

JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
THURSDAY, 14 DECEMBER 2017**

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 1.21 pm

Professor KEITH EVANS

Chief Advisor, Public Policy, Silver Chain Group, examined:

Mr MARK COCKAYNE

General Manager, Health Care WA, Silver Chain Group, 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-Jane Sanderson, I am the Chair of the joint select committee. We have Hon Dr Sally Talbot, MLC; Reece Whitby, MLA; Dr Jeannine Purdy, our principal research officer; Simon Millman, MLA; Hon Colin Holt, MLC; Hon Nick Goiran, MLC; and Hon Robin Chapple, MLC, who will be joining us very shortly. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and to highlight any gaps that might 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 may say outside of these proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Would you please introduce yourselves for the record?

Prof. EVANS: Thank you for the invitation to be here. My name is Professor Keith Evans. I have the role as the group adviser, public policy with Silver Chain Group. I am based in Adelaide but am a member of the group executive of the organisation and I have a conjoint appointment with the University of Adelaide in the School of Public Health. My background is as a psychologist and a registered psychiatric and general nurse with the speciality in palliative and end-of-care work.

Mr COCKAYNE: I am currently the general manager of our healthcare services for Silver Chain in Western Australia, which incorporates a range of services, including palliative care. I moved to Western Australia seven years ago. My background is in nursing as well; I am a registered nurse. I have predominantly worked in oncology and palliative care for probably the last 25 years.

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

The WITNESSES: No, thank you.

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

Prof. EVANS: Just very briefly. Silver Chain Group here in Western Australia, in Perth in particular, has been responsible for the community-based approach to palliative care for something over 32 years, so a decision was made—a decision not made by other states—by the government of the day to provide its major focus in terms of end-of-life or palliative care as wards in the community setting. So we have a unique experiment, if you will, of a significant proportion, something like 3 000 people a year, who are being cared for in the community at the end of life, so in their own homes within the community. There is a very significant contribution that we can make from the data collected over all that time in terms of personal preference. We know that approximately 80 per cent of people when asked will identify home as their preferred place of choice of death. We know that, nationally, we get nowhere near that figure for people at the end of their lives. What we know within the context of our program is that, of those people who enter the program and say, "Our preference is to die at home", something like 80 to 85 per cent achieve that goal. Just recently, the state of New South Wales has asked us to replicate the program that you have here in Perth for

Western Sydney, which is about the second or third largest health district there. The decision was taken by the government to say, “We want to apply a similar model in that place because we feel that what you have in Perth is something that we believe we should have for the people of Sydney.” So it is a trial under what is called a social investment bond by Treasury, but that trial is now underway, so there is some significant interest in transference of the program out.

I think the only other point I would make is that one of the things that, certainly for me, denotes the success of what happens within the Perth environment is the level of interaction or coordination of effort between the government as funder, Silver Chain as provider and the panoply of other programs that sit out there. There is a very strong connection point. The other thing is the ability to deliver 24-hour, seven-day-a-week medically led, nursing led in many instances. The capacity to employ people across the spectrum, including care workers and others, really does mark out the difference between what you have here in Perth and what I experience in Adelaide and Sydney.

The CHAIR: Can we talk about advance care planning first. I understand you have had our questions sent?

Prof. EVANS: Yes.

The CHAIR: Do you want to address us on this topic in relation to the questions?

Prof. EVANS: What we thought we might do, with your forbearance, is that Mark, as the expert in the area and has been managing the program here, will address most of the technical descriptions of what we do, and where I feel I can add value, I will, but I suspect that that will not be in very many places.

The CHAIR: That sounds fine.

Mr COCKAYNE: Although Keith might be surprised!

In terms of advance health directives, a number of the questions talk about training of workers. Social workers as part of our team are probably the key resource within our multidisciplinary team who take a real lead in this space in terms of advance care planning, advance health directives and enduring powers of guardianship. We really work in a team model from that perspective. They take a lead in this space.

As part of our admission process, one of the things we do is talk to people about whether they have an advance health directive in place. That then really helps to inform their care plan that we have as part of our service. We also have quite a discussion about their preferred place of care and preferred place of death, which is important in terms of establishing the context of the care and the goals for each individual as well, which are really important. That is something we also record within our data system and that we will update at various points in time, depending on what the goals of the care of the client are as well, just so that we are all very clear about their preference to be cared for at home and whether dying at home is actually what they want to do and what they want to achieve.

As I mentioned, we also note advance health care directives. Where a person does not have an advance health directive in place, we provide information. All our nurses and our staff will have various written materials that we are able to provide to people as well. We will talk to them about that. Many people want to go away and think about it and have conversations with their family. We will also support and facilitate a conversation with them to put an advance health directive in place if that is what they so choose.

[1.30 pm]

The other thing for us in terms of the context of our service is that we provide a service to people, on average, for less than three months. So I think it is an important thing, because when we have looked at our data, we know that 40 per cent of the people we will admit to our service over the course of a year are with us for only one month from admission through to death. In terms of the context of an advance health directive, I think one of the most important things is that, probably in terms of our services, that requirement to have this in place prior to them getting to us is something that is really important. We will put it in place for some people, because there will be some people we will admit to our services who we will have, they will become stable, we will actually discharge them from the service, they will be supported by their general practitioner or others within the community, and they might come back and re-enter our services perhaps a number of months or a year or so down the track. So having an advance health directive in place perhaps prior to entering palliative care is really, really important and, in fact, may be one of the real enablers to actually supporting people to access palliative care services much sooner than they currently are.

The CHAIR: Can I just clarify: when you say “our people” talk to clients about advance health care directives, who specifically would do that?

Mr COCKAYNE: It would predominantly be social workers, our nurses and doctor or medical staff as a part of the team. With our medical staff, we have a range of medical staff. We have palliative care medicine consultants. We also have registrars and residents, because we provide junior doctor education and training through the service. We also have GPs. Again, in terms of what Keith was talking about, it is really one of the strengths in terms of the model that is very different and differentiates it from a lot of the other states, where we have around about 30 general practitioners who are employed by the organisation and work as part of a team environment across the whole of metropolitan Perth.

The CHAIR: Are they specifically trained in advance care planning?

Mr COCKAYNE: In terms of formal education within Silver Chain, no.

Hon Dr SALLY TALBOT: Are they specifically trained for palliative care provision?

Mr COCKAYNE: The doctors? Yes, absolutely. The palliative medicine physicians have done further training—postgraduate training—in palliative medicine. For many of the general practitioners, we have training modules for our doctors that they go through as well, but most of the doctors we have in our service have probably been there on average for around about 20 or 25 years and have lots of experience.

Hon NICK GOIRAN: I think I heard you say that there are 30 GPs working across the metropolitan area.

Mr COCKAYNE: That is right.

Hon NICK GOIRAN: Silver Chain also operates outside the metropolitan area.

Mr COCKAYNE: We do.

Hon NICK GOIRAN: So there are no GPs outside the metro —

Mr COCKAYNE: No. The contract for palliative care service provision with the department is a metro-based contract. You are right; Silver Chain provides services across all other regions in Western Australia, but we do not have a contract for palliative care service provision across any of those other regions. WACHS has primary responsibility in terms of palliative care services. There was a recent tender for palliative care services in the great southern. We have tendered for that and we are awaiting the outcome of that. There are some other smaller providers and of course the palliative care network, and I think you have had Amanda Bolleter here in the past couple of days.

The palliative care network also supports palliative care nurse coordinator roles in each of those regions.

Hon ROBIN CHAPPLE: I know that you were servicing Jigalong for a while. Are you still doing that?

Mr COCKAYNE: I think in terms of social care services; I do not believe for healthcare services. We are providing aged-care services, personal care, home help and those types of services, I think, in that area.

Hon Dr SALLY TALBOT: This might be the place to ask about the palliative care training of other staff, as well as doctors—so, your nurses and your social workers. You might need to take that on notice, but could we have some idea about how many of them have specific training and/or qualifications?

Mr COCKAYNE: That would be great. We can certainly come back to you in terms of numbers. I can talk broadly about our approach, because we do have a number of staff that obviously have postgraduate qualifications in terms of nurses or social workers or our allied health staff specifically in palliative care. What we also do is encourage people through clinical scholarships with the organisation. Not everyone does of course, but some might be at a postgraduate qualification and others to a master's level, and even nurse practitioners within palliative care. But we can certainly take that on notice and provide the number.

The CHAIR: Do you think there is a need for more community education about advance health care directives and EPGs?

Prof. EVANS: To start off that response, the general answer, which is a bit trite, is there is never enough education. One of the measures that I have of assessing the intrusion of an organisation into its community is to ask the taxidriver and others that I meet when I fly into Perth every second week. There is an enormous amount of understanding of Silver Chain within this community because most people have been touched by it in some way, not always of course by its palliative care programs, but by its wound care and by Hospital in the Home and so on. There is an enormous level of understanding, and there is an understanding that we do deliver end-of-life care. I think part of the difficulty is that because of the complexities that occur, there is often not an understanding of what palliative care is and is not, and what it can and cannot do, and also, as there is more discussion about the legal frameworks around end of life and assisted dying and so on, there is certainly, I think, an educative piece of work that needs to be done to help people to understand that. There is a view amongst some people that palliative care is almost like a medical intervention, when it really is a program. It is a system around which you manage people for whom curative medicine is simply not an option. But it is a system of care. It is not like asking the question: does palliative care work? It is less focused than asking the question, "Does methadone work for drug addicts?", where we can show that there is a direct line. The palliative care program wraps around people at a range of different levels and, as a whole, is difficult to be able to focus in and say, "Does it work?", unless you ask the prior question which is: to what end does it work? Does it work to give people a good death? Does it work for people who wish to be pain free? And so on and so forth.

The CHAIR: My question is specifically related to advance health care directives. Do you think that there is generally a good understanding in the community around AHDs?

Mr COCKAYNE: I think there is a reasonable understanding—I think an increasing one. For most, there is still a sense of advance health directives being required as you age, yet many of the people we see—probably one-third of the people we are seeing—are under 65. We will see children from as young as one day of age. There are many people in their 20s and 30s with life-threatening illnesses. I certainly believe that there needs to be more education about what it is. It is not just about planning for end of life because it is imminent; it is actually about what the goals are for your

life and what you want your care to be. As I mentioned earlier, I think it will be and is increasingly a greater enabler in terms of access to palliative care simply because people have had the conversation with their family, are very clear about what they want in regards to goals of care and their treatment, and then are more amenable to having that conversation with their general practitioner and others. Referral to our service is really the gateway, so it then relies upon the general practitioner or the hospital or whoever to believe that this person actually needs referral to palliative care. I think the more that individuals can initiate that conversation and initiate then a referral, the better it will be for everybody.

The CHAIR: Do you think the system would be improved with a central register of advance health care directives and EPGs?

Mr COCKAYNE: Yes, we do, and I think the My Health Record obviously we would see as being the predominant repository for that. Clearly, that is going to require some significant changes. We are grappling with it internally in Silver Chain as well as to how we are going to integrate and work with the My Health Record ourselves, but clearly that seems to be the predominant repository. But it then requires all people working in health care to actually link with it, access and share information in that space, and be disciplined and diligent in going there and understanding what people's needs are.

Prof. EVANS: One of the issues with My Health Record has been historically the debate about is it opt in or opt out. Now that it is an opt-out model from mid-2018 or so, it makes it much easier for us.

Hon NICK GOIRAN: We were told this morning that the opt out kicks in on 1 January. I think the evidence was effectively that that will quite radically change the benefit of it, because there will actually be some significant volume of patients and so forth. At the moment, does Silver Chain have access to My Health Record if it wants to?

Mr COCKAYNE: We do. I think we were a trial site going back two years ago for our software, which is ComCare, which is our enterprise system across the organisation, so it has the ability to interface with My Health Record, yes.

[1.40 pm]

Hon NICK GOIRAN: So if a Western Australian that you might be engaging with in their home in the metropolitan area has an advance health directive and it is registered on My Health Record, you would know about it.

Mr COCKAYNE: We should, yes, in the future. We are certainly not in that space at the moment where we are accessing the My Health Record of individual clients at the moment.

Hon NICK GOIRAN: You are not?

Mr COCKAYNE: No, not at the moment.

Hon NICK GOIRAN: But did you not say you were part of a pilot program.

Mr COCKAYNE: We were. The systems are set up for us to be able to do that, and we are working through how we are actually going to go about implementing that. We can access information through the My Health Record; that is one way. Obviously, there is a whole lot of procedure around consent and all those types of things to be able to do so. The question for us internally is about what we share within that system. It needs to be a two-way process if it is going to be really meaningful. It is about how do we then share what we currently have perhaps as paper-based records. We have a number of electronic records. We still have some paper-based records like a care plan that may

be in the home. How do we meaningfully go about sharing that information into the My Health Record, which has great implications for then the GP and others as part of that team?

Hon NICK GOIRAN: I am just not 100 per cent clear. We are not at 1 January yet. If you went into somebody's home this afternoon and they had an advance health care directive, because it is an opt-in system at the moment, if they were on My Health Record and if their AHD was on there, would you be able to access it today?

Mr COCKAYNE: Yes, we can access it, but we do not. What we do is we ask the questions as part of our admission process. We document that then as part of the care plan. If the person wants to share their advance health directive directly with us, we will keep that as part of our records as well.

Hon ROBIN CHAPPLE: Just on that, after 1 January, and the program gets up and running, how does it interface with your dataset? Jane Grey is going to be under your administration. Does her name going into your system flag My Health Record?

Mr COCKAYNE: I believe so. I can certainly have a conversation with our IT people, but that is my understanding. There is a flag in the system so that when we admit someone, it then pops up an alert on our system that recognises that this person has a My Health Record, it looks at those three points of identification and, based on that, we can then go into that My Health Record, as long as we have consent.

Hon ROBIN CHAPPLE: So it is not a manual process.

Mr COCKAYNE: No.

Hon ROBIN CHAPPLE: That is good.

The CHAIR: With the committee's permission, I am going to go straight to Silver Chain's provision of palliative care in WA, and we may get back to the broader palliative care questions. What are the challenges facing Silver Chain in the provision of palliative care?

Mr COCKAYNE: I think there are a number of challenges. Obviously, as a provider that works across both metro and country, clearly the provision of a palliative care service across country provides a great number of challenges for us. Whilst we have nurses on the ground in a number of places across country, rural and remote, we predominantly have a generalist workforce. So we might be fortunate on occasions to have people with specific palliative care skills, and we will obviously always look for that, but we do not have a particular contract to provide palliative care in those spaces, so that presents challenges. The challenge of workforce, both metro and country, and just recruiting the right people increasingly is a real challenge—people with the right experience and the right skills.

A key challenge for us is really around resource and demand management. We are provided with a contract where we provide services across all of metro Perth for palliative care. On any given day the team is constantly making decisions. We have enormous numbers of people being referred to the service—on average about 3 000 people a year, so large numbers of people being referred. Obviously, in terms of the resources you are provided with, they enable you to employ a large team of people that can adequately support, on any given day, around about 650 clients. There is a fine balance in just trying to manage that load, so one of the things in terms of demand management is really assessing, ongoing, the needs of individual people, and it might be that people come with us for a period of time; it might be a couple of months. They then become stable, so they have got no symptoms, no pain, and they are quite well controlled. We may then discharge them from our service, because we know that we have got other people who are being referred today, yesterday, who are wanting to get in and receive services. We are constantly making those decisions, and then those people would then come back to us perhaps in time. That is really just about the resources we have got. I think that, to a degree, limits our ability with regards to the numbers of people that

we might otherwise be able to take on and continue to provide support to over a longer period of time.

Prof. EVANS: If we just think in terms of numbers, there are about 16 000 deaths in Western Australia a year. We are looking after, as we have said, just under 3 000. The World Health Organization and others have looked at what is the percentage of the rest of that group that are dying, because not everybody needs palliative care. The figure would come out at around about 10 000 people who could benefit from a palliative care program—not necessarily ours, but a palliative care program. That is one of the great problems—160 000 people across Australia are dying annually, but a fraction of that number are actually able to access, so from a demand point of view and a resource point of view, you are always constrained by your capacity to spread the money as far as you can.

The CHAIR: Are you able to provide the number of palliative care clients Silver Chain has assisted over the past 10 years?

Mr COCKAYNE: Yes. It is approximately 30 000 people that we have been able to provide services to over the last 10 years.

The CHAIR: Have those numbers increased?

Mr COCKAYNE: They have, yes. Over the last 10 years there has been a steady increase year on year, and it is probably reflective of slight increases in funding, just to do with increasing numbers of people being referred to our services.

Hon NICK GOIRAN: The comment was just made that you are dealing with about 3 000 per year, and I think you said the World Health Organization indicated that there might be about 10 000 out of the 16 000 per year who would benefit from palliative care. Of course, 3 000 is just the figure for Silver Chain. A big proportion of, let us call it the missing 7 000—I am not going to use that word. In fact, it is the 7 000 who are not being handled by Silver Chain who will be dealt with by hospices, hospitals, general practitioners and others in the Western Australian community. Do we therefore have a sense as to that 7 000? Are any missing out entirely in terms of access to palliative care?

Mr COCKAYNE: I believe that there are, because they might enter an aged-care facility and perhaps not have access to the right resources in terms of palliative care services. They may go into a hospital, but that does not mean that they are being seen by a palliative care consultancy team in any way. Whilst we have very good inpatient palliative care services here in Perth, again, the number of those beds is not huge, and many people are dying in hospitals. We have consultancy services there, but not all people obviously are being surrounded or supported by palliative care services, but I would only be guessing in terms of what the quantum of that would be.

Hon NICK GOIRAN: Would you be able to refer the committee to anybody else who might know what the quantum is? Is this just one of those unknowns?

Prof. EVANS: It is. The World Health Organization generally tends to look globally rather than locally and say that between 20 and 40 per cent of people are not accessing anything, but then they are including developed and developing countries and so on. Possibly Palliative Care Australia would have a view of the percentage of people who could benefit who are not receiving access to what would be described as a comprehensive palliative care service.

Mr COCKAYNE: Is Lorna Rosenwax from Curtin University appearing at all before you? Lorna and Bev McNamara are two researchers who have done a significant amount of research in this area, particularly looking at death, and death within communities and death within hospitals in Western Australia populations using data linkage, and we have very powerful data linkage here in

Western Australia by comparison with other states. They have written prolifically on this, so I am sure that Lorna would have a real sense of that.

[1.50 pm]

The CHAIR: Can you just describe how clients are referred to Silver Chain's hospice care service?

Mr COCKAYNE: Referral to the service predominantly requires a referral from a medical practitioner, so that can be either the general practitioner, a hospital specialist or a hospital doctor or a nurse practitioner.

The CHAIR: What proportion of Silver Chain's current HCF clients who are eligible for subsidised home care and are required to make a financial contribution, receive these services on a fee-paying basis?

Mr COCKAYNE: In terms of the palliative care service we provide, there are no costs at all associated with that service. We provide a range of services as well as equipment and other things.

The CHAIR: So there is no gap?

Mr COCKAYNE: No. Well, there is no charge at all to the client in terms of the provision of palliative care services. There is no fee and there is no cost at all. We do not routinely collect the number of people that we are providing services to that might also have a home-care package, but we actually recently did an audit for a conversation with the department, and at that time—this was only about two months ago—seven per cent of all the people we were providing services to did actually have a home-care package in place. We certainly work quite hard, particularly our social workers who are part of the team, to try to get whatever resources that are out there to supplement the care that is absolutely going to be able to provide the support to enable that person to stay at home. I think one of the challenges with home-care packages, as you are probably very aware, is obviously access to those in terms of ACAT and then being on a waiting list to get a home-care package itself. When you think about our client group, the average length of stay is less than three months, and the majority of those people are not going to be able to access those services within that time frame if they do not already have them in place. So, again, the importance of advance health directives, proper planning, thinking about what people's requirements might be further down the track to ensure that they have these things in place is pretty critical.

The CHAIR: Do you provide any palliative care services on a fee-paying basis to clients?

Mr COCKAYNE: No, we do not.

The CHAIR: Just for our government contracts?

Mr COCKAYNE: That is right.

Prof. EVANS: One of the issues nationally is that the numbers of people who have been assessed as being eligible for home-care packages is far larger than the number who are able to access them, so timeliness between assessment and access is a national issue for us.

The CHAIR: Do you have any data on that?

Prof. EVANS: There is data. It is not data that we hold with respect to the palliative care component of our program, but because we are the largest provider of in-home care in Western Australia, we do have some data that—if you just pop a question to us, we will attempt to answer, but it is a significant issue.

Hon NICK GOIRAN: That data is a national one.

Prof. EVANS: Yes, but it is also broken down by state.

Hon NICK GOIRAN: Okay. So, is the problem as significant in Western Australia? It sounds like we are leading the country in this area.

Prof. EVANS: I think I would be guilty of that thing about misleading you if I was to claim that. I have to constrain myself. There are differences between different parts of Australia, but I am not sure where Western Australia sits within that difference. Western Australia has been somewhat more concerned to hold onto the programs that it had, so it has only relatively recently joined the national approach in a number of areas, including the NDIS, but if we get the request, we will try to answer that one for you.

The CHAIR: Thank you; I appreciate that. Can you set out the kind of assistance provided by Silver Chain for the carers and families of HCF patients?

Mr COCKAYNE: Yes. We provide, obviously, the medical services that I mentioned, nursing, social work, care aides, particularly in support of personal care issues, chaplains, volunteers. We provide equipment to people. Again, there is no cost associated with that, and that may extend to beds and other supportive equipment to enable people to be able to stay home. In terms of the care aid component, obviously there is a limited resource associated with that, so again that really is one of those things that is really important for us in terms of looking at support outside of that palliative care funding, like home-care packages and other supports to augment the care that is provided at home. The other area is bereavement support. When the client dies, we then provide a limited bereavement support service as well to family and carers.

The CHAIR: Many of the submissions express deep admiration and gratitude for health professionals working in palliative care. Does this work extract a cost from individuals in comparison with other areas of health care?

Prof. EVANS: If I can start the answer to that, it is very interesting that large numbers of studies have been done, whether it is looking at nurses or medical professionals, and asking which areas extract the most in terms of stress. The evidence is that palliative care is no more an area that is going to lead to concern and stress for practitioners, other than the fact that every death is stressful, and every family approaches death in a different way. We put a lot of effort into supporting our staff. People who migrate to work in this area tend to be people who have a passion to be looking after people at the end of their lives, and there will be people who come in who think that that is their passion, and discover relatively quickly that the pain and stress of the environment is not for them. As Mark was saying earlier, we have people who come in to work in this program, and work in this program over a very extensive period of time, whereas we have others who would not wish to work there.

Mr COCKAYNE: There is an element of self-selection, to a degree, so there are some people who may come and start to work as a part of the service and perhaps work out fairly quickly that it is not for them. For many people it is a lifelong pursuit. We have, I think, one of the questions about the numbers of staff who leave. It is less than three per cent in terms of turnover in our palliative care service, so it is very low. Importantly, it is really around the supports we provide that support people in their role, so it is clearly a real team approach. There are various things that we will do in support of those teams on a day-to-day basis—but the employee assistance programs and various other things that we can wrap around depending on what the individual experience has been.

The CHAIR: Are there any sites, either metro or rural, that you would recommend the committee visit?

Mr COCKAYNE: If it was to come and visit us, then there are a number of sites that we have. In terms of metro Perth, we have three predominant service delivery centres, at Jandakot, Maddington and

Kingsley, where we have discrete teams set up there that work then with our other healthcare services, like our home hospital program and other clinical services, but we would certainly welcome the committee to come and have a look at those services, and perhaps go out on the road with people and see what it is like in terms of going into people's homes and the care that is provided there, and just being able to meet and interact with the team.

The CHAIR: Great; thank you. I am going to talk a bit about limitations of palliative care. Before I do, do other members have any questions on Silver Chain specifically?

Hon NICK GOIRAN: I am interested in the challenges in rural and regional areas in providing in-home palliative care services. I think you have given us some information in respect of the challenges generally. Are you able to identify key challenges for regional and remote areas?

Mr COCKAYNE: I think for us, where we are providing palliative care for people, probably some of the challenges are really around on-call, in terms of workforce, because you have small teams based in these country areas. So, again, that often may require one or two people to share on-call for particular clients over a long period of time. That is a challenge in resourcing that and supporting those staff to be able to do that. There is the tyranny of distance, clearly, where you may have some people that might be an hour away from where that nurse is. Let us say it is three o'clock in the morning, and if they are an hour's drive, then that presents some challenges, so looking at innovative solutions like telehealth and others and having devices in people's homes where they can interact through video technology clearly helps with that, but where it is required, and you need to have a nurse in the home, then that clearly is a challenge in terms of the country.

Seven days a week, just providing services across seven days a week; palliative care is not a Monday to Friday, nine-to-five, type of work, so providing services seven days a week in geographically constrained areas is a challenge for us in terms of workforce and obviously costs associated with that as well because if we are going to do it, we are wanting to provide the right supports around that individual. We are not going to leave them in the lurch on a Saturday or Sunday.

[2.00 pm]

Hon ROBIN CHAPPLE: Just following on from that, if I may, I am really interested in the service provision to Indigenous communities and remote Indigenous communities. For example, could you provide us with some data about how many hours or days you are able to service? I have a personal interest in Jigalong, but I know there are some constraints there, and I would like to figure out what is driving those constraints. Some data around that, to me personally, would be very, very useful.

Mr COCKAYNE: We can put that on notice and we can certainly provide that to you.

Hon ROBIN CHAPPLE: Thank you.

The CHAIR: Your submission indicates that HCS care plans are proven to work within three days 97 per cent of the time for clients in the unstable phase of dying. It is the unstable phase when death is imminent?

Mr COCKAYNE: No, it is not necessarily. The unstable phases of care, in terms of the language and definitions, come through the palliative care outcomes collaborative, and we provide data on a regular basis to that, which is a national collaborative. Just in terms of that definition, an urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care or the patient experiences a rapid increase in the severity of a current problem and/or the family carers' circumstances change suddenly, impacting on patient care. It is about a change, unexpected, where the person is then unstable, so it may but does not always mean that they are approaching the last days of life or terminal phase. I think one of the important things here, then, when you look at that statistic, is that

clearly not all people enter an unstable phase of care. There are some people that may be stable, then are deteriorating in terms of their condition, and become terminal, so they may not even have an unstable phase of care. We are talking about a small subset of the whole client cohort that we provide services to that might have an unstable phase of care. Perhaps the other important thing, then, is that it is not only the client; it is also about their carers and family as well—that the unstable phase may be put in place because of the family and carers, too.

The CHAIR: Does this mean that some patients will go up to three days without significant symptom relief?

Mr COCKAYNE: In extreme cases there may be some people, but, again, it is a very small number of people for whom that would be the case—where they are still in that unstable phase, it has not been able to be resolved adequately enough to the satisfaction of the client or the healthcare professionals in providing that service—but it is a very small number.

The CHAIR: Okay, that leads me to my next question. Is palliative care 100 per cent effective for all patients?

Mr COCKAYNE: No, and I do not think anyone can provide that guarantee. It really depends on what the goals of care are for the individual in terms of—our experience would be that the majority of people do not have an expectation that all their symptoms, pain or distress is going to be taken away 100 per cent of the time.

The CHAIR: If it is not 100 per cent, are you able to put a figure on that small cohort who cannot get their symptoms under control?

Prof. EVANS: Around about two per cent. Again, if I may, being mindful of your earlier admonition about misleading, that is work that we have done fairly recently. It is not published, but it is the collective wisdom of the medical, nursing and other staff who work within our program. We have said, for instance, how many people in that area today would fit that category, and then we have extrapolated that across and assumed a similar level, so approximately two per cent of people. But it does come very significantly back to: what is the goal for the individual who comes to our program? What do you want? Does it matter to you most to be absolutely pain-free—it might to me—or does it matter to you most that you have other goals in your life that you still wish to achieve? Just as an aside, there is a very interesting piece—I cannot quite remember where I saw it—over the last 48 hours by Keneally; not Keneally the politician, Keneally the writer, who is 85 and has just written a very interesting piece about his experience of the change in his thinking about what he wants towards the end of his life. Our experience is exactly that: people change and they change often within the twinkling of an eye about what they want. So, does palliative care work? If we can match it up with what people want, absolutely.

Mr S.A. MILLMAN: Just in terms of that research that you have alluded to, is it finished, and when it is finished, would you make it public?

Prof. EVANS: That was not the intention. The intention was rather more around the case that you asked the question in your queries to us, and therefore we went out. So it is informal and I am always mindful about the difference between that and something that someone can put one's hand on one's heart for. But what we can do is attempt to get slightly more solid edges to that and we are happy to provide you with that, but it would not be our intention to publish, no.

The CHAIR: That is very helpful, thank you.

Hon NICK GOIRAN: What is the two per cent figure based on?

Mr COCKAYNE: It is really just, I think, what Keith was talking about. It is really just based on current cohort of clients on a given day, and the numbers of people who were then satisfied with that definition of where they are in an unstable phase of care beyond that period of time.

Hon NICK GOIRAN: So this is a cohort of Silver Chain?

Mr COCKAYNE: Silver Chain.

Prof. EVANS: Yes.

Hon NICK GOIRAN: Would there be a proportion of the two per cent who would benefit from seeing a palliative care specialist?

Prof. EVANS: We have palliative care specialists, so people who fit into that category are the ones most likely to be seen by our most senior physicians. However, we are very, very clear that if in our view the management of that individual is going to be better attended to in a hospital or in a different setting, then with their permission we absolutely will refer. We will either refer so that there can be some process put in place and there may be some things they can do that we cannot. The process is put in place. The person then stabilises. We will take them back. We do a lot of that, or there is a general view that that is the best place for them and we would derive no pleasure out of keeping people at home because that is our belief about where care should be delivered. We believe care should be delivered where it is going to be best for that individual.

Hon NICK GOIRAN: That is helpful. There is a proportion of the two per cent of Silver Chain clients who are deemed to be more appropriately served in another setting?

Mr COCKAYNE: Yes, absolutely. Whilst the general population, maybe 70 or 80 per cent of people, express a wish to be cared for and to die at home, there are many who do not—and if that is their choice, then that absolutely is the most appropriate thing. We are not advocating that everybody should die at home; we are trying to provide the right supports. We do know that there are a number of people who might enter this journey with Silver Chain and other palliative care providers where they may believe that they are not going to be able to die at home and, through the provision of care and respect and trust that builds in terms of provision of services with the team, that they may then change their mind because it is more a case of: “Today I’m okay. Let’s give it another 24 hours; we’ll see what tomorrow brings. Tomorrow’s okay; let’s go another day.” But for some people, absolutely, going into an in-patient palliative care unit or a hospital with a palliative care team is where they most feel comfortable and we will support that and encourage that if that is their desire.

Mr S.A. MILLMAN: Earlier today we had some evidence from a representative from the Royal Australian College of General Practitioners and one of the questions that was asked of him was: how many patients have intimated or indicated a desire to have a conversation about voluntary assisted dying or that sort of thing? Is that something that comes up with your employees, and if it does, is there some mechanism to capture that data? Is that something that is recorded?

[2.10 pm]

Prof. EVANS: We would not specifically have a system to capture that particular data. We have systems for tracking conversations with patients that are about their changed desires with regard to their needs. There would undoubtedly be data that clearly people—and as this issue of voluntary assisted suicide or dying comes up, more and more people are thinking about it and therefore there will be discussions going on. Just to be clear, it was in our submission that, as an organisation, we have had an intense look at the question on the back of what was happening in South Australia and Victoria, and the vast majority of the senior people and some of the very much frontline people within our organisation came together and we had a day where we talked through this issue. To put it in context, our view, which is supported by the board, which met last week, is that we will accept

whatever the legislative provision is in the jurisdiction in which we work, so that is the first point. We do not have a formal view as to whether it is a good idea or not a good idea. Secondly, we are palliative care program, and will continue to offer what we believe to be gold-standard palliative care to anybody who is seeking it, and that we are funded to deliver in Western Australia, in Perth. So those are two things. The third is: if somebody comes to us and says, “Notwithstanding that you are doing a good job or whatever, I still want to access this”, we will refer people to a program that is legitimately established and legally established to provide that, and we will not attempt to dissuade people who have made a firm decision that that is what they wish to do. If somebody does decide that, we will continue to provide the palliative care to that individual, alongside whatever else is happening, and we will provide the bereavement care afterwards. So that is where we are with regard to the issue generally.

Mr S.A. MILLMAN: I appreciate the submission; it was comprehensive. My question was not so much about the hypothetical as to what might happen in the future, but is there a proportion of your client population that has canvassed it with your clinical staff? That was my question.

Mr COCKAYNE: There certainly is, and it is on occasions. I am not sure of the exact numbers, so it is not a particular data point that we capture in terms of the number, but if we went back and did an audit of records, then clearly that conversation would be documented and would become then a part of the care plan in terms of the service we are providing to people as well. It often may then elicit other members as part of the team in terms of their involvement, such as it might be a social worker or the chaplain or other people to support that client as well.

Mr S.A. MILLMAN: The context in which that conversation comes up could be precipitated by myriad factors. It might be in the context of a conversation about terminal sedation or refusing hydration and nourishment and things like that.

Mr COCKAYNE: It could be; it could be at the first admission visit.

Hon Dr SALLY TALBOT: I was going to ask the same question as asked by the honourable member of the committee, so it remains to me to seek one point of clarification: in jurisdictions where voluntary assisted dying is available to people, the data suggests that by far the majority of people—I believe it is in the region of 97 per cent—end up not activating that option, so presumably those people, many of whom would be pretty literate about end-of-life choices will avail themselves of palliative care. Did I understand you to say that if the law was to change, you would not seek to become a provider of VAD services, but you would continue to provide palliative care for those people who may have in their advanced health directive or whatever mechanism is appropriate?

Prof. EVANS: Absolutely.

Hon Dr SALLY TALBOT: And then you would refer at the point where they chose to activate, for the very small cohort who choose?

Prof. EVANS: That is absolutely right, and the core issue for us is the choice of the individual. The whole of our program is designed around what is it that the individual’s choice is. You are quite right: in all those countries where there has been a change to the law, the percentages of people who indicate that they might compared to actually do take up the option is different, and it is different depending in part on the level of support people have of a palliative nature in those communities. So if you look at some of the communities where there has not been a particular focus on palliative care, you will see slightly higher rates of choosing the other option.

Hon Dr SALLY TALBOT: So your decision at this stage, recognising that by the very nature of the existing law it is a provisional decision to some extent—a theoretical decision anyway—based on a resourcing issue rather than an ideological objection to the availability of VAD?

Prof. EVANS: I do not think it is a resourcing issue for us, if I am hearing you correctly. It is not an ideological opposition to the program; it is basically saying we are established to deliver palliative care. In the context of palliative care, assisted dying is not part of the palliative care journey; it is a separate program.

Hon Dr SALLY TALBOT: A separate program, okay.

Prof. EVANS: As a separate program, we certainly would not be looking to be resourced to deliver that separate program.

Hon Dr SALLY TALBOT: Yes, okay.

Hon NICK GOIRAN: If I hear that correctly, you are saying that assisted suicide is not palliative care?

Prof. EVANS: At this point in time I think Palliative Care Australia and others would say it is a program that sits out there—it is a medical intervention that sits out there—that is not traditional palliative care. I mean, it is clearly not traditional to the palliative care service. Our services, whilst they are not curative, we do not have the aim of ending somebody's life. Nothing that we do is undertaken to hasten death. So if you take that as the divide, would that be fair?

Mr COCKAYNE: Yes, absolutely. I think perhaps importantly in terms of the position that Silver Chain has taken, it is really about not putting off people accessing palliative care services. So we hope that that will certainly continue to encourage people who want to receive palliative care services and die a normal, hopefully peaceful, death at home, and not feel as though we are going to intentionally end their life because we have that as a part of our organisation. So we have specifically said the provision of assisted death will not be something that we will do, but we will certainly respect the wishes of individuals, we will refer them to the appropriate service where that is required, but continue to provide that support for both them and their family. I think, as you mentioned, whilst many people might believe that that is the course of action they want to take, it is not as though everyone actually ends up doing that. We want to continue to provide those services around them. We do not want to separate them and then believe that you have chosen a different journey, and then feel as though we will leave you on that journey. We want to continue to provide that support.

Hon NICK GOIRAN: So are you concerned that if Silver Chain were to provide assisted suicide, it would put off clients from accessing Silver Chain in the first place?

Mr COCKAYNE: For a part of the community it may, you know. If Silver Chain was providing that service directly, then some people may connect dots and infer that actually that is what you might do, irrespective of what my wishes are.

Prof. EVANS: We have certainly heard—not in the context of Western Australia but in other work that I have been involved in—of the concerns that people have that if you put out the shingle that says we do assisted dying, that somehow people will be encouraged to take that approach. Then you get the risks of different groups of people being encouraged to that approach—people with disability, people who have dementia and so on and so forth. So there is that risk that that is what people think, but that was not the determination of our decision. It is that we are very clear of the boundaries of palliative care, we use the same model as Palliative Care Australia and palliative care physicians use globally, and that is what we are good at and we should do what we are good at.

Hon NICK GOIRAN: Yes, which was my original question: is assisted suicide part of palliative care? I think the response was something about traditional palliative care and —

Prof. EVANS: In 20 years' time people may define palliative care very differently to now, but at this point in time most people—perhaps everybody; I am not clear it would be everybody—in palliative

care would say that assisted dying is not part of it. Fundamentally, we recognise that people die—we are there with them when they die—but we do not hasten death.

Hon Dr SALLY TALBOT: Following on that line of questioning, just again seeking clarity, people who made the decision not to access palliative care services through Silver Chain because of some perceived association with a hypothetical in the future voluntary assisted dying program would clearly be mistaken, would they not?

Prof. EVANS: Yes, absolutely.

Hon Dr SALLY TALBOT: Presumably Silver Chain would incorporate that into all the information you provide to the community?

Prof. EVANS: Yes. That is what we have been reflecting on in light of the change in Victoria. We operate in Victoria—we do not operate a palliative care program there but we have a program in Victoria—and at any point in the future we might choose to look at ways in which we could deliver our palliative care service. So we have to be mindful of the law changes, and we are looking at what materials we will then need to produce in any jurisdiction in which we operate that would clarify for our potential clients and our existing clients what our position is.

Hon Dr SALLY TALBOT: I think the evidence that you have given us is very evocative in terms of emphasising the point about the choice of people who are dying. It seems to me, without wishing to put words into your mouth, that it may be that certain people choose to opt for voluntary assisted dying as one of their options as part of the ways of expanding their choice.

Prof. EVANS: Yes.

The CHAIR: I am conscious that we are on a time constraint, so I am going to move through fairly quickly some of the practices around palliative care so that we can let you go in a reasonable time frame.

One of the areas I want to go to is the practice of terminal sedation. Your submission states that Silver Chain has provided terminal sedation. Can you describe to the committee what terminal sedation is, and can the practice of terminal sedation hasten death?

Mr COCKAYNE: I guess the concept of terminal sedation—other people may call it palliative sedation—is really standard practice in palliative care. Again, it is a practice where there is significant distress or suffering of the individual that may not be fully controlled or adequately controlled. It really is at the end of life; it may be within the last 24 to 48 hours of life. We are again looking at a very small part of the client group, so, again, probably less than two per cent of all clients that terminal sedation may then apply to or palliative sedation. It is something that is also resourced differently. I think one of the key components of this in terms of identifying people who may have a terminal restlessness that may then require palliative sedation is that we also increase the resources to the family. So there may be multiple visits as well as part of that, by nurses, by doctors. Importantly, in terms of this treatment, it needs to be informed in terms of the individual, their family as well, so that people are very informed about what is happening and what the choices are for them. What the treatment can be needs to be agreed, and, clearly, one of the important things is that it is regularly evaluated as part of that course of treatment.

The CHAIR: Is the person's consent sought for terminal sedation?

Mr COCKAYNE: It will, yes, absolutely, where they are able to give consent, or it may be their next of kin.

The CHAIR: The submission states that a patient will then die of disease, starvation or dehydration. Does that mean that the actual cause of death is either the existing disease or starvation or dehydration, rather than the sedation?

Mr COCKAYNE: The cause of death, yes, will continue to be the disease itself. It is interesting in terms of the issue of starvation and dehydration. As people deteriorate, it is just a natural process in terms of their declining appetite, declining hunger, thirst—all those types of thing—where people will just gradually decrease their intake over a period of time. So in those final last couple of days, their intake might be minimal to nothing at all. So it is just a normal part of the natural process of dying.

The CHAIR: In instances where terminal sedation is administered, can that in and of itself hasten death?

Mr COCKAYNE: It may.

The CHAIR: Did members have any questions on this?

Hon ROBIN CHAPPLE: No, I think that is fine.

The CHAIR: I just want to touch on the doctrine of double effect and your understanding of what the double effect is and what medications are involved in cases where the doctrine might apply.

Mr COCKAYNE: Referring to your last question in terms of double effect and could palliative sedation hasten death, it again is in this concept of double effect where what we—importantly, the intent is to relieve distress. It is about appropriately titrating various medications, whether that be an opioid for pain, and titrating the dose at a required level that then minimises or relieves the pain, and a double effect might be that it might also decrease respirations that might have an impact on hastening death at the same time. But the intent is about relieving suffering and distress, and I think that is the most important thing.

The CHAIR: Can you just step out for me the process? So if someone is receiving home care, they will have a pump?

Mr COCKAYNE: Many will, yes, indeed.

The CHAIR: Most people would have a pump for continuous pain relief. In the instances of terminal sedation, whether it has been requested or suggested, what is the process for that? Is it not via the pump?

Mr COCKAYNE: No, it most often is by the pump. It just depends on the medications that are being used. It might be that you may require two different syringe drivers as well, simply because there may be an incompatibility of the medications being mixed in the one syringe. The syringe driver would be if the person is unable to take the medication orally, then it would normally be in a syringe driver, obviously, that would be provided, that just injects under the skin, subcutaneously, slowly a dose of—an appropriate titration of—the medications that are required.

Hon NICK GOIRAN: If the person is very agitated, I think you indicated that might be a circumstance where the sedative is needed?

Mr COCKAYNE: Yes.

Hon NICK GOIRAN: So how do you deal with that situation, if you have an agitated client and they need a needle?

Mr COCKAYNE: So it might be an individual dose that is required to get on top of that. It might be a subcutaneous administration of a particular medication that actually helps to build a level within the blood stream that actually then starts to manage some of that agitation. What you then do is

you then add that medication within the syringe driver so that it is slowly injected over a 24-hour period so that it is just keeping it at that base level that relieves the distress.

Hon NICK GOIRAN: I think I understand that. When I say agitated, I probably am also thinking of physically agitated. Could there be a circumstance where it is difficult to inject because of the physical agitation as distinguished from some form of mental or emotional agitation?

Mr COCKAYNE: Look, it could be. But I think with support, whether that be other people as a part of the team with the family, it is about administering the medication appropriately so that it has the required effect. But it could be, yes.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for the correction of minor errors. Any such corrections must be made and the transcript returned within 10 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 transcript of evidence. The committee will write to you with the questions taken on notice during the hearing. In addition, we will include the proposed questions that we were unable to address due to the time constraints. Thank you very much.

Hearing concluded at 2.28 pm
