

STANDING COMMITTEE ON PUBLIC ADMINISTRATION

INQUIRY INTO THE PATIENT ASSISTED TRAVEL SCHEME

**TRANSCRIPT OF EVIDENCE
TAKEN AT CARNARVON
FRIDAY, 29 AUGUST 2014**

SESSION NINE

Members

Hon Liz Behjat (Chairman)
Hon Darren West (Deputy Chairman)
Hon Nigel Hallett
Hon Jacqui Boydell
Hon Amber-Jade Sanderson

Hearing commenced at 3.18 pm

Ms KYLIE LAURIE-RHODES
sworn and examined:

The CHAIRMAN: Thank you.

Ms Laurie-Rhodes: Can we go?

The CHAIRMAN: Please, if you will.

[Witness took the oath.]

The CHAIRMAN: You are appearing here as a private witness and we have your contact address?

Ms Laurie-Rhodes: That is right.

The CHAIRMAN: Have you signed the document entitled “Information for Witnesses”?

Ms Laurie-Rhodes: Yes.

The CHAIRMAN: Have you read and understood that document?

Ms Laurie-Rhodes: Yes, I have.

The CHAIRMAN: The proceedings are being recorded by Hansard and a transcript of your evidence will be provided to you. You will not have a document, so you do not need to quote from the title of the document. I just remind you that your transcript will become a matter for the public record. If for some reason you wish to make your statement to us today in private, you should request that that evidence be taken in closed session. If the committee grants your request, any public and media in attendance will be excluded from the hearing. Please note that 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 may constitute a contempt of Parliament and may mean that the material published or disclosed is not subject to parliamentary privilege. Kylie, would you like to tell us your PATS story?

Ms Laurie-Rhodes: Firstly, thank you for coming and thank you for listening to people. I am probably the new kid on the block. To give you an idea I am probably coming at PATS from a couple of different angles. On 19 December 2012 my dad had a major stroke as a 79-year-old man. I live on the east coast of Australia, I have never been to Carnarvon in my life, and I know why! It is just so remote, sorry, and that is one of the reasons why I had never been here. My parents have been here for approximately 14 years—it was so remote and very expensive when you are raising a young family. After some time, when I actually found out, I flew over to Perth and met my dad in Perth. He was airlifted down by Royal Flying Doctor Service. I then came up here and picked up my mum. I got her well enough to travel because my mum was in dire, desperate need—my dad was my mum’s full-time carer, as such—and then I had to take my mum to Perth to see my father. As things worked out, they were entitled to PATS, and I am not too sure how that worked or how that went. As it worked out, we would have needed to be there because I became my dad’s full-time carer and I also became my mum’s full-time carer. I went from being an independent little vegemite to being tied down with two adult children who both had very diverse medical issues. The first time this happened, the first stroke, we got petrol vouchers and we drove down. The reason why was that I was not too keen on getting on that small, little plane but my mum had a lot of special things that we needed to take with us. She has a chair for the bathroom, she has a lot of other bits and pieces of equipment and she was a chronic asthmatic, and at that point she was not confirmed as a COPD client, which only makes the matter worse now when we travel. We got PATS for that and I am

probably very grateful for it, but my parents, luckily, are in a situation, through doing all the hard work and saving, they foot the bill for the rest. I learned today that as a carer I am entitled to \$15 a night or something, from someone else speaking. I have never known about that; I have never heard about that, and if there is a way that I can sort of help pay the costs of this, I would like to be involved or help assist my parents with that. I do not think I should be coming here to find out what I am entitled to or that there might be something that I can receive to accommodate all these costs that we are incurring. To give you an idea, my father had a major stroke then. He has not been able to drive. I have been the full-time everything for him.

The CHAIRMAN: Are you registered as his carer through Centrelink?

Ms Laurie-Rhodes: Yes, through both of them. And you know, like, they are my sole thing; my whole life revolves around that. My family and everything else that I walked away from comes second. I have children ranging from 23 down to 12, and I have just had to walk on a plane and come over here and look after them. So it is a huge issue just in itself as a carer, and not knowing, to find out from someone else today that I am entitled to something was a shock. The second time this happened, a couple of months ago, we were told we were not entitled to anything to go down. On both occasions I needed to be there because this second time I had to learn how to feed my father, how to shower him safely. You have got a grown man who has been independent for as long as he can remember having to be washed, bathed, toileted by his only child, and being a female that did not commute. You know, he taught me how to change a car tyre, but the thought of me ever having to change his diaper was never ever on his radar. But I had to be there, otherwise it was not going to work. The cost of the second trip, my mother incurred the whole cost of that. The first time we were told that PATS would pay for us to stay at certain places, but they were so far from where we had to go and we needed a car then to travel, otherwise it would be limiting how long we stayed and where we would go, and that was another issue. So it is not always consistent, I find, using PATS here. It depends on who you speak to and it depends on what advice you get given, what way to go and what you can do and what you cannot do. The situation now with my mum being a CODP patient is we need to take oxygen bottles, we need to take a portable oxygen concentrator with us—preferably two, one that she is using and another one we use in the motel room; it is a bigger one. We have all the other furniture we have to take. I have a ute that is packed just to go to Perth, because we need barstools, we need these other stools, we need special chairs and everything else. So driving for us is the only way to do it. My mum needs to go and see a respiratory specialist. She is putting it off because if I fly down with her and she foots my bill—that is what we have been led to believe that she would have to foot my bill for me to go with her—there is no way she can. She could not walk anywhere, so we would have to catch taxis. She cannot carry her own handbag, so how is she supposed to carry her luggage if I did not go with her? Now, to get down there, what do we do with my father? That is why we are taking the option of driving if we have to go somewhere, even to Geraldton, to go down there and to do that type of thing, because we all can travel together, we are not having people separated and isolated because of our own family circumstances. The other thing I wanted to raise is—sorry, I tried to put as many notes in my hand!

The CHAIRMAN: We would have given you a piece of paper if you had asked for it!

Ms Laurie-Rhodes: I do not think it could have got any bigger! I just did not want to leave anything out.

The other issue is with dental with PATS. PATS will only cover you as an adult with wisdom teeth, nothing else. As you can see, I am missing a few teeth and I need to lose the rest. No dentist in town will touch me, because they will only do it in the chair, and because of other medical issues I have, they cannot do it that way. I have found a dentist in Geraldton who will operate under hospital conditions; no hospital in Geraldton will take me because of my health conditions. So my next saga is I have to go to Perth. On top of the cost, which I am looking at this time around probably another \$10 000 on what I have already spent. I have already paid a dentist \$3 000 in Geraldton and we

have already been down to Geraldton on probably four occasions of which one of them I was going into hospital the next day, and at five o'clock on the night before I was due to have my teeth operated on it was cancelled because they said, "No, you're too much of a medical risk." I now have to go to a specialist dentist in Perth, have a couple of trips down, I would imagine, and then on top of that I have got to pay for it all. Then it is another problem because it is a long way between here and there to go. Then I have got the issue of the cost, the recuperating and then coming back.

The CHAIRMAN: Who will care for your parents whilst you —

Ms Laurie-Rhodes: That is another social issue, because I am running out of respite time. I have had to use respite time this year for my father and I am going to go into the negative this year, because when my father got airlifted back from having the second stroke, we drove back and I had to alter every room in the house except for the kitchen and the laundry. We have had to have a massive lot of work done so we could keep him at home, and I had to keep him in hospital under respite. The situation was so grim there that I had to work even harder to keep him here because they were running out of staff and they wanted to send him back to Perth. For someone with dementia, that is the last issue you want. You want to keep him close and keep the continuity of care to see him. And the problem with my teeth is that under a commonwealth scheme, which they had just recently, where they look at doing major dental work up to \$5 000 free for people on low income or people who could prove that they had medical health issues that affected the health of their teeth, because of prescription medication, I qualified under that, but because the scheme closed after I got here, I could not access that treatment. So I have got proof that my teeth have deteriorated because of a medical condition. I am living on antibiotics permanently nearly, so my poor old dentist is not impressed about keeping on giving me antibiotics, "When are you going to get the teeth fixed? When are you going to get the teeth fixed?" So not only have I got the cost of getting them fixed, but the cost of getting there, accommodation and getting back. It is a catch-22 situation. And the more remote you live, the harder it is to get these things done. I just would like you to consider if there is some sort of way—I did not know there was even an avenue until today about the exceptional circumstances. I was not made aware of that at all, and I have even rang Perth to double-check on that information, whether I could qualify for PATS. It probably would have been good if I knew it was exceptional circumstances and you could appeal it or could put a case forward. The other thing I would like for you guys to take into consideration is that when you do get the statistics from the hospital for the unusual circumstances or special circumstances, there are a lot of people who do not even know that that existed or were not told that they could go through that avenue.

The CHAIRMAN: That is the unfortunate part; we cannot determine that. It is hard; how do you quantify how many people do not know something? You cannot quantify that really, so that is the difficulty.

Ms Laurie-Rhodes: Yes, and I think everybody who has spoken today, they have all learnt something from the previous speaker, you know, as in what you can get out of PATS and what you cannot get out of PATS.

Hon JACQUI BOYDELL: I think the underlying issue with that is having transparent access to what the —

The CHAIRMAN: The information.

Hon JACQUI BOYDELL: Yes, to what PATS can deliver you. It seems there is a bit of a lack of understanding or, I guess, knowledge or willingness on either part to impart that information.

Ms Laurie-Rhodes: Yes, and in a small town you hear all the bad stories about it before you hear anything about how it works, the good things about it and how you can get it to work for you. I did not know until today that if my mum has to go to see a specialist, if the doctor ticks on the yellow form "requires a carer", that that covers me. I did not know that until today. My mum has just been

willing to pay for me if she has to go somewhere, so it is a catch-22 situation. Okay; thank you all very much.

The CHAIRMAN: Thanks Kylie, that is fantastic. That brings us to the end of our hearings for today.

Hearing concluded at 3.31 pm
