

STANDING COMMITTEE ON PUBLIC ADMINISTRATION

INQUIRY INTO THE PATIENT ASSISTED TRAVEL SCHEME

**TRANSCRIPT OF EVIDENCE
TAKEN AT ALBANY
MONDAY, 25 AUGUST 2014**

SESSION FOUR

Members

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

Hearing commenced at 11.43 am**Mrs JANE FORTE, sworn and examined:**

The CHAIRMAN: Hi, Jane. I need to go through the formal part of swearing you in as a witness. Just bear with us while we do that. I ask you to take an oath or an affirmation.

[Witness took the affirmation.]

The CHAIRMAN: The capacity in which you are appearing in front of the committee today is as a PATS user.

Mrs Forte: User, yes.

The CHAIRMAN: You did sign a document entitled “Information for Witnesses”. Did you read and understand that document?

Mrs Forte: Yes.

The CHAIRMAN: The proceedings today are being recorded by Hansard. A transcript of your evidence will be provided to you. To assist the committee and Hansard, please quote the full title of any document you refer to during the course of this hearing for the record. Please be aware of the microphone and try to speak into it, and do not cover it with any papers. I remind you that your transcript will become a matter for the public record. If for some reason you wish to make a confidential statement during today’s proceedings, you should request that the 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. That is all the formalities over and done with.

Jane, if you would just like to tell us your PATS story, please.

Mrs Forte: I have five main points to make. The first one is gratitude for the system. Over the last four years, my daughter has had a process of diagnosis treatment and surgery for some severe gastrointestinal issues, and my husband has had heart specialists and surgery, so we have actually used the system quite a bit just in those last few years. Particularly from the country, it is actually quite challenging to organise time off work to make appointments particularly when you live in the country. As we heard before, it is challenging to organise time off work to make appointments—as we have heard before, getting appointments to fit in where you can get up and get them done and stuff like that. It is difficult to do that, so the actual financial assistance with that really helps at a time when you have enough worries to keep going. The system is fantastic and I really appreciate that. So thank you very much.

My first issue is maybe consideration of special cases. Earlier this year, my daughter, who was at the time 17, needed to go to Perth to have her bowel removed. She, instead of being in hospital for one week, was in hospital for three, and then had to remain in Perth for a further week with nursing visits and what have you. Unfortunately for her, she turned 18 three days after she had that surgery, which was less than ideal for her but, from my point of view, I was mum, her carer, her escort, and the PATS accommodation allowance for me covered the first three days until she turned 18, and then when she turned 18, she did not need mum anymore, so my accommodation was not covered. The accommodation, when she came back to the caravan park cabin with me for the week that we had to remain in Perth, was covered by the PATS system. My husband had to drive up and ferry us

around. It was all a bit complicated. But the fact that all of a sudden she became not needing me or my support was a bit interesting, particularly when I had to do visits to ostomy associations and stuff even when she was in hospital. So there was stuff I was actually doing to help with her care at the time as well. I guess that was a bit of an issue. Probably the main issue was that I kind of assumed that we would get some PATS money for that accommodation. Over \$5 000 has been spent now on accommodation for her surgery and stuff, and a fair bit of that has not been covered because I am her mum and she is 18 and everything is fine.

Hon JACQUI BOYDELL: I am sorry to interrupt you, but before you move on to your other points: was there an opportunity for you to apply under a carer rather than a dependent child; and did the PATS clerk give you that opportunity?

Mrs Forte: I was told that when someone is in hospital they only need an escort when they are a child. As soon as they turn 18, they no longer need an escort; therefore, mine is not covered. I guess this relates to one of the things that I will say at the end, which is my recommendation suggestion. It would have been a lot easier for me if I had gone up, knowing that we were not going to get money for those weeks in the sense that, to me, what is paid for and how the system works is not particularly transparent. We have been using it for a few years and I have picked up a few ideas as we have gone along. I know that they do \$60 for the commercial accommodation. I have learnt that just through dealings. But if I knew that beforehand and if I knew that we were not going to get money, I guess it would not have come as such a disappointment at the PATS office when they sort of said, “No, we’re not going to cover that.”

The CHAIRMAN: Following on from what my colleague said, I would have thought that, given the nature of the surgery that she had, you would have needed stoma training for the colostomy that she obviously would have had post-surgery and that you would have then become her carer. I do not think that at 18 she was then going to leave home and not be with mum and dad. I would imagine that there is an expectation that she might still be at home with you now.

Mrs Forte: I was told that once she was 18, she was being looked after in hospital and that would not be covered. There was no question and no discussion entered into at that point.

The CHAIRMAN: So no-one made you aware that you could be a carer for an adult dependant?

[11.50 am]

Mrs Forte: They said, “No, we’re not going to cover that.” There was no further discussion.

The coming home process and the flight issue: she was certainly not in a position where she could fly. She had been out of action for a month and was pretty unwell, needed to fly home and needed me to fly with her. There were no qualms with that. I contacted PATS and said that we were seeing the doctor on the Monday afternoon, that he would be clearing her to fly home and that we planned to fly home on the Tuesday early afternoon flight. I had contacted them the week before. They said, “Oh, we can’t do anything until you’ve seen the doctor.” On Monday afternoon we were seeing the doctor and getting yes, we can fly home; so, fine. I contacted them again, and basically they sort of said, “Oh, well, at this stage it won’t be approved until tomorrow. We’ll let you know.” So they were actually looking towards booking flights not till Tuesday morning for an early afternoon flight. I was needing to leave the caravan park and pack up. My husband had actually driven down and back again to take the car home, so it was all a bit messy and complicated, but basically we had to leave our accommodation and gear up, ready for flying home. So what I did was just rang and booked flights. There were very few seats available at that time and there was not a wheelchair available for her. So, in the end, she had to struggle along, which she did, but barely, even on the Monday afternoon. I guess we are really lucky that I was able to afford to do that—to book and to pay for those flights. We have since been reimbursed for them, but at the time I was very stressed, to be honest. It was quite stressful.

The CHAIRMAN: How long was the period of you paying for the tickets and receiving a reimbursement, roughly?

Mrs Forte: Two or three weeks probably; I could not tell you exactly. We are lucky to be in a position where that is not going to be a big drama for us. I know there would be lots of other people out there who would not be in that position. I guess that is what my concern is. This threw up a situation that we managed, but there will be other people who will not be able to manage. On the flight issue, we had not particularly charming or helpful or pleasant phone calls and discussions over all of that. On the itemisation of payments, I think my husband had emailed Peter earlier on, making the suggestion. When we get a PATS payment, we get a cheque. It has a date, I think, but there is no itemisation at all. So you get an amount of money. That amount of money might be for airfares, accommodation or travel; we have got no idea. You get this piece of paper with absolutely no idea of what the rate of payment is and what has actually been paid for. I ended up getting a cheque from that session that covered, I think it was, \$600 or \$700. I think it was for two airfares and a bit of petrol money—they did not pay much accommodation. But there was nothing on there to say what it was they had covered. I ended up having to ring and say, “Look, can you tell me what all this is for?” which they did quite happily, but I thought it would have been much easier if that was on the bit of paper in front of me. I guess if people are using it a lot, you would like to know where you are up to. Because there is quite a delay in the forms and then the payments, it would be really helpful, I think, to know which visit that is to do with and how much they have covered. The other bit that goes with that, which I alluded to earlier, is knowing that if you are staying in commercial accommodation, they will pay \$60 a night on the basis of only if the child is there or the person is there, rather than the escort or whatever. I think a lot more transparency in terms of what is being paid and what the requirements are would be quite helpful, from my point of view as a user.

Hon NIGEL HALLETT: Jane, where do you find the breakdown in the system? Is it that Perth becomes the impersonal place, or do you find the local people know your case and offer you that, or are you finding the whole system is very impersonal?

Mrs Forte: I have never gone to Perth. I have only ever spoken to great southern, so my contact with the whole system—I assume the cheques might come from Perth; I do not know.

Hon NIGEL HALLETT: So your breakdown is really in communication.

Mrs Forte: The phone calls that I have made were direct to Albany, because they are the ones that had the forms; they have always been made direct to the great southern. The last one is to do with the actual paperwork, not so much the GP paperwork. We have to have a referral to the doctor, so you get that done every year, and hopefully you remember that, but sometimes when you do not, they will fairly curtly tell you that you have to. The issue that I have with the blue form, where there is a tick box for the flight, is that over the four years I have given the PATS form to a number of doctors in both Princess Margaret and in St John’s and private specialists. Most of them do not even touch it. With most of them, the signature and the information is put on by the secretary. So, they do not even do the ticks. I fill out the form, put the name bits in, put all of the bits in, and the doctor does not have anything to do with it.

The CHAIRMAN: Apart from signing the form.

Mrs Forte: No, they do not even sign it; the receptionist signs it, because on the form it says “a doctor or practice member” or something. With most of them, the signature is actually done by the secretary. Now, I guess I have had a few issues with PATS coming back and saying, “You’re not allowed to write anything on the form. It’s got to be the doctor. We’ve got to have letters.” So, over a few years we have had several specialists who have been—I need to acknowledge this—really cognisant of the fact that we live in the country, and they have gone out of their way, both specialists and surgeons, to make a big effort to accommodate us, set appointments up that will work. They have really made quite an effort, and I feel incredibly embarrassed when I have to go

back to them and say, “Sorry, can I have another letter that says this? Can I have another letter that says she needed to fly up because she needed access to a toilet on a regular basis?” I have had to go back and back to specialists to ask them to write a letter for PATS. They are doing a damn good job and they are working really hard in the care of my family, yet you are having to put them on the spot in terms of more paperwork. I do not know whether you can actually do it on the form, where there are some more explicit bits and pieces that go on the form. I guess the online bit appeals to me. Also, the doctor training—if PATS is not going to accept me writing stuff on that blue form, doctors need to know that, because I feel I am being really embarrassed by asking them to do it. If I am not supposed to write it on the form, then they should not be putting me in a position where I am having to and then getting it knocked back and having to ask for another letter. I guess talking about educating doctors in terms of what is required by the PATS system is probably the other side of the thing there, as far as I can see.

The CHAIRMAN: Jane, thank you so much for coming today. We have had three private witnesses today and they have been three very different experiences and stories. We are obviously going to be building up quite a good picture of what it is like for the end user. Do you have anything further you would like to say to us, or you are happy with that?

Mrs Forte: No. I think that has covered it.

The CHAIRMAN: Just tell me: your daughter still at home with you now and still needing ongoing PATS treatment.

Mrs Forte: She has a liver condition that has been in place for four years, and she will need ongoing specialist treatment in Perth. It will not be anywhere near as intense, purely because the bowel issue that occurred about 18 months ago, because of the surgery, is now resolved and she has had the reversal. So she has got rid of the bag and she is a happy vegemite and she is well. She will be off to uni next year, so will be able to go and see specialists very easily. But, certainly, while she is still here, there will be further specialists, which have worked really well in the past.

The CHAIRMAN: She will have to access that system on her own now because she is 18 and you do not care for her.

Mrs Forte: Yes. It is interesting, because the cheques are actually being sent to her now. The last couple of cheques, because she is 18, have been addressed to Fiona. I can understand why, because her name is on the form, but because she turned 18, the however many hundred dollars that is reimbursement have gone into her bank account, and it is like give, give, give, give and get it back off her, which she will happily do as well, but I am the one who paid all of that money; it was not her. That is another little issue, and I guess that is kind of hard to accommodate on the forms.

The CHAIRMAN: And you are not registered as her carer.

Mrs Forte: Not as such. She does not need a carer, in general.

Hon JACQUI BOYDELL: She probably did.

Mrs Forte: She certainly did for a period of time there; yes, absolutely.

The CHAIRMAN: Thank you very much for coming today. I hope it was not too daunting an experience for you, but it has been incredibly helpful.

Hon JACQUI BOYDELL: Thank you so much.

The CHAIRMAN: Thank you, Peter; good to see you. We were very impressed with the Albany Hospital; we thought it looked lovely.

Hon DARREN WEST: We are very impressed with your constituents, too.

The CHAIRMAN: Ladies and gentlemen, that concludes our hearings for today. We go into private session now and there are no further hearings to be had in Albany. Thank you very much for coming today.

Hearing concluded at 12.01 pm
