it is a very emotional time for people and people may feel they are not getting want on occasions, too. I get, generally, positive feedback from the standard providers in aged care. Again, GPs are very hard to get into and to get information out of and get statistics. The problem we have as carers, we believe that with GPs, there is a great space there to identify and educate carers. But they are focused on the 10 to 15 minutes for the client. They are not worried about what is going on with the family around; they have not got time to do that.

Mr R.R. WHITBY: Mr Coates, what would be the obvious things we could do as a community to ensure people get to spend their last days at home? Is there anything obvious that springs to mind?

Mr COATES: Yes. I am talking from a carer's family perspective. If you have an educative process where families who find themselves in this position, there is no point putting courses out there and getting people in. If you have a quite open educative process with families about, "This is what this is going to look like." You have to pick the right family members. It is okay for me to take that in, I have got background and there are lots of other things, but some families cannot cope with it. If there is a full educative process about, "This is what potentially it is going to look like in the next few weeks." I have been identifying the appropriate family members. That can make a big difference because towards the end of life, it is not all beeping machines in hospitals; it is in the home. It can be quite a drawn-out process. It can be quite an emotional process, so educating on the process

itself—what it will look like, what supports they can get to do that, or give them that emotional support during that time—can make a massive difference.

Mr R.R. WHITBY: Do you find that family members are up to that or is it something that depends who the carer is?

Mr COATES: Again, I can go through what I am told and from personal experience. It is like anything in life, you might have a family of eight people and there might be a couple who actually equipped through their own life experience to be able to deal with those hard questions. When I found myself in my role, I was probably better equipped because of my background to do that. Because I knew my family, I could communicate what I knew was going to happen in a certain way to minimise distress. You cannot get rid of it. I think it is identifying the family carer within the family. That education is not necessarily going and sitting behind a desk with a PowerPoint presentation. It could be the staff within the community and districts, you know, giving briefings and talking to members at different stages during the process. They have had some quite controversial things in England. They call it the “Liverpool pathway” for example. I realised even in my case with my sister, who died at 49 from breast cancer that spread. I guess when you are coming to that end of life, I did not understand what phases like active dying were and what would happen. By getting an understanding of that, I could sort of prepare the family and even give them some quite close time skills, having had weeks and weeks and months and months of a process leading to that. It was on a Sunday, and I understood the nature of the medication—what that meant and what was happening there. Somebody without that prior knowledge and education, might have thought, “Oh, they’re just being given something to make them comfortable”, but it was pretty clear that there was stuff going on which was bringing the thing to a close, to be honest with you. It is quite controversial in some ways.

Mr R.R. WHITBY: That is the “Liverpool pathway”.

Mr COATES: Yes, although the people doing the Liverpool pathway would not claim it is that. That is our interpretation of it.

The CHAIR: From a carer’s point of view, how easy do you think it is to navigate the palliative care services and coordinate between government and non-government?

Mr COATES: For people in that role, that is just one aspect of it. I guess if coordination comes in if it is in the home, you get a care provider in the home to do what is needed at that point in time, whether that is medication, dressings or whatever it is to make them comfortable, even personal care like bed washing. That is when they limit the coordination. I found myself going and getting the medication when I was in England, so you have those sorts of jobs. It is keeping the person comfortable. You are coordinating that, which is the direct stuff, but then there are all sorts of other stuff that come into it—social services type of stuff and benefits type of stuff. You are actually coordinating family members as well and often you are trying to keep a job going, so you are coordinating your paid work as well when you are doing that. It is difficult and it is not just a matter of coordinating medical and palliative care; it is actually all the other stuff that is going on. You may have kids you have to take to school. It is coordinating life. I guess when you are in that position and if you are lucky enough to have the right sort of supports from a Silver Chain and that, it makes certain things easier. But not everyone has that. It depends what you have.

[9.30 am]

Hon NICK GOIRAN: Would you be able to inform the committee of any examples of support that is available to carers in the metropolitan area that is not available to carers in the regional areas?

Mr COATES: I think the extent of community services—Silver Chain is a good example. There may be availability, but just the pure distance and availability of services is what the big issue is. What you find in a lot of these rural communities is actually it is a different type of person who lives in those communities. Some of the assistance you might have got from more formalised services is given by families and other families and that within the area.

Hon NICK GOIRAN: Just to help us understand that: if you are a carer in the metropolitan area and you have the availability of Silver Chain and if you are a person in the region and you do not have availability for Silver Chain, what impact does that have? What does that look like in terms of the difference for the patient?

Mr COATES: It puts a lot more pressure on the family in the latter, the regional, because some of the personal care stuff—the basic cleansing—personal care stuff—as well as the support in terms of the medical or clinical aspect of it, as well as the emotional support that you get. Just somebody coming into the home and doing bits and pieces for the person in palliative care is a comfort to family members, whereas that is a lot less when in regional areas. If you are lucky you might get the odd visit here and there. So all that emotional support is placed more on yourself, if it is a family member, or friends who are helping out. That is what it looks like, I guess. There is a feeling that if something becomes a bit more acute during the palliative care process that needs to be dealt with—a catheter falls out, or whatever it is that might go on—you are going to get more instant help. It is things like that that look like you are getting a better, more immediate health intervention or clinical support.

Hon NICK GOIRAN: In the metro area?

Mr COATES: Yes.

The CHAIR: Do you think palliative care is 100 per cent effective for all patients?

Mr COATES: I would probably think no, but I do not know. Again, I refer to research and —

The CHAIR: You could not put a figure on it? A percentage?

Mr COATES: No. I could not put a figure on it.

The CHAIR: Do you think that carers are aware of the legal position around caring and end-of-life treatment and what the legal framework is around that?

Mr COATES: No. As a generalism, no. Like I said, there would be certain people and certain families who get themselves up to speed with all that stuff. As a general community? No.

The CHAIR: We have had a lot of submissions from people who talk about their experience with their loved one wanting to end their life and end their suffering. You think that carers are pretty much not across what their legal requirements are in those instances?

Mr COATES: Not in detail. They probably understand that you cannot have somebody medically terminated. They probably understand some of the basics. But as I said—I am probably saying something controversial—there are certain clinical interventions which are probably designed to assist the process by not taking them; medical.

Hon ROBIN CHAPPLE: In relation to family carers, quite often a lot of people want to be at home in the last days of their lives but often their partner or the person who is the carer is themselves not particularly up to speed or competent enough or healthy enough to assist. How does Silver Chain then pick up that slack, so to speak?

Mr COATES: It just depends on the availability of services and the needs that they have assessed for that client rather than the family, because the assessment is more about the client than the family

which is an issue in itself. Perhaps part of the assessment should be the capability of the family around them. I think when they are delivering services they see what is going on in the home and see where they might be required to do more than in other circumstances. Whether they are always able to pick up all of what is required is probably unlikely, because it depends on the circumstances—you have described the extent of support and help. The problem is that you have a lot of conflict in choices and emotions going on here. If a person says, “I want to die in the home”, that has an impact on the family. If the family is very limited or there is one person at home who themselves has a number of disabilities or issues that they are trying to deal with—healthcare issues—then that person does not get given that choice, do they? The choice is often focused on the client who needed palliative care without necessarily—and sometimes then legally, emotionally or psychologically that choice is taken away from the people providing the care in the home. I think what would be good in these circumstances—again a way to improve services—might be, yes, to provide support to them, but it is providing support to the person in the home; whether that is emotional—dare I use the word “respite”—a bit of in-home respite, people sitting overnight with their loved family member as a sort of night-watch person who is there enabling the family member to get some sleep and that sort of thing.

Hon ROBIN CHAPPLE: I am not sure whether it is something you might be able to address, but when it comes to the provision of services, whether it be a hospital, hospice or at home through Silver Chain, the funding from all those comes from different areas. Is there any analysis carried out as to cost effectiveness of looking after somebody at home versus in a hospice or a hospital? Is any of that known?

Mr COATES: There is, and the people talk to would be Silver Chain. They have done an analysis of the cost of someone dying in the home compared to in medical facilities. I think they came up with about \$6 000 or \$7 000, but have a chat with Silver Chain. Ask them for that research. Chris McGowan is the CEO.

The CHAIR: Do you think the current laws are too constraining on health professionals providing palliative care?

Mr COATES: It would be a personal opinion, and my personal opinion is probably yes. Having been through this sort of situation three times, I have a certain view of life. My view of life is that it gets to a point where the quality of life is so minimal, and if you know the person well and love the person you would have knowledge of their wishes that there were medical interventions you can do to alleviate that suffering.

The CHAIR: I am going to go to an area I think you have alluded to, which is terminal sedation and the doctrine of double effect. Do you think the practice of terminal sedation is well understood by carers?

Mr COATES: No.

The CHAIR: What do you think needs to be done to improve that?

Mr COATES: I guess it is a bit of what I was saying earlier about how you have to look at the family and see who is in that family—if anybody—who is able to deal with and have an understanding of these processes, and then making sure that family member who has that capability has the right sort of education in processes. Then it would be for that family or family members to manage that process with the rest of the members of the family. I do not think a big training of a —

The CHAIR: No.

Mr COATES: — is the way to go. It is identifying who has the strength and understanding of it.

The CHAIR: In trying to flesh out the experience of the primary carer, if you like, when we get to that point of end-of-life treatment would the doctor generally fully explain if they were going to use a level of opioids that would that potentially put them into a state of sleep or unconsciousness and that was likely to be their last conscious moment? Is that well understood by carers at that time, do you think?

Mr COATES: I cannot answer categorically because I have not had a lot of people come back on this. I can only go from personal experience and some odd anecdotal experiences. Certainly in my personal experience I developed a relationship with the clinicians—these are district nurse clinicians—and we developed an understanding, so things did not have to be said directly to understand what was happening. It is developing that relationship. It is not a blunt instrument, in my view. It is not, “Well, here you are. Here’s what’s going to happen. Terminal sedation means you are going to do this”, and bang, that is it. It is developing a relationship and understanding first. It does take a bit of time in coming to that knowledge. No-one told me directly, but there was enough in the relationship to know what was going on.

[9.40 am]

The CHAIR: Are there any more questions on this topic?

Hon NICK GOIRAN: Which topic are we on?

The CHAIR: Sorry; we skipped to the terminal sedation section. I am going to go back to refusal of medical treatment. Do you think carers understand the laws and arrangements around individuals refusing medical treatment?

Mr COATES: No, there probably needs to be more clarity in that. There are instances where, as I say, certain medical intervention has been documented as not being wanted, but then the individual finds themselves, from an acute episode, in a medical facility and what was the wishes was actually delivered to try and make that patient more comfortable.

The CHAIR: Sorry; could you just elaborate on that?

Mr COATES: Yes. So, you have refusal of medical intervention. Even when people have it documented that in certain circumstances they do not want this or that, if something happens to that individual that is acute—it could be a bee sting or something—and they get rushed into hospital, elements of that treatment could be exactly what is documented as they do not want. There are cases that have come to me of that. So, no, I do not think it is fully understood, and even when it is understood and documented, circumstances may prevent that being followed through. I feel for the medical profession. They have certain principles like the Hippocratic oath and all that sort of thing. I think there is a need to have a clear set of circumstances and guidance for them to be able to operate within. They are in a real rock and a hard place with some of these things.

Hon ROBIN CHAPPLE: Can I just go back to palliative care in the regions. I have worked with a lot of Aboriginal communities. One of the issues that crops up is that people want to be on country, but there is a little or no Silver Chain service. Jigalong has one visit a week for 16 patients. There is, from a health perspective, a requirement to provide better services, and usually that entails taking people out of community. I am wondering, again—sorry—if there has been any analysis of whether it is socially better to take people down to Perth and put them in a hospice or whatever else, rather than on their community and the provision of the services. We have had in Jigalong a lady called Fannie who devoted her time in her retirement to use her pension to go out there and help people. Eventually, that service was taken away and Silver Chain had to provide a service, which meant they had to come from Newman and it was one day a week, as I say, for 14 people. I am just wondering if there has been any analysis at all of whether, cost effectiveness or socially, there is a better way.

Mr COATES: Going back to Silver Chain—you have probably already talked with them—but there is analysis about the cost: what it costs and how it is cheaper in the home than it is in medical facilities. That is probably a self-evident thing. What you described there is a whole range of issues. There is the culture thing. They want to die on country. You said, “Is there any analysis of any social benefit?” No; none that I know of. It would be a very difficult thing to analyse, because you take someone out of country against what might be their cultural wishes, but you might have a better medical result. But whether the social impact of that better medical result is better as a result, if all these wishes and the wishes of family have been disregarded, how do you measure that? How do you know?

Hon ROBIN CHAPPLE: Again, proffering some commentary, quite often people in Aboriginal communities have been taken off country. That is almost akin to having the bone pointed at you, so you actually fall away quite quickly because you are not on country. So it actually has a double effect. Have you had any experience of that?

Mr COATES: No, I have not, and I would not be able to point to any sort of studies into that. It sounds as though you have. I certainly have not. I just know that when people are in those situations, they can go downhill quite quickly, maybe from a psychological perspective. But if the end intervention is, from a pure clinical, medical thing, a better result, who is right and who is wrong? I am not sure how a study can get that. What you would have is a study that says, “This is the impact, emotional and otherwise, on the family, but here is the clinical impact that we have now solved, or we have made the person more comfortable.” You are analysing two different outcomes.

Hon Dr SALLY TALBOT: Mr Coates, you obviously bring a unique perspective to these issues, both in a personal sense and the work that you do through the organisation. Can I just take you back to some points you made earlier about the fact that people who have a terminal diagnosis and their families are often not aware—maybe they have been not comfortable to think about palliative care or maybe it is just a lack of information. Can I ask you whether in the metropolitan area you would be of the view that there are some services that are not being utilised because the community does not understand that they are there?

Mr COATES: It is hard to do studies of what is not being utilised because you do not know the circumstances. I think there are services that provide support to families, that we provide as an organisation. Certain families may not be aware of our services or might not be of the mentality to utilise the services. I do not know. Emotional counselling and emotional support is an example. Not everyone wants counselling or emotional support. When you get into the country, they tend to want it less because of the mentality of people in the country. They may not access because they do not feel they want or need it, or they are not aware of it—they do not know that they can get free counselling with our organisation, for example; there is no cost to it per se. Equally, although a particular carer may feel that they do not need it, there may be other family members who do need it, but whether that family member is sharp enough to identify that and then find a service and access to the services is probably unusual at best. I think family only access the support-type services—the information, emotional but even the limited respite things that are around—if they are in the know. I think there is a whole lot of people who are either not aware or not interested in accessing those services.

Hon Dr SALLY TALBOT: If we rolled out some sort of education and awareness program and if there was the kind of cultural change that made people more comfortable to do this kind of planning, what would be the mismatch between the demand and the available resources? Would there be a mismatch? That is really my question.

Mr COATES: Probably, yes. There probably would be, but it is all guesswork. On this palliative care group I am talking about now, they are talking about an awareness program. That is fine on one

level, but they tend to hit the broader community. The broader community will not be thinking about that unless they are in that situation. That is how life is. My concept of awareness is better training for those clinicians who interact—who go to the home. If you are a nurse or a doctor, you are going to go there, you are going to look at the patient and you are going to try to do all you can to make that patient comfortable. The family and that is secondary. Some may then look at the needs of the family and accessing services and may possibly refer them to them, but it is all about the training of that clinician in there. It might be something as simple as identifying that the primary carer is looking totally emotionally drained and physically on the edge and saying, “Do you know these services are available? I feel you need a bit of support. You need to give this number a ring and see what they can do for you.”

Hon Dr SALLY TALBOT: I purposely framed my question in terms of the metropolitan area, because you have already drawn the distinction between metro and non-metro. What do you think the situation is in regional places?

[9.50 am]

Mr COATES: The same as with clinical services. There is stuff around but a lot less of it. We as an organisation—we are based in the metropolitan area—do regional visits. There is stuff online you can do as well. In a regional area, if someone just needs somebody to talk to, it could be a telephone counselling service. I say “counselling” in the broadest sense, or even emailing counselling. There is stuff you can do from a distance, certainly from the emotional side of things. The more physical practical supports like respite, which is becoming less and less available around the state anyway and probably even less in the regional areas rather than the metropolitan, is the area that needs addressing. It is having that person able to sit with the person overnight in palliative care to give somebody a better night’s sleep.

Hon COLIN HOLT: You have probably almost answered my question. You mentioned a free counselling service. My question was around how far that reaches and what is the gap in that reach from your perspective?

Mr COATES: We are in a modern world so as long as you can get NBN or whatever it is out there now and get connection, you can do email counselling, which suits some people because some people do not want to talk directly to someone because it triggers more emotions or when they have a break, they can offload. It could be an offloading; it is not a clinical thing necessarily. That can be email or telephone counselling. We do regional visits as well—groups. Sometimes groups come together. That impacts as well because then they meet people in similar situations, just like going to an education awareness raising event. We might do some regional things there. There are all sorts of organisations around in regional areas. I guess my view of what we need to do is to be less siloed. There might be an area where there is a really good mental health provider and really good people there but not an aged care or chronic illness and not for profit, for example.

What I have done in the past—I could give an example in Esperance. There was a mental health provider. They were employing somebody for three days a week. I said, “Why don’t we pal together and I’ll pay for two days a week, so for three days a week you can do the mental health thing that you want to do because you’re a mental health organisation; the other two days a week, that person can support families who are non-mental health.” Perhaps a bit less of a siloed place: use what you have got there but do not just say, “They get Mental Health Commission funding, that’s all they can do”; or the mental health contract might say, “You can only deal with clients who have mental health issues and they are your numbers and that is what you are reporting back.” The fund has been a bit more open to saying, “Although we’re funding the contract for a mental health service, if you

happen to be providing for people with other issues, chronic illness and stuff like that, that's fine as well."

The CHAIR: I just want to go back to the area of sedation. We talked a bit about the information. A family is required to provide consent for doctors to increase the amounts of pain-relieving medications which may cause death?

Mr COATES: Yes.

The CHAIR: Are a family and carer ever responsible for administering opioids or other sedating medications?

Mr COATES: Not that I am aware of legally.

Hon ROBIN CHAPPLE: Just on that, we have obviously just lost the partner of one of our colleagues. She was provided with a wide range of medication, which through training she administering during her partner's last days of life. I do not know whether any of those were opioids but there were many different medications. At what level are carers provided with medication? I am really asking: on what authority do they administer the various drugs to help nausea, to help a range of issues, that their partner is going through?

Mr COATES: I guess in my situation, there are actually a lot of drugs in the house; in the case of my sister, OxyContin and all sorts of stuff. It was quite accessible. Whether there is any legal right to do it, rightly or wrongly, in that situation in the UK, there was a lot of medication around. If you wanted to administer that, you could. I would give those sort of medications to my sister but I thought you were thinking more —

Hon ROBIN CHAPPLE: I am just wondering if there was any parameter of what medications can be provided.

Mr COATES: It is a bit like stuff over the counter, saying, "You can only have this amount this frequently." Some of that will be left with families to do.

The CHAIR: My question was more related to morphine and opiates.

Hon ROBIN CHAPPLE: I just did not know what the line was.

Mr COATES: OxyContin is pretty full-on. There were several packets of those in the drawer with my sister.

Mr J.E. McGRATH: So you are not aware of any situations in which families or carers have administered medications for pain relief with the knowledge that it could hasten death?

Mr COATES: I am not aware.

The CHAIR: Are there any other questions for the witness?

Hon ROBIN CHAPPLE: Just on end of life and refusal of medical treatment. Obviously, that might be an advance care directive but if a patient, either in hospice or at home or wherever, says, "I do not want any", what checks and balances are carried out into the mental state of a person saying, "I don't want any further medication" and at what level do the healthcare professionals have to take that on board?

Mr COATES: I think it is a quiet understanding that when the directives are drawn up that the person is of a sound mental state. Ultimately, the clinician can override these things for medical reasons, and do, either knowingly or not, and they can give a medical reason for doing that. It is not black and white, given.

Hon ROBIN CHAPPLE: And that would all be recorded?

Mr COATES: What the clinician has done?

Hon ROBIN CHAPPLE: Yes.

Mr COATES: I would assume so in that case, and the reasons why. That is assuming that they have the document that outlines all these things available to them anyway, which is a big assumption.

Mr J.E. McGRATH: You would support the system in which only the clinician can administer anything near the end of life for someone, whereas in some jurisdictions, I think the patients themselves have been able to carry it out when they have had the treatments prescribed for them and they can do it themselves, something that I have always had difficulty with. Do you think it should be the clinician or in some cases could it be left to a carer or the person themselves?

Mr COATES: I think there is a legal and a moral element to this. Some pretty powerful drugs get put into the home and permission is given to use those for pain relief. OxyContin is an example of that in my case. It is potentially available there anyway. It might not be as direct as an intravenous opioid overdose but it has the same effect. The moral question is whether people should be allowed to do that themselves for a specific purpose; that is what we are coming to. It is not with a clear answer, to be honest with you. It is a grey area. My personal opinion is—this is a personal opinion from experience as a family member—it gets to a point in some of these processes, there is no doubt that there will be an end but whether it will in a week or two weeks or three weeks, there is doubt and there is zero quality of life and the impact it is having on the family is quite severe mentally and otherwise. It becomes a sort of extension. The question of whether you would give those rights, medical administration of drugs there, you are dealing with people who are in a very emotional state. As much as I am for that ability, you have to be very careful. I believe the system should be allowed, that they can have a conversation with a qualified medical practitioner about where you are in the process and what options are available to you to make that process end in the best way for everybody concerned. I think you can have the power in the medical thing but you have to give them the freedom to be able to go down certain pathways that are best for everybody concerned, including the person who is coming to the end of their life.

The CHAIR: Thank you for your evidence before the committee today. The 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. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence.

Thank you very much, Mr Coates.

Hearing concluded at 10.00 am
