

JOINT SELECT COMMITTEE ON PALLIATIVE CARE IN WESTERN AUSTRALIA



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
THURSDAY, 3 SEPTEMBER 2020**

SESSION FOUR

Members

Mr Chris Tallentire, MLA (Chair)
Hon Nick Goiran, MLC (Deputy Chair)
Mr Zak Kirkup, MLA
Mr Shane Love, MLA
Hon Kyle McGinn, MLC
Hon Alison Xamon, MLC

Hearing commenced at 1.35 pm**Mrs SHIRLEY NEWELL****Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, sworn and examined:**

The CHAIR: I will just do some introductions. On my left here is Hon Nick Goiran, deputy chair; our Hansard team here; Hon Kyle McGinn; Kimberley Ould, our advisory officer; Hon Alison Xamon; and Shane Love, member for Moore. I am Chris Tallentire, member for Thornlie and chair of the committee. Thank you very much for joining us.

Just before we begin the broadcasting, if you have any notes that you want to keep confidential, keep them flat on your table, and then they will not be picked up by the camera. Now we can begin the broadcast, if that is all right.

To start off with, would you mind introducing yourself, stating your full name and the capacity in which you appear before the committee, please?

Mrs NEWELL: My name is Shirley Newell. I am a Badimia woman from the Yamatji nation, but I am actually here representing the Aboriginal Health Council of Western Australia.

The CHAIR: Before you, you have either an oath or affirmation; if you would like to take one of those, please.

[Witness took the oath.]

The CHAIR: You have signed a document entitled “Information for Witnesses”. Have you read and understood that document?

Mrs NEWELL: Yes.

The CHAIR: Thank you. The proceedings are being recorded by Hansard and broadcast on the internet as well. Please note that the broadcast will also be available for viewing online after this hearing. Please advise us if you object to the broadcast being made available in this way.

Mrs NEWELL: That is fine.

The CHAIR: Thank you. A transcript of your evidence will be provided to you. To assist the committee and the Hansard reporters, could you please quote the full title of any document you may refer to during the course of this hearing. Please be aware of the microphone and where possible speak into it. I remind you that your transcript will be made public. If for some reason you wish to make a confidential statement during today’s proceedings, you should request that the evidence be taken in private session. If the committee grants your request, any public and media in attendance will be excluded from the hearing. Until such time as the transcript of your public evidence is finalised, it should not be made public. I advise you that publication or disclosure of the uncorrected transcript of evidence could constitute a contempt of Parliament and may mean that the material published or disclosed is not subject to parliamentary privilege.

I would like to invite you to make an opening statement and then we have a series of questions that we would like to put to you.

Mrs NEWELL: As I said, I am here representing the Aboriginal Health Council of Western Australia. We are the peak body for Aboriginal health in WA and represent 23 member services of the Aboriginal community-controlled health services throughout the state. I guess one of the documents that I will be referring to is our submission that we put to the inquiry into palliative care

in Western Australia. From an Aboriginal community-controlled health perspective, like I said, we represent the regions. In our sector¹, there are seven regions within WA. We are basically here to ensure that the Aboriginal health perspective on palliative care is heard and that the needs of the Aboriginal people related to the palliative care process are supported.

The CHAIR: Which of the ACCHSs in WA provide palliative care services?

Mrs NEWELL: Currently, it is very ad hoc. We do not actually have a palliative care service as such in the ACCHSs. It is usually at the moment run through one of the tertiary hospitals. It has gone through the Western Australian Country Health Service, and they will then contact the Aboriginal community-controlled health services if they need assistance for that. The provision² of palliative care, especially in our remote and very remote areas, is very, very poor. They have to go to one of those small hospitals within the region. They do not get the opportunity to have palliative care services provided to them at the place where they are living.

[1.40 pm]

The CHAIR: Thank you very much for that submission; it is really good. Your submission notes —

... Aboriginal people and their communities must have a clear understanding of what palliative care is, and must have the choice to receive palliative care services at home and on Country.

First, dealing with understanding about palliative care, do the AHCWA and individual health services adopt a particular definition of “palliative care”?

Mrs NEWELL: They do not. One of the big issues that we have had in the past with our ACCHSs and with Aboriginal people in general is that palliative care initially was very much, I suppose, advertised to do with cancer, so it was always like cancer and palliative care. In the Aboriginal population and the community, cancer used to be a very taboo subject, and it has taken a lot of education and a lot of work, because cancer for them meant death. If you had a palliative care service that was linked to that cancer, there was very little uptake in a lot of the regional areas, because basically it meant that if you were going to palliative care, you were dying because you have had cancer. All of those linkages that have come from that previous education around palliative care with cancer basically now need a lot more education and knowledge to change those ideas around. They do not have a clear indication of what palliative care is. Our feedback has been given that they definitely still do, a lot of the time, link it to cancer and are unaware that they can tap into palliative care services from a chronic disease perspective, such as renal disease and heart disease, which we know are very common in the Aboriginal populations, so they have not felt that.

The other thing is that because they do not have that capacity in their ACCHS at the moment, or they have not had the capability of doing that, it is very late in the process that the Aboriginal people, especially in the remote rural areas, are being inputted into palliative care. That is an issue in itself. I do not think they realise that if somebody is a renal patient and they are starting to deteriorate, it is right at that start that the palliative care program should actually be coming in and helping them and assisting them with their journey. It has very much been that their concept of it is that it is that very last, end of life, where you are either given medication to assist you with some pain relief, and that is basically how they see it in a lot of the regions still. There will be a huge lot of input to have to change that in the community. I think that is one of the things that we said in that submission, that it is not only building the capacity of the workforce et cetera in the ACCHS, but it definitely

¹ Witness correction: Should read “sector”, not “language”

² Witness correction: Availability and access is very poor, not the actual provision when it occurs.

needs to be around the education and the development of resources that are appropriate to be able to change that perspective within the populations or within the communities.

The CHAIR: Increasing that awareness in general in the population?

Mrs NEWELL: Yes, and it has to be done in a culturally appropriate way. Like I said, we have got seven regions in WA. There are over 90 language groups and dialects within the Aboriginal population. A lot of the time people think we have developed an Aboriginal resource, but unless it is really significant to that local area, and that is what the ACCHS can actually help you do, because they are in those regions and they know what the languages are of the people who they are coming to be with, so they can actually advise on that. Like I said, we often have that, that people go, “Yes, there is an Aboriginal resource”, but that is only an Aboriginal resource for one particular tribe or one particular region, and it is not actually appropriate in other regions. So, a lot of those documents for education, for end-of-life type things like your advance health directive and things like that, need to be appropriated in a way that is relevant to the regions, I guess, and in their language and in something that they can understand.

The CHAIR: Are there some examples of those misconceptions about palliative care? Have you got some examples of how that has come to your attention?

Mrs NEWELL: It was just through talking with a couple of people that I know myself. When this came up previously in palliative care, I used to work in the WA Cancer and Palliative Care Network, and we were just having a general conversation previously around things, and I was talking to a couple of people in the community and they basically said, “Oh, no, we don’t want palliative care”, and I said, “Why wouldn’t you want palliative care?”, and they said, “Because that means that you die.” I said, “It’s assistance to help you be comfortable”, and that obviously does lead to the death, but he said, “I don’t want cancer.” It is not always related to cancer. It is basically that end-of-life care to help you support yourself to be comfortable, to still maintain your dignity, to encompass all those things that are important, such as staying on country, having your family around. It is about looking after you at that end of life. It does not matter which disease you have or how you are actually going to die.

We have an ACCHS model of care that was done in WA, and it encompasses eight different elements which relate to health, and even in dying, those things need to be considered. That is your community; your family; your connection to country; your language; your physical, emotional and social wellbeing. Those sorts of elements still have to be there at the end of life, not just at the forefront of trying to fix health in a primary healthcare aspect.

The CHAIR: On page 2 of your submission you note the input that the Aboriginal Health Council has had into various inquiries and consultations, and that throughout those engagements, the health council has strongly recommended the need for the ACCHS to lead the end-of-life choices discussion with Aboriginal people. Just to know, to what extent do you see this is happening at the moment?

Mrs NEWELL: Again, at the moment, like I said, we tend to be the last person that is consulted. They will be discharged from a tertiary hospital to a smaller regional area, not actually understanding that the ACCHS would have that capability. One of the things with our ACCHS is that it does not matter what skill mix they have, they will find it and they will do what they have to do to be able to support their people on country. So, if they have to change the hours that people are working, if they have to get more equipment in, or they have to do something to be able to support a person, then they will definitely do that. However, usually they are the last people that are consulted; it is at that very last stage that they actually get to know. So that early consultation with them is really important. Through the sustainable health review, one of the big things is Aboriginal people for Aboriginal health. What we want to do is build those capacities, because at the moment we just do not get the

funding. They are still doing this. They are still supporting people in their end-of-life time, supporting families, supporting the community, and providing the cultural safety, but not actually getting funded to do it, and that takes away some other elements within the clinic at the time. Definitely building that capacity up is really, really important within the ACCHS, and they have the cultural knowledge and the cultural understanding. One of the things that all of them have recognised is that the other service providers will do cultural safety training—or some do not, but we would like them to all do cultural safety training. People think that because they have done that, they understand the culture that is there. But there is actually some very intricate cultural knowledge that is not allowed to be shared outside that community. You could have a visiting specialist or a visiting palliative care team come in, but it is not actually allowed to be discussed outside the community. So if you have ACCHS within that community, they can provide that specialist care in accordance with what their community aspect is around death and dying.

Mr R.S. LOVE: Is funding for the groups typically block funding from the federal government? Where does your funding normally come from, and does it not encompass palliative care? Is that something that you think should be addressed?

Mrs NEWELL: We think it should be addressed. We get various pots of funding from different things, depending on whether it is on the commonwealth radar or on the state radar, but as to what we actually have to do, we feel that there is nowhere near the amount of money to involve and I suppose explore more the palliative provision of care to the community at all.

In our core funding, I suppose, there are elements that you have to address, but even just things that are not taken in note is getting people trained up in those areas. The expense and the geographical locations—they do not go out to every area and do courses. Just the expense of flying somebody, especially at the moment, from those regional areas down to Perth and providing accommodation et cetera, the small amount that you get from your funding—they might say that there is a travel budget of \$1 000; well that does not even cover one person to be trained up. They really need to take into consideration the geographical locations, the remoteness and the Aboriginal health worker perspective on what it takes to actually provide that care to their family and clients.

[1.50 pm]

Mr R.S. LOVE: I have more questions for later but I have to leave now. I am just trying to explore the tie-up of WACHS's increase of funding with any increase on the ground that might have been offered to you. But I have to go for a short while. I am very sorry.

The CHAIR: We will come back to your questions.

Mr R.S. LOVE: If we have questions about that later I am sure that members can ask it then.

Mrs NEWELL: I could say something there.

Hon ALISON XAMON: You can still answer the committee, please.

Mrs NEWELL: We did actually have Steph Barrett from WACHS approach us only a couple of weeks ago to say that they had been given some funding and we were going to actually work with her to see what their model of their thinking they want to implement and how that would possibly assist us in the Aboriginal community-controlled health services as well, and what we could do to use that increased funding to assist our ACCHSs to build their capacity as well.

Hon NICK GOIRAN: Recognising that your health council is the peak body for all of the Aboriginal community-controlled health services, where in Western Australia is palliative care being provided to Aboriginal people well?

Mrs NEWELL: I would not say that it is. I suppose that is probably a very personal view. I think when they come to the city, when they come where there are services and specialists here, I would say that is very much provided well to Aboriginal people, especially in the metro where they still have access to domiciliary palliative care and they have very culturally appropriate palliative care teams. But once you leave from here out, there is in the Kimberley one palliative care team and they have an Aboriginal health worker who I am pretty sure to date is still the only one Aboriginal palliative care health worker that is trained in basically all of the state that is assisting. There is one element of the Kimberley, but she travels from one hub to all the different regions and areas. She is very stretched for that, but that does work quite well. Of course, the things that we have found obviously during COVID as well is that once you cut off one of those regions or you have a border impacted or people cannot travel into the community, there is nothing locally on the ground for them to fall back on.

Hon NICK GOIRAN: With regard to that Aboriginal health worker who is specifically trained in palliative care in the Kimberley, is there no such person in the metropolitan area?

Mrs NEWELL: In metro it tends to be the Derbarl Yerrigan Health Service that does it specifically. There is no actual person who is delegated to a palliative care team that I am aware of through the ACCHS here in Perth. I suppose because there are other organisations that are providing that in the metro, whereas in the other communities, like I said, they will pick it up. There will be somebody that is assisting people, but I do not think that they have had the funding or the availability of staff to designate one particular person to do that. There have been quite a few people that have been trained in what we call the PEPA course, which is the palliative care course. There have been quite a few health workers that have been trained in that and we have been doing that with the Cancer Council and AHCWA and they have been coming down to do that. However, when they go back, it is very much that they are supporting a palliative care person. There is not actually a palliative care program as such that they are doing, it just depends on what happens because they just do not have the funding or the capability to be able to put that person solely into that role.

Hon NICK GOIRAN: That Aboriginal health worker who is specialising in palliative care in the Kimberley, would they be working with the Kimberley Aboriginal Medical Services?

Mrs NEWELL: Yes. They come out of the Kimberley Aboriginal Medical Services and I am pretty sure they are also aligned with WACHS³. They have managed to ensure that they are notified, I suppose, when there is a patient. It is not in all areas of the Kimberley. It is very much, you know, that Broome and just out of Broome area. They will actually get notified. I think that is one of the big things that the ACCHSs have been asking through this is that we need that discharge planning for the ACCHSs to actually be involved in that straightaway. A lot of the time, like I said, they go to another smaller region or a smaller regional hospital et cetera and the ACCHSs are left out of the loop. They are never asked if they have the capacity or capability at that particular time to help this person that could go back and die on country. That is where they have done well in the sense that they do have that line into that palliative person to say, "This person is coming back. What capacity do you have to look after them or what do you do?" She is stretched. When I have talked to Kimika, she is saying that she is at capacity, basically, of providing those services.

Hon NICK GOIRAN: If we use that Kimberley example as an example of things, even if you are not comfortable describing it as "us doing it well", at least it seems like we are headed in the right direction as a minimum in the Kimberley there. What time investment would be required for an

³ Witness correction: Kimika is actually employed by the Western Australia Country Health Service (WACHS) and liaises with the Kimberley and Broome Aboriginal Medical Services regarding patients in their area.

Aboriginal health worker to then get to that standard of qualification? Is it merely doing the PEPA course or are you looking at something more than that?

Mrs NEWELL: Just from your first bit, I just want to go back to that. Although the Kimberley have got a good area, there are different regions obviously in WA and we would need to consult with them what would work best for them. Although it is a good example of how they have worked it out, I really think you need to go to each region and ask them how it would work best for them. One of the big issues, I suppose, that we have is that the Kimberley are very proactive; they get a lot of money through mining and stuff like that so they have a lot of capability. A lot of the time, people want to base everything on what the Kimberley do, and they do a great job in a lot of areas, but I think we need to just make sure that we are aware that there are other regions in WA, including right down to the south where they do not have ACCHSs in those areas. There are a lot of areas that are not covered by Aboriginal medical services or ACCHSs. I will take that back to that particular area but, yes, they do do well.

From an Aboriginal health worker perspective, once they are trained, it is a matter of, firstly, them having a vested interest so that they can be empathetic and be in that community enough to want to do the palliative carer course. But that is basically the recommendation that they say at the moment is to do the PEPA course. That is a week-long course, to be involved.

The CHAIR: I just want to check in a bit more about what is a culturally secure palliative care—what that looks like? Could you tell us a bit more detail around that?

Mrs NEWELL: Again, going back to our model of care for an ACCHS, it needs to encompass all those things that are very important to an Aboriginal person: your family; your community; your connection to language and connection to culture; your physical, emotional and social wellbeing; and your spiritual healing. All of those things need to be encompassed. We are very holistic in the way that we approach health. That is why the ACCHSs are so different than just a mainstream GP; we look at all that encompassing stuff that goes around. The involvement of family and them having the opportunity to die on country if they want to. I think there is this stereotype that everybody wants to go back to country and die and some people do not want to do that. We are making sure that people are educated to know that they have that opportunity of where they do want to die and what they want to do. Understanding from a cultural perspective the grief side of things. People will be grieving for that person obviously before they die if they are in that palliative state.

Those nuances, like I said, that each culture has things that I would not be aware of. I can only sit here as a general broad person, I am not an expert on everybody's culture that goes around, so that consultation needs to happen. For it to be culturally secure, it needs to be culturally secure for the region that it is in, for the people that that care is being provided for, and that can only come from consultation in those various regions that is appropriate for their language, is appropriate for the way that they can explain it, and put it out to their communities, and they are aware of that in the ACCHSs. They know the best way to approach their people about things. They know the best way to educate their people on what they are doing and they also know what their cultural practices are for that particular region.

[2.00 pm]

There are other elements in some cultures where if a person dies in the house, you are not allowed to go back in there, so a lot of people will not want them dying in the house because it means that they have to move house. All those types of little things that need to be gleaned out from an individual cultural perspective is what is around cultural safety. Just even having Aboriginal people present, especially one who is a local and understands the family and community, that goes way beyond a lot of things that are happening at the moment. It means a lot for them to have somebody

there who understands what they are going through, who knows their family and can support their family. I think a lot of the palliative care models, even when we talked to Stef a couple of weeks ago, it was very much like having a regional hub and they would go out to do things. That is fine with a specialist, as long as they have a contact in that community that will sit with them and provide that cultural knowledge around it. But, like I said, it will mean consultation with all those regions and not just saying, “Well, I think this is good for this region. That’s what we’re going to do as a blanket thing.” That is what cultural security basically is—that they feel comfortable with the people that they are with, that they have the cultural knowledge to be able to support them and that they make them feel safe.

The CHAIR: A couple of years ago, a parliamentary committee produced a report—the Joint Select Committee on End of Life Choices—that made recommendations around this. Have you seen any improvements since those recommendations came out—improvements over the last couple of years?

Mrs NEWELL: I could not actually say; I would have to take that on notice and ask a few other people around. Still, from a broad perspective, I do not think so. I will be honest, we are finding, from a broader perspective, a lot of non-Aboriginal companies are getting invested money to go and provide care into Aboriginal communities and that money could be used to build capacity and workforce et cetera in the regions. From a broad perspective, I would say no, but I honestly could not answer that. Is it just from a palliative care perspective?

The CHAIR: From a palliative care perspective, yes.

Mrs NEWELL: I could not honestly say that. Again, I think that the ACCHS just pick up and do what they have to do for their people. Whether that is an improvement because they have put it as a priority so they have started doing that, I could not 100 per cent honestly answer that. I would have to go back and consult with them and ask.

The CHAIR: We can take that on notice, if you want to go back and ask?

Mrs NEWELL: Yes; take it on notice.

The CHAIR: That is question on notice 1.

One submission to the committee, entitled “A Positive View on Palliative Care Service Delivery in a Remote Indigenous Community”, states that clients are encouraged to stay at home with their families for as long as they choose or when the family needs more support and care to move the client into the community care centre, which is used to deliver various services, including palliative care. The submission also describes some aspects of cultural end-of-life care as delivered in that community. Could you please provide us with a comment on that model of care including how common the model is in remote communities? Is that something you have knowledge of?

Mrs NEWELL: Again, it is basically due to the fact that the Aboriginal community-controlled health services will do what they need to do for their people. They may not have funding and they may not have expertise in the area, but they will find a way to provide that care to keep that person in the community if that is what they want to do. Like I said, a lot of time, if people have been moved out and they are put back, discharged, somewhere else, they do not necessarily have control over that. But if people are in their community, it may not be that there is a particular model, it may not be it that they have funding, but they will rally to make sure that that community basically looks after that person because that is what an Aboriginal community does.

A lot of the time, like I said, the Aboriginal community-controlled health services are running that the best way that they see fit. I would not say that that was a model of palliative care in their area

or that they have been given the expertise or the funding to do it, it is just: “We will look after our mob and we will rally around and do what we have to do to be able to look after them.”

The CHAIR: In your submission you note—you have been saying it now—that the ACCHS have varying degrees of capacity to deliver palliative care services. Can you give us a bit more of a sense of the range of capacity that is there?

Mrs NEWELL: Again, it depends on what funding they are getting and what their main core service is and how close they are to provision of services as well. Obviously, if you have in the metropolitan area or the big regional centres a palliative care team, then they would probably link in with them to provide assistance. But when they are out remotely, you do not have that opportunity. Again, it depends on what staffing they have available.

With COVID there has been a huge impact on the capacity for the ACCHS to provide care because a lot of their workforce had been FIFO, so with the hard border closures et cetera, it has obviously taken a big impact. One of the things that we have had to really look at is that we have depended on that, because we have not been able to build the capacity within the ACCHS due to funding and due to that time. Everywhere is different, depending on how your clinic is set up. There are a lot of really very small remote areas that are only single-nurse clinics or single-people clinics—that is more with WACHS. But with the actual Aboriginal community-controlled health services, it depends on what their focus and priority is, because they are community controlled. It is dependent on what that board has said is a priority for their area. That is where that other consultation would have to come in—to put that on the agenda to make sure that it is brought down from the top for the ACCHS to put in. The capacity really depends on your Aboriginal health workers, what other programs are there, their capacity to be able to train those workers, but also their capacity to have done some education in the community for those people to actually want the palliative care and demand that service, because, obviously, if they are doing that out in the community and we are getting more demand, then they would provide that service within the clinic and build that capacity more.

It is a two-way effect: if the education and the cultural—the language and the resources—are not put into educating Aboriginal people in the community, there is not going to be the demand for that service either. What they would then put as a priority, I suppose, in the ACCHS to build that capacity would depend on that. It is sort of a twofold way. I think a lot of the really big programs, like the diabetes and things like that over the years that have been well done education-wise, have then put a demand for the board and the community into the Aboriginal community-controlled health service to actually attend to that, so they have built capacity. That is how I see palliative care going the same. If we can get that education out there and if we can change those perspectives that Aboriginal people have of it being associated with cancer, that it is an end-of-life choice and that we have the capabilities, then, of course, they are going to demand it more, which will improve the capacity and the capability within the ACCHS to do.

Just at the current time, I would say it is a very individual service according to what is going on in their community. I could not say that there is a capacity throughout the whole lot to be able to do it and I would not be able to say what capacity they have in each individual service, because it really would depend on the demand of service at that time.

The CHAIR: Looking at domiciliary palliative care services, in your submission you talk about the need for that to be provided in a comprehensive way, including symptom control and end-of-life care, that it must be available to all people living in regional and remote areas. We have had another witness advise that in the East Pilbara, in-home palliative care services are not available and that aged-care patients and their families are faced with the difficult decision of going to residential

aged-care facilities hundreds of kilometres away or having limited assistance with end-of-life care at their homes, which is often suboptimal. Is that a common situation throughout the state?

[2.10 pm]

Mrs NEWELL: Definitely. That is where that removal of country really, from them and their spiritual wellbeing at the end, has a huge impact as well because the family really do struggle. If the patient is saying that they want to stay connected to country and stay on country, but the family are like, “We can’t give you any help here, but we have to actually take you there to get help”, it is a real struggle.

There is a lot of those other cultural aspects as well around that. Like I said, sometimes people do not want them to die in their house because it means they have to move and stuff. Quite often they will say at that very last point, “Can we move them somewhere to be able to do that?” But to be able to do that, you still need that end-of-life palliative service at the area where they actually are. For a lot of times on so many other aspects of things, we have actually had people travel hundreds of kilometres, you know, for services, not only in palliative care but other things. It breaks their heart. The family are then separated from them, unless they can all start up and move and go with them wherever they have to get those services from, or they choose to die on country and die in pain and not have that dignified, nice end-of-life time that they could actually have, surrounded by family, surrounded by country. Their spiritual capacity and things like that are taken away when they have to actually go hundreds of kilometres away to have some palliative care.

The CHAIR: On page 2 of your submission, you note three key enablers for the provision of quality palliative care by ACCHSs. What progress is occurring on those enablers?

Mrs NEWELL: I think for us COVID has had a big impact relating to telehealth. Prior to that, the Aboriginal communities were very reluctant to go into that space. We have always tended to be face-to-face people. Even with your learning especially, Aboriginal people—it is a generalised stereotype—but we do tend to learn better visually and face to face than what we do online. COVID left us with no other options a lot of the time and the health services have actually really embraced it and they have utilised it. They have actually realised that there are a lot more benefits to it, obviously. I think that would be a really good start in that sense where you have a discharge plan that it is not going to the hospital down the road because that is who they know; they could actually telehealth into the local Aboriginal community-controlled health service. They could be doing that discharge planning and saying, “Do you have the capacity? Do you have the ability to be able to provide this certain care? If not, how do we best support that at that particular time?” I think the digital health area is a huge area that has been improving from that perspective.

Of course then you have your connectivity issues regarding NBN and the stability of their internet connections and things like that, that also address into the regional areas. Some of them do not actually have NBN or they cannot do video calling because they do not have the capacity with their connection. That is one of the things that AHCWA, as a peak body, we have been really trying to hammer home, especially obviously with COVID and everything has gone online. Our services and our communities and Aboriginal people in general, or anybody that is living in remote areas, should have the same capability of connectivity as what we do here in the city. I think that is definitely one of the ones that is increasing. At the moment, AHCWA is also developing a platform called Mappa, which is like a log-on service that you can go and find. If I am here in Perth and I have got a patient that is in from Beagle Bay, I can go on there and hit “Beagle Bay” and it gives me a contact person for that particular community. I can ring up and have a chat to them without having to go through

all those other things of finding contact people and all of that. It tends to be from a tertiary hospital to a regional hospital because they already have those contact details, and it is easy to do. We are hoping, with the Mappa platform, that it will actually encourage people to ring the local ACCHS. It does actually list on there what their capabilities are and what visiting specialists are or what they can provide. We are hoping that that will be a big inroad into assisting us with that.

There is so much knowledge and so much skill and expertise in these ACCHSs. I get surprised sometimes when I ring up and I am talking to somebody, where they have been and where they have come from and what they have done. A lot of the time that is not recognised. A lot of the time, too, we are the last ones to be consulted. Even with some of the palliative care stuff that has come out in the past, it has been consulted with this group of people and that group of people and that group of people and then we will come and consult with the ACCHSs or the Aboriginal groups for a different streamline. But it should actually be right from the start that they were in that consultation.

As I said previously, a lot of the time the ACCHSs are getting notified when they are just about to die and not when they have been down here and had treatment. It should be the ACCHSs where they are going back to is consulted and said, "Joe Bloggs has been down here, he has had this treatment, he has had this," so they can start their palliative care for him very, very early and not just that last little end-of-life stuff. Like I said, there is a lot of skill and expertise, but I do not think that that is recognised very well by the tertiary hospitals, but I think from their community perspective they recognise it very well who is there. Again, that genuine investment and capacity and capability to deliver palliative care has not come through the Aboriginal community controlled service or the Aboriginal funding. Like you say, at the moment there is money that has gone to WACHS and then it is sort of like, "We will see where we can fit the Aboriginal part of it in." There has got to be that level where you consider actually spending money into the actual ACCHS themselves, not just as an offset of another bucket of money that has gone from elsewhere.

One of the things that has been identified in a lot of the work that I have been doing on all different public health issues is that is what tends to happen and then they wonder why things do not work. It is like, "Because you've got a mainstream organisation trying to teach these people what to do or tell them what to do"; it is not applicable for either their way of life or their cultural aspect of it. I still think that that needs a lot of work. There has got to be a genuine investment into the Aboriginal community-controlled health services themselves, how they would run that palliative care service, doing the needs of what their specific community is. Because, like I said, you cannot just say, "We're going to model it on the Kimberley or model it on the metro", it really has to be an individual ACCHS. Even in the Kimberley, you have got East Kimberley and West Kimberley and they are very, very different.

You could not just model one model of care, even up there, and say it is an "all fit". They would really need that consultation. Like I said, the ACCHSs investing in those, to do that, would be your best capability of getting that palliative care out there.

The CHAIR: In 2019, the government announced funding of \$6.3 million for community-based palliative care services. This included \$2 million for domiciliary home care services throughout the state. To your knowledge, has any of that funding been allocated to ACCHSs?

Mrs NEWELL: That would be the next one to put on notice. I could not actually tell you that.

The CHAIR: Sure. That will be question on notice 2.

The government has also announced funding of \$27.2 million for an additional 61 full-time equivalent staff to be employed across regional WA, including Aboriginal health workers. Are you aware of how many of those additional staff will be Aboriginal health workers and where they will be employed?

Mrs NEWELL: Again, I would have to take that on notice.

The CHAIR: Sure. That will be question on notice 3.

Have you been involved in consultations with the Department of Health in relation to the employment of additional Aboriginal health workers?

Mrs NEWELL: There is actually a lot of workforce talks going on at the moment with AHCWA with the Department of Health; that is across the board, not just for palliative care. I am actually involved in the WA palliative care advisory group that they have going at the moment to be looking at the best plan of action across the board. I sit on that. When it comes to workforce, that is another issue in itself. It is a very big, broad element that I think we need to work on hugely because the way that it is at the moment just is not working for a lot of our ACCHSs. I have not personally been involved in it, but I know between AHCWA and the Department of Health and the WA Aboriginal advisory group et cetera, workforce is a huge topic that they are discussing.

Ms Newell continues

Again, I could not tell you if it is all around that palliative care specifically, but workforce in general is something that is being spoken about between the health department and AHCWA.

[2.20 pm]

The CHAIR: Could you please expand on the issues relating to discharge mentioned on page 2 of the submission, including the role that can be played by telehealth? I think you did —

Mrs NEWELL: Yes; we sort of mentioned that a little bit. Like I said, a lot of the time in the past, we have not had the capacity for telehealth. As I said, some of the remote areas still do not, but being able to sit and basically case conference on telehealth when they are going to discharge a patient from hospital, and sit down and talk to the family at the other end and have a person from the Aboriginal community-controlled health service there to be able to support them and understand the terminology, I suppose, that they use and the language that they use would be a huge benefit. As I said, at the moment a lot of the time they do get discharged to another region or other remote place and not actually back home. We are hoping that we can get telehealth to be a big focus around being able to discharge people back to country and utilise that. Discharge planning, again, when it comes to the Mappa platform, we are hoping that people will actually use that to ring an ACCHS and see if there is one in that particular place where the person is from and speak to them first instead of going through three other different centres or regional areas before the local ACCHS hears about that particular patient and where they are from.

The CHAIR: You have been giving us some really good, thorough answers, but just to go back to the issue of capacity-building measures that we could implement through the ACCHSs for palliative care, are there any further thoughts that you have on that—what capacity-building measures we could adopt?

Mrs NEWELL: Again, more funding to be able to put more staff in to be able to go and train for palliative care and be able to actually afford to upskill them into that area. Also, as we said earlier, you cannot just say, “Well, here’s a palliative care service.” That capacity also needs to involve the production and the development of appropriate resources for that particular area—the education of the community around what that service would be and what it entails. You cannot be just building that capacity in the ACCH. It needs that community focus around, like I said, the development of resources and educating the communities as such, and also the family, because the family obviously play a big part in any Aboriginal person’s end-of-life choice or their pathway, so ensuring that they are aware of those things as well. The capacity building definitely needs to be around education, cultural awareness, cultural safety for those providing it and also the funding in the ACCHSs to

actually employ health workers, get them trained to an appropriate capacity and be able to have that link in with those professionals. Is it a telehealth thing that they could link into a professional in Perth that can guide their care for that person? Again, the capacity to be able to connect to the internet and be able to build that telehealth capacity and even the telehealth items come down to that as well—your Medicare items.

At the moment, we have some through COVID and they are saying that they are going to end in September. Our services have utilised them so well and we would hate to see that go. Again, they still provide that service just without the funding. When they have a telehealth conference or a doctor calls around discharge, they will always have somebody at the other end with that person and they take that out of their own funds, because at the moment there is not an MBS item that says, “This particular person is spending sometimes two to three hours on a case conference.” It could be one of the doctors in the ACCHS or an Aboriginal health worker sitting there doing that but there is no Medicare item for them to claim the time that they are actually doing that. The capacity building could also be around funding those things—they are doing them anyway—so that they could then maybe employ some other people to cover when people are doing those telehealth items. MBS is a huge factor when it comes to building that capacity, because, like I said, you need those other staff to be there.

I think just having that cultural knowledge as well. Obviously, we will not have every bit of expertise in the service. There is going to be specialist staff and people who need to be consulted with, but ensuring that they have had cultural training and are very aware of the cultural needs of the people they are going to look after. I think that capacity is really important as well, because, like I said, we will not have all the expertise in different areas sitting in that ACCH. There will have to be external people involved; it is really important that they are aware of the cultural needs of people as well.

The CHAIR: When it comes to communicating to Aboriginal people all issues around palliative care, have you got any examples of cases where the appropriate language, appropriate images have been produced?

Mrs NEWELL: There are some very generic ones around. There is a really good one that was more around advance care planning that was put out by NACCHO, and it gives an example of being able to talk and initiate conversations about what you do want at end of life. Like I said, it was more around advance care planning not palliative care. It really highlighted them. We have discussed this in the regions that a lot of those things really do highlight those conversations about what to have. It gives a little example in that book of “Uncle Harry has a stroke and he can’t communicate. Nobody knows what to do. What do we do?” Whereas, if we had had these conversations, we could all be on board. That was a good one. It talks a little bit about palliative care. I cannot think of the name off the top of my head, but there is like a card game that you could play. You hop on and it has cards saying, “What is important to you at the end of life?” You could pick one about culture; you could pick one about family; staying on country, and pick these cards. Again, it was something to start the conversations around what you would want moving forward, which is obviously planning what your palliative care journey or your end-of-life journey is going to be. They were done quite well. But, again, you need that person there supporting that person to be able to do them. I think this is a topic where you are going to have to have the individual ACCHSs and individual communities themselves putting in what they think is relevant in their packages.

The CHAIR: Has the Department of Health been involved in those discussions with you at all about how to design these packages and what they might look like?

Mrs NEWELL: No; it is something that when we talked to WACHS a few weeks ago about the palliative service money that they got to see what we could do, we did actually say that if there is

anything you could do around ensuring the resources in the different regions and that they were language appropriate and stuff for people to understand, that would be a huge element for us. Otherwise, I am not aware. Palliative Care WA has a booklet that is very comprehensive, but it is more aimed at the carer than the actual person going through palliative care. We have been in discussions with them for a while to see if we can adapt that to a more simple, generic version for Aboriginal people. But, again, we looked at it and it would need to be regional to be specific. It is okay in Perth to say you have all these services, but each individual region does not have access to those things wherever you are going, depending on whether you are really remote or regional. It would depend on what you have available to you to be able to develop some sort of resource like that.

The CHAIR: Your submission did talk about that need for cultural training for health professionals providing health care to Aboriginal people. Do you know to what extent the training of that kind is provided to health professionals at the moment?

Mrs NEWELL: We used to run the cultural safety training at AHCWA and that has come off scope now because there are other providers that are actually doing it. The health department does a really good one as well and it is literally one or two days' training. Depending on which course you take, you can do a quick overview. I would hope that they would not be just a quick overview if they had not been out to an Aboriginal region before. There is cultural safety training available through the Department of Health that people can link into and log into.

The CHAIR: Great. We are just about out of time, and I have got three remaining questions that just relate to the issue of voluntary assisted dying. The thrust of it really is: is there a sense that people have got confused between voluntary assisted dying and palliative care?

[2.30 pm]

Mrs NEWELL: I would not say that there has been a lot of education around the voluntary assisted dying that I am aware of at the moment until it really gets some traction in the Aboriginal communities. I think one of the things that we have acknowledged is, like I said, there is just confusion generally around palliative care and the end of life and advance health directives and advance care planning. All of those elements of the end of life, I think, are so confusing sometimes to me, and I take on board all of those things. So, I would not say that that has confused them in that sense, but then, again, you would have to consult with the individuals or the individual communities around that. There have been, obviously, discussions around voluntary assisted dying because there has been consultation for the other papers and submissions that have been done, so there has been that talk.

Like I said, the things that I was hearing from the palliative care were mainly related to that "it relates to cancer", and they do not think of it from another chronic disease or other end-of-life element, and they actually think of it as, like I said, that very end of life where it is just give some medication to assist you, and they do not actually think that it is a journey that starts from here and goes a long way down the track—that they should be implementing that palliative care at the commencement of their chronic disease or things like that. So that is where I think the confusion has been, because at the moment if you said to somebody that was just diagnosed with renal disease, and they were quite unwell, that you are going to start on a palliative care journey, they would basically think that you were going to kill them. I do not think that has come from a voluntary assisted dying topic; I think that is already what they thought palliative care was previously.

The CHAIR: That has been a very comprehensive hearing and thank you very much for all the information. We do have those questions on notice for you. This will, though, be a formal thankyou. That has been really useful for us. A transcript of the hearing will be forwarded to you for correction.

If you believe any corrections should be made because of typographical or transcriptional errors, please indicate these corrections on the transcript. Errors of fact or substance must be corrected in a formal letter to the committee. When you receive your transcript of evidence, the committee will also advise you when to provide your answers to the questions taken on notice. If you want to provide additional information or elaborate on particular points, you may provide supplementary evidence for the committee's consideration when you return your corrected transcript of evidence. Thank you very much again; that was really helpful. Thank you.

Hearing concluded at 2.32 pm
