JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

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

TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
FRIDAY, 2 MARCH 2018

SESSION FIVE

Members

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

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Hearing commenced at 2.31 pm

Mr MARK LEONARD TEALE
Chief Executive, Council on the Ageing WA (Inc), examined:

The CHAIR: On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson. I am the Chair of the joint select committee. We have with us today Hon Dr Sally Talbot, who has just stepped out and will be with us shortly; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; Reece Whitby and Hon Robin Chapple. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia and to highlight any gaps that 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 that you say outside 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 TEALE: No. Thank you.

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

Mr TEALE: If I may, just a short one. Council on the Ageing, as members may know, is the peak body in Western Australia representing the interests of older Western Australians. We do not necessarily put a number to that age. We have a very wide constituency, as you might imagine. We have about 1 800 individual members and a much, much smaller number of organisational members. We are also part of a federation of Councils on the Ageing across Australia. We have access to their information and their experiences as well as our own. We are quite a small organisation that does not receive recurrent funding. Like many other not-for-profits, it is a matter of finding money where we can to do what we do. The main part of our operation or the reason for our existence is policy work and advocacy on behalf of older Western Australians.

The CHAIR: In relation to palliative care, your submission indicated that palliative care in WA is seen as very high quality but there are issues with access. Can you elaborate on what you mean by "access and equity"?

Mr TEALE: Sure. I suppose it could be as much about gaps in the system in terms of what we are seeking to outline there; similar, I think, to other evidence that has been presented, particularly from Palliative Care WA, our colleagues in this sector. We would agree that there is potentially geographic disadvantage in terms of where people live in terms of access. There might be demographic disadvantage. That is of particular interest to us, clearly. We do have some concerns about people's ability to access specialist palliative care when they are in a residential aged-care setting. We also agree around potential diagnosis-related issues to access. Again, people with dementia can experience some difficulty accessing services. We know from our experiences that the patient or carer initiative and understanding of the system is really important. If they are aware of it and they know how to access it, that is a good thing, but often that knowledge is not there; and the difference, I suppose, between specialist palliative care and people's ability to access that versus the non-specialist palliative care.

The CHAIR: Can I just take you back to the comment you made around access to specialist palliative care in the aged-care setting.

Mr TEALE: Sure.

The CHAIR: And your concerns around that.

Mr TEALE: Our concern around that is it very much relies on the initiative and understanding of the workers within the residential aged-care facility. We are not saying that none of them know about these sorts of services, but we are concerned about the potential level of knowledge across staff within residential aged-care facilities as a whole. We see that unless that facility has a very high level of knowledge and knows how to apply that knowledge, there is much greater potential for residents to miss out on accessing services simply because it is not something that is pursued.

The CHAIR: What are the consequences for those residents?

Mr TEALE: The consequences may well be that they miss out on the sort of care they would otherwise be entitled or eligible to receive, noting of course some of the issues around access to specialist palliative care. In a situation where they do not have access to something that they otherwise should have, and where we know that specialist palliative care has generally very good outcomes for people in terms of assisting them, we can only speculate that they are missing out on something that would help them.

The CHAIR: We have seen some evidence that people diagnosed with cancer, in the terminal phase of cancer, seem to have a smoother pathway to palliative care as opposed to other degenerative illnesses and people dying of natural causes. Would you extrapolate that to aged care?

Mr TEALE: I think it is difficult to say for us on a data or evidence base. I am not sure about that. Certainly, we would defer to others with a bit more experience in direct palliative care or other areas. I think that is a bit difficult for us to comment on. Having said that, where we do see some issues arise, like in residential aged-care facilities, it lends us to think that what others are saying is probably correct.

The CHAIR: Do you agree with the view that for some people who access palliative care, interventions do not work?

Mr TEALE: To a limited extent, I think. Again, we look at what others are doing and saying, and some of the evidence around. Certainly with regard to specialist palliative care, the evidence seems to be fairly strong that that has a great benefit to people. I do not know so much in terms of general palliative care. I would say that there is always going to be a number of people for which any kind of intervention, service or support might not work. Nothing is going to be perfect 100 per cent of the time. By and large, it seems to be very effective.

The CHAIR: We have received a lot of evidence around some of the palliative care practices, including refusal of treatment, terminal sedation and palliated sedation. Have your members or their families ever raised concerns with COTA regarding these treatments?

Mr TEALE: Not substantially. That sort of information is not the medical-type information that we would generally collect. That is not really an area that we could comment on with any sort of confidence.

Mr R.R. WHITBY: I notice in your submission you talked about advance health directives. I understand you do workshops with people.

Mr TEALE: We have in the past, yes. We are not currently doing any, but we have in the past undertaken those sorts of workshops.

Mr R.R. WHITBY: The evidence we have had is that there is a very low uptake of Western Australians who bother with them. We have also heard evidence that they are very difficult to fill in.

Mr TEALE: Yes.

Mr R.R. WHITBY: What are your thoughts on overhauling the system or making it a simpler system?

[2.40 pm]

Mr TEALE: I think making it a simpler system is critical. It is a very, very difficult set of documents to complete. I reflect on my own experience, and they are tricky and the use of certain medical terminology, what it means and how to apply it in a wide range of potential scenarios I think is really difficult. In one sense, there is a really high bar. You might be engaged but then to move into actually completing documentation is very difficult, so I think a simplification of that documentation would go a long way and the use of language that is accessible to people and that people understand is absolutely critical, really, to getting a bit more uptake of that sort of documentation and those sorts of directives and planning. The other thing is community education and awareness. It is a difficult thing for people to talk about, generally, and you do not like to think about it. But we are very keen on advocating to people, "Look plan while you can. In the event that unfortunately something may happen, at least you have done something about it whilst you have been able to do so. Once it is done, you may need to revisit it, but it is there if something does happen. It is not only for your benefit but it will make a great deal of difference to your family as well."

Mr R.R. WHITBY: I think you are also a very big advocate for an electronic registry.

Mr TEALE: We are and we will look with interest to see how My Health record goes. That being introduced, I think in October this year as an opt-out system, it will be really interesting to see whether or not that has a difference in terms of access to those plans by a treating medical profession wherever a person might happen to be.

Mr R.R. WHITBY: A real interesting concept was raised in one of the hearings earlier today that we are now getting the baby-boom generation entering the senior years and I guess your organisation has seen that.

Mr TEALE: Yes.

Mr R.R. WHITBY: This generation has ruled the roost through the decades. They are all on autonomy and determining their own way. How do you see that playing out as those people reach 70-plus?

Mr TEALE: I think have you alluded to a lot of it in your question. They are certainly much more capable, if you like—willing is probably a better word—to self-advocate. There is a different generation before them that perhaps was not as willing to self-advocate and, in many ways, were grateful for the service they did receive no matter what it was. So I think you will see a greater deal of self-advocacy. You have got people who I think are more aware of their rights. There is a shift too in the medical system, I think, to start to try to wrap their heads around what it means for the person to be at the centre of the planning and the services provided. I think digital literacy in the context of access to plans, wherever a person may be, and baby boomers are generally pretty good, I think that also makes a difference, because there is a group, although getting smaller, for whom access to computers, even at what most of us would think at a very basic level, is simply not possible and it is unlikely to happen. Those things together we are going to probably see a more informed group and more access to the sorts of information that is needed in a situation that is unforeseen.

Mr J.E. McGRATH: I was shadow Minister for Seniors at one time. I got the feeling that you had a lot of self-funded retirees in your membership. Can you give us a snapshot of where your members come from? Are they pensioners?

Mr TEALE: It is a mix. There is a diversity of membership. Our membership is not age-based. It is and it is not in that you do not have to be a particular age. We do have a real mix. It is as diverse as the older Western Australian community is, really. Certainly, there often is a bit of a difference in terms of what might work for self-funded retirees around particular issues versus what might work for pensioners around particular issues. Palliative care is probably not one of those other than some aspects possibly around access to it. I would say that it is difficult for me to pin down exactly what percentages there might be, but my experience is that it is generally quite a diverse mix. We probably take more a constituency-based approach than a membership-based approach. Whilst we are very aware of our membership, at the same time we are aware there are a lot more older Western Australians out there than there are members, so we are very keen to make sure we take that sort of constituency-based approach.

The CHAIR: Going back to advance health directives, you have talked about a central register. Do families or your members ever raise concerns of health-care professionals not honouring an advance health care directive?

Mr TEALE: In a very limited way. I am talking maybe two or three stories that have been related to us. Whilst I am not making any judgement about the veracity of those stories or otherwise, it is a bit difficult for us to draw a conclusion from that. I would say from what hear, there is the potential.

The CHAIR: Do you think members are aware of the difference between an advance health plan and an advance health directive?

Mr TEALE: I would say not. I would say most people would be unaware of that. It is language you tend to wrap your head around only when you really need to and, unfortunately, that is often during a time that is very stressful anyway. No; I do not think there is. I do not even know that there is a good deal of knowledge of, say, the difference between an enduring power of attorney and an enduring power of guardianship, for example. I think all those sorts of terminology are alien to people until they have to come to grips with them and deal with them, which is why if you can get some of that sort of early education out there is really important.

The CHAIR: You said education is one way we could improve that and perhaps making the form more a little bit more user friendly. Are there any other ways we could improve the uptake of them?

Mr TEALE: Certainly community awareness more generally. I do not have evidence to inform this, but I think part of it is saying that it is not only about you as an individual because that is often easy to overlook and say, “It’s not there; it’s not there and I won’t know anyway, so it won’t matter.” But it is about your family and in many ways, it is a gift to your family if things are very clear. They do not have to think about those sorts of things during a time that is already really emotional and difficult. I think too what is really pleasing is there is starting to emerge a number of both not-for-profit and for-profit organisations that are looking at this and making some translation and interpretation between the very difficult language in forms and a much more practical stepped-out way of working your way through it. So I think that is another bit of the mix. It is not necessarily education per se; it is about equipping people with the actual tools to do it and helping them to step through the things they need to do to cover off on a range of things. That has been pleasing to see. Certainly, we like the not-for-profits in that space. Palliative care is doing some really good stuff in that space and there are others. The combination of things, particularly the tool kit, is really important.

The CHAIR: I want to go back to voluntary assisted dying. Has COTA surveyed your members on this issue?

Mr TEALE: No, we have not; not directly on voluntary assisted dying. Any sort of views we have formed have been on the basis of, if you like, anecdotal evidence that has been provided to us.

The CHAIR: By members?

Mr TEALE: Yes, exactly, and others—constituents if you like—that we may talk to.

The CHAIR: You noted, quite rightly, that you support individual choice, but with concerns around the potential for abuse and elder abuse being a significant issue in the community. If a voluntary assisted dying legislation were introduced, what protections would you like to see built into the legislation?

Mr TEALE: It is a bit of a difficult one, I guess. Our membership has a variety of users around it. Were it to be brought about, probably definition of terminology becomes really important, so that there is a common language and everyone knows exactly what is meant when a particular term is used, so we do not have any of that fuzziness and grey area that can easily pop up. That we think is fundamental.

I think also it is about clearer identification of roles and responsibilities within that: Who is responsible for what and what is the extent of their authority, if you like, or their ability to access information that might be held? How can they act on that information when they have it? What disincentives or penalties might exist for inappropriate access to or inappropriate use of that sort of information? I do not know what these safeguards particularly might be but, obviously, safeguards that ensure that any request from a patient around voluntary assisted dying is a voluntary request. It is an informed request—again that issue of informed choice—and making sure there are not any red flags or significant risks that might point to that request not being an entirely voluntary request.

Training, of course, is really important—so mandatory training for those involved and, more broadly, including in the education phase, if you like, when people are first training—and, alongside that, community education and awareness stuff to make sure that people are aware that this exists and how they can best prepare and plan for it.

We think that there may well be value in establishing then an independent body to investigate any cases that are not on the surface as they appear they should be. That is one that we would have to look at more carefully, but it is an idea that we would throw in the mix at this point in time that would help to build our knowledge around what sort of safeguards are effective and what might not be working.

[2.50 pm]

Mr R.R. WHITBY: Presumably, that body would get to be involved before any action was taken?

Mr TEALE: Absolutely; safeguards for medical professionals is one I have missed out, but that is really critical and important. We know that by far and away the majority of medical professionals are there doing the right thing under very, very difficult circumstances, so those sorts of legal safeguards for medical professionals, we believe, are also very important.

Hon NICK GOIRAN: Further to that, an independent body would only look into the matter beforehand, not afterwards?

Mr TEALE: No; I may have misled you there. I think what I am saying there is that they would only look into cases—sorry, it would be retrospective, I think, so that there could be some learning, because I think it would be difficult in the first instance for them to intervene in the particular care of an individual, because at what time and how does that get referred through would be tricky. What was more to the point was that it would be about a review to make sure that there were

learnings from, understandings from and changes made where we could see that particular risks and issues were emerging.

Hon NICK GOIRAN: In your submission you expressed extreme concern about the possibility of older people being pressured. The Chair picked up on that with respect to the issue of elder abuse. Are you able to inform the committee to what extent your organisation is involved in the current state and national initiatives around elder abuse?

Mr TEALE: We have put a submission into the state inquiry, and at a national level we are participating in the federation's approach to both—well, both on a state level in other jurisdictions where we are learning from what inquiries are occurring and what inputs they have had, and also understanding what the federal position is, if you like, from COTAA. For us, it is about really collecting evidence and data to help us improve and inform our actions in the area of elder abuse and, of course, making sure that there is, as far as possible, a harmonisation of approaches across the various state jurisdictions, because people are mobile and they travel. I think there is always the thorny issue of the definition and does it include persons of trust or does it not. I think for us it is about, "Well, let's decide and then let's go with that particular definition", knowing that there may be instances of things that occur that do not sit within that and need to be addressed. So, I think for us those are the probably the key. We take a very strong interest. We are neighbours with Advocare; they live next door to us in our building. They do a lot of individual advocacy work in this space. It is also about the relationships and partnerships we have within the sector.

Mr J.E. McGRATH: You might have covered this—I know you mentioned it. You talked about the geographic disadvantage and demographic disadvantage of people being able to get palliative care. Do you get many people coming to you saying, "Listen, I'm in a bind. I can't get into palliative care"?

Mr TEALE: We do not, to be honest; and, if we did, we would be referring them through to people like Palliative Care WA. I would not say that that is the sort of phone call we would get on a typical basis. We are far more likely to get phone calls about access to residential aged care and community-based care. I would not say we receive a lot of calls or requests for information in that space.

Mr J.E. McGRATH: Further to that, the demographic—people who are on private health cover and things like that, do you think they have greater access than people who are not?

Mr TEALE: I do not know the answer to that question around private health insurance versus public. I do not know the answer to that.

The CHAIR: In relation to the voluntary assisted dying framework, does COTA have a view on who should or should not be eligible to access VAD?

Mr TEALE: It is very difficult from a consumer-based perspective to talk about who should and should not have access. I think in an ideal world, which clearly does not exist, everyone is able to make an informed choice and that is the ideal answer. Should there be people who are not able to access? Clearly, there is, I think, with voluntary assisted dying the sort of medical condition that is at play and the condition that that person has. That obviously needs to be clearly defined. There are aspects to that that mean that if you do not have that diagnosed condition or set of conditions, then you should not be eligible. I think there has to be an awareness of a person's ability to make that informed choice. I am not sure what the answer to that is, but there may well be some people for whom voluntary assisted dying—there may need to be a higher level of testing, if you like, about that person's ability to make a truly voluntary decision. Whether that means that they should be excluded from being able to access it, I think is a really difficult one, and ideally they would not be. But I think we have to acknowledge that there are some circumstances in which it would be very difficult to ascertain whether it is voluntary or not.

The CHAIR: I am interested in your comments earlier on about the organisation's concerns about access to palliative care for people in residential aged care.

Mr TEALE: Yes.

The CHAIR: I am really quite interested in that. We have had two providers give evidence this week, who say they are part of the metropolitan palliative care service, that they access Silver Chain. If you have any further evidence, or even anecdotal or actual data, of people's access to palliative care in residential aged care, we would be very interested to receive that.

Mr TEALE: I will certainly go back and have a chat internally with staff; and, if we have any of those that we can pass on, we will certainly do so.

The CHAIR: At whatever level you can break that down, whether it is patients with dementia and Alzheimer's who are not necessarily advocating for themselves, and others, that would be very useful for the committee.

Mr TEALE: Absolutely.

Hon ROBIN CHAPPLE: You mentioned earlier on that your members had not had the discussion around end of life and voluntary assisted dying. Would that be something that you might pursue in the future?

Mr TEALE: Absolutely. Whereas I say that, what we have not done is hold particular dedicated forums. But if I look at, for example, last year, just pre–state election, we had a forum where older people came along and asked representatives of Labor, Liberal and the Greens about their approach—we invited others as well. That was an open forum for questioning. That issue of voluntary assisted dying came up probably four times in questions that were asked. We had not anticipated that, I will be honest, but neither did we want to shut that down. That was a reasonable indication of at least, if nothing else, a group of people who were extremely interested in it. It just was not one of the issues, I suppose, that came up as key in people's thinking when we asked them about the election.

Hon ROBIN CHAPPLE: When it comes to elections, that is not —

Mr TEALE: Yes, that is exactly right. I think you are right. We would be keen to do so, because certainly one of our key messages to people is to plan; plan while you can. Plan for the worst and hope for the best, really. We are aware of what else is happening, obviously. It is about partnerships. It is about making sure that we are in the right space and the right people to do it. But, certainly, that information provision is something that we hold very dear and something that we would like to pursue further. We do it in other areas and we think we could that too.

[3.00 pm]

Hon ROBIN CHAPPLE: If you were to initiate that discussion, would that be a long way in the future? I am thinking in the terms of when we are reporting.

Mr TEALE: No, I do not think so. I mean, certainly we take opportunities like that to get out there and in the first instance make sure that what we think we know we do know in terms of where people are at and then use that information to help us think about what our best response might be for the community more broadly. But what you want to do, I suppose, is harness the momentum of when the issue is out there and people are talking about it, so that is one of the things that we will take into consideration. Really, we have got to focus on a much greater level of engagement than there has been perhaps the case in the last three years.

Hon COLIN HOLT: I take your point that you are probably an advocacy organisation rather than a specific-membership organisation.

Mr TEALE: Yes.

Hon COLIN HOLT: I would assume that you have a sister organisation in Victoria?

Mr TEALE: Yes, we do.

Hon COLIN HOLT: Are there any learnings from them about what has happened, because they are obviously a bit further down the track?

Mr TEALE: Yes, they are, that is right.

Hon COLIN HOLT: What sort of lessons are there from a similar organisation to you?

Mr TEALE: I think part of what they talked about was really that issue of harnessing a moment in time. There was also clearly a range of views expressed in that debate. Part of the position of COTA Victoria and us and others is about the ability to make an informed choice, which inevitably in a way leads to supporting and enabling legislation. I think there is the opportunity for us to learn in more depth and more detail, and we have been having some discussions already with COTA Victoria around that. That is part of the beauty of being a Federation. There are other jurisdictions where this conversation is taking place. Whilst everything holds true for Western Australia, of course, it happens elsewhere. There are certain things that are common. Those are the sorts of benefits we get out of being part of it and that is why we have a conversation and chat about they have approach things.

Hon COLIN HOLT: Any lessons for us out of those conversations that you can think of?

Mr TEALE: I think one certainly is language and how language is used. It is not necessarily Victoria, but the language that can be used around this sort of conversation can be very emotive and it can be used not always in the interests of good conversation and debate. That has been one issue that has been highlighted—that is, the importance of thinking about the language that is used and how it is used. That would be one thing. I think the other is that this is in many ways quite a divisive conversation to have. People hold very strong views one way or the other. I guess we know that anyway, but I think it is important that we acknowledge that people do have, and that is okay. It is about the conversation that happens around that then and where we go. I think those are probably the ones I would reflect on—that is, those issues of how the debate is held, really, and how views are sought and respected.

Hon NICK GOIRAN: How long has COTA WA been in existence?

Mr TEALE: Since 1959 in various names and guises.

Hon NICK GOIRAN: Is there a sister council for the Northern Territory?

Mr TEALE: There is as well, yes. They have had some similar issues happening. We have not talked to NT in as much depth as we have with COTA Victoria and that is primarily due to their resourcing capacities and ours, but they are certainly another area that we can learn from and speak to.

Hon NICK GOIRAN: You are conscious of the fact that the Northern Territory have lived experience, whereas Victoria have just had legislative debate?

Mr TEALE: They have just started, yes, absolutely. I think one of the big things for the Northern Territory was the initial overturning, if you like, of their decision by the federal government, so that, I think, stung and was not well received, as you might expect. That was something that was probably critical in their journey.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If

the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your transcript of evidence. We will write to you with any questions taken on notice during the hearing. Thank you, Mr Teale.

Hearing concluded at 3.04 pm

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