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TRANSCRIPT OF PROCEEDINGS

O/N H-1050322

**THE HONOURABLE R.R.S. TRACEY AM RFD QC, Commissioner
MS L.J. BRIGGS AO, Commissioner**

**IN THE MATTER OF THE ROYAL COMMISSION INTO AGED CARE QUALITY
AND SAFETY**

MILDURA

9.34 AM, WEDNESDAY, 31 JULY 2019

Continued from 30.7.19

DAY 41

MR P. GRAY QC, counsel assisting, appears with MS E. HILL and MS E. BERGIN

COMMISSIONER TRACEY: Please open the Commission. Yes, Ms Bergin.

MS BERGIN: I call Kay Gray. Ms Gray is now being sworn in by a solicitor in Port Macquarie.

5

<KAY GRAY, SWORN

[9.35 am]

10 <EXAMINATION-IN-CHIEF BY MS BERGIN

MS BERGIN: What is your full name, Mrs Gray?

15 MS GRAY: Kay Gray.

MS BERGIN: Where are you today, Mrs Gray?

MS GRAY: In Port Macquarie.

20

MS BERGIN: Where do you live?

MS GRAY: Port Macquarie.

25 MS BERGIN: Have you prepared a statement for the Royal Commission?

MS GRAY: I have.

MS BERGIN: Is there a copy there in front of you, Mrs Gray?

30

MS GRAY: Yes.

MS BERGIN: Operator, could you please bring up WIT.0310.0001.0001. Mrs Gray, is this your statement?

35

MS GRAY: Yes.

MS BERGIN: And do you have any amendments to your statement?

40 MS GRAY: No.

MS BERGIN: Is it true and correct on the basis of your knowledge and belief?

MS GRAY: Yes, it is.

45

MS BERGIN: I tender the statement of Kay Gray dated 26 July 2019.

COMMISSIONER TRACEY: Yes, the witness statement of Kay Gray dated 26 July 2019 will be exhibit 7-16.

5 **EXHIBIT #7-16 WITNESS STATEMENT OF KAY GRAY DATED 26/07/2019
(WIT.0310.0001.0001) AND ITS IDENTIFIED ANNEXURES**

10 MS BERGIN: Mrs Gray, you and Clive have now been married for 52 years; is that right?

MS GRAY: Yes, that's right.

15 MS BERGIN: How many children and grandchildren do you and Clive have, Mrs Gray?

MS GRAY: We have three children, eight grandchildren and four great grandchildren.

20 MS BERGIN: When did you meet Clive?

MS GRAY: Gosh, I met him when I started work in his office. He was only an employee at that time and that was – gosh, about 54 years ago.

25 MS BERGIN: What are some of Clive's hobbies, Mrs Gray?

MS GRAY: Clive used to love bowling. His work was mainly his life, running his own accountancy business. He used to be involved in service clubs and he was very, very caring for his older members of his family.

30 MS BERGIN: What are your interests, Mrs Gray?

MS GRAY: Mainly when we got married I had three children very quickly, and we used – I used to always look after the older members of our family. His mum lived with us for quite a while. She had Alzheimer's also, and we looked after her for many years till she had to go into care. My parents were also not well; we looked after them. And other than that, I didn't get to do too much for myself. It was mainly looking after family, older family members, and then when Clive got sick, looking after him.

40 MS BERGIN: Operator, could you please bring up the first photograph. Mrs Gray, could I ask you to describe this photograph.

MS GRAY: That was taken on your 50th wedding anniversary in 2017.

45 MS BERGIN: Operator, could you please bring up the second photograph. Mrs Gray, when was this photograph taken?

MS GRAY: That was taken on the same day. Clive's birthday had been just a few days before our wedding anniversary, so we had a double celebration.

5 MS BERGIN: Thank you, operator. You can remove the photograph now. Mrs Gray, when did you first start caring for Clive in a carer role?

10 MS GRAY: Probably after he had his heart surgery. In 1998 he had heart valve surgery, and during that surgery he had a stroke and he was not expected to live. We were all called, the family were all called because he was on life support after the stroke, but he recovered. They then told me he would never walk again, but he did. I got him on his feet after about 12 months, but he had to give up his accounting practice because he was not fit to work again.

15 MS BERGIN: Mrs Gray, you and Clive lived together until very recently in a retirement village in Port Macquarie.

MS GRAY: Yes.

20 MS BERGIN: What were Clive's care needs while Clive was living with you?

MS BERGIN: Well, once he got really bad with Alzheimer's, he – he – more or less, my entire life became focused around his requirements, particularly towards the last three years. He needed showering, toileting, dressing, undressing, shaving, helping to eat; I even had to remind him to keep drinking. He would forget to drink and he needed to drink water because of urinary tract infections, but it was more or less full time, 24 hour.

30 MS BERGIN: Mrs Gray, Clive was on a home care package level 4. What assistance did this provide to Clive and yourself?

MS GRAY: Well, towards the last couple of years we were able to get – I used to get somebody in to shower him. I started off four days a week and then I got five, and they would just shower him. They would take him for an ice-cream one day and for a drive for an hour. That would give me a little break. I would not – I would just stay home and relax in that time. Another day one of his carers would take him for a coffee in the morning and there again, I would just relax while he was gone. They used to help – one of the carers, the lady carer that came in a couple of times a week would do my floors for me in her time there.

40 MS BERGIN: Mrs Gray, when Clive went into respite care, which we will come to in detail in a moment - - -

MS GRAY: Yes.

45 MS BERGIN: - - - was he able to access his home care package to pay for the respite care?

MS GRAY: No.

MS BERGIN: What is your view about whether a home care package should be able to be used to contribute to the cost of respite care?

5

MS GRAY: I really do think that if you were able to use your package, people would be able to take more respite. Sometimes with respite you don't want to go away, you just want to stay home and relax and kind of get your body back into normal mode instead of having that 24-hour carer's role. It would be wonderful if you could access your level 4 package to pay for the respite.

10

MS BERGIN: Mrs Gray, how did you look after yourself while you were caring for Clive and he was living at home with you in Port Macquarie?

15

MS GRAY: That's a hard one. I – I think you just kind of put yourself on the backburner. You – you just – you've just got to do what you've got to do and you don't think too much about yourself. I used to – I have had breast cancer and I used to make sure I went for my regular check-ups and that type of thing, but other than that your whole life, or mine did, just become – revolved around Clive.

20

MS BERGIN: How did you get a break or a holiday at this time?

MS GRAY: Well, the – I had never had a break or a holiday. I had – we went for a couple of overnight trips with the My Aged Care, so I then got the respite into the home which they will pay for, but that was just for a 36-hour stint on two occasions. My daughter took me down to see my new great granddaughter overnight on another occasion. Other than that, I hadn't had a break from Clive until I put him into the first respite centre that I put him into.

25

30

MS BERGIN: How did you get advice at this about Clive's condition and how to manage it?

MS GRAY: I read a lot. I read a lot of books. I got a lot of written information on it. Having looked after his mother with Alzheimer's I was pretty clued up. It wasn't as if I didn't know anything about Alzheimer's, and we looked after her till she became really bad and we had to put her into care. But other than that, I just – I just read about it and I said it's pretty – pretty much commonsense, really.

35

40

MS BERGIN: So you read about it. Did you read about it on the internet or did you borrow books from the library?

MS GRAY: No, I got some books. Some of the ones – when I – when I was seeking my package, and I interviewed a couple of different places, some of them – one of those gave me some really good information on it which was good, a really good – particularly a book. I can't even remember the name but I've still got it, but it was very good.

45

MS BERGIN: And was that book given to you by an aged care provider?

MS GRAY: Yes, yes.

5 MS BERGIN: Mrs Gray, you decided to look into options for respite care in 2018 when you planned to have a holiday with one of your daughters; is that right?

MS GRAY: Yes, yes.

10 MS BERGIN: You looked at a range of options for Clive.

MS GRAY: Yes. Yes, and this – the one that we put him into was one that people said to me, “Yes, they’re very good”.

15 MS BERGIN: Was kind of facility was this, Mrs Gray; was it residential care style facility or was it a cottage day care style facility?

MS GRAY: No, it was the residential, yes.

20 MS BERGIN: How long was Clive’s planned stay in respite care?

MS GRAY: He was going for two weeks. I was staying home for the first week just to refuel my system, then my daughter was taking me away for four days just up the coast from Port Macquarie just for a relaxing time. So he was going for two
25 weeks initially.

MS BERGIN: On that first day when you first arrived with Clive, what did the facility say about visiting Clive during the first three days of his stay?

30 MS GRAY: They told me that I would probably be better off to stay away till he settled down, which I was a little bit worried about.

MS BERGIN: How did that make you feel, Mrs Gray?

35 MS GRAY: It made me feel a little worried. I thought, well, yes, perhaps the first day but I myself, you know, wasn’t happy about not seeing him for that time.

MS BERGIN: When you took him into the facility on that first day, what
40 conversations did you have with facility management about Clive’s care and his care needs?

MS GRAY: I more or less told them that he was 24-hour care and that he was not
45 capable of thinking for himself as far as drinking and that type of thing going. I definitely stated to them, you know, the severity of his situation.

MS BERGIN: Did you explain that Clive needed assistance with his meals?

MS GRAY: Yes, yes, that was one of the main things, and I told them he was – knife and fork, he just didn't comprehend. You had to cut it up and he would eat with a spoon. But even then, sometimes he would, halfway through his meal, genuinely think it was all gone. They would then have to prompt him and assist him.

5

MS BERGIN: Mrs Gray, did you mention that he needed assistance with showering?

MS GRAY: Yes. Yes.

10

MS BERGIN: And you took - - -

MS GRAY: And dressing and everything, yes.

15 MS BERGIN: And dressing. So you took a change of clothes in with him?

MS GRAY: I took probably about five changes, probably too many. Yes, I made sure he had plenty of clothes.

20 MS BERGIN: Mrs Gray, did the facility prepare a care plan or do an assessment of Clive's needs when you arrived on that first day?

MS GRAY: Not that I know of. They did do his obs when we came in but they didn't kind of say what they were going to be doing or anything like that, or didn't tell me anyway.

25

MS BERGIN: Did they ask for a copy of the ACAT assessment that had been done?

MS GRAY: No.

30

MS BERGIN: How did Clive enter the facility? Did he walk in by himself?

MS GRAY: Yes, he walked in by himself. I was holding on to him but he was walking in by himself. And at that stage Clive looked quite good because I was looking – really looking after him, you know, at home and if you looked at Clive you wouldn't have realised that he was as severe as he was.

35

MS BERGIN: On that first day – I'm now going to take you through a day-by-day account in the way you've set out in your witness statement and ask you about what happened on each of the days that Clive was in the respite facility.

40

MS GRAY: Yes.

MS BERGIN: What observations did you make about the respite facility on day one, which was Wednesday, 28 November 2018?

45

MS GRAY: I thought that they – I was a little bit worried that they weren't really trained in Alzheimer's. I had to – they more or less said there's a buzzer here, you can ring us, you know, when you want us. And I had to explain to them that he was – could not comprehend the idea of using buzzers or anything like that, and that he would regularly need to be checked on to make sure that he was okay and that he was drinking water.

MS BERGIN: Mrs Gray, Thursday, 29 November 2018 was day two of Clive's stay in the respite facility.

MS GRAY: Yes.

MS BERGIN: You don't mention day two, the Thursday, in your statement. Is that because the facility had told you, as you said before, that you weren't to visit for the first three days?

MS GRAY: Yes. I decided that I wouldn't go the Thursday. I thought well, I will give it one day seeing they had suggested that to me but by Wednesday – by Friday the 30th I – I did visit.

MS BERGIN: What time did you visit on the Friday, Mrs Gray?

MS GRAY: At lunchtime.

MS BERGIN: How was Clive's lunch presented to him?

MS GRAY: He was sitting in the dining room quite confused. His meal had not been cut up and he was just given a knife and fork, and he was just sitting there not knowing what to do.

MS BERGIN: Did you ask for a knife and fork so that you could cut up his lunch for him?

MS GRAY: Yes. I – I cut it up. He had a knife and fork so I cut up his meal and I asked for a spoon so he could eat it.

MS BERGIN: Mrs Gray, what was your next contact with Clive and the facility?

MS GRAY: On Saturday, 1 December I got a phone call to say that he'd fallen during the night in the en suite in his room, and that they don't know how long he had been there. He could have been there between one and four hours. I asked if a doctor had seen him and they told me no, that he was fine, and that he didn't need to see a doctor.

MS BERGIN: When you say it could have been between one and four hours, Mrs Gray, is that – what's that a reference to?

MS GRAY: To the fall. They said he could have been lying on – they found him lying on the floor and, apparently, he was calling out but his room at the facility was away up the very end. It couldn't have been further away. Apparently, they – somebody must have heard him eventually calling out. How long he was there, I don't know. He was sharing the room with another man, but that poor man was in the last stages of life which was very sad. So he wouldn't have been able to hear him or anything, you know, so they said to me they don't know how long he was laying there. He wouldn't have been able to get up by himself.

5

10 MS BERGIN: Mrs Gray, how did he appear when you visited?

MS GRAY: He was very distressed and confused, and then again, his meal had not been cut up.

15 MS BERGIN: Had he been left to use a knife and fork, Mrs Gray?

MS GRAY: Yes, just with a knife and fork again.

MS BERGIN: Did you raise that - - -

20 MS GRAY: I – sorry?

MS BERGIN: Did you raise that with the facility, Mrs Gray?

25 MS GRAY: Yes, I had a conversation with the staff and told them that he definitely could not use them.

MS BERGIN: Mrs Gray, what observations did you make about Clive on day five, which was Sunday, 2 December when you visited him?

30 MS GRAY: There again his meal was served with a knife and fork. I was then going in at – at lunchtime, you know, to check on all these things. I approached the staff again and then I – when I took him back to his room I noticed that his water glass was empty, and there was a full bottle of water on the table with the lid screwed on which he would not be capable of undoing anyway, and I poured him a glass of water and he just – he drank nearly the whole bottle he was so thirsty. I approached the staff and asked them if they had been topping up his water. They said they didn't know they had to. They assumed that he was capable of pouring himself a glass of water and knowing to drink it. And this was despite me telling him – they just didn't seem to comprehend the severity of Alzheimer's.

35

40

MS BERGIN: How did that make you feel, Mrs Gray?

MS GRAY: It made me feel very angry, yes, very upset, yes. And at that stage I was starting to think why did I put him in here, you know, I was starting to get really, really worried.

45

MS BERGIN: Mrs Gray, what observations did you make about Clive on day six, which was Monday, 3 December 2018 when you visited him?

5 MS GRAY: I was so upset that I contacted the admissions manager and I asked for a meeting. And she saw me, which was very good, but she was unaware of the fact that Clive had fallen. She wrote everything down that I was concerned about and when I left she was going to see the staff about it, she said.

10 MS BERGIN: Did you return - - -

MS GRAY: And – so when she said that she would get him moved into a room closer to the nurses’ station so they could keep a closer eye on him. And she said that if his health started to – kept deteriorating, they would get – one of the two doctors that visit the facility would have a look at him.

15 MS BERGIN: Mrs Gray, when you visited the next day had Clive been moved?

MS GRAY: No. No, he was never moved the whole time he was there.

20 MS BERGIN: What time of the day did you visit on Tuesday, 4 December 2018?

MS GRAY: Well, this day was the best day of care that I had witnessed, and I thought well, she’s obviously given them a bit of a shake-up. His food was cut up, he was provided with a spoon. However, on that day he was in the same clothes that he had been wearing the previous day and I just thought well perhaps he hasn’t been showered yet.

25 MS BERGIN: Mrs Gray, having observed this improvement, but noting that he was still in the same clothes as the previous day, how did – how did your visit on day eight, Wednesday, 5 December 2018, go?

MS GRAY: Well, when I arrived, I noticed that he was still in the same clothes. I asked the nurse why this was the case, and she more or less bit my head off and said, “How can you expect us to put him in clean clothes if he hasn’t got any?” So I said to her, “Come over and have a look.” I pulled the drawers out in his room and they were full of clothes, and she just had a bit of a giggle and said, “I guess I didn’t have a good look, did I?”

35 MS BERGIN: How many days had you observed Clive in the same clothes for, Mrs Gray?

MS GRAY: That was the third day.

40 MS BERGIN: What did Clive say to you this day about how he was feeling?

MS GRAY: He was complaining about his neck. He was – with his Alzheimer’s, as I say, he cannot tell you if he’s got a headache or anything like that. If he – if he ever

had a headache he would just hold his head, and I – I learnt after all those years to read what his movements indicated and he was holding his neck like this, when I walked in. And I said to him was his neck sore and he said, “Yes.” And every time he moved his neck, he would go – you know, grimace. So I asked the registered
5 nurse about it, and she said – well, I asked to see the registered nurse. It took her about an hour and a half to come and see me. And I thought, “Well, here’s an 88 year old man complaining of a sore neck and he has had a fall. Surely, it should have been checked better than that.”

10 Anyway, she eventually came. and she told me that he had probably been sleeping on too high a pillow. And she arranged for a heat pad to be brought. Well, the nurse brought the heat pad in and more or less stood in front of him and threw it on his knee. And I looked at her and said, “There’s no point in doing that. He doesn’t
15 know what it was for.” So he just – he didn’t have a clue what a heat pad even was but they had made no attempt to put it on his neck. So I then sat with him for about another hour and held the heat pad on his neck for him.

MS BERGIN: Did Clive have other visitors while he was in the facility at this time?

20 MS GRAY: Yes. My daughter and her husband used to go and see him, and both our carers – both his carers went in to see him on separate occasions, just popped in to see how he was going.

MS BERGIN: In your statement you mention that your daughter visited on, I think
25 the – your daughter visited on Thursday, 6 December with her husband.

MS GRAY: Yes.

MS BERGIN: Were you there when they visited?
30

MS BERGIN: No. No, they went after work, after my daughter had finished work and, apparently, they just walked into the facility; weren’t queried or anything and just went. And they found him sitting in the lounge room watching telly, which it was good that they had him out of his room, but he – even television, he is not
35 capable of watching.

He doesn’t watch telly, but at least he was out of the bedroom. But that’s where he was when they arrived. But when they got home from visiting him, they were so concerned that they rang me, that he had deteriorated. They hadn’t seen him for a
40 little while. They had been away for two or three days. And they were so concerned at how he had deteriorated in the short time that they said to me that if I didn’t leave – get him out of there, he would not leave there.

MS BERGIN: When you say “he would not leave there”, Mrs Gray, what do you
45 mean?

MS GRAY: Well, they said “He will leave here in a – on a –” what is it that they have, you know, when they pass away? That’s what they said to me. They said that’s how worried they were. They said the way he’s deteriorating – they said, “He will either end up in hospital or he will pass away.”

5

MS BERGIN: So what, then, occurred the next day, Mrs Gray?

MS GRAY: Well, I was due to go on holidays that day with my daughter for the four-day break. I just – I went to see him before my daughter came to pick me up because I wouldn’t be able to see him for four days. When I arrived and walked into the ward, I could hear music playing and I thought, “Oh, this is wonderful”, because I told them Clive does love music and he will clap his hands and tap his feet, and he will sometimes have his eyes closed but he will still be kind of relating to the music. And I thought, “Oh, this will be lovely. He will be enjoying this. Perhaps things are getting a bit better.” And when I walked into the room where they were, I couldn’t see him. And I asked him where he was and they said, “Oh, he mustn’t have come down.” And I said to them, “Well, he’s not capable of knowing where to come or making the decision to come down.”

20 So I went up to his room and I found then that he had been showered and dressed in – in, you know, his clothes had definitely been changed, but he hadn’t been shaved, and the nurse – the orderly was still there, and I said – asked the orderly if he was going to shave him. And he said to me “Oh, I thought he was capable of shaving himself.” And I said, “Well, surely a man that can’t shower himself and can’t dress himself cannot shave himself.” And he was still holding his neck and very confused, and he just looked shocking. He looked so different to when I had taken him in nine days before. So I decided to remove him immediately.

MS BERGIN: Mrs Gray, what happened when you told the facility that you were going to remove Clive from the facility?

MS GRAY: Well, I went to the front desk in the ward and said that I – I was going to take him home and that I was going down to the little office desk to pay the account. The sister didn’t say to me, “Why are you taking him home?”, or anything. I went down and paid the account. They there again did not ask why I was taking him home five days early. I did – I asked for somebody to help me out to the car with him because by that stage he needed a wheelchair. His legs had gone, and I could not walk him out to the car to remove him.

MS BERGIN: How did you feel, Mrs Gray?

MS GRAY: I was in tears. I was so upset. And I was more or less blaming myself for leaving him there as long, you know. I thought I should have taken him home probably three days before, but you just – people had said to me when I said I wasn’t happy with the way he was being treated, “But you can’t expect any better”, and – you know, I thought, “Well, am I being picky?” But by that stage I knew I wasn’t.

MS BERGIN: Mrs Gray, did you take him to the doctor after - - -

MS GRAY: Yes.

5 MS BERGIN: - - - this experience?

MS GRAY: Yes. My daughter had arrived by that stage, and she was just so upset when she saw him. She comes from Singleton, and she had not seen him probably for about five or six weeks, and it just gave her such a shock, you know, when she
10 saw him, but it was only in those last few days that he had gone downhill. So I rang my doctor and they told me to bring him up, and they took him straight into the nurses' station and the nurse rang through to the doctor and said, "I think you should see Clive. He's - you know, he really needs to see you. I can't assess him."

15 So the doctor saw him, and he was just shocked. And he immediately arranged for him to have a CAT scan and an MRI, which I took him and had done. He was really sure there had been some damage done. Fortunately, there hadn't, but he had strained neck muscles and - I mean, this may or may not have been the result of a fall that he suffered, but it seems very, very suspicious that it was.

20

MS BERGIN: Mrs Gray, you explained at the start of your evidence that the reason you decided to take Clive to the respite facility was because you were planning to have a holiday with your daughter.

25 MS GRAY: Yes.

MS BERGIN: What did - what happened to your holiday plans, Mrs Gray?

MS GRAY: Well, we spoke to the doctor and I - my daughter - I said to my
30 daughter, "Look, we're going to have to scrap going away." And she said, "Well, we will talk to the doctor and just see." She said, "We'll just take Dad with us." So that's what we ended up doing. The doctor said, "Yes, you can take him", you know, that - and so we took him with us, which didn't give me a break, and he was so - he was a lot worse then than when I had put him into the facility, and he was even
35 showing signs of anger towards us, which he had never done. He's always been a very, very placid man, even with his Alzheimer's, and he was - I would go to touch him and help him and take him to the toilet and that and he was even swearing at me, which he has never done in his life. But it - you know, he was like that for about three days till he settled down, and I think he realised that he was back with
40 somebody that cared for him, you know.

MS BERGIN: Mrs Gray, I should have asked you, in relation to the doctor's visit, did the doctor advise you whether he - his hydration was okay?

45 MS GRAY: No. He said - that's the first thing he did when he walked over and saw him. He pinched his skin and that and he said, "He's dehydrated." And that - of

course, he was him with a UTI and he – that was making him confused, apart from the Alzheimer’s, you know. It’s a different type of confusion, it was, yes.

5 MS BERGIN: Mrs Gray, how long did it take Clive to recover from his stay at the facility?

MS GRAY: Look, it would have been – it would have been a good three or four weeks before I got him back, and he didn’t get back to what he was like. He had – he had deteriorated a little bit, but that can happen with Alzheimer’s. Whether it was
10 the cause of him being in there, I don’t know, but they can deteriorate, you know, in – sometimes they don’t deteriorate for a little while, and then, all of a sudden, they will deteriorate. But he had – he never got quite back to what he was the day I walked in with him.

15 MS BERGIN: Mrs Gray, the day you walked in with him, you walked in together and you explained to the Commissioners that on the 10th day he left the facility in a wheelchair.

MS GRAY: Yes.
20

MS BERGIN: How long did it take for his mobility to improve?

MS GRAY: That again – that was the thing that probably did never come back properly. He wasn’t as mobile as he was before he went in. He didn’t get back to
25 the – he was – he wasn’t – I mean, he couldn’t run a marathon or anything like that, but he was quite capable of walking, you know. I’d hold on to him when we would walk anywhere, you know, but it never got back to that.

MS BERGIN: How did this this experience make you feel, Mrs Gray?
30

MS GRAY: Well, I felt really bad about it, and I kept saying – I thought it was my fault, but the family kept saying to me, “No, Mum, it wasn’t your fault.” But it made me feel that no way would I ever, you know, put him in another facility.

35 MS BERGIN: Mrs Gray, after this experience of respite, did you make a complaint to the facility?

MS GRAY: Yes. Yes.

40 MS BERGIN: And what response did they give you, Mrs Gray?

MS GRAY: Well, eventually, I got a letter delivered by a courier from the facility, and when I opened the letter they were calling Clive Mr Barlow. So anyway, and

45 MS BERGIN: Who’s Mr Barlow, Mrs Gray?

MS GRAY: I don't know. I still don't know who Mr Barlow is, but they were calling him Clive Barlow and Mr Barlow. Anyway, then the next day I got another hand-delivered letter from the facility apologising for calling him Mr Barlow, and they had written that properly then, and called him Mr Gray. Anyway, then the next
5 day I got a phone call from the CEO, is it, or whatever they are, and he on the phone "I just wanted to make sure you got your – and apologise again." Then he started calling me Mrs Barlow.

10 MS BERGIN: Who is Mrs Barlow?

MS GRAY: We don't know. We don't know where Mr Barlow is or what's going on. But he started calling me Mrs Barlow and apologising, "I'm so sorry", and that. So I just gave up. So I – but haven't – didn't hear from them since. I haven't heard
15 from them since. But we're still wondering who Mr Barlow was, and it was – you know, even after they had realised their mistake and he rang me, he then started calling me Mrs Barlow. So I don't know whether Mr Barlow is still there or they've lost him or what.

20 MS BERGIN: Mrs Gray, how did that make you feel, being referred to as Mrs Barlow - - -

MS GRAY: Well - - -

25 MS BERGIN: - - - and Clive being called Mr Barlow in written correspondence?

MS GRAY: I was fairly angry at first, and then I kind of sat there and laughed. I could see the funny side of it and I thought, "Look, I'm giving up. You know, that's it. You know, it's crazy."

30 MS BERGIN: It didn't fill you with confidence.

MS GRAY: No, it certainly didn't.

35 MS BERGIN: How is Clive doing now, Mrs Gray?

MS GRAY: Well, we now have him in a new facility. My son-in-law was recommended this facility by a client of his, and we went and saw them and talked to them and had a look at the facility. So I put my name down to go in for respite for
40 two weeks, and within about five or six weeks I got a phone call from them to say that they could take him for two weeks. So I took him in. He was in a – put in a private room, which was lovely. He had his own en suite. It was a beautiful, lovely, big room. An older facility, not a big – big, new one, but it was lovely. And across from his room there was a little lounge room and then you could get out of that into a
45 little garden area, and it was just lovely and – you know, it was very homely.

So I thought "Well, this –" so for the first week, I was there every mealtime, but they were doing all the right things. And they've been absolutely marvellous. And then

at the end of two weeks, they offered me that he could stay, and they said they really thought he needed to be there. He was starting to fall out of bed night and this type of thing. And I said, “Well, can he stay in that same room?” And they said, “Yes, he can stay here. You can just make it his.” I could take pictures in and
5 everything. And they have been absolutely wonderful. I’ve seen the – I’ve seen the bad, and now I’ve seen the good. So - - -

MS BERGIN: You say in your statement that Clive moved into this facility in April
10 2019?

MS GRAY: Yes.

MS BERGIN: How was the adjustment for you after Clive moved there?

15 MS GRAY: Very hard for me. I’m still finding it hard. As I said, after kind of being with someone for so long, being married for so long, I’m finding it very hard without him. I miss him terribly. Even though he had Alzheimer’s – pardon me – he was still there. You still had his presence, and I miss that. But I know that he needs to be where he is and that it is better for him. And I will adjust eventually, but it is
20 hard.

MS BERGIN: Commissioners, that concludes my examination of Mrs Gray.

COMMISSIONER TRACEY: Thank you.
25

COMMISSIONER BRIGGS: Mrs Gray, thank you for your evidence. Thank you for your evidence. I would like to ask you, there’s such a difference between the two facilities that Mr Gray has attended. What do you think were the reasons for that? Was it the management of the place? Was it the staff? What might it have been that
30 led to such an enormous difference in how he was cared for or not?

MS GRAY: I think it was probably a combination of both. I don’t think the staff were capable of probably handling severe Alzheimer’s patients. Clive kind of, when he went in, did look fine. You would look at him and think, well, he looks a healthy
35 88-year-old man, but that is not what Alzheimer’s is all about. And I think they really couldn’t understand, even though I had written it – I had written a report, I had told them, you know, repeatedly. I don’t think the staff fully understood how to care for Alzheimer’s patients.

40 COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising?

MS BERGIN: Nothing arising. If the witness may be excused, please,
45 Commissioner.

COMMISSIONER TRACEY: Yes. Mrs Gray, as you said a minute ago, you've seen the best and the worst of respite care, and we're very grateful to you for having described your experiences and pointing out how people in your husband's position can be badly looked after, and on the other hand well looked after. And the work of
5 the Royal Commission is designed to ensure, so far as we can, that everybody gets well looked after, and your experience helps us to understand what's needed in that regard and we're very grateful to you for taking the time to recount the events that we've heard this morning, prepare your statement and give your evidence. We're very grateful. Thank you.

10 MS GRAY: Thank you.

COMMISSIONER TRACEY: We will break the link now.

15 **<THE WITNESS WITHDREW** [10.16 am]

MS BERGIN: I call Danijela Hlis.
20

<DANIJELA HLIS, AFFIRMED [10.17 am]

25 **<EXAMINATION-IN-CHIEF BY MS BERGIN**

MS BERGIN: Before I start your examination, Ms Hlis, did you want to pour yourself a glass of water?
30

MS HLIS: Thank you.

MS BERGIN: Ms Hlis, what is your full name?

35 MS HLIS: Danijela Hlis.

MS BERGIN: How old are you, Ms Hlis?

MS HLIS: 70 next month.
40

MS BERGIN: Where do you live?

MS HLIS: In Buderim retirement village, Buderim, Sunshine Coast.

45 MS BERGIN: Have you prepared a statement for the Royal Commission?

MS HLIS: Yes, I have.

MS BERGIN: Is there a copy of your statement there in front of you?

MS HLIS: Yes, there is.

5 MS BERGIN: Could you please identify it as your statement by turning the pages.

MS HLIS: This is my statement.

10 MS BERGIN: Is it true and correct on the basis of your knowledge and belief?

MS HLIS: It is.

MS BERGIN: Do you have any amendments to your statement, Ms Hlis?

15 MS HLIS: No, no amendments.

MS BERGIN: I tender the statement of Danijela Hlis dated 24 July 2019.

20 COMMISSIONER TRACEY: Yes, the witness statement of Danijela Hlis dated 24 July 2019 will be exhibit 7-17.

25 **EXHIBIT #7-17 WITNESS STATEMENT OF DANIJELA HLIS DATED
24/07/2019 (WIT.0320.0001.0001) AND ITS IDENTIFIED ANNEXURES**

MS BERGIN: Ms Hlis, you were born to parents in Slovenia.

30 MS HLIS: Yes.

MS BERGIN: Your parents continued to live in a small village in Slovenia.

MS HLIS: Yes.

35 MS BERGIN: You travelled and moved to Sydney in 1979.

MS HLIS: Correct.

40 MS BERGIN: Where did your parents meet?

MS HLIS: In a small place called Šoštanj in Slovenia where I was born.

MS BERGIN: When did they get married?

45 MS HLIS: In '49.

MS BERGIN: What was your role in the family?

MS HLIS: I was the first born. It was an unhappy family. I left my home when I was 15. My younger brother and sister stayed at home.

5 MS BERGIN: Your parents moved to be with you in Tasmania where you were living in 1996.

10 MS HLIS: Yes, life is full of surprises. Wherever I lived in foreign countries, I went home visiting my family every year or every second year. They stayed in Slovenia. I lived all over the world and then when I was living in Bicheno in '96 in Tasmania their health became very poor. They were old and lonely, scared of having to go into a residential care facility in Slovenia, and my brother, sister and myself were all living in Australia at the time, and Australia had that wonderful family reunion, still possible. So they migrated to Australia, to Tasmania.

15 MS BERGIN: Why did your parents need the assistance of yourself and your two siblings?

20 MS HLIS: My mother had severe depression and addiction problems. She also was diagnosed with cancer. My father had severe diabetes. He was supposed to be on regular meals and medication, but Mum wasn't able to care for him and he certainly wasn't able to care for himself. So we were advised by our neighbours in the village that it was too sad to leave them like that.

25 MS BERGIN: Ms Hlis, did it fall to you as the eldest child to look after your parents?

30 MS HLIS: No, we actually discussed between my brother and sister and we decided we will share the responsibility in Australia between me in Tasmania, my sister in Sydney and her partner, and my brother who was in Albury at the time, and that's what we told our parents and that's what we tried. Unfortunately, it didn't work out with the other two. So they came to live with me.

MS BERGIN: How did they settle into Tasmania, Ms Hlis?

35 MS HLIS: Incredibly well. I couldn't believe it. Just the fact that they were near their children, in my care. One took one hand and the other one the other one, and they said, "Okay. Love us, care for us," and they settled in well. The community accepted them well. They didn't have any English, but they managed without that. There was a bit of homesickness on my mother's behalf but not for long.

40

MS BERGIN: You mention in your statement, Ms Hlis, that you had to learn all about dementia. How did you go about this?

45 MS HLIS: Well, that happened a bit later because at the beginning mostly the problem for mother was withdrawal from her addiction substances and severe depression, and my father with his disability and his depression. So that was the beginning and later on when Mum had dementia and I had never heard of the word

before, I started Google search, joined workshops, bought books and DVDs, and only after I started understanding the condition was I able to become a better carer for my mother.

5 MS BERGIN: And how did your father's health progress once he moved to Tasmania?

MS HLIS: Well, he got better. They got both better for a little while at the beginning because of the change of diet, because of feeling secured and loved and
10 respected. We changed his medication. He never needed the insulin injections every day which was predicted and so on. But then the age and, you know, the two wars that they went through caught up with them and he had a few heart attacks and he was paralysed at this stage in Hobart Hospital, and I was told to put him in a nursing home because he will never walk again and so on. And I insisted and they kept him
15 for six weeks of intense physiotherapy and occupational therapy. He came walking home with a walking stick and he was just happy to be back in Bicheno.

MS BERGIN: What was your mother's experience of dementia?

20 MS HLIS: I think at the beginning nobody understood, least of all herself, what was happening. I remember her often saying to me, "What's happening? Am I going mad? It's crazy. I don't understand." But at that time nobody quite knew what was going on or why all those symptoms and all the GPs kept saying, "It's her personality, it's her depression. You have to put her in the home. She's going to
25 ruin your life" – meaning my life, because she just needs constant care and constant attention. And yes, so it was – with misdiagnosis and late diagnosis, I would say the first four years were extremely hard for both of us. By then father was gone.

MS BERGIN: Operator, could you please bring up the three photographs in
30 9999.0125.0001. Ms Hlis, could you please describe this photograph for the Commissioners.

MS HLIS: Yes. It's a very poor-quality photo because it's a photo of a photo I
35 carry in my purse every day. My parents who had a very, very difficult and abusive marriage, got somehow happier and better towards each other in Tasmania. And we – the photo is taken on the Spirit of Tasmania. I'm taking them to Melbourne to a Slovenian club and church to meet other Slovenians as a present for their 50th anniversary.

40 MS BERGIN: Operator, could you now please bring up photograph RCD.9999.0133.0002. Could you please describe this photo, Ms Hlis.

MS HLIS: That's a photo of my mum with one of her dolls. She had three children. She believed they were her babies. We went op shopping, buying clothes for the
45 babies and changing them. Yes, she believes they were her babies and I was her mum.

MS BERGIN: And was this photograph taken during that period when your mum had developed dementia.

5 MS HLIS: Yes, she was already diagnosed by then, by then, and she often took the doll with her when we went walking by the sea and so on. It was her constant companion, she wouldn't go anywhere without her baby.

10 MS BERGIN: Operator, could you please return to the first photograph and leave that up on the screen while I continue to examine Ms Hlis. How can the experience for dementia from someone from a CALD background vary?

15 MS HLIS: I always say it's at least 100 per cent harder than for an English-speaking person in Australia because there are cultural differences. The food, it's different, the language, it's different, and if the person with dementia of CALD background goes into respite or residential facility and there is no ethnic specific care available, that person, it's totally lost, partly because of dementia and partly because nobody understands them. I remember the first time Mum was in respite and I visited her on the first day of her second week; she was sitting on her chair like this and she wouldn't move and the carer said "We can't move her from the chair. We don't
20 know what's wrong."

25 Anyhow, as soon as I approached her I could smell, and she said, "Take me away. Take me away. Wash me." So I asked them what had happened at the beginning, before she sat down in the chair and they said, "She kept saying things but we couldn't understand". So obviously all she wanted was to find a toilet. Nobody understood her. They didn't use the culture, bi-cultural posters and took in albums that I had given them, and she had her first accident ever and she felt dreadful.

30 MS BERGIN: How did you feel on that day, Ms Hlis?

35 MS HLIS: Well, angry, sad, ashamed that I had to put her in respite at the time, but also started negotiating with the management of the facility about possible cultural awareness trainings that Migrant Resource Centre where I was working at the time would deliver, and so we put into place a few training sessions.

MS BERGIN: Why was cultural-specific care not available to your mum?

40 MS HLIS: I don't think we have paid much attention in Australia to the needs of the people born outside Australia until now. I'm extremely grateful to be here today. I think all the migrants who have helped build Australia are now ageing, forgetting their English, either due to dementia or just old age. They have been excluded from dementia or aged care-related research. We allow researchers to get research grants with discrimination centres such as English proficiency required for participating in research. And so these are thousands and thousands of people who have lived here
45 are now reverting back to their culture and their language, but they have not been heard or included or listened until now. That is my finding. I'm sorry.

MS BERGIN: Ms Hlis, when you talk about “reverting back to their language”, are you referring to people who’ve developed dementia – who speak English and have developed dementia and then - - -

5 MS HLIS: Yes.

MS BERGIN: - - - forgotten how to speak English?

10 MS HLIS: Yes, through my work – my – I can’t say that, you know, my parents were entitled to any special ethnic-specific care because we took – the children, we took them on as our responsibility. So that is another story. But nevertheless as a carer, I didn’t get any support. But I am talking of thousands and thousands of people who have actually been educated in Australia, who came here, like little children, for example, and became engineers and lawyers and doctors, and are, 15 because of dementia, reverting back to their mother tongue. These people too have an enormous problem because they are married to Australian partners. Their children are born here and have not learned the mother tongue of that particular parent. And so I know of people who live in their own family but have no communications with them any more because all they remember, it’s Italian or Greek or whatever. 20

MS BERGIN: Ms Hlis, you mentioned your work in a migrant resource centre. Tell us about your other roles which you’re drawing upon in giving your evidence now. 25

MS HLIS: So I suppose since the arrival of my parents in ’96 and after father passed away and it was just Mum and me, I became to realise that we don’t have enough bi-cultural workers, that we are not involved enough in research, and so on. So I have been volunteering with an HMRC in dementia research with Dementia 30 Australia as a dementia advocate. Migrant Resource Centre, Multicultural Council introducing bi-cultural tools, different universities in producing training videos for better inclusion and participation of people from CALD background in everything related with aged care disability and dementia.

35 MS BERGIN: Thank you, Ms Hlis. You cared for your dad, you said, until 2001.

MS HLIS: Yes.

MS BERGIN: And you then cared for your mum until 2011. 40

MS HLIS: Yes.

MS BERGIN: How did these years as a carer for your parents in Bicheno in Tasmania impact on you? 45

MS HLIS: I suppose at first they destroyed me completely, because I was totally unprepared and unaware of what it is to give up your life and career and dedicated

yourself to the lives of your parents. But that is what caring is. Just hearing the lady from before, whether it's one person or two, you cannot do anything for yourself without making great organisational plans as to how to replace yourself so that somebody else is going to do something for the ones you care for.

5

I had to – I did try to commit suicide. They saved me. And after that I decided that if I'm going to continue being a good carer to Mum and Dad, I needed to get some counselling. So psychiatrist, psychologists, priests, Buddhist monks, read books and finally come out of that black tunnel, and then life became easier for all three of us.

10

MS BERGIN: Ms Hlis, your mum then spent three years in an aged care facility.

MS HLIS: Yes.

15 MS BERGIN: You continued to cook for her and spent most days with her.

MS HLIS: Yes, that was the idea. At least I was able to have some sleep at night, because one of the problems with Mum was that she remembered the Second World War and the hunger. So what she tended to do during night-time was to get up quietly around midnight, empty the fridge, hide everything under her covers of the bed and hope that it will still be there in the morning. And that included the raw chicken or butter or whatever. So we didn't have much sleep. And so once she was in a residential care facility, at least I was able to recuperate a bit. But I would pick her up at around 11 every day and I would take her back there around 3 pm. She really enjoyed her life with me with dementia because it allowed her to forget all the past traumas and suffering.

20

25

MS BERGIN: So your mum had moved to Australia at an advanced age when her health was poor. How did you ensure that your mum's Slovenian culture was respected while she was in the aged care facility?

30

MS HLIS: So, firstly, we gave her her own television and DVD player. We put the instructions on the wall for the staff to know how to operate it. She had her – this is my life book with all the pictures and everything. I got her a very, very good bi-cultural tool called Talking Album, into which you put photos of loved ones, or things to remember, like a toilet, or food, and you record in my voice sentences like, "Hello, Mum. I will be there for a cuppa in five minutes."

35

So if she's distressed, the staff can play that message for her and show her the picture, or show her the picture of the toilet and press the button and it will say, "Mum, I think it's time for a little visit to this room," and things like that. So all that helped. She had lots and lots of DVD, music and films in Slovenian. And, of course, constant visits.

40

MS BERGIN: Ms Hlis, how was your mother's experience of the aged care facility generally speaking?

45

MS HLIS: It took us about 12 months for her to stop hating it and crying and despairing, and my sister and brother helped a fair bit during that time. She just hated us, all three, but especially me because I was the one who was abandoning her. So, unfortunately, she – she was a hard case for the residential care facility, but then
5 she settled in and the fact that we were always going out and coming back and having fun. And also with reverse psychology, for example, when I had to leave her there, I would say, “I have to go back to work to earn some money so we can spend it.” If I said just that I was leaving, she would cry and she wouldn’t let me go.

10 MS BERGIN: Ms Hlis, you stay in your statement that you believe that if staff – you talk about the night that your mum died.

MS HLIS: Yes.

15 MS BERGIN: And at paragraph 39 – have you got a copy of that paragraph in front of you.

MS HLIS: Yes.

20 MS BERGIN: Could I ask you to read that out.

MS HLIS:

25 *I believe if the staff that night would have communicated with Mum by using a bi-cultural poster and the pain scale and called me as soon as she started crying instead of assuming it was one of her moments of depression, sadness or loneliness, we could have saved her. I think it is their duty of care to call a family member or an interpreter when a client is in distress and cannot explain why. All the tools were provided. Nothing was tool – nothing was used. I*
30 *believe she died unnecessarily.*

MS BERGIN: What do you mean when you say that your dear mother died because she wasn’t understood?

35 MS HLIS: She obviously had pain. When they put her on the phone for me, she just said, “Danijela, come, come, come,” and she was crying. They misunderstood her tears just for loneliness and attention-seeking, not for pain. They didn’t call the ambulance or me or anybody – or an interpreter to actually find out why was she in such a distress. I believe it is our duty of care that when a person is in distress and
40 you cannot understand the person needs or wants or distress, then you immediately arrange to have somebody present who will or you – you use, you know, the tools that you have available. Interpreters are not used enough and family members are not called soon enough.

45 MS BERGIN: Ms Hlis, it sounds like this was a difficult time for you and it came at a personal cost. Is there information or advice that would have assisted you about supports available for carers?

MS HLIS: Yes. I have to admit that through Carers Tasmania at the time, I was given a psychologist who came home to me and – and offered some counselling because I was so shocked by the whole experience and my – my Mum’s passing which was totally unnecessary and premature. And still today, which is nearly five
5 years/six years later, I have never been able to go anywhere near that nursing home. I think carers are taken so much for granted because especially carers of cultural different backgrounds are in many countries expected to look after our parents.

10 In some countries, and we have – I know people in Australia, in some countries, dementia is madness. In other countries, it’s punishment for God. In other countries, it’s a curse. And so these carers are facing enormous difficulties in caring for their parents, sometimes, yes, basically, 24 hours a day for years and years and years, because especially with dementia, if a person is otherwise physically, reasonably well it can go on for many years. So I really think that one of the things that is
15 important, it’s to remember that we should never be looking at home care assistant package for the client alone. The client and the carer are a partnership, and so when – when this assistance is given, both should be taken into consideration because without the carer, the person will end up in a nursing home very soon.

20 MS BERGIN: Ms Hlis, when you say that “the client and the carer are a partnership”, and this is relevant to home care, do you think it’s – it would be of assistance if carers’ needs were included in ACAT assessments?

MS HLIS: Absolutely. I know from a personal experience that for my brother-in-law, for example, carers’ needs of his partner, my sister, have never been asked. In fact, if he was – if he had different personality and he would say to his support
25 workers who come through the service provider, “Just sit here with me and watch television with me”, that would be the required thing to do. So it’s only through negotiating with the service providers that my sister and myself have been able to come to an agreement where they can help out with other things as well.
30

But – for example, my sister is 64, so she’s under the age of 65. She can’t have her own ACAT assessment. We have tried with other community services, with care link respite, everything. She lives in a regional area. There is nothing for her. When
35 she needs to go to the doctor, when she had her cancer operation, where I had my cancer operation, we couldn’t find anything through government assistance for carers that would work. We had to pay people from our pocket, that took care of him for that amount of time.

40 MS BERGIN: Ms Hlis, you mentioned your sister. She lives in Queensland.

MS HLIS: Yes, in Kuranda.

MS BERGIN: In Kuranda. Your sister met your brother-in-law in Slovenia.
45

MS HLIS: Correct.

MS BERGIN: He had migrated to Sydney.

MS HLIS: Yes.

5 MS BERGIN: And your sister moved her to Australia.

MS HLIS: Yes. They fell in love in Slovenia while he was on holidays there. And – and after a while he sponsored her as a spouse and she joined him in Sydney.

10 MS BERGIN: Operator, could you bring up document RCD.9999.0135.0001. I think the three – the middle digits are 0135. Just while the operator is bringing up that photograph, your brother – you talked about your brother-in-law; what's his name?

15 MS HLIS: Stan.

MS BERGIN: Your brother-in-law had a stroke when he was 64.

MS HLIS: No, hold on, he had it five years ago, he's 84, so 79.
20

MS BERGIN: Thank you for correcting me, Ms Hlis.

MS HLIS: Sorry.

25 MS BERGIN: What was your sister's age at this time?

MS HLIS: So she would have been 59.

MS BERGIN: What were your brother-in-law's care needs after the stroke?
30

MS HLIS: Well, when he had the stroke, similar to the other carer before me, we were told in Cairns Hospital that he would probably die. He was in coma for nine days so it was a very severe stroke. He was totally paralysed. His speech impairment, his throat was damaged, he couldn't swallow, he was on artificial food.
35 So very, very bad case of stroke. Because we insisted that we wanted to bring him home and care for him home, he stayed in the hospital for quite a while. He was receiving occupational therapy, physiotherapy, some speech treatment and so on. After six months, by then he was feeling better, but still quite unwell. He was very high care. I asked the hospital to arrange for ACAT assessment so that we could get
40 the package in place and move him home for Christmas.

MS BERGIN: Ms Hlis, when you say get a package in place, that's a home care package.

45 MS HLIS: Home care package, yes, because I knew that my sister wouldn't be able to do it on her own and the hospital knew the same, too. However, I had enormous, enormous problems with the hospital who delayed and delayed and delayed that

ACAT assessment until finally I told them I will go public and I will complain. And they said that it's not possible to have ACAT assessments in hospitals or – lots of excuses, and finally I got on to ACAT myself and arranged the assessment.

5 MS BERGIN: Was the ACAT assessment done in the hospital?

MS HLIS: Yes. They sort of listened to me more than they listened to the hospital but then they understood that there was a possibility for them doing such a direct assessment.

10

MS BERGIN: Ms Hlis, your brother-in-law now lives at home with your sister?

MS HLIS: Yes, it's been now about five years in between – as I mentioned before both myself and my sister had cancers and surgeries and so on. He has been in
15 respite a few times. It's always been a disaster. All he wants – because of his high level care, his culture and his language, it's to have in-home respite. I provide it every three, four, months for a couple of weeks.

MS BERGIN: How do you provide in-home respite for your brother-in-law, Ms
20 Hlis?

MS HLIS: Well, I travel up there. They pay for my travel expenses because I'm a pensioner, and then my sister usually goes away and visits her grandchildren in Sydney. And I take over and, yes, it's everything from washing to changing
25 incontinence pads, to showering, to cooking for him, culturally appropriate food which is the only one he eats. Spending a lot of time with doing exercises, doing speech exercises which he loves. He's very happy with my support and assistance. Unfortunately, I can't do that full time so when he goes into respite because of his needs, he always gets very, very sick there.

30

MS BERGIN: So why does your brother-in-law prefer in-home respite?

MS HLIS: I think it's complicated. I think for the people of CALD background, anything away from home psychologically means that they are no longer loved, that
35 they are abandoned, that they are not wanted. When they go into residential care facility, either for respite or to stay, even when they're going to day respite centres, a lot of people from different cultures feel that they are not wanted or welcomed at home. But, on top of all that, there is the food that he doesn't recognise.

40 There is the fact that he doesn't get the exercise. There's the fact that nobody looks at the plan we prepare for him, where it clearly says that his food needs to be cut up, where it clearly says that he can't swallow six tablets at a time without sitting up properly and assistance because of his swallowing problems.

45 It says about him not being able to put DVDs into his DVD player. So he will go for hours and hours looking at the white wall. And because of his culture and personality – and lots of other people from different cultures are like that – they are

not the complaining type. They are, yes, thank you, type. That's what they had in their countries where they, you know, had wars and so on. So yes, he's just a zero that nobody sees and cares for.

5 MS BERGIN: What level home care package is your brother-in-law on, Ms Hlis?

MS HLIS: Four, the highest possible. But if I may say that it's still about 16 hours per week, and for a carer, that's about 150 hours per week. So there is no life for a carer personally. There is just taking care of the loved one that matters.

10

MS BERGIN: Is in-home respite available through your brother-in-law's home care package level 4?

MS HLIS: No. That would mean then that we would miss out on the length of the package in a financial year. So what happens is that all the time that he does not go into care link respite, which can be up to 63 days per – per year, it's wasted money. That money goes back to the government. The money in the home care package, it's not for respite either, as we've heard before. So the time that we organised him, his carers from the support – the service provider to look after him for six, seven days cost him between six and seven thousand dollars just for that short period of time. My point is for people who don't go into residential care facilities for respite because of reasons just mentioned, that money should – should be added onto their level 4 home care package and used for in-home respite. That would only be fair.

25 MS BERGIN: Ms Hlis, are you saying that your brother-in-law has to choose between domestic assistance and showering on the one hand or respite care in the home on the other hand?

MS HLIS: Yes.

30

MS BERGIN: And when you say that it's wasted money, is that a comment about wasting the funds in the home care package on respite, which - - -

MS HLIS: No, the waste of money, it's when he does not use his 63 days per year entitlement in a nursing home facility respite.

35

MS BERGIN: Okay. So you're saying that he would prefer care at home.

MS HLIS: Correct.

40

MS BERGIN: Instead of using the 63 days.

MS HLIS: Even – even if the carers are not family, not friends, they are professionals, as long as he can stay in his home where he recognises everything, where he's not scared of what's going to happen or how – how he's going to be just one in hundred for example. He's never taken out into the garden when he's in respite. When he comes home, like the other gentleman, he needs weeks to recover.

45

MS BERGIN: I see. So you're saying it's wasted because he won't use residential respite.

MS HLIS: Correct.

5

MS BERGIN: Ms Hlis, you provide some suggestions for reform at paragraph 56 of your statement. And I just want to take you to one of those in the time we have remaining. You mention education initiatives would assist educate people from non-English speaking backgrounds about dementia. Could you tell the Commissioners a bit more about your idea there?

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MS HLIS: I think that the – the belief that certain people or certain specialists know best what the people of CALD background with dementia or what carers need, this belief, it's wrong. We need to get together a lot of people with experience, members of FECCA, for example, who have been service and delivering ethnic specific care. Migrant resource centres and so on. I think cultural competency audits should be conducted in aged care facilities as well as day centres.

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MS BERGIN: What's a cultural competency audit, Ms Hlis?

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MS HLIS: Well, to my knowledge it doesn't exist, but I have a very clear picture of how it should look. For example, if you see the advertisements of service providers or residential care facilities or even day centres, they will say "We welcome people of all cultural backgrounds. We have people – we have staff – people speaking your language", and they promise a lot and so people go and go there. But the point is that just because you may have a couple of workers from Philippines or India or Italy speaking those languages and knowing those cultures does not mean that you understand your client's need who might be something totally different.

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So competency audit in that case would look at who are your residents, what are their languages and cultural needs, who are your workers from CEO down to everybody else and what are their training for dementia, for cultural competency and so on. Liaise with ethnic specific clubs, churches, SBS and so on to really raise awareness about the needs of these people that have for so long been misunderstood.

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And I think mobile aged care information vans would reach more people, raise awareness about dementia, about the aged care ACAT assessment. Especially people of CALD background are really, really struggling to understand the – how to navigate the system, and I've tried myself and it's hard and – yes.

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MS BERGIN: Operator, could you please bring up paragraph 43 of Ms Hlis' statement. Commissioners, you'll recall that we heard in Adelaide hearing 2 evidence from Ms Mary Patetsos from FECCA which has been referred to this morning by Ms Hlis, and she gave evidence about the proportion of Australians from a non-English-speaking background over the age of 65. Ms Hlis has included an extract from a paper by Access Economics about dementia prevalence and incidents among Australians who don't speak English at home. Ms Hlis, you said in your

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evidence and in your statement that it's very important that CALD representation is very important. Could you talk the Commissioners through the statistics that you've quoted in this paragraph.

5 MS HLIS: So currently about 12.4 per cent of Australians with dementia, around one in eight do not speak English at home. People with dementia who do not speak English at home compromise one in eight in New South Wales residents with dementia, one in six Victorians with dementia, one in 15 Queenslanders with dementia, one in nine South Australians, one in 29 Tasmanians, one in nine Western
10 Australians, one in five Northern Territorians, and one in seven people with dementia in the ACT.

MS BERGIN: Is - - -

15 MS HLIS: Higher proportions of people who do not speak English at home are directly related to significant cultural populations, in particular jurisdictions, for example, indigenous people in the Northern Territory and Greek people in Victoria. Overall in the period 2001 to 2015, there is projected to be a fall in the proportion of
20 Australians speaking English, 83.8 per cent or 82.4 per cent and other European languages, 7.6 per cent to six per cent with a greater proportion speaking Asian, 6.0 per cent to 8.3 per cent, and Middle Eastern 1.8 to 2.3 per cent languages.

MS BERGIN: Thank you, Ms Hlis. Why was it important for you to give evidence to the Royal Commission today?

25 MS HLIS: Well, because I care, because I believe that we can all work together to improve the situation, because I have hands-on experience with not only caring for my parents and my friends and my aunty who all had dementia, but also working as a bi-cultural diversional therapies, bi-cultural social support worker, being volunteer.
30 And so hopefully, just by being invited to speak, I am filled with hope and gratitude and look forward to better times.

MS BERGIN: Commissioners, that concludes my examination of Ms Hlis.

35 COMMISSIONER TRACEY: Well, we have valued your contribution enormously. We have not previously heard evidence specifically dealing with the impact on the care of people with – who don't speak English or who have related cultural issues, and you've shone a great light on that, and we're very grateful to you for having
40 done so.

MS HLIS: Thank you.

COMMISSIONER TRACEY: Thank you for your evidence.

45 MS HLIS: Thank you.

COMMISSIONER TRACEY: The Commission will adjourn until 11.20.

<THE WITNESS WITHDREW

ADJOURNED [11.04 am]

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RESUMED [11.24 am]

10 COMMISSIONER TRACEY: Yes, Ms Hill.

MS HILL: Commissioners, I call Darren Midgley, Maree Woodhouse, Xenofon Voukelatos and Jennifer Garonne; I call them as a panel. They are presently seated at the witness table, and I indicate that there are some appearances to be made.

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COMMISSIONER TRACEY: Very well.

MR AUSTIN: If the Commission pleases, my name is Austin and I appear with Mr Clarridge for two of the participants and the organisations which they're part. I should clarify who that is. I appear for Princes Court Home Incorporated and its chief executive officer, Ms Jennifer Garonne. And I also appear with Mr Clarridge for Chaffey Aged Care Incorporated and its chief executive officer, Mr Darren Leigh Midgley. If the Commission pleases.

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25 COMMISSIONER TRACEY: Yes, thank you, Mr Austin. Are there any other appearances?

MS HILL: No, Commissioner.

30 COMMISSIONER TRACEY: Very well.

<JENNIFER GARONNE, AFFIRMED [11.26 am]

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<XENOFON (FONDA) VOUKELATOS, AFFIRMED [11.26 am]

<MAREE ELIZABETH WOODHOUSE, SWORN [11.26 am]

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<DARREN LEIGH MIDGLEY, SWORN [11.26 am]

45 MS HILL: Mr Midgley, could I ask you to please state your full name.

MR MIDGLEY: Darren Leigh Midgley.

MS HILL: And what is your role, Mr Midgley?

MR MIDGLEY: I'm the chief executive officer at Chaffey Aged Care.

5 MS HILL: And, Mr Midgley, have you prepared a statement dated 23 July 2019?

MR MIDGLEY: Yes, I have.

10 MS HILL: And do you have a copy of that statement in front of you?

MR MIDGLEY: Yes, I do.

MS HILL: And are the contents of that statement true and correct?

15 MR MIDGLEY: Yes, they are.

MS HILL: I tender that statement, Commissioners.

20 COMMISSIONER TRACEY: Yes, the witness statement of Darren Leigh Midgley dated 23 July 2019 will be exhibit 7-18.

25 **EXHIBIT #7-18 WITNESS STATEMENT OF DARREN LEIGH MIDGLEY
DATED 23/07/2019 (WIT.0294.0001.0001) AND ITS IDENTIFIED
ANNEXURES**

MS HILL: Ms Woodhouse, could I ask you to please state your full name.

30 MS WOODHOUSE: Marree Elizabeth Woodhouse.

MS HILL: And what is your occupation?

35 MS WOODHOUSE: Director of Clinical Services.

MS HILL: And where are you a director of clinical services?

MS WOODHOUSE: Wimmera Health Care Group.

40 MS HILL: Have you prepared a statement dated 24 July 2019?

MS WOODHOUSE: Yes, I have.

45 MS HILL: And have you got a copy of that statement in front of you?

MS WOODHOUSE: Yes, I have.

MS HILL: And are the contents of that statement true and correct?

MS WOODHOUSE: Yes, they are.

5 MS HILL: Mr Voukelatos, can I ask you to state your full name, please.

MR VOUKELATOS: My name is - - -

10 COMMISSIONER TRACEY: Excuse me, do you warrant to tender - - -

MS HILL: I do want to tender that, Commissioners, thank you.

COMMISSIONER TRACEY: Yes, the witness statement of Maree Woodhouse dated 24 July 2019 will be exhibit 7-19.

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EXHIBIT #7-19 WITNESS STATEMENT OF MAREE ELIZABETH WOODHOUSE DATED 24/07/2019 (WIT.0297.0001.0001) AND ITS IDENTIFIED ANNEXURES

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MS HILL: As the Commission pleases. Mr Voukelatos, could I ask you, please, to state your full name.

25 MR VOUKELATOS: My full name is Xenofon Voukelatos.

MS HILL: And what is your role, Mr Voukelatos?

30 MR VOUKELATOS: My role is a general manager of strategy and business development at Uniting AgeWell.

MS HILL: And have you prepared a statement dated 23 July 2019?

35 MR VOUKELATOS: Yes.

MS HILL: And you've advised the solicitors for the Royal Commission that, in fact, there is a change that you seek to make to that statement.

40 MR VOUKELATOS: Yes.

MS HILL: And that change is found at paragraph 62 of your statement.

MR VOUKELATOS: That's right.

45 MS HILL: What change did you seek to make at paragraph 62 of your statement?

MR VOUKELATOS: Seeking to change the number from over 2000 CHSP providers to a number of 15 – of over 1500 CHSP providers.

MS HILL: And that's on page 11?

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MR VOUKELATOS: Page 11, yes.

MS HILL: And so that second sentence should commence:

10 *With over 1500 CHSP providers.*

MR VOUKELATOS: Yes.

MS HILL: And with that change, is your content – is your statement otherwise true
15 and correct?

MR VOUKELATOS: Yes.

MS HILL: Commissioners, I tender that statement.

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COMMISSIONER TRACEY: Yes, the amended statement of Fonda Voukelatos dated 23 July 2019 will be exhibit 7-20.

25 **EXHIBIT #7-20 AMENDED STATEMENT OF XENOFON (FONDA)
VOUKELATOS DATED 23/07/2019 (WIT.0296.0001.0001) AND ITS
IDENTIFIED ANNEXURES**

30 MS HILL: As the Commission pleases. Ms Garonne, could I ask you to please state your full name.

MS GARONNE: Jennifer Anne Garonne.

35 MS HILL: And what is your role, Ms Garonne?

MS GARONNE: The CEO - - -

MS HILL: And - - -

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MS GARONNE: - - - of Princes Court Homes.

MS HILL: And, Ms Garonne, have you prepared a statement for this Royal Commission dated 19 July 2019?

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MS GARONNE: Yes.

MS HILL: And have you got a copy of that statement in front of you?

MS GARONNE: Yes.

5 MS HILL: And are the contents of that statement true and correct?

MS GARONNE: Yes.

10 MS HILL: Commissioners, I tender the statement of Jennifer Garonne.

COMMISSIONER TRACEY: Yes, the witness statement of Jennifer Garonne dated 19 July 2019 will be exhibit 7-21.

15 **EXHIBIT #7-21 WITNESS STATEMENT OF JENNIFER GARONNE DATED 19/07/2019 (WIT.0295.0001.0001) AND ITS IDENTIFIED ANNEXURES**

20 MS HILL: As the Commission pleases. Witnesses, I will commence my examination of the panel by asking you each the same three questions, and I will move to you in turn. Mr Midgley, could I ask you to describe to the Commissioners what respite means to you.

25 MR MIDGLEY: So respite, as an aged care service provider, has a significant meaning to me. Respite is an opportunity to provide a service to our community to meet the needs of care recipients and the informal carers' family and support members who are involved in the caring and life of the care recipient. For me as a care provider it's also an opportunity in the residential care setting to showcase the aged care services that we offer. It's an opportunity to bring people from the
30 community into our facility and demystify the experience of aged care, and it's an opportunity to – to model – to model aged care for our community. And so it provides an opportunity to – really to shine a great light on the experience of – of an aged care facility and it forms a very simple and effective marketing opportunity as well.

35 MS HILL: And is that why respite is offered by Chaffey Homes?

40 MR MIDGLEY: Respite is offered by Chaffey Aged Care for a number of reasons. It is – we have an allocation of places which enable us to do that. For us, it's a service that we offer to our community to meet the needs of our community. But for us also it's an opportunity where we have bed vacancies, and a lower occupancy rate to actually fill those beds and to ensure that, along with a higher level of occupancy, that we have optimised the income for our organisation as well.

45 MS HILL: Whereabouts is Chaffey Aged Care located, Mr Midgley?

MR MIDGLEY: Chaffey Aged Care is located approximately 10 minutes from Mildura, so we are possibly the northern, or the north – probably the north-westernmost aged care facility in the State. So about 10 minutes from here.

5 MS HILL: And what respite options are offered?

MR MIDGLEY: We offer both low and high care respite for members of our community.

10 MS HILL: And is that within a residential care setting?

MR MIDGLEY: That is within residential care.

15 MS HILL: Ms Garonne, can I turn to you, what does respite mean to Princes Court Homes?

MS GARONNE: It really means that opportunity for us to provide to our community, to provide the informal carers with that opportunity to have a break, and to provide them with much-needed time out to be able to restore them. It – it is – it's
20 a really important aspect in regard to that, but at the same time it does give the individuals and also the carers an opportunity to also have a look at our aged care facility and to provide them with that opportunity to – to experience it, and to have an understanding of what we are offering.

25 MS HILL: What's the motivation of Princes Court in offering respite?

MS GARONNE: We have two allocated rooms for respite, and you know, that we need – we need to provide, and as I – I said, it is to provide the community with that ability for carers to have that much-needed break.

30 MS HILL: And again, that respite is offered in a residential care setting?

MS GARONNE: Yes, it is. Yes. Can I say, in regards to Princes Court Homes, our facility has a number of units which is different to the normal residential aged care
35 facilities, so we have 11 individual units with most of the areas where respite is undertaken with eight residents in those independent units.

MS HILL: How is respite accessed, Ms Garonne?

40 MS GARONNE: Respite is accessed by – the carers contact us and really identify that they would like to – to partake in respite. We – we would then have a look and see whether we have availability in regards to respite. Normally if somebody is looking to respite they would have already undertaken the ACAS assessment to be part of respite. So it's a telephone phone call in most cases. Occasionally it will be
45 from the hospital who are looking for respite for some of their – their patients.

MS HILL: And whereabouts is Princes Court Homes located?

MS GARONNE: We're located in Mildura, in the heart of Mildura, so we're very locally orientated and we have been operating for 60 years so we're the oldest aged care facility in this region.

5 MS HILL: Mr Voukelatos, what does respite mean to Uniting AgeWell?

MR VOUKELATOS: Respite for Uniting AgeWell means that we take a holistic view of the caring relationship, and that includes the person who's the informal carer and the person that they're caring for and in combination we work through an
10 approach that suits both parties. We see as respite being a critical factor in supporting and nurturing that relationship but it's only one part of the equation. There's so much more to the informal carer's roles, their responsibilities, their life, and respite plays a critical role in that.

15 MS HILL: What's the motivation for offering respite?

MR VOUKELATOS: Just building on my previous response, the motivation for offering respite is to acknowledge that we have a care recipient. We predominantly also have carers as well, so as an organisation we actually want to serve both cohorts
20 of people and to make that sure that they're well supported and that they achieve their goals and aspirations together and independently as well.

MS HILL: What respite options are available?

25 MR VOUKELATOS: So from an organisational perspective, we offer a range of respite options, that includes residential respite. In the Loddon Mallee region our respite services are all in the community. We operate our service in the southern part of Loddon Mallee through the Greater Bendigo area. There are three components to that: flexible in-home respite which is one-to-one respite with the care recipient and
30 that could be in the home or in the local community. We offer cottage-based respite and we also offer centre-based respite where people come into one of our centres; they undertake activities with like-minded people and it's an opportunity for a carer to have a break and for them to do their own thing as well.

35 MS HILL: How does the cottage-based respite work?

MR VOUKELATOS: Cottage-based respite works – operates from Friday
afternoons at 3.30 till Monday, 10 am. It operates 26 weeks per annum. It is funded by the Commonwealth Home Support Program. It's been a longstanding initiative
40 that Uniting AgeWell has been involved with. We – it's a small group home. It's an old house that's been refitted, purpose refitted to accommodate up to four people who have got respite needs.

45 Also, one of the rooms can actually accommodate an informal carer as well. So if an informal carer wanted to stay overnight with their loved one they could do that as well. There's a kitchenette, there's a lounge area. There's a quiet library as well, open garden. People do activities within the centre like cooking, etcetera, gardening,

but we also take people out of the centre for activities as well, and visits into the local community.

5 MS HILL: Ms Woodhouse, could I ask you to describe to the Commission what respite means to the Wimmera Health Care Group.

MS WOODHOUSE: It's an opportunity to provide unpaid carers with a break from their caring role.

10 MS HILL: What's the motivation for providing respite?

MS WOODHOUSE: It's part of our funded suite of services as a public health service that we provide to the community.

15 MS HILL: What respite options are provided?

20 MS WOODHOUSE: We have cottage respite at Barkuma House which is a three-day weekend stay which operates currently 17 weekends a year. We have centre-based groups that access that cottage as well. We have in-house – in-home respite care, and we have the social support groups under the national carer respite program and residential respite in the residential homes.

MS HILL: And how is respite accessed in the Wimmera Health Care Group.

25 MS WOODHOUSE: A number of ways. We can have people contact us directly. People navigate, if they're already involved in our service, you know, through social workers, that type of thing, or externally through a referral from My Aged Care.

30 MS HILL: And do people who are seeking respite express a preference for the type of program from Wimmera Health Care Group?

35 MS WOODHOUSE: I think a lot of people that approach for respite don't really – when they're first entering the system wouldn't know a lot about the different opportunities for respite, and what it means and what you can have. It's quite a complex system depending on whether you've got a CHP program or a home care package and the costs involved, what assessments that you need. It's different for each program so they would be supported through their case manager or coordinators or our community option program to navigate through that, and what best suits their needs.

40 MS HILL: Mr Midgley, who are the sorts of people that are approaching you for respite care?

45 MR MIDGLEY: It varies. Sometimes it can be a care recipient themselves. Usually it's the partner, the wife or husband, the spouse of, or child of the care recipient. At times it will be a community case manager. At times it will be a social

worker or nurse from the hospital who will make an approach around accessing respite care.

5 MS HILL: Ms Garonne has given evidence that it usually starts with a phone call. Is that your experience also?

MR MIDGLEY: Usually it does, yes.

10 MS HILL: And is there a set number of respite beds that are on offer by Chaffey?

MR MIDGLEY: There are – there are a set number of dedicated respite beds on offer by Chaffey and by that we have available two permanent beds which are available 365 days a year for the purposes of respite. However, it's our experience in – in recent years that the need for respite care has substantially grown, and each year, 15 year-on-year, our organisation has made application to the Federal Government to increase our allocation of respite bed days. And so over time year-on-year, the number of days of respite care that we have provided has grown.

To give an example of that, if you bear with me, I can give you some concrete 20 figures on that. So in the financial year 2016/2017 our organisation provided 813 respite care days. In the financial year 2017/2018 that number increased to 1395 respite care days. And then to meet our community's needs in the financial year 2018/2019 we made application and increased our respite bed days again and provided 1821 respite care days to our community.

25 MS HILL: Do you know why those numbers have gone up?

MR MIDGLEY: They – there's probably a number of reasons. My observation would be for our community we have an ageing population, as much of Australia 30 does, but in our region that population seems to be ageing at a greater rate. There is more demand and more pressure on families to provide care, but families now are busier. People are working longer. People now are working where in years gone by perhaps some elements of the family might have been home-carers, rather than – looking after domestic home duties, looking after their children. Now, they're in the 35 workforce and so there's not the ability to meet all of the needs of care recipients in the community.

So we are finding that there are – my experience has been that there is more and more demand for urgent or emergency respite care in crisis situations, or from 40 referrals from the hospital where somebody is not really safely able to go home and there's many pressures on our – on our regional hospital. So we do our best to assist the hospital where we can to take pressure off our community hospital and to meet the needs of care recipients and their families within the community.

45 MS HILL: Ms Garonne, what's the experience of Princes Court been with demand for respite in recent years?

MS GARONNE: Our – our demand for respite has also increased over the last three years too, so in the last 12 months our actual allocation is 730 days. We completely provided that. In the previous year it was approximately 600 days, and prior to that I think it was 550. So it has been certainly gradually increasing. At the – at the
5 moment we have four people on our list that are really requiring emergency respite. If we get an overall – if somebody drops out of respite at the moment, we – we have respite that is booked in for our two permanent beds for the next two to three months. And we have some people who are booking respite in for 12 months in advance. So the demand is certainly stronger than what it has been before.

10 MS HILL: How do those people, the four that are on your list, how do they come to be on that list waiting for the urgent respite place?

MS GARONNE: When people are looking for respite, they – they call us and if we
15 – we have a look at see what our situation is and whether we can put them – we book them in for a time period in the future. If there – there isn't any respite and they would like to, then we – we include them in a list and – yes, and then if there's an opportunity, we will assist them, yes.

20 MS HILL: Is respite available in an emergency or last-minute situation at Princes Court?

MS GARONNE: Rarely. We – we're 100 per cent occupancy and we have a strong demand for our aged care beds, so it's very difficult that we – and very rarely we
25 would have a bed that we would be able to provide somebody with emergency respite.

MS HILL: Mr - - -

30 COMMISSIONER TRACEY: Is there some arrangement amongst the providers in the area under which there is combined knowledge that, although you may be full, one of the other institutions may have vacancies and there can be an on-referral?

MS GARONNE: Quite often the need for emergency respite would be coming from
35 the hospital and it would be the social workers at the hospital. So the hospital and those representatives would know where respite would be available across the community, and then they would – they would ring to see if there was any opportunities at the different organisations.

40 COMMISSIONER TRACEY: But that's not going to help somebody who's at his or her wit's end at home with an elderly relative who needs placement because the carer has got to go away for a while. I'm more concerned to know whether there's an arrangement, formal or informal, amongst the local providers under which there's a bank there and knowledge that can be ascertained by one phone call from a social
45 worker or - - -

MS GARONNE: Yes, there's certainly an opportunity to be able to do something in a more formal sense in relation to that. Certainly, we engage a residential liaison officer, and she would certainly have a reasonable idea on where other – whether people could be provided with respite. So she would – I'm sure she would be referring them to the other areas, the other aged care facilities to – to try, yes, as much as she can.

MS HILL: Mr Midgley, how often would you get a call from the local hospital or from a carer seeking emergency or urgent respite care?

MR MIDGLEY: That varies throughout the year. There are peak times in the year when demand seems to be higher.

MS HILL: And when are they, Mr Midgley?

MR MIDGLEY: They tend, in my experience, to be over the winter months, and I suspect in relation to an increase in respiratory disorders, colds, flus and like disorders, but also over peak holiday seasons and around the Christmas and December/January period where families – where I guess the – my observation would be the – the informal carer might be seeking to visit with family or friends or see grandchildren, attend weddings, things like that. So they seem to be the hot points where demand seems to be – seems to be greater. Your question was around urgent - - -

MS HILL: Urgent last-minute care needs.

MR MIDGLEY: That tends to happen multiple times a week, two/three times a week, in my experience, where families or maybe the hospital are seeking an urgent placement for respite to meet the needs of a consumer.

MS HILL: And what do you do in those two to three times during the week?

MR MIDGLEY: If we have capacity, we do our very best to accommodate the admission. It might be that our permanently allocated respite beds are occupied but we might have a bed – a permanent bed that has become vacant, and so we will use that bed in the interim to accommodate the needs of the urgent respite care recipient whilst we are working through our waitlist to enable a permanent resident to come in. So we do creatively use our beds and our bed stock to meet the needs of care recipients and our community where we can.

MS HILL: Is a residential care facility such as Chaffey Aged Care in a position to respond to urgent needs for respite care?

MR MIDGLEY: It's very difficult. It depends upon – there are a number of factors, I guess. One is bed availability. You can only accept an admission if you have a place in which to accommodate that person, and in circumstances where you have an allocation of bed licences which enables you to be funded from the Federal

Government for providing that service. But some of the other challenges are around the – when it’s an urgent or an emergency presentation, it can be difficult to have the necessary documents that are required to undertake the necessary assessments to ensure that you can deliver safely and safe and appropriate care for care recipients.

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Usually an experience of Chaffey Aged Care where we have a planned admission for – for a respite place, we would undertake a – a pre-admission clinic and have the care recipient and their support person there, their informal carer come to the facility. They would have an orientation, we would undertake a series of assessments, we’d make sure that we have all the documents in place, provide them with the information about what needs to happen before they come in, so that – with a planned approach to delivering respite care, things would move fairly smoothly and you head off at the pass, I guess, the difficulties around not having the appropriate documentation such as a drug chart, clinical parameters.

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You know as an aged care provider what to expect in terms of care delivery, how that person is to be transferred, how they’re toileted, what their continence needs are what their food preferences are. Some of these things in an urgent or an emergency situation, an aged care provider needs to work very quickly upon admission and in the hours thereafter to try and get the information together to ensure that we can adequately provide for the safe care of the care recipient.

20

MS HILL: Putting those urgent circumstances to one side, what’s the minimum period that you have people in for respite?

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MR MIDGLEY: There isn’t a specific minimum period. People can come for days, they can come for weeks, they can come for – in some circumstances they can be with us for months. As an aged care provider, there’s a huge amount of work that goes through a process of administering and assessing the person entering care, and that requirement to meet the level, a standard in the aged care standards is the same whether the person is there for a day or a month.

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And so for an organisation delivering respite care, because of this huge amount of work in assessments and in determining the care plans to ensure the safe provision of care, it’s better for us to have somebody for a longer period of time. So whilst Chaffey Aged Care don’t have a minimum period of time, we – we tell care recipients that we will prefer that they have a minimum of two weeks simply because there’s a huge amount of documentation that has to be completed to enable the safe care of that care recipients over the course of the admission.

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MS HILL: So carers or care recipients are advised that the preference of Chaffey is about two weeks, and you’ve indicated that Chaffey’s preference is, in fact, that it’s longer. What do you mean by “longer”?

45

MR MIDGLEY: There’s no – no real limit on – on the term, other than the – that the days that a respite recipient is enabled to access. So the Federal Government will – will provide funding for 63 days in a – in a year for a care recipients and there are

provisions within the Act that enable – enable application to be made for 21-day extensions, and at times that’s needed to happen. So, you know, we don’t really have a maximum length other than for the – other than what is limited by the funding that we can receive. So, obviously, we’re not in a position as aged care providers to
5 accommodate people where there will be no income beyond the funded 63 days.

MS HILL: Ms Garonne, if someone rings up Princes Court seeking respite care, what’s that person advised in terms of the period of time that respite care is available for?
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MS GARONNE: We have a preferred two-week period also for the reasons that Mr Midgley has mentioned. At the same time, we have some flexibility in regards to that where they need it for a shorter period of time, yes, it’s for that two-week – for the amount of work that needs to go in and the assessments and the information and the agreements, a two-week period is – is what we prefer.
15

MS HILL: In your statement, Ms Garonne, you describe that the admission process can take up to 10 hours. Could I ask you to describe how that time is accounted for?

MS GARONNE: From the initial telephone call, there is an overall assessment that would need to be taken, especially if that person is coming in in high care. So it would be a case of the director of nursing and the clinical staff understanding what the needs are of that individual coming in. The – then it would be a case of working through the agreements and understanding – providing that information to the individual and also to the – the carer in regard to what the arrangements were at our facilities.
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Then the – the person would – the carer and the care recipient would come into the organisation and – and be provided with that overall understanding about the financial side, and also have a further assessment with the clinical care that would be provided with a tour of the facility, introductions to the different staff, and then they would come in, in the admission. During that process it would then be another orientation. There would be an understanding of all of the needs such as their medical concerns, their dietary requirements, understanding their – their – you know, what their different requirements would be while they were there. Then it’s a case of orientation – them with the units, with the people that are in the units, providing them with an understanding about how the – how they have – their meals are provided.
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So it’s quite a process on that overall initiation. At the same time, that room would – would need to be cleaned. So we’re talking about a three-hour process from, you know – so, you know, there’s a whole range of different aspects that need to be included and, you know, 10 hours is what we have put forward as – that’s what it would really take, yes, resources-wise.
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MS HILL: And that process, Ms Garonne, is that the same process that you would undertake at Princes Court for a permanent resident?
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MS GARONNE: Yes, it would. Yes.

MS HILL: Mr Midgley, you've described a pre-admission clinic; how does the pre-admission clinic work?

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MR MIDGLEY: The pre-admission clinic is an opportunity for our organisation to look at what the care needs of the care recipient will be upon their entry. It's an opportunity for us to compare the information that we are able to download from the My Aged Care website in relation to the care needs of the care recipient with the reality of their care needs. One of the big issues is that the information that we're able to download from the My Aged Care website in relation to the care recipient's needs often is dated. And it might be, for example, 12 months or more old and the care needs of the person has evolved over that time.

15 So it's a time when – where our registered nurse can ask questions and undertake assessments, including assessments like a falls risk assessment tool to look at the falls risk of a person, we can explore their continence needs, their toileting preferences, their meal preferences. We can look at their swallowing ability. We can look at their skin integrity and potential for skin integrity issues, using a Braden assessment tool. We can use the pain management tools that we have to assess their potential pain. And that helps us to formulate a plan for how we will deliver their care upon entry to the aged care facility but also it helps us determine whether or not we can safely and adequately provide for the care.

25 MS HILL: Does that pre-admission process differ to if someone's entering on a permanent basis?

MR MIDGLEY: Very similar. There's very little difference. We're using the same assessment tools because, as I mentioned, we're held to the same account, to the same standards for whether somebody is a respite or permanent resident whether they're there for a day, a month or a year. So it's very important to us to ensure that we have a very good understanding of their care needs and that we've assessed our ability also to meet their care needs once they're admitted to the facility.

35 MS HILL: Ms Woodhouse, in your statement you describe a face-to-face assessment that occurs when someone comes to Wimmera Health Care Group for the purposes of respite. Could I ask you to describe how that occurs.

MS WOODHOUSE: So I think in my statement I refer that's the process in somebody accepting respite care at Barkuma cottage respite. So once we've had a referral and a priority assessment done as to need, our coordinator would attend to the home generally and meet with the carer and the care recipient and do a full assessment to ensure that the care recipient is actually low care, and could be cared for safely in the respite cottage setting.

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MS HILL: If someone isn't low care, what happens?

MS WOODHOUSE: Then we would work with them to get them respite in our residential facility or get in-home respite or access the social support group. So depending on how urgent a need was would be what would guide our practice. There are examples where there has been a care recipient at home that's needed
5 emergency care and was uncomfortable with having the assessment and was unsafe to travel, was unsafe in the home, and our care coordinator attended at the home within a couple of hours of the phone call and then we worked with our local providers. We're fortunate often at our Dimboola Campus we have four acute beds plus 26 residential beds. Often the acute beds aren't 100 per cent occupied so for a
10 need there we would put them into the acute bed, get an ACAT assessment, which we could do within 24 to 48 hours, organise non-emergency transport to get the client there who could then transition into respite at Dimboola.

MS HILL: What informs whether someone is a priority for respite?
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MS WOODHOUSE: It would be an – there would be a guideline that assesses any intake worker on how they – what questions they ask and what process they go through. A big part of it would be on the carer's stress and need and the burden at that time. It may be that, you know, they've got to go into surgery and they've just
20 got the call and they've got to go in tomorrow. So that may be a need that we just have to sort out on a day or it may be that a care recipient's condition has declined and they're no longer safe in that environment.

MS HILL: Mr Voukelatos, what processes are in place for when someone enters
25 respite care?

MR VOUKELATOS: When someone is eligible for respite care, their initial point of contact ideally would be via My Aged Care. So they go through My Aged Care on a high front and then they go through the regional assessment service and get a
30 face-to-face assessment there. And as part of that assessment, and the formation of their service plan, if respite is identified as a service type they will be referred to respite services within the local region. If one of those services is Uniting AgeWell and if it's either around in the Loddon Mallee south region, flexible in-home respite, cottage-based – sorry, centre-based respite or cottage-based respite, we would
35 receive that referral.

And we normally go out and visit. We call up, obviously, the carer initially, and we go out and we undertake a co-assessment process and I've outlined that around
40 paragraph 40 in my statement. The co-assessment process is a tool that's been – an evidence-based tool, it's around consumer-directed care. It's been designed to be co-populated by the carer, the care recipient and the provider being Uniting AgeWell. Normally what we do, because we offer planned respite options, we send out an information pack with the co-assessment form, so that people can start their journey before they've even come into Uniting AgeWell for formal services. When we go
45 out, we complete the form with them. That then drops into developing their goals and aspirations and how we can have a meaningful, you know, provide meaningful respite services tailored to their needs.

MS HILL: Once someone has entered respite care under – with Uniting AgeWell, Mr Voukelatos, how is the care delivered?

MR VOUKELATOS: Yes. So we, as I've said, we offer three forms of
5 community-based respite. It's delivered from a Commonwealth Home Support Program. We're funded discretely for each one of those programs that we deliver. So flexible respite has got its own funding source and units. Cottage-based respite the same and centre-based respite the same. In terms of when someone enters
10 Uniting AgeWell we deliver the services ourselves so in the form of flexible in-home respite we have a small direct care workforce and that direct care workforce is matched up with the care recipient and delivers respite in the home or in the local community. In terms of the centre-based activities that we run, we employ our own personnel, and we train our own personnel to actually deliver those lifestyle and community-based services. And for cottage respite we do the same; we employ our
15 own people for that.

MS HILL: Ms Garonne, how is care delivered once a person is in respite care at Princes Court?

20 MS GARONNE: Care is delivered the same as any other resident that is at Princes Court. So the care is delivered, they are provided with their meals, breakfast in their units and we also have meals, both dinner and tea at our communal dining room. The recipients are provided with an opportunity to be involved in lifestyle activities. We provide lifestyle activities twice a day, including at the weekends, and if they are
25 – they aren't interested in that, well, then we will also provide them with an opportunity with different things in their – their rooms. We – we are a little community and certainly the staff and also the volunteers and the lifestyle activities certainly make them feel very welcomed at our facilities, and in some circumstances even the other families who come and visit.

30 We certainly encourage the care – the carers to also be part of our community and come and visit the care recipients, and we have a cafe so it's quite a community gathering, and everybody certainly is very pleasant to each other and, you know, we provide them with an environment where they feel welcomed. We've got, our staff
35 are just – are very friendly and we are often getting compliments in regard to the way that our staff acts in relation to the residents. The care recipient is provided with the same sort – the same assessments, etcetera. Every day they are assessed as per their skin, dexterity, with showering and also whether there's any concerns in regard to that, or any bruising, etcetera.

40 We – the – any changes are reported in our reporting system which is called Manad, and any changeover in shift, if there's any change in behaviour or medicines or any concerns then the information is fed from one shift to the other. And the clinical care coordinator is regularly keeping an eye in regard to that overall respite resident's – if
45 anything, the respite residents are provided with some – some really excellent caring. I know our lifestyle activities person regularly visits every day, and just to make sure that they're happy and comfortable in the surroundings.

MS HILL: Mr Midgley, is there a difference between the care that is offered to a respite residents and a permanent resident at Chaffey?

5 MR MIDGLEY: There's not really any substantial difference between the care
offered to respite or permanent residents. Respite residents can, from a social
perspective and lifestyle perspective, can and do access the activities programs that
we offer. There is a plan of care for every resident. So our care and nursing staff are
delivering the assessed needs – care needs of the resident and informed by the care
plans that we have developed and the risk assessment tools. The experience really is
10 very, very much the same for care recipients, be they respite or permanent.

MS HILL: Are there referrals to allied health or specialised services for a respite resident?

15 MR MIDGLEY: Yes, there are, but some basic allied health services are provided
within the facility. There are circumstances where, in some cases, a respite resident
may require some allied health services that are not the obligation of the provider but
we do assist those people to access those services.

20 MS HILL: Turning to you, Ms Garonne, does Princes Court engage allied health
and specialised services for respite residents?

MS GARONNE: Given that it's only a two-week period, we rarely have a need in
regard to the allied health services. But if there is a need, well, then, we would
25 certainly provide that referral and offer the services. At the same time, as Mr
Midgley said, there's a number of areas there where our staff can provide some
services, such as if there's pain concerns, well, then, our nurses can offer nurse-
initiated pain-killers – so pain, yes, and also they can also provide heat packs and
also massage if there's a need. Some of those basic allied health requirements.

30 MS HILL: Ms Garonne, do you consider whether there's scope for something like
an exit assessment or otherwise that would contrast the position of the resident when
they enter for respite and when they leave?

35 MS GARONNE: I – we would certainly be assessing the – when a person comes in,
their actual assessment, and on a day-to-day basis we are providing that
understanding with regard to how they are and what is occurring. In regard to
whether we would need to undertake an exit to see whether there's any change, it's
certainly something we could consider, yes. On saying that, we – the overall
40 understanding from my staff is that most people who do come into respite are really
very pleased with the – the overall treatment they are provided with, and many may
have been apprehensive in regard to coming into aged care. By the end of the two
week period they really want to book the next opportunity to have some further
respite.

45 MS HUTCHINS: Mr Midgley, does Chaffey Aged Care conduct any exit
assessment or a review of a person at the time that they're leaving their respite?

MR MIDGLEY: We assess our care recipients all the way through. So as their needs are changing or evolving, we're assessing them each day to ensure that we're providing appropriate care. Taking up on your point about an exit assessment, I would raise the point that – that there may be value in that, but the issue falls in what happens with that information then.

It could be used as a quality-control opportunity for our organisation to determine that we've met the needs that we've – that the person's completing their respite in a better state of health or with improved outcomes, but there is a disconnect between aged care providers and – there's not the communication.

So what happens with that information, if an aged care provider determines that somebody's care needs have evolved and changed, what happens when that person goes home if there's no connection with other services that may be involved? Because at the moment, there's not usually a formal process to enable that exchange of information.

MS HILL: Do you say that there should be an exchange of information?

MR MIDGLEY: I think that it would be immensely helpful if there was a structure and a system which enabled that information to be shared.

MS HILL: Mr Voukelatos, what records are kept of a person's time in respite with Uniting AgeWell?

MR VOUKELATOS: So we would keep a range of records for the individual. Those records would include their assessment via the Regional Assessment Service, any assessments via the Aged Care Assessment Service. We also keep a record of the assessments that we undertake – a co-assessment that we undertake with a person. There's a range of other paperwork as well, including agreements we have. Also further to that, a care plan, dated notes and any evidence of reviews. So, basically, have a whole suite of elements that we document and we – we keep on – on file.

MS HILL: And what happens to those records?

MR VOUKELATOS: So – so we maintain those records. So if a client's accessing respite, we keep a living file, I suppose, for a better term, and at the point of review we review their records and, you know, reassess and see what else needs to happen.

MS HILL: And are those records shared at any point in time with any other service that may be providing care to that person?

MR VOUKELATOS: Yes. So – well, if I go back to my initial comments, the – there's already a sharing of information in the form of – via My Aged Care, you know, the commencing with client records there and via the ACAT teams. If we are referring to third parties, then we will complete a service authorisation or we will

send information to that third party to support the coordination of care after seeking consent of a carer and/or the care recipient.

5 MS HILL: Ms Garonne, people enter Princes Court for respite when they're often on a home care package. Does Princes Court ever receive information about that person's experience and time on that home care package before they enter Princes Court for respite?

10 MS GARONNE: Not that I'm aware of.

MS HILL: Is that something that Princes Court seeks out?

15 MS GARONNE: I would – I really wouldn't be able to – to – to say that. Obviously, we do an overall assessment on the individual and would ask a set number of questions that we would, yes, normally ask of any resident that's coming into the facility.

20 MS HILL: Ms Garonne, you've given evidence to the Commissioners that you – yourself and your staff observe people's condition improve when they're in respite. On what basis do you make that observation?

25 MS GARONNE: Really, it's from the feedback that we get from the respite recipients. One of the areas in particular is that they indicate that they have really enjoyed the social aspect of being at Princes Court Homes, the interactions with others, which in some respects they're not normally getting within the overall community.

30 MS HILL: Beyond that which you've already described, are there deliberate program in connection place for respite residents at Princes Court?

MS GARONNE: They are offered the same as – as all of our permanent residents, so they're no different.

35 MS HILL: Mr Midgley, at Chaffey Aged Care, does Chaffey offer its respite residents programs to improve their condition whilst they're in that respite period?

40 MR MIDGLEY: We – we do, and, like Princes Court, the programs that we offer for our respite residents are the same programs that we offer for our permanent care residents, and we do orientate our respite residents to those programs and encourage them to – to engage with those. I'm sorry, could you repeat the question?

45 MS HILL: I might ask this question. I will rephrase it, Mr Midgley. Does Chaffey Aged Care offer its respite residents programs to assist to improve their condition whilst they're in respite?

MR MIDGLEY: The simple answer to that is yes, as we offer all of our – our care recipients programs to assist them. That might take the form of a – a social

experience or a lifestyle program to assist them to become more socially engaged. Or it might take the form of – of a falls and balance program to assist them with mobility and reduce the risk of falls. Our system for – and structure for wound care provision. So there are a range of different programs and service offerings that we
5 use to meet their needs and improve their outcomes. And again, that’s all determined by their assessed need.

It might be simple things like food preferences and nutrition. And it is our
10 observation that whilst not all care recipients leave a – leave a respite experience better than when they came in, most do, and my observation is that that’s largely because they’re getting their medications, the right doses and the right medications at the right time. They’re getting a high quality nutritional intake and they’re socially stimulated.

15 MS HILL: What’s happening in those circumstances where people leave respite less off?

MR MIDGLEY: Sometimes it might be that – that they have had a fall whilst
20 they’ve been in respite. They might have developed a urinary tract infection, which people can develop at any time in any place. It might be that they – their confusion has exacerbated if they’ve had dementia and come into a new environment and struggled with the changes that that new environment brings. So there are circumstances certainly when people may not leave an aged care facility from a respite placement in the same state that they may have come in.

25 MS HILL: Is Chaffey Aged Care able to offer any reablement programs specifically for its respite residents?

MR MIDGLEY: Yes, in a sense that we – we encourage our respite residents to
30 engage with the enablement program that is we offer for our permanent residents. It is difficult because the nature of respite placement is often a fairly short-term placement, may be weeks at a time. So that’s not a lot of time to actually deliver some significant and meaningful outcomes for people who are attending respite care. The other point that I would make is that even with the support of an allied health
35 team and some restorative health practices, that may not be able to be followed up in the community following discharge, so any gains may well be lost potentially from discharge.

MS HILL: Ms Woodhouse, out of the respite programs that are offered by the
40 Wimmera Health Care Group, are there any that support the reablement of the care recipient with respect to respite?

MS WOODHOUSE: I would think the social support programs would have
45 programs tailored more to – there’s exercise programs that they do there and mental stimulating programs and physical separating programs, and they would be tailored to what the care recipients need. I think also in the cottage respite, because it’s such an intimate homelike environment, the care recipients are often known to the team.

It's only a very small team of staff that work down there, and very little changeover of the staff. So they really get to know the care recipients and the carers, so their programs could potentially be targeted.

5 MS HILL: How long do care recipients typically spend in that cottage respite environment?

MS WOODHOUSE: As in the – accessing the day programs?

10 MS HILL: Yes.

MS WOODHOUSE: I'm not exactly sure, but I think it would be some time. I think they would stay on the programs unless they went to permanent care generally.

15 MS HILL: So is that a question of months or years?

MS WOODHOUSE: I'm not entirely sure.

20 MS HILL: I will turn to complex care needs, which you've all touched on in your evidence this morning and in your statements, and - - -

25 COMMISSIONER BRIGGS: Ms Hill, before you do that, I just might ask a general question around re-enablement. We've heard a lot of evidence in this Royal Commission that apart from the time when people – carers take a holiday, entry to residential care for respite purposes, or for respite more generally occurs at a time of crisis, as you've described today, out of hospital, change of condition, different circumstances for the carer. That tends to suggest that there's a heightened need for more intensive focus on the needs of the person who's coming in for respite while their carer is away than there might be for others who are in your care on a longer-term basis.

30 Am I right about that, or am I missing the mark entirely? And I'm not castigating you for anything. I'm just following this up as a matter of inquiry. Are there things you can do to really re-enable that person so they can go home and operate at home better than they might have been able to do before and, similarly, take off some of the pressure on the carer?

35 MS WOODHOUSE: I think from our perspective in residential services, for example, that would be difficult, and one of the things that would impact that would be the nurse-to-patient ratios. And, for example, on a night shift, one nurse is looking after 15 residents, and they don't all sleep at night, obviously. And, you know, one in eight in the afternoon compared to the acute setting where the clientele are not dissimilar, you've got five patients that you will be caring for. So I think practically on the ground to provide that better would be challenging, not – I think it would be – it would be great if we could. I think there would be a need. But I think in the current system, that's challenging.

COMMISSIONER BRIGGS: The rest of you?

MR MIDGLEY: Commissioner, if I could respond. I would say that there is much that could be done in residential aged care around supporting the needs and working
5 with a restorative health focus for care recipients coming in for respite care, as for permanent care recipients. However, the funding model is a very big constraint and there just are not the resources to enable – to enable a high level of restorative care to be provided for care recipients. And also compounding that is the skills shortage, particularly in regional areas where we struggle to recruit and retain, for example,
10 allied health staff, physiotherapists, occupational therapists. It's a real difficult – real difficulty for or community in particular, and I know it's an issue nationally in regional areas.

So the constraints of our funding model and the skills shortages presents some really
15 significant challenges in aged care providers implementing a robust and effective restorative care focus to care recipients.

COMMISSIONER BRIGGS: You're nodding.

20 MS GARONNE: Yes, I would concur with Mr Midgley completely. It is about having the resources to be able to offer what you're suggesting. We do the best that we can with the staff that we have, but certainly if there was some additional funding, that would – would certainly help the situation and – and also, as Mr Midgley has said, just trying to – to obtain the – the qualified staff that we need and
25 the workforce to be able to provide it is a real issue in the regional setting.

COMMISSIONER BRIGGS: Thank you.

MS HILL: Thank you, Commissioner. In respect of complex care needs in respite,
30 all four of you have said in evidence this morning, and indeed in your statements, that you're unable to receive complex care needs in respite. Ms Garonne, in your statement, and at paragraph 27, in fact, you indicate that Princes Court would turn away about 10 per cent of people for complex care needs. Why can't those complex care needs be received?

35 MS GARONNE: There's a couple of reasons there. Initially, it's because of the way that our facility is laid out. We – so we have three areas. We've got advanced care, where we've got nurses where they need to provide two-people assist, and they have the more advanced medical conditions. We have the special care area, where
40 it's a dementia and behavioural. And then we have the low care, which is really not low care. It's low to – to medium care that's required, where the – the residents are able to – to be a little bit more independent but not – not that much more independent.

45 So if – take into consideration we are pretty well 100 per cent booked, it's very difficult – and we've got two respite beds in the low care, quite often it is very difficult for us to offer a complex-care person to come into our facility when we

don't have the beds available in the advanced care or the special care areas, which is – it's very difficult, and I know the staff really struggle with it because it's very difficult when you – you know there's people within the community that do need support and we aren't able to offer that ability to provide that support.

5

MS HILL: What happens to those people?

MS GARONNE: First of all, the – I know our residential liaison would try the best that she can to – to be able to facilitate entry into – or referral to other aged care facilities in the – the community. And then, obviously, we would do what we can to put that person on emergency. So if there is an opportunity that does come – become available we're able to look after that – that care recipient and the carer. You know, it is just a difficult thing when there aren't enough facilities in the regional area to be able to provide for the demand that is – that is there.

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MS HILL: Mr Voukelatos, once someone is receiving respite through one of the Uniting AgeWell respite programs that you've written about in your statement, what sort of contact would Uniting AgeWell have with that care recipient's carer?

MR VOUKELATOS: So the contact that we would have outside of the initial visit, which is face-to-face, would be regular phone contact. If we're providing services, for example, cottage respite, we either transfer or transport the care recipient over to the cottage respite service or the carer brings in their loved one into the – the service. We have regular check-ins, we run regular reviews around care plans just to make

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So we survey our carers and care recipients to actually understand their needs and understand their satisfaction. There's probably more work that needs to happen in that area from understanding the true outcomes of – of care for care recipients and their carers. But we – we have continual contact with carers in terms of checking and making sure they're okay and that they're happy with the services they're receiving.

30

MS HILL: Ms Garonne, when would a carer be contacted when a care recipient is receiving respite at Princes Court?

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MS GARONNE: They would be contacted as we do with any permanent residents, where an event occurs that they need to be known – notified about, where there's a medical condition that has changed. And also there's a behaviour concern that we need to – to contact the care recipient to let them know what has occurred.

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MS HILL: Mr Midgley, if I can take to you paragraph 45 of your statement, and at paragraph 45, Mr Midgley, you describe that:

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A further issue of concern is that for those care recipients who are on respite, often their only support has left the district to take advantage of the break that the respite affords them. This means that when a care recipient needs

additional clothing, items from home or transport to an unplanned medical appointment there is no means of meeting these requirements other than by relying on the goodwill of aged care providers who are not resourced or funded to provide this level of additional service.

5

Is it your experience, Mr Midgley, that care recipients or their carers expect you to be doing those things whilst the care recipient is in respite?

10 MR MIDGLEY: There, in my observation, is a general expectation that we will fill the void, that we will meet the care recipient's needs. And again, this is one of the reasons why we try very hard to have a planned approach to respite and to have our pre-admission clinic so that we can anticipate the care needs and that we can have the conversation about what needs to come with the care recipient, the clothing that they need, the fact that it will need to be labelled so that when we wash it we don't lose
15 their socks in the washing, simple things like that. It's important for us to try and anticipate what the care needs are so that it doesn't involve a drain on our resources later.

20 Because the reality is if a staff member has to be provided by the facility to step in to meet the needs of the care recipient and that might be to collect something from – from – or to escort somebody to the general practitioner, then that staff member generally has to come off the floor because, unlike in – in – in perhaps urban areas, there are no agencies available here to call in extra staff and if we have – if our pool of casual staff are already engaged and working, there's nowhere to draw from. So it
25 takes resources away from other people. So it's important that we have a planned approach and it does – it does create at times, not often but at times it does create a problem.

30 MS HILL: If a carer isn't absent do you ask the carer to pick up the clothes, to take the care recipient to the appointment?

MR MIDGLEY: Yes.

35 MS HILL: And what contact would you have with a carer whilst someone is in respite at Chaffey Aged Care?

40 MR MIDGLEY: Generally, we communicate to the extent that the – that the carer is – is requesting. They – we encourage them to ring and to ask questions if they need to, if they want to know how the care recipient is settling in, they're free to ring at any time and to visit at any time. Unlike a hospital, we consider the aged care facility to be a home and care recipients can receive visits 24 hours a day. Usually the circumstances in which we would – we would call are if the – if there has been an adverse event, if somebody has had a fall, so we would ring and advise the carer of
45 the incident. If the care recipient is distressed and unable to be settled, we might phone, and sometimes talking to the – the care recipient talking to the carer at home helps to settle them. Sometimes the care recipient will ask if we could ring so that

they can speak to their – to their spouse or carer at home and we accommodate that as well.

5 So generally we try and meet the needs as best we can, but there are times, if there's
been a deterioration in the condition of the carer – or the care requirements have
changed for the care recipient, we will ring and advise the carer and it might be that
we request a review about the medical officer, and if a medical officer won't attend
to the aged care facility then there's no alternate but to try and organise for a review
10 of the care recipient at the general practitioner's or in some cases it does require the
transfer to hospital.

MS HILL: Ms Woodhouse, using Barkuma House as an example, when someone is
receiving cottage respite at Barkuma what contact does Barkuma have with the
15 carer?

MS WOODHOUSE: I think that would be case by case, so there would be a
conversation with the carer prior to them coming into cottage respite and that would
be planned before entry, whether they wanted regular contact. They would be
contacted if there was a deterioration or an event that they needed to be notified, but
20 otherwise it would be at the end, they would be provided update and handover and
we also do follow-up phone calls to see how the care recipients transition back into
home and how the stay was.

MS HILL: Mr Midgley and Ms Garonne, you've both described the administrative
25 burden combined with having someone come to respite at either Chaffey or Princes
Court for a shorter period of time and, Mr Midgley, you've touched on the funding
difference for someone that's received for respite compared with a permanent
resident. What are the implications of that for Chaffey Aged Care, Mr Midgley?

30 MR MIDGLEY: The implications are significant, and across the board there is a
general inadequacy of funding for the provision of aged care services. And if I can
highlight that for the Commission, looking back through the data of our organisation
over the past 12 months, it was my observation that for the respite service that we
offered, 55.4 per cent of respite care days were for low care assessed care recipients.
35 Now, the issue with that, for our organisation, and every organisation will be
different, but for our organisation, I estimate based on the funding from 1 July
forward for the rest of this year, on the actual low care respite care bed days we
provided in the last financial year, that we made a loss of \$67.47 per low care respite
care day that we provided.

40
For our organisation, that was 1009 low care respite bed days and that equated to a
loss for our organisation of \$68,077.23. This is – for an organisation that's a not-for-
profit organisation, but this is an organisation who is anticipating to make a financial
loss for the financial year just ended, and which is budgeting for a financial loss for
45 the coming year and when I speak to collegiate not-for-profit organisations every
single one I've spoken to is budgeting on a financial loss for the coming financial
year. And most have experienced a financial loss in the financial year just ended.

The problem is for us as an organisation who have ramped up and ramped up and ramped up our respite care bed days and capacity to meet our community's needs, we're doing that at a significant loss and we're subsidising – subsidising, really, a service that we don't have the capacity to continue to do. That's my experience as an
5 aged care provider. It's the experience of Chaffey Aged Care. I think it likely that that is the experience of most aged care providers delivering low care respite care within our community.

10 MS HILL: Mr Midgley, you've described earlier the incentive payment that you received for meeting a 70 per cent respite capacity, and you've described that respite capacity at Chaffey Aged Care has gone up and up over the past few years. How do you determine the respite capacity on that initial basis of it being two beds?

15 MR MIDGLEY: So for our organisation we permanently have two beds that we quarantine and only use for respite. But what we do is we make additional respite bed days available when we have an unoccupied permanent bed and that might be – there might be a period of a couple of weeks between when a resident passes away and the room becomes vacant and when the next resident might be able to come in, and we make use of that time to meet the needs of the community through offering it
20 as a respite bed. But as I alluded to earlier, there's multiple reasons for doing that. One is to meet the needs of the community. The other is because of the inadequacy of aged care funding we need to keep those beds occupied to generate sufficient funding to continue operating as an aged care service.

25 As an aged care provider, whether that bed is full or empty has very little impact on our expenditure. One bed on its own doesn't mean that we can change our staffing profile. In fact, we can have seven empty beds and still not be able to reduce staffing because we can't cohort the empty places into one area and reduce the staff member. They might be scattered across an organisation covering many, many hundreds of
30 square metres and, in fact, the empty beds might be two or three hundred metres apart.

35 So utility service use is minimal. Whether the bed is occupied or not, you're still heating a large space and cooling a large space. Our kitchens produce the same volume of food. It's not practical to reduce the food produced because there's an empty bed. So as a provider, occupancy becomes critical, and we seek to occupy our beds as much as we can possibly do to optimise the occupancy, as I said, to provide a much needed service to our community, but also to optimise our income within the constraints of a very highly regulated funding instrument that we have. And if we
40 are not optimising our funding to meet our community's needs, many aged care providers won't be here in the longer term.

45 MS HILL: Do you ever not make that 70 per cent capacity to receive that incentive payment?

MR MIDGLEY: We – in my experience we have, every year, reached the 70 per cent capacity. And as you'd see from my – my statement, there have been – most

years we have looked like we're going to – going to need additional beds to meet – additional respite bed days to meet community need and we've had to apply each year, and you will see year on year a dramatic increase in the number of respite bed days that we're offering as a service provider to our community.

5

MS HILL: If looked like Chaffey Aged Care wasn't going to be able to make the target that it set itself, what would you do?

10 MR MIDGLEY: We would, in advance, be anticipating and modelling the likely occupancy rate. And if it looked like we weren't going to reach the 70 per cent allocation, then we would make application to the government to reduce the number of respite bed days so that we were not further financially disadvantaged.

15 MS HILL: Mr Voukelatos, can I turn to you and ask you about home care packages. Are you able to explain how Uniting AgeWell manages home care packages for its clients?

20 MR VOUKELATOS: Yes. Uniting AgeWell runs a number of home care packages on behalf of clients' levels 1, 2, 3 and 4 across Victoria and Tasmania. In a lot of the Mallee region, as per the statement, we currently have 512 home care packages, and that – that means 512 clients receiving a level of home care package across all the region. We deliver our home care package services across seven different offices within Loddon Mallee. Three offices in the northern part of the region, including here in Mildura, in Swan Hill and in Kerang, which is the Shire of Gannawarra, and
25 four outlets within the southern part of the Loddon Mallee region.

How the process works is that someone is obviously assessed for home care package eligibility. They're on the national priority queue. They're now referred to Uniting AgeWell for a home care package. Now, that package could be at their appropriate
30 level, or it could be an interim package. As part of a process, clients receive a letter before they come to Uniting AgeWell that notifies them that the package is available. They run through a range of actions, including an income-tested care fee through the Department of Human Services. Then we come out, we make a suitable time and we run through the co-assessment process that I spoke about before, because we apply
35 that across all our home care services at Uniting AgeWell.

Part of our process includes sending out an information pack to people before we visit. Within that there is very – there's a handbook around home care packages and what to expect from a home care package at Uniting AgeWell. It runs through our
40 process on a very high level in terms of what people can expect as part of their visits.

There's a range of transparency statements with – when we go out, we explain to people what a home care package is, what level of package they're on. We run through a checklist with people. We do a co-assessment, develop a care plan, sign an
45 agreement with people. We've got a simple agreement in place and trying to take all the overly complex legal jargon out of it, but you still need to, obviously, frame it in a legal – legal approach under the Aged Care Act. But we've also got simple-to-read

terms and conditions that we also give to I a client and we explain that to them as well.

5 MS HILL: Ms Woodhouse, do people come – people come to cottage respite or day centre respite, are they generally receiving a home care package at that time?

10 MS WOODHOUSE: When they commence with Barkuma House, they can often have a Commonwealth Home Support Program funding, and they may transition to a home care package. And that's the same as the day centre or the social support group.

15 MS HILL: If I can take you to paragraph 78 of your statement, and at paragraph 78 and what follows you describe an example of a challenge community members need to deal with. Could I ask you to explain that example to the Commissioners.

20 MS WOODHOUSE: So under the CHSP program, our service offers around about two and a half hours of care per week. And then when they transition to a home care package, at the top level that can equate to roughly eight hours per week. Once you transition to the home care package, those services are charged on a full-cost recovery to the package, and, unfortunately, clients do fall through the gaps then because the – what they're receiving on the home care package and the additional service that they need, because they are deteriorating at home, often means that instead of paying \$6.50 to attend the social support group, each visit is charged at \$100.

25 And, often, they don't have the money in the package to pay for that, so they can't attend and they become socially isolated, and that's another form of much needed respite for the carer. Some of the carers – care recipients can be attending those programs up to two or three times a week, which allows the carer to work or have a break or play golf or that sort of thing.

30 MS HILL: Mr Voukelatos, if clients of Uniting AgeWell who are on home care packages don't have the funds to access respite services, what do you do?

35 MR VOUKELATOS: Well, there's a – there's a range of things that we can do. Under the Commonwealth Home Support Program guidelines 2018, the Commonwealth Home Support Program stipulates full criteria where if someone has maxed out their home care package, why they could still be eligible for CHSP – CHSP services on a short-term basis, including respite care. So if someone has fully expended their budget on a home care package, they could still, if we go back through My Aged Care or Regional Assessment Service, give them – prioritise or still access a Commonwealth Home Support Program for the short term.

45 What we tend to do is, as an organisation, we will work with a client as part of that initial visit to determine if they're going to be advantaged or disadvantaged in coming on to a home care package. Where there's an opportunity, and indeed that continuity of care, so the day activity, for example, can continue, we will negotiate

with My Aged Care and the local provider to see if we can still have that service coming in, maybe at a reduced fee, and we negotiate fees. It's not always the case but that's what we try to do.

5 Optimally, there would be around arrangement between organisations to still continue that care, but CHSP providers – and we are one of them in a certain part of the region – our focus is on – our priority is on clients who are being assessed for a Commonwealth Home Support Program, and where we have capacity we will support people for – for a home care package.

10 MS HILL: Ms Woodhouse, what observations do you make about the difference between the Commonwealth Home Support Program and HCP?

MS WOODHOUSE: Well, apart from the additional hours that you can get - - -

15 MS HILL: I should be clear, I apologise - - -

MS WOODHOUSE: Yes.

20 MS HILL: - - - Ms Woodhouse. In respect of respite that's available to care recipients.

MS WOODHOUSE: Well, I – my observation is from our service that it can be detrimental because the range of services that they then require as they deteriorate may mean that they can't access some of the social support respite that they need.

MS HILL: Ms Garonne, in respect of Princes Court and the experience of being a residential care provider, is it your experience that families are using respite to try out residential care for their loved ones?

30 MS GARONNE: Predominantly, the people that are coming to our facility are more where the care – the carer needs a break than anything else, and we – we do have residential respite residents who – who actually come – come in for the two-week and then continue to – to come back on an ongoing basis, more so than – than any other. When they do come into respite, though, because of the – because how much they like the environment, quite often they will, one way or another, end up being our ongoing permanent residents.

40 And I've been given the indication that this is about 20 per cent of the respite residents. It's not one of the – the reasons why they come into respite, but it does end up being one of the reasons why they do then move into permanent residential care. I think it's – it's – it's – in some respects it's the – the overall carer who – who is also not just the care recipient but it's also the carer having that understanding about and them feeling comfortable that their loved ones will also be happy in the environment. So they're also doing the trial, not just the actual carer, the care recipient.

MS HILL: Mr Midgley, how many respite residents of Chaffey Aged Care would ultimately become permanent residents?

5 MR MIDGLEY: So in the 19 – in the 2018-2019 financial year, our records show that of the 68 discharged residents from our respite service, 30 were then directly admitted as permanent residents, and that amounted to 44.1 per cent.

10 MS HILL: And you've described in your statement that the funding structure of respite can often be an incentive to families to use respite to get their affairs in order before getting their loved one into permanent residential care. Could I ask you what you mean by that?

15 MR MIDGLEY: For a care recipient and their family, if they have their 63 days of respite entitlements and can use that, then their contribution to the cost of their care is essentially just their daily care fee over that time. So – so for some families who are savvy, they might choose to place their – their – the care recipient into respite whilst they are completing the financial assessments that are required and the relevant documents that are required, as it is a more low-cost means of ensuring their care is provided for whilst those documents are being completed and – and receipt – and whilst they're awaiting receipt of an assessment outcome.

MS HILL: And do carers come to Chaffey Aged Care seeking guidance on how to best enter permanent care?

25 MR MIDGLEY: Do you know, it is such a complex – complex system we have in our country for entry pathways into aged care. And it's very difficult for care recipients and their carers and their families to navigate. And most care recipients and their carers, when they come, are seeking information. They're seeking direction. They're seeking advice on what has to happen next. There are some things that we as an aged care provider can provide, there are things that we cannot, and we refer on for assistance, particularly with regard to financial matters.

30 MS HILL: Are there particular challenges that you identify being an aged care provider in a regional setting?

35 MR MIDGLEY: There are plenty. Perhaps the ones that come to mind, certainly the inadequacy of funding as I've alluded to is a major issue for our industry, and I draw – I draw this from the StewartBrown report – which I'm sure that the Commissioners have received over – over the time the Commission has been running – which points to the fact that 45 per cent of aged care providers are making a financial loss currently in Australia. Although for rural providers, and that includes our organisation, 67 per cent of Australian rural providers are making a financial loss in delivering aged care services. So that is significant.

45 The other issues are around workforce issues around attracting and retaining appropriate staff to – to meet the organisation's and care recipients' needs. Aged care as an industry are not able to compete with acute care for wages, so it's difficult

to attract, for example, nurses who can be paid so much more in the acute sector and have a lot less responsibility than they do in an aged care environment. The same goes for allied health professionals, and I draw to – I draw, I guess, the case in point that in an aged care facility, there may be one registered nurse for 100 care recipients supported by two enrolled nurses, who the registered nurse also has an obligation to oversee their clinical practice under a delegated model of care.

The registered nurse might also have an obligation to oversee the clinical practice of the personal care assistants, and there might be 12 or 14 for the 100 residents. So one registered nurse who has an obligation for overseeing the care of 100 care recipients, it's a fairly big ask when in the acute sector they would be paid more, they're better remunerated and have a responsibility maybe for four or five patients in that environment, and are more able to meet their own professional standards around the care that they provide. They're more able to control what's happening for their four or five patients.

It's a very big ask for one registered nurse to be overseeing the care of 100 care recipients in an aged care environment, plus supervise the clinical practice of enrolled nurses and – and personal care assistants. So the other issue is around personal satisfaction around nurses being able to meet their own professional expectations around the care that they provide and meet their own standards of care. It's a tough ask.

MS HILL: Those particular challenges you've described; is that something that can be overcome by paying staff, paying nurses or PCAs more and having more staff, more nurses as per aged care provider?

MR MIDGLEY: That's part of it. I think as an aged care – and I'm a registered nurse and an administrator in an aged care facility, my experience is that I would like to have – I would like to better pay our staff, but to better pay them, we need to be better paid by the aged care system. We need to be better funded to enable that. But I would also like to increase the number of nurses that we have to get to a point that we can reasonably oversee the care of the care recipients, that we can reasonably as nurses oversee the professional practice of the enrolled nurses under the registered nurse, and the personal care assistants and better meet the care needs and deliver outcomes for the care recipients.

So it's that, but it's also – it's also the issue around perceptions of working in aged care, and aged care is not seen as an attractive place to work by acute care nurses. It is seen – historically it's been seen very differently. It's been seen as a place where you don't get to use your skills. Well, my observation is very different.

Aged care nurses need to be – need to have a very diverse skill set. They need to be very proficient in palliative care and complex care and respiratory medicine. They need to be very good at assessing a deteriorating resident. They need to have very good interpersonal skills. They need to have very good conflict de-escalation skills. They need to have very, very advanced leadership skills.

You need to be an expert in a number of domains in aged care, and contrary to perceptions within the industry, nurses in aged care have to have a very highly developed skill set to meet the various and many demands that they have within their roles.

5

MS HILL: Ms Woodhouse, in your statement you describe in very positive terms the role of cottage respite. In your experience, do you have a preference for cottage respite over respite that's offered in a residential care facility?

10 MS WOODHOUSE: Well, in our current setting it probably depends on the care needs of the recipient and how much care they need. But it is a lovely home-like environment. It's a tiny little three-bedroom weatherboard cottage at the back of the health service site. So the team that work there enjoy working there. They're caring for two care recipients that might be there for a weekend, if we talk about ratios, so
15 it's one health care worker for two residents compared to in the nursing home there would be eight. So we are able to retain our staff that way because they enjoy that style of work and it's – they really get to know the care recipients and the carers and it's a nice model for – when it suits their needs.

20 MS HILL: Mr Voukelatos, does respite care have a role in assisting in the transition to residential respite or permanent residential care?

MR VOUKELATOS: Well, when someone is assessed for residential respite, it normally happens via the Aged Care Assessment Service and it's in response to the
25 carer and the care recipient needing that form of respite. I'm probably not equipped to talk through specific numbers in terms of people transitioning through, but what I can say and in our own – in my own experience is that people – carers try before they buy. I think moving into residential respite, like with any form of respite, can be very challenging, very confronting for people. There's a lot of loss and grief
30 happening. There's a lot of thinking and emotional matters going on for the carer and the care recipient for that matter so it's a big decision to go into residential respite.

If they have a great experience, then they will continue with that service. That's
35 been my experience often and when the time's right and appropriate, as part of a continuum of care and if they feel safe, secure, well equipped and well supported they would potentially end up in that facility. If their experience is not so good then they will go and look at another facility or may look at other forms of respite.

40 MS HILL: Ms Woodhouse, in your statement on page 16 you describe a co-located facility. What's the role for a co-located facility?

MS WOODHOUSE: We have a vision – we're hoping down the track to build a new nursing home because our current infrastructure isn't adequate, and in an ideal
45 setting we would love to see the cottage respite located next to the residential nursing home.

MS HILL: Why is that, Ms Woodhouse?

MS WOODHOUSE: Well, it's the introduction to services. When carers have been at home caring they are reluctant to put their loved ones into care at times and care recipients are reluctant to enter care for a number of reasons, and I think by that slow introduction of whether it's coming into the cottage for day-based activities and transitioning into weekend stays and being able to flex between the two services, so from time to time we may not have full – all of our beds occupied for the weekend retreats. It means the staff can slip across and help the team members in the nursing home. Equally you've got more highly skilled – we've got registered nurses perhaps in charge in the nursing home that could perhaps go across and support the team in the cottage.

MS HILL: Commissioners, I note the time. That concludes my examination.

COMMISSIONER TRACEY: Thank you. We are very grateful to you for your collective insights into the intricacies of respite care. It's not an easy area and it's one that obviously needs considerable development and making our recommendations, we will certainly have regard to the evidence you've provided us this afternoon. Thank you each and every one for your evidence.

MS HILL: I should have indicated, Commissioner, when I tendered the statements of each of the members of the panel it was my intention that the statements along with their attachments to those statements be tendered.

COMMISSIONER TRACEY: Yes, the attachments will form part of each exhibit.

MS HILL: As the Commission pleases.

COMMISSIONER TRACEY: The Commission will adjourn until 1.45.

ADJOURNED [1.10 pm]

RESUMED [1.50 pm]

COMMISSIONER TRACEY: Yes, Mr Gray.

MR GRAY: Thank you, Commissioner. Commissioners, next and finally, the evidence we're calling is from a panel of three Commonwealth officials, two from the Department of Health and one from the Department of Social Services. I call - - -

COMMISSIONER TRACEY: I think Mr Kennett wants to announce his appearance.

MR G. KENNETT SC: Yes, if the Commission pleases, can I announce my appearance with MR DIGHTON for the Commonwealth.

COMMISSIONER TRACEY: You have that leave, Mr Kennett.

5

MR GRAY: I call Fiona Kathryn Buffinton, Nigel Murray and George Sotiropoulos, and all three are already in the witness box.

10 <GEORGE SOTIROPOULOS, SWORN [1.51 pm]

<NIGEL PATRICK MURRAY, AFFIRMED [1.51 pm]

15

<FIONA KATHRYN BUFFINTON, AFFIRMED [1.51 pm]

MR GRAY: Ms Buffinton, I'll start with you. What's your full name?

20

MS BUFFINTON: Fiona Kathryn Buffinton.

MR GRAY: You've recently made a statement for the Royal Commission dated 22 July 2019 and that's the second statement you've made for the Royal Commission; is that right?

25

MS BUFFINTON: That's correct.

MR GRAY: The first statement for the record is exhibit 2-89. Ms Buffinton, I will ask the operator to put an image of the first page of your statement of 22 July on screen. It's WIT.0299.0001.0001. While that's coming up I will just ask you, Ms Buffinton, are there any amendments you wish to make to your statement?

30

MS BUFFINTON: No, I don't.

35

MR GRAY: To the best of your knowledge and belief are its contents correct?

MS BUFFINTON: They are.

MR GRAY: Commissioners, I tender that statement; that's the statement of Fiona Kathryn Buffinton dated 22 July 2019.

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COMMISSIONER TRACEY: Yes, the witness statement of Fiona Kathryn Buffinton dated 22 July 2019 will be exhibit 7-22.

45

**EXHIBIT #7-22 WITNESS STATEMENT OF FIONA KATHRYN
BUFFINTON DATED 22/07/2019 (WIT.0299.0001.0001) AND ITS
IDENTIFIED ANNEXURES**

5

MR GRAY: Mr Murray, what's your full name?

MR MURRAY: Nigel Patrick Murray.

10 MR GRAY: Thank you. You also have recently made a statement for the Royal
Commission also dated 22 July 2019, haven't you?

MR MURRAY: Yes, that's correct.

15 MR GRAY: I'll ask that that be displayed for you, WIT.0338.0001.0001. Do you
see the first page of the statement displayed?

MR MURRAY: Yes, I can.

20 MR GRAY: Mr Murray, do you wish to make any amendments to your statement?

MR MURRAY: No, I do not.

MR GRAY: To the best of your knowledge and belief, are its contents true and
25 correct?

MR MURRAY: Yes, they are.

MR GRAY: I tender the statement.
30

COMMISSIONER TRACEY: The witness statement of Nigel Murray dated 22 July
2019 will be exhibit 7-23.

35 **EXHIBIT #7-23 WITNESS STATEMENT OF NIGEL MURRAY DATED
22/07/2019 (WIT.0338.0001.0001) AND ITS IDENTIFIED ANNEXURES**

MR GRAY: Commissioners, a witness from the Department of Social Services has
40 made two statements addressing certain issues. Upon further inquiries being made in
relation to other issues, Mr Sotiropoulos is attending but he is not the maker of the
statements in question, however, I wish to tender those statements. I will do so now.

COMMISSIONER TRACEY: Yes. Who is the deponent?
45

MR GRAY: Emma Kate McGuirk. The two statements, I will deal with them separately, the first is WIT.0298.0001.0001 dated 23 July 2019. I will tender that statement.

5 COMMISSIONER TRACEY: Yes. The witness statement of Emma Kate McGuirk dated 23 July 2019 will be exhibit 7-24.

10 **EXHIBIT #7-24 WITNESS STATEMENT OF EMMA KATE MCGUIRK
DATED 23/07/2019 (WIT.0298.0001.0001) AND ITS IDENTIFIED
ANNEXURES**

15 MR GRAY: And the supplementary statement of Ms McGuirk dated 30 July 2019 is WIT.0298.0002.0001.

COMMISSIONER TRACEY: Yes, the supplementary statement of Emma Kate McGuirk date 30 July 2019 will be exhibit 7-25.

20 **EXHIBIT #7-25 SUPPLEMENTARY STATEMENT OF EMMA KATE
MCGUIRK DATE 30/07/2019 (WIT.0298.0002.0001) AND ITS IDENTIFIED
ANNEXURES**

25 MR GRAY: Mr Sotiropoulos, what's your full name?

MR SOTIROPOULOS: George Sotiropoulos.

30 MR GRAY: What is your role in the Department of Social Services?

MR SOTIROPOULOS: I'm the group manager for disability and employment and carers group.

35 MR GRAY: Thank you. The format we will adopt for this evidence in concurrent panel is that I will direct questions to particular witnesses. If the given witness exhausts their knowledge they should indicate that and it may be that we can save time by simply re-directing the question to one of the other witnesses. Ms Buffinton, I wish to start by addressing some questions to you. Were you present yesterday
40 when the expert panel gave its evidence in the afternoon?

MS BUFFINTON: I was not, but I've read the transcript.

45 MR GRAY: Thank you. The expert panel's evidence yesterday afternoon was that it's imperative to provide early intervention, offering support services such as education to informal carers, together with respite that's flexibly adapted to the

particular needs of the carer and care recipient. What's your view on those propositions? Do you agree with those propositions?

MS BUFFINTON: I agree with those propositions.

5

MR GRAY: And it was pithily put by Dr Gresham at the end of the expert panel that an ounce of prevention is worth a pound of cure. Adapting that axiom to the support to be afforded to informal carers so as to sustain the care relationship; do you agree with that?

10

MS BUFFINTON: Yes, I think early intervention is always the best approach.

MR GRAY: Thank you. If you would kindly keep your voice up, I would be grateful.

15

MS BUFFINTON: Thank you.

MR GRAY: Thank you. So if we just take that proposition a little further and apply it to the particular context of support for informal carers, if we can equip informal carers with the skills they need to sustain them before strain upon them reaches breaking point, that's obviously a good thing, isn't it?

20

MS BUFFINTON: Yes.

MR GRAY: And that's not just a matter of common humanity, although that's very important; it's also sensible in terms of sustainability of the aged care system, isn't it?

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MS BUFFINTON: It is, because informal carers make a very well acknowledged and incredible contribution to care of older people in Australia.

30

MR GRAY: Yes. Now, Dr Gresham gave evidence about the efficacy of intervening early, including with educative programs for informal carers, particularly in the context of caring for people living with dementia. Did you note that evidence as well?

35

MS BUFFINTON: Yes, I did.

MR GRAY: I want to ask you about whether the department has a view on whether early interventions of the kind Dr Gresham referred to have the sort of efficacy that Dr Gresham claims from her studies, that is, that those interventions serve to delay and perhaps prevent some people entering into permanent residential care?

40

MS BUFFINTON: So the area of support in dementia and dementia – carers of dementia, that actually doesn't sit in the division that I cover. So, certainly, in terms of people accessing and being supported in the system and getting information early so that decisions aren't being made in a crisis. But, also, that carers in particular are

45

aware of the supports that are available to them, whether it's dementia-related or not, is something that we strongly support, and we work with the Department of Social Services in their focus in the education of carers and support to carers.

5 MR GRAY: I will just ask that paragraph 6 of your statement be put up on the screen, and we will just try to work out exactly the scope of your responsibilities, particularly with reference to the point you've made that there's somebody else in the department who's really knowledgeable about dementia care, and you're not claiming any particular knowledge about dementia care.

10 MS BUFFINTON: Well, that's not my area of expertise, no.

MR GRAY: Right. So if we look at your responsibilities as first assistant secretary in the In Home Aged Care division of the department - - -

15 MS BUFFINTON: Yes.

MR GRAY: - - - does it follow that you're the person who's across all forms of in-home care that you subsidised by the department?

20 MS BUFFINTON: Yes, in terms of – well, in terms of Commonwealth Home Support and in terms of the Home Care Package Program, they are the areas that I do cover. There are some other subprograms that others have responsibility for. But in terms of in the main between Commonwealth home support, home care, I look after, 25 whereas I don't look after residential care.

MR GRAY: All right. We know in residential care that care of people living with dementia is an increasingly important topic with over 50 per cent of residents in residential aged care facilities living with dementia. In the community, presumably, 30 the figures are not as high as that, but it's still a significant issue, isn't it?

MS BUFFINTON: It would be.

35 MR GRAY: Yet, even though you're responsible for the various forms of care that are provided, in particular under the two programs you mentioned, you don't have knowledge about how dementia care should be delivered in the community setting. Is that how you – is that what you're saying?

40 MS BUFFINTON: So I have colleagues – you can imagine that the aged care system is quite a complex system and our colleague Jo Mond, who has appeared before the Royal Commission, has the focus of how dementia care is offered across the spectrum of aged care.

45 MR GRAY: I want to suggest to you that dementia is a progressive illness involving progressively worse deterioration in cognitive ability - - -

MS BUFFINTON: Yes.

MR GRAY: - - - and that it has special challenges, it presents special challenges to a person who's the primary informal carer for a person - - -

MS BUFFINTON: Yes.

5

MR GRAY: - - - living with dementia.

MS BUFFINTON: Yes.

10 MR GRAY: And if that person is trying to care for that person in the community, that person needs a great deal of support in order to embark upon and complete the journey of caring for that person living with dementia. You agree with all that?

MS BUFFINTON: I agree.

15

MR GRAY: I was asking about Dr Gresham's evidence concerning the efficacy of early intervention in delaying a permanent entry into residential care, and I don't think you gave me a direct response – pardon me if I'm wrong. Does the department have a view about whether the provision of early interventions, particularly in the form of education of informal carers, can have an effect in delaying entry of the person cared for into residential care?

20

MS BUFFINTON: Yes, I – we agree that – and not exclusively for those that are looking after people with dementia, but the more that people are aware of the aged care system, what is available to the person to be cared for, and also what sort of supports are available for the carers, considering it's a system that does rely on the role of informal carers, we would agree that that's an important focus.

25

MR GRAY: Well, it can delay entry into permanent residential care, which, amongst other things, will save a lot of money to the system.

30

MS BUFFINTON: No, absolutely.

MR GRAY: Yes. Now, in paragraph 13 of your statement you've said that the department hasn't conducted a cost benefit analysis of the – in effect, the investment into respite in sustaining a care – carer relationship and preventing entry into permanent residential care.

35

MS BUFFINTON: That's correct.

40

MR GRAY: And that remains the case since you made your statement only a few days ago, I assume.

MS BUFFINTON: That is correct.

45

MR GRAY: Are there plans underway to conduct any cost benefit analysis?

MS BUFFINTON: Well, prior to being asked that question, we – we hadn't, but we have discussed that this is an area that we think that there is – there would be benefit in looking into this.

5 MR GRAY: And there would be benefit in looking into that because then you would know, or you would have a better understanding of what level of investment is justified in respite in terms of saving money to the aged care system in respect of the costs of permanent residential care, wouldn't you?

10 MS BUFFINTON: Yes.

MR GRAY: Now, there are some other troubling – well, my word – troubling aspects of the landscape concerning the data that's available. I just want to ask you about whether the department has an understanding of the use to which home care
15 packages are put with regard to respite. In your statement, I think you say the department doesn't collect that information.

MR BURTON: So with the Home Care Package Program, currently we, in effect, give a level of subsidy that is then, in effect, divided by 12 and provided to the
20 provider. The – the person is assessed for that level of need and a range of services are recommended by the assessor, and then the care recipient and the care provider work on delivering a plan that the care recipient wants. We as the department do not get a feedback on the – what services an individual is taking up or in what volumes they're taking that up.

25 MR GRAY: So the short answer is that the department doesn't know the extent to which home care packages are being used to purchase respite care at all; is that right?

30 MS BUFFINTON: That's correct.

MR GRAY: So the department, I suggest, has no sound empirical basis in data to make policy decisions concerning the allocation of resources into respite on the one
35 hand or permanent residential care on the other. What do you say to that?

MS BUFFINTON: Well, the – the – the respite investment is done through the home care packages, so we – so if we go into Commonwealth Home Support, where we're giving grants for that respite care, but if you look at the home care package, if
40 somebody is wanting care in the home, then it's on a demand basis. So it's not that we're allocating resources to respite for that purpose; it is coming through the package.

MR GRAY: My - - -

45 MS BUFFINTON: And - - -

MR GRAY: My question was about whether you have an empirical basis for making policy decisions to allocation of resources to respite on the one hand compared with - - -

5 MS BUFFINTON: And that's what - - -

MR GRAY: - - - permanent residential care on the other.

10 MS BUFFINTON: And that's what I'm saying, is that in terms of policy in home care, it's – it's not us that is putting investment into that respite. That investment is coming through the home care package itself in home care.

15 MR GRAY: Well, that sounds, doesn't it, as if the government is just abdicating responsibility for formulating policy in this particular area and just saying, "Look, here's some money", to a home care package client", "And you decide what to do with it." Is that a fair summary?

20 MS BUFFINTON: What it allows is the home care recipient, that's part of Consumer Directed Care, that they are making choices of if they've been assessed and they are needing and choosing respite, that they can ask for a couple of hours of respite or whatever it is, and their provider will be supplying that service. It's not that we're investing in respite services. So just to be clear, for residential respite, which is available for somebody on a home care package, that is not part of the Home Care Package Program, so they do have access to up to 63 days of care in a residential care home. That sits outside the Home Care Package Program, and, 25 obviously, home care sits separately to Commonwealth Home Support.

30 MR GRAY: Ms Buffinton, I asked you whether the department collects information as to the extent to which home care packages are used to purchase respite services, and you accepted that the Commonwealth doesn't keep that information; doesn't seek that information.

MS BUFFINTON: Yes.

35 MR GRAY: The Commonwealth also hasn't attempted to do the cost benefit analysis about what investment in respite would be justified in terms of achieving savings in permanent residential care. What I'm suggesting to you is that, in those two respects at least, there's an absence of a proper empirical foundation for formulating policy, amongst other things, policy concerning where to put the 40 resources, resources into respite, resources into permanent residential care and in what proportions. There's simply no basis in the data for the Commonwealth to make those discussions.

45 MS BUFFINTON: So we can understand what the demand for – is for residential respite, we – I acknowledge we do not know the volume of respite care that is being utilised in a home care package out of their home care package. It's an area more broadly that we are looking at can we pay the subsidies to the provider in different

ways in the future in order to get a feedback of what are the – what are the services being utilised under home care, in what volumes.

5 MR GRAY: You're looking at ways to achieve that, but nothing has been done yet.

MS BUFFINTON: That is not how the initial setting up of the Home Care Package Program in 2017 – that is not how it was based.

10 MR GRAY: So nothing has been done yet.

MS BUFFINTON: The current system is what we have at the moment.

MR GRAY: Yes.

15 MS BUFFINTON: But we're looking at alternatives.

MR GRAY: Okay. Now, I want to ask some questions of you. Again, Ms Buffinton, I will be directing these questions to you, and if you can't answer a particular one, please say so, and it may be that Mr Sotiropoulos might be able to
20 step in on the DSS side of the ledger. The topic I'm addressing now is one that I think of as pathways. That might not be the entirety of the topic. I will just mention the other issues that arise under this topic.

25 They include the recognition of a person as having a status of an informal carer, measures for outreach to people who are carers, whether they recognise it or not. In particular, post-diagnosis outreach seems to be an acute issue when we come to care of people living with dementia because of the evidence that we've heard about the significant impacts on people caring for people with progressive irreversible cognitive decline. It's the availability of information and navigation of the system,
30 including at key decision points. It's that topic; I'm calling it pathways.

MS BUFFINTON: Yes.

35 MR GRAY: Pathways and navigation and information. Now, Ms Buffinton, has the department got a position on what's the scope of definition of carers, informal carers to whom the department intends or wishes to provide support services?

MS BUFFINTON: So formally, as you suggested, the focus of the carers themselves and the direct supports for the carers, that is what the Department of
40 Social Services looks after. The focal point for the Department of Health in terms of aged care is – our primary focus is the person who is being cared for. But everything we design from whether that be the initial pamphlets, the website, thing contact centre, how we conduct assessments, the information we provide in order to help people select service and then going into services themselves, we take into account
45 both the person cared for but the person and the support network, the carers and the support network, and we co-design those with those – those people in mind.

MR GRAY: I'm going to ask you about the assessment process in some detail under my next topic.

MS BUFFINTON: Yes.

5

MR GRAY: But just pausing there, in terms of how the Department of Health conceives the carer, albeit subject to the proviso that you've expressed that the focal point is on the person who's receiving care in the DOH world.

10 MS BUFFINTON: Yes.

MR GRAY: And the DSS – on the DSS side of the ledger, Mr Sotiropoulos, is that fair what Ms Buffinton said, that it's DSSs primary focus, relevantly for the purposes of this discussion - - -

15

MR SOTIROPOULOS: Yes, it is.

MR GRAY: - - - on the person providing the care?

20 MR SOTIROPOULOS: Yes, it is.

MR GRAY: In terms of DSSs conception of the scope of the carer, does it include people who may not even recognise that they are, in fact, an informal primary carer?

25 MR SOTIROPOULOS: Yes, it does.

MR GRAY: And there needs to be outreach to those people so that they're made available as best as can be achieved of the services that are available to help them. Would you agree with that?

30

MR SOTIROPOULOS: I would agree with that.

MR GRAY: And do you agree with everything that Ms Buffinton has agreed with about an ounce of prevention is worth a pound of cure.

35

MR SOTIROPOULOS: Absolutely.

MR GRAY: Yes. Now, in your department's portfolio, if I put it that way, there's an integrated carer support service program. It began a couple of years ago in phase one and it's now coming to a phase where there's going to be regional delivery partners who are going to be rolled out in a number of areas. I'm going to ask you about that in some detail a little later on. But just before we get to that, in terms of reaching out to people who may not even realise they need help, what's the current system for local assistance, local know-how to be leveraged to reach out to those people, particularly in rural communities?

45

MR SOTIROPOULOS: At the moment, the primary mechanism is through our carer respite and care link centres, so they're contracted to – their primary focus is on the delivery of emergency respite, but within the broader package of – of the program, there is an allowance for things like outreach and education, but they're
5 very small discrete packages of work and they're not nationally consistently delivered across the country. So it would depend on the particular centre.

MR GRAY: What's the allowance for planned respite?

10 MR SOTIROPOULOS: There are targeted financial packages of \$4200.

MR GRAY: And that's the consumer-directed respite care packages?

MR SOTIROPOULOS: No, that's actually packages that are directed – pardon me,
15 yes, for the carer, directed by the carer.

MR GRAY: They seem to be renamed carer-directed respite packages; is that right?

20 MR SOTIROPOULOS: No.

MR GRAY: No. What are they going to be – are they going to be renamed something in the near future?

25 MR SOTIROPOULOS: They're not going to be renamed anything under the new integrated carer service.

MR GRAY: Are they just going to remain in situ under the new integrated carer support service?
30

MR SOTIROPOULOS: They will remain in situ. There has been an adjustment made to the funding levels based on program data.

MR GRAY: Does it go from 4200 to \$3000.
35

MR SOTIROPOULOS: That's correct, but there will be an increase in the number of packages provided which will be increased to 5024.

MR GRAY: So some respite is available out of the \$3000 in the 12 month period; is that right?
40

MR SOTIROPOULOS: Absolutely right.

MR GRAY: Cottage respite, we're told by Ms Buffinton in her statement, at a full cost recovery basis would be about \$700 a night; do you accept that?
45

MR SOTIROPOULOS: I'm not familiar but I take Ms Buffinton - - -

MR GRAY: If that's right, then the \$3000 package will pay for about four and a bit nights of cottage respite in a year?

MR SOTIROPOULOS: If my maths is correct, that's right.

5

MR GRAY: I suggest to you that the carer-directed or consumer-directed respite – respite care packages that are available through the current carer respite – I beg your pardon – the Commonwealth Respite and Carelink Centres are not well adapted to providing the sort of regular preventative planned respite that would be optimal for sustaining carers on – on a long difficult journey of caring for a person with severe conditions such as cognitive decline.

10

MR SOTIROPOULOS: Yes, what I would like to say on that point – and I won't disagree with you on that point, is that the delivery of planned respite is really the responsibility of the other service systems. So DSS and the programs we – we run are for the benefit of carers in their own right. Respite is very much in the – in the purview of the other service delivery systems and it's through those systems that the quantum of the planned respite would be delivered. Ours are only intended to be very small packages, they're flexibly provided.

20

MR GRAY: And when you say "the other programs", what we're talking about here when we're talking about carers of older Australians is My Aged Care, isn't it?

MR SOTIROPOULOS: The My Aged Care system, that's correct.

25

MR GRAY: The carer has perhaps come to the Carer Gateway and has sought some planned respite and has quickly realised, in the scenario I'm putting to you, that there's not going to be much available through the CRCCs, and really has to go to My Aged Care to try to obtain planned respite subsidies, is that right?

30

MR SOTIROPOULOS: That's right. It is the CRCCs role to support that person with them, their access to My Aged Care.

MR GRAY: The materials say that – well, I will come to what the new ICSS materials say on that, but you say it's the role of the CRCCs and that is again the carer - - -

35

MR SOTIROPOULOS: Commonwealth Respite Carelink - - -

MR GRAY: The Commonwealth Respite Carelink Centres.

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MR SOTIROPOULOS: That's correct.

MR GRAY: The CRCCs. It's the role of those centres to, what, to refer the person who sought that planned respite to My Aged Care?

45

MR SOTIROPOULOS: Yes, to make them aware of the My Aged Care service and - - -

5 MR GRAY: What in practice actually does that involve? Providing them with a website URL, and a call centre number or something more?

MR SOTIROPOULOS: I must say that's beyond my – my knowledge, so I wouldn't be familiar with what - - -

10 MR GRAY: Okay. So I think we're probably back to the Department of Health then, Ms Buffinton. If we're talking about planned respite of the kind that seems, on the evidence of the expert panel, to be adapted to that longer term preventative
15 sustaining function, we're really in My Aged Care by the sounds of the answer Mr Sotiropoulos has given. So I'm going to have to be directing questions to you about the detail of the respite programs that are available under My Aged Care and whether they really fulfil that preventative – that preventative function. Is that – is that a fair summary of where the evidence has got to?

20 MS BUFFINTON: Yes. I should note that the CRCCs do play a role in residential respite, that they often, on behalf of the residential providers, are effectively the broker and when somebody rings the CRCC saying they need residential respite, typically it's a CRCC that is aware of what the vacancy rate and when things are available. So that is a role that the CRCCs play with one of our programs.

25 MR GRAY: So the CRCCs are aware of what the vacancies for respite beds might be - - -

MS BUFFINTON: In resident – for residential respite.

30 MR GRAY: For residential respite in one of the - - -

MS BUFFINTON: Aged care - - -

35 MR GRAY: - - - 54 or so regions.

MS BUFFINTON: Aged care planning regions, that's correct.

40 MR GRAY: All right. Are you saying they inform the person who's making the contact with the CRCC of who's got vacancies and then hand over to the person who's making the inquiry to follow-up those vacancies?

45 MS BUFFINTON: Mr Murray can make some further comments but as I understand it, they often will – they will act as the broker or point of access to some of those residential care providers, and some of the residential care providers choose to be contacted directly, in which case then they will hand – provide them with the contact details.

MR GRAY: A little earlier I asked you both questions about, what about people who don't even realise they have a need and the imperative of outreach to them. You both agreed that that would be good policy. So far, is this a fair summary of the evidence: you've been talking about avenues that depend on a person on behalf of
5 the carer, in effect, picking up the phone or clicking on a mouse to contact either the CRCC or My Aged Care. That's a fair summary of the evidence, isn't it?

MS BUFFINTON: Well, in the – in the beginning, when somebody is a carer, we would like to think that we can make them aware that there are supports and I'm sure
10 we're going to come to it, what's the role of ringing My Aged Care or going online or having an assessment and information they get through that assessment. So as part of that, sometimes it could also be a general practitioner or others that outline that if they were to ring My Aged Care, that there is no wrong door there, that they can be put in contact with the full range of supports.

15 MR GRAY: Now, I've heard a suggestion that is additional to picking up the phone or clicking on the mouse, which is that the GP might inform a particular person that they have some – they have some access to some support in their role as an informal carer, so that's a valuable suggestion. Are there other means that the department has
20 in mind in trying to achieve some sort of reaching out, some sort of outreach to people so that they're apprised of the availability of these services?

MS BUFFINTON: Okay. So we publish probably over a million pamphlets a year that we put out into the community through community organisations, through a
25 wide range of CALD and indigenous languages as well as in terms of seniors and various organisations where they may be picked up. We also annually usually work through a commercial organisation that runs videos in GP surgeries, so usually there's four videos that run in GP surgeries and one that runs in the staff – in the staff room of the practice. So one is informing the staff themselves about us being a – sort
30 of an access point but also it's around about My Aged Care and what the, you know, ringing My Aged Care what's available and so forth.

We do from time to time do other media and obviously many of us, including
35 ministers, go round and talk at many different organisations and do advertorials and so forth to make people aware of My Aged Care as a number – as a website in order that people are aware that there are – there are supports available.

MR GRAY: What I'm not hearing in any of that is an initiative to address the sort of thing that Ms Hlis spoke about this morning, something directed to people in an
40 ethnic community where it might be just an accepted or a socially imposed role that, because of a particular familial relation you just do a certain job. You may never reach consciousness that you're actually a primary informal carer. Is the department doing anything about this?

45 MS BUFFINTON: So we have a lot of relationships and if we take organisations like the Federation of Ethnic Communities and so forth, we do quite a lot of outreach. We do quite a lot of funding, and we do quite a lot of design. In fact, in

March when Mary Patetsos outlined her concerns about the available information for ethnic communities, we immediately understood that they felt that there wasn't sufficient focus on the needs of ethnic communities and there's part of the new website that we launched at the beginning of this month, we engaged with amongst
5 other communities, FECCA and the CALD community to make sure that the information and how it was displayed was relevant to their community. So we're constantly – it's not because we've got it all - - -

10 MR GRAY: This is a slightly different point, with respect, Ms Buffinton, it's not simply a linguistic point.

MR BURTON: Yes.

15 MR GRAY: It's a point about reaching out to people who are perhaps, because of social norms in often highly gendered – in a highly gendered way in a particular role, and not conscious that they're actually primary carers.

MS BUFFINTON: Yes.

20 MR GRAY: Any specific program you can point to, to try to break through that barrier?

MR SOTIROPOULOS: Could I possibly be permitted to speak on that?

25 MR GRAY: Yes.

30 MR SOTIROPOULOS: Because outreach is one of the fundamental principles underpinning the development, design and implementation of the Integrated Carer Support Services that we're about to introduce. So early on in consultations, we identified through our consultations and research – you've mentioned prevention. That is another fundamental underpinning principle of the new service system. We're shifting to a preventative model as opposed to say reactive model.

35 In terms of outreach, it will be an explicit expectation on the regional delivery partners – and they will have funding for this – to do outreach within their service area, across their whole service area, build and maintain relationships with all the key service providers to effectively build community capability and understanding of what a carer is.

40 And, importantly, at the back end of our program, we will also be collecting much more – much better data to understand, because you identified earlier, you know, we – there is an issue with data, even through our programs, but we've edge acknowledged that, and we're building a very – a much better – we're going to be having a much better data and information base on which to – to assess progress and
45 assess carer wellbeing.

MR GRAY: Thank you, Mr Sotiropoulos. Now, that program you're talking about is the Integrated Carer Support Service rollout.

MR SOTIROPOULOS: That's correct.

5

MR GRAY: And in particular, the next phase that's beginning in September, which is the - - -

MR SOTIROPOULOS: With the - - -

10

MR GRAY: - - - rolling out of the regional delivery partners.

MR SOTIROPOULOS: Absolutely right, yes.

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MR GRAY: There's been a tender to 18 areas; is that right?

MR SOTIROPOULOS: 16 areas.

MR GRAY: 16 areas. Thank you. Is that 16 areas across the country?

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MR SOTIROPOULOS: That's correct.

MR GRAY: So those 16 areas will cover the entire country.

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MR SOTIROPOULOS: That's correct.

MR GRAY: All right. Now, have you noted the evidence that's unfolded so far in this hearing in Mildura, Mr Sotiropoulos? Have you had an opportunity to read transcript or - - -

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MR SOTIROPOULOS: I've read transcripts, and I've been informed in summary.

MR GRAY: You will have heard about, in effect, the emergence of volunteer groups to provide local networking opportunities for people in informal caring roles, and in the - on the witness of some of the - the deponents of the witnesses in this hearing, those support groups have been very, very important to their ability to survive - literally to survive. For example, Mrs Rosemary Cameron spoke of the Woodend Lifestyle Carers Support Group. Do you recall - - -

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40

MR SOTIROPOULOS: I'm not familiar with that.

MR GRAY: All right. And we've heard quite a lot of evidence about a body which receives some funding from Carers Victoria, which is the Mildura Carers Hub.

45

MR SOTIROPOULOS: I am aware of that one.

MR GRAY: Yes. Now, would you agree that the success of outreach in – particularly in rural and regional communities, depends very heavily on local knowledge and local connections within close-knit rural communities in fairly confined locations?

5

MR SOTIROPOULOS: Yes, I would.

MR GRAY: So if we're talking about a program of regional delivery partners which is going to cover the whole country with only 16 areas, the devil is going to be in the detail, in the sense that each of those winning – each of those entities that wins the tender for their particular area to be the regional delivery partner will have to perform outreach over, really, an enormous area. Would you agree with that?

10

MR SOTIROPOULOS: I would agree with that, but – but it's not only the regional delivery partners. They will be partnering with other organisations. There will be subcontracting organisations.

15

MR GRAY: So that's what I mean by the devil has got to be in the detail.

MR SOTIROPOULOS: Absolutely right.

20

MR GRAY: The responsibility is going to be reposed in organisation for each of these 16 areas, so it might be as many as 16 organisations.

MR SOTIROPOULOS: That's correct.

25

MR GRAY: And then it will be left to them to make subcontracting arrangements, in particular in local communities; is that right?

MR SOTIROPOULOS: Yes, that's correct, but the department is also taking responsibility for the success of implementation. So we've already got steps in train to engage the CEOs of each of those RDPs. We will be getting data every three months. We're looking at conducting an evaluation after one year to determine how things are going on the ground. Because while we would hope that implementation run smoothly and there are no glitches, I think, as you've mentioned, devil is in the detail. So we need to keep an eye on that, and we will be.

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35

MR GRAY: It's, at best, uncertain how successful this program will be in really effectively reaching out in local rural communities, isn't it?

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MR SOTIROPOULOS: It is uncertain, and that is why we're putting in place a range of measures post-implementation. It's not about just saying, "Here's the contract. Off you go." It is actually the department taking a share of the responsibility to ensure effective implementation in recognition of the role of carers.

45

MR GRAY: And one thing you're doing in that respect is CareStar, is it, to evaluate the effectiveness of areas?

MR SOTIROPOULOS: That's correct. So every carer that comes through the system will be – will undertake this needs assessment. It will – it will result in a support plan for that carer. There will be follow-up every – as a minimum, every six months, there will be a proactive follow-up with that carer. But if, within their plan, there is something like, say, a few sessions of counselling, our expectation would be that after that counselling, there will be a follow-up conversation with the carer just to touch base.

MR GRAY: CareStar is only going to be available for the people who actually make contact with the RDPs, isn't it?

MR SOTIROPOULOS: That's correct. So again, that's where outreach comes into it to ensure that way we actually get to a broader range of carers.

MR GRAY: Right. Now, we probably traversed a couple of topics and I've departed a little from my structure, but I will just finish on that topic, and I will move to the topic of assessment of carer needs, formal assessments. Now, Ms Buffinton, directing questions to you about assessment in the aged care context, the Royal Commission has heard a lot of evidence about how this occurs as a result of a person entering the My Aged Care gateway seeking aged care in one form or other. They may not know what form they need it in, and they're referred to an assessment. That's right, isn't it?

MS BUFFINTON: That's - - -

MR GRAY: And there's a screening process by which - - -

MS BUFFINTON: Yes.

MR GRAY: - - - the My Aged Care operator or the person on the end of the email or the website makes a decision whether this looks like a person who has only entry-level care needs, and they will be referred to a RAS, Regional Assessment Service - - -

MS BUFFINTON: ACAT.

MR GRAY: - - - with the expectation that if they get anything it might be Commonwealth Home Support Program, CHSP.

MS BUFFINTON: That's correct.

MR GRAY: If it looks like they have more advanced needs, they might be referred to an ACAS or ACAT with the possibility of obtaining higher level monetary support in the form of home care package.

MS BUFFINTON: Home care package, residential respite and permanent residential.

MR GRAY: So there's a gradation of services available for greater need.

MS BUFFINTON: Yes.

5 MR GRAY: Now, in your statement at paragraph 15, I think it is, you say:

10 *The department is of the view that reablement or rehabilitation services should be offered in conjunction with residential respite to ensure that, to the extent possible, the care recipient can continue to live as long as possible in the community.*

And then you refer to other forms of respite services as well. At paragraph 18, you say:

15 *When a person is first assessed for aged care services, options for reablement or, where relevant, rehabilitation should be included in all services and covered by the support plan. This may include the range of supports as outlined in paragraph 16.*

20 There are various kinds of respite that you referred to in that paragraph and in addition to residential respite. And then you go on to discuss the forms of assessment that are available. And in the context of the Regional Assessment Services, the RASs that are assessing people with, in effect, the expectation that that person is going to come in as assessed for CHSP, you say:

25 *The department is currently returning a trial –*

This is paragraph 20:

30 *...of a new reablement-based assessment model with five RASs across the country.*

MS BUFFINTON: That's correct.

35 MR GRAY: How many RASs are there?

MS BUFFINTON: 17.

40 MR GRAY: Okay. And is that trial just a selection of the people who are approaching those RASs, or is it all the people approaching those five RASs?

MS BUFFINTON: It's an extensive trial. I will have to confirm whether it's all.

45 MR GRAY: Okay. And looking at the rest of your statement, the concrete steps that you can point to along the lines of a trial of a reablement approach at the assessment level seems to be limited to the RASs and the CHSP.

MS BUFFINTON: So in this formal trial it's part of the – the trial is the Regional Assessment Service, but I think I might also outline that as part of the – the government's announced a streamlined assessment model to come into the future, and we see as part of that – and we've gone out with a discussion paper on that – that
5 a reablement – a wellness and reablement focus should be across all assessment types, but this particular trial is the Regional Assessment Services.

MR GRAY: So that's fair, that you've raised the discussion paper about the streamlined assessment process, and I will come to that. But in terms of things that
10 have actually been done - - -

MS BUFFINTON: Yes.

MR GRAY: - - - including trials, we're really just limited to this trial for the RASs
15 , which is with a view to the CHSP being used with a reablement focus.

MS BUFFINTON: That's right, because part of the first stage has been that in 2018 to 2020 funding agreements for Commonwealth Home Support, that we have moved – that for a focus on reablement is part of the Commonwealth Home Support. Now,
20 our next stage is looking at how that is complemented by how we go about doing the assessment itself, an active assessment of, "Show me what you can do", rather than a model, and that's complementary. And then the next stage would be to look at the streamlined assessment and how we bring reablement model into all our services going into the future, obviously dependent on the evaluation of those trials.

25 MR GRAY: Just talking about the present and what's happened up - - -

MS BUFFINTON: Yes.

30 MR GRAY: - - - to the present, if we go to the aged – the Aged Care Financing Authority's report of 31 October 2018 report on respite for aged care recipients, which is tab 26, we see that one of the issues that is raised is a concern about whether the assessment process is sufficiently focused on the needs of carers. If we go to
35 page 104, please, Operator, we see in the first bullet point in the – just above the middle of the page, we see amongst the issues raised in the submissions, the importance of giving consideration to carer needs as well as care recipient needs.

We've heard evidence in this hearing that although carers were entitled to be present during interviews with ACAT assessment teams, they didn't feel that their needs
40 were a focus of the conversation. And if we go to tab 28, please, Operator, at page 20, this is a submission of the – an article of University of New South Wales. If we go to page – native page 20, please.

We see that based on Carers New South Wales data, less than half of the informal carers involved in assessments of people they were caring for reported that their
45 needs were part of the conversation. Are these matters that are of concern to you, Ms Buffinton, that the evidence seems to be suggesting that informal carers don't feel

that they've been included in the assessment process conducted by ACAT teams in the sense that their needs have been a focus of the assessment?

5 MS BUFFINTON: So as a person who's observed a wide range of assessments, and I know that the Royal Commission has both the national screening assessment forms and our guidelines to assessors, so the – as we've discussed, the first focus is the care recipient, but, as you can see through the national screening and assessment form, that continues to be improved. Last year we brought in sort of the next stage of the national screening and assessment form, but you will see as you go through those
10 forms that there are – first of all, one, what is the availability of carers, and what is their capacity to support?

Having observed how that is done, so the first part of the assessment is typically show me within the home what you, the potential care recipient, can do, but then
15 when it comes to well, what supports can be – what supports can be in place, for example, would grab rails or seats in showers or ramps, or preferencing whether the support required is more domestic assistance or out – work outdoors, that my observation of having gone through a number of assessments is that that's both discussed with the potential care recipient but absolutely taking into account - - -

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MR GRAY: So operator, we will go to tab 45.

MS BUFFINTON: What, just to complete, takes into account some of the preferencing of what the - - -

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MR GRAY: Is this the document you're referring to?

MS BUFFINTON: So that is the national screening and assessment form, yes, it is. And then how it's used is that's the what. The - - -

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MR GRAY: These matters are not specified on page 0006 but you're saying they might be, and you've observed some interviews where they have been fleshed out - - -

35 MS BUFFINTON: I think if you proceed through it is what's – what is – first of all, what's the availability of carers. You can also go into our manuals that you have copies of on explaining that assessors are expected to outline to the informal care network of the availability of the Carers Gateway and there are supports for them.

40 MR GRAY: Let's just take this a step at a time, Ms Buffinton.

MS BUFFINTON: Sure.

45 MR GRAY: Page 0006, if we show the entire page please. Thank you, operator. The expert panel was taken to a similar page during its evidence yesterday, although I think it was the NSAF that applies to home support and this is the NSAF that applies to home care. Now, the focus of these questions, although there is a

reference, of course, to caring relationships, the focus seems to be is the caring relationship going to be sustainable and what's the strain on the caregiver; is that right?

5 MS BUFFINTON: Yes, in effect, this is the form that they're filling in, yes, but it – because it goes with a manual which is all about how the questions and the intention of the questions are asked.

10 MR GRAY: All right. Let's go to the manual. The manual is at tab 26, please, operator. No, that's not right. Pardon me. Tab 46. Now, if we go to page 7650 please, operator, we have here a heading about approval processes. If we go over the page, we have here, in effect, a direction to the ACAT – this is the manual that the ACAT applies when deciding on what forms of aged care the person should be assessed for.

15 MS BUFFINTON: Yes. Prior to that it also outlines that when they're going through the assessment that they should be also cross-referencing the supports available to the care recipient and that they should be outlining the availability of the Carer Gateway and the supports that come through the Carer Gateway.

20 MR GRAY: Thank you. And when it comes to actually deciding what level of care the person, that is, the care recipient is going to be approved for, there's a direction to apply the guidance framework for home care package level if home care package is under consideration; is that right?

25 MS BUFFINTON: Yes.

30 MR GRAY: So we have to go to that document to decide, or to see what the guidance provided to the ACAT teams is. So if we please go, operator, to tab 69 and then tab 70, there are two sheets that constitute that guidance framework. Is that right, Ms Buffinton?

35 MS BUFFINTON: There are. Of course, there is also extensive training materials that are provided to ACATs that go with these materials, yes.

MR GRAY: All right. And there are questions similar to the sustainability questions in the NSAF form that I took you to, about considering the sustainability of caring relationships.

40 MS BUFFINTON: Yes.

45 MR GRAY: Now, in we go to the second of these pages and we call out the bottom section, there's a series of boxes about the directions or the guidance given to the team in determining whether to go from the entry level support program, which is CHSP, isn't it?

MS BUFFINTON: That's correct.

MR GRAY: Through to one of the higher levels of CHSP and they go progressively higher then to address higher levels of need. That's right isn't it?

MS BUFFINTON: That's correct.

5

MR GRAY: If we look at those little scales down the bottom, the first one at the cusp between CHSP and level one HCP is to consider requirement for coordinated care and transition to regular coordinated care. And then there's, in level 1, no particular reference to the sustainability of the caring relationship. So that's – that is
10 HCP and so it's a higher level of need than CHSP but it's not really directed to sustaining the caring relationship on the face of this material; is that right?

MS BUFFINTON: Yes. So typically, some of the things that are taken into account are if a person has no carer relationship so they're living on their own with no
15 support, is, by being involved with a single provider providing their home care, or at least coordinating their care, that provides a greater level of service than in Commonwealth home support where typically people have – are coordinating their own care, so they may be getting the similar domestic assistance or Meals on Wheels but one is – a provider is making sure that all – all of those two or three services are
20 being delivered in Commonwealth home support. Typically, the individual or the individual involved with the carer would be checking that. So that's the concept of the package at level 1.

MR GRAY: So services such as social support might be considered but the
25 presence of an informal carer would, if anything, be a bit of an offsetting factor tending to suggest that you don't need social services – sorry, I beg your pardon, don't need social support; is that right?

MS BUFFINTON: The classic social support that I think a carer appreciates - - -
30

MR GRAY: No, I'm not talking about the carer. I'm talking about – you agreed that the focal point of the My Aged Care assessment process is the person receiving care.

MS BUFFINTON: Yes.
35

MR GRAY: So I read this as services such as allied health, social support or transport could be included for the benefit of the person receiving the care.

MS BUFFINTON: Yes. And having observed the assessment taking place, that's
40 where in addition to a form, the assessor is talking through with both the – my observation – the individual who is the focus for the care, the care recipient and the informal care network, often the spouse, and that's where would – things like social support groups, going out, that's good for cognition and support, but it also often
45 gives a couple of hours for the carer to have some time out. So they have a dual purpose.

MR GRAY: And incidentally you might get a respite-type benefit for the person giving the care.

MS BUFFINTON: Yes.

5

MR GRAY: But it's not the focus for the assessment.

MS BUFFINTON: No, that's what's the care requirement of the older person requiring care.

10

MR GRAY: And it doesn't look on these materials – we'll come back to the manual in a minute but it doesn't look on these materials as if the focus is in any way on providing a long-term program of planned regular respite for the caregiver, does it?

15 MS BUFFINTON: So part of the assessment is, one, outlining what supports there are for carers but also in outlining that what the needs of the care situation and that's where outlining as part of the support plan it could be centre-based – recommendations for centre-based respite, or - - -

20 MR GRAY: But my question was on these materials it doesn't look as if there's any emphasis to be given by the assessors on assessing the needs of the caregiver for some sort of long-term regular respite that might have preventative effects on the strain building up on the caregiver, does it?

25 MS BUFFINTON: I think if you take the materials and if you were to ask ACATs across Australia, including the – their formal training, do they - - -

MR GRAY: I'm just asking you about these terms materials; can you point to something in these materials that suggests - - -

30

MS BUFFINTON: So generally it's part of the sustainability of the care situation and if somebody is saying, I really feel like I need some time out or I need some support, and typically the ACAT would be then saying okay, well, as part of the support plan we will include the need for centre-based respite and we will also give you – give the person being assessed access to residential respite or other aspects. It is taking - - -

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MR GRAY: But that's only if there's a threat to the sustainability of the caring relationship in the immediate term, isn't it?

40

MS BUFFINTON: If somebody is saying that they would like support, that's – that's at that point. One of the things that I think that this does bring out is the – one of the things that we like to get across to carers, and I think that we can do better on this, is ensuring that this is a point of time assessment and these circumstances might change, and that there is the opportunity if circumstances change for reassessment to get - - -

45

MR GRAY: I'm not sure if you've answered my question. My question is the focus that you say does exist on providing some respite for the caregiver, I'm suggesting to you that on these materials that's only if the sustainability of a care-giving relationship is under threat in the immediate term. If you need in the immediate term
5 to do something virtually on an immediate basis to ensure that the care relationship can carry on a little longer, then there's allowance in this assessment process for respite, but apart from that there doesn't seem to be a place for it. Certainly no place for a long-term regular preventative form of respite.

10 MS BUFFINTON: I – I highly recommend that you might like to go and observe the ACAT assessments because the social support services are discussed in terms of that would be good for the person - - -

MR GRAY: All I can do is go on these documents and if we look at the very next
15 window in relation to step – steps up in assessment from level 1 into the other levels, the directions to the ACAT team are:

20 *Consider client needs as identified through assessment and the extent to which they're being met through current formal or informal support arrangements when determining recommendation for HCP level 1 to 4.*

Let's just stop there. I suggest to you that the sense of that direction is that if informal support is being given then if anything that is an offsetting factor which tends to suggest that the person doesn't need to be in a higher level. Do you agree
25 with that?

MS BUFFINTON: Yes, we take into account the informal support and the care that's being provided.

30 MR GRAY: In a way that diminishes the chances of the assessment being that a higher level of package will be provided; correct?

MS BUFFINTON: Because the current care needs, including taking in account as the - - -
35

MR GRAY: Well, you're giving me a reason but not an answer, Ms Buffinton. Do you agree with the proposition - - -

MS BUFFINTON: So the question is asked of the person being assessed and their care network, that's why we do it in the home, as to what is the care situation. Are they currently happy and feel comfortable in offering that care, and so - - -
40

MR GRAY: No, no, Ms Buffinton, I'm just asking you about these words. Do you see them there?
45

MS BUFFINTON: Yes.

MR GRAY:

5 *Consider client needs as identified through assessment and the extent to which they are being met through current formal/informal support arrangements when determining recommendation for HCP level 1 to 4.*

I suggest to you that the gist of what is being directed there is that if and to the extent that the needs are being met by, amongst other things, informal care - - -

10 MS BUFFINTON: Yes.

MR GRAY: - - - then you don't need to grant a higher level of HCP.

15 MS BUFFINTON: If – if the carer is saying that they're currently happy, not under strain and they are willingly offering that level of care at that point, yes.

MR GRAY: Okay. And that's the importance of the next line, isn't it:

20 *Consideration should also be given to sustainability of carer arrangements in the immediate term –*

that's why I was referring to the immediate term a minute ago:

25 *...in the immediate term when recommending a higher or lower level HCP.*

So you're right to this extent: if in the immediate term it looks like the care arrangements aren't going to be sustainable, then the ACAT is corrected to consider the need for respite of the carer. Correct?

30 MS BUFFINTON: Or a higher level.

MR GRAY: Or a higher level of need, a higher level of HCP which might provide some money for respite.

35 MS BUFFINTON: So now if – we're in the home care program, so that would give them a higher level of package which they should draw down against whatever the respite care they choose.

40 MR GRAY: Okay. They could use it for respite, or they could just use it to lighten the load for the informal caregiver.

MS BUFFINTON: Yes, that's their choice.

45 MR GRAY: But the important thing is the restriction of this direction or guidance to the immediate term. Now, that's the antithesis of an ounce of prevention equals – beg your pardon – an ounce of prevention equals a pound of cure.

MS BUFFINTON: So this comes down to where I was agreeing earlier, which is how do we take the opportunity of educating carers? This is not part of the – well, part of the ACAT assessment is actually educating carers as well. But it's making sure that carers are aware of the – the DSS programs for carers.

5

MR GRAY: Didn't you agree with me before that this is the framework document that the ACAT teams are directed by the manual to apply when they're deciding what level of - - -

10 MS BUFFINTON: Absolutely. And also - - -

MR GRAY: - - - HCP to assess?

15 MS BUFFINTON: Also in the manuals and also the training materials is also the Carer Gateway.

MR GRAY: Are you walking away from – are you resiling from - - -

MS BUFFINTON: No, I'm not.

20

MR GRAY: - - - the words that have been used here?

MS BUFFINTON: No, I'm not.

25 MR GRAY: No, but you're saying that I've got to go and actually observe - - -

MS BUFFINTON: We - - -

MR GRAY: - - - how it's done in practice.

30

35 MS BUFFINTON: We assess for – at a point in time, the – the care needs of individuals, and that is what the – this assessment and those words are referring to. What I've conceded is that we've got to make sure – and this is something that we've been reflecting on, is making sure that when people are assessed, that both the – the person, the care recipient but also their caregivers, the informal care network are aware that if these circumstances change, including whether the care arrangements change, that they are aware that they can ask for a reassessment or a review of the support plan.

40 MR GRAY: Mr Sotiropoulos, under the earlier topic, I asked you about the focus of assessment for, in effect, the somewhat limited amount of money that's going to be available under the carer directed respite packages. It's going to be \$3000 per year. I think you – I was suggesting to you that that's not really tailored to the provision of planned respite and in the context of carers of older Australians, if we come back to
45 the My Aged Care system to have that need assessed. Is that right?

MR SOTIROPOULOS: That's correct.

MR GRAY: Okay. I want to move to another topic, which is the evidence that the Royal Commission has received about the potential for disjunction between the two systems that are operated by the respective departments, that is, the My Aged Care system on the one hand, Ms Buffinton, and the Carer Gateway on the other, Mr Sotiropoulos. And the Royal Commission is aware that there are policy choices to be made here, because the Carer Gateway is not only catering for the carers of older Australians but carers of a number of other categories of people in their care. That's correct, isn't it, Mr Sotiropoulos?

10 MR SOTIROPOULOS: That's correct.

MR GRAY: And on the other hand, Ms Buffinton, your program in particular, focusing on in-home care, we're talking about the care of older Australians, and I'm advocating, as you can tell, robustly, the reorienting of the way that system assesses needs so that a much greater place is given to a holistic assessment of the caring relationship, including the needs of the person who's giving the informal care. I want to explore the extent of the linkages between the two systems and whether things are being put in place to ensure that people don't fall through the gaps. There is quite a range of evidence now before the Royal Commission that people have found it very difficult to understand, let alone navigate, the bifurcated elements of the system.

So, Mr Sotiropoulos, I will come back to that issue that you had raised, and I asked you briefly about it. When a person contacts the Carer Gateway and they need planned respite, I think that you already answered the question and you weren't able to give detail on exactly the level of assistance that can be provided by the carer gateway to put the person making the inquiry in touch with respite services.

MR SOTIROPOULOS: There's probably two elements to that on listening to your further questioning. When it comes to the planned respite component, the required – the – the expectation there would be that the person would be referred to the My Aged Care services. If it was emergency respite in a situation where the carer was at a point in time and they just needed a break, certainly currently they – the CRCCs are responsible for brokering and funding that respite service.

35

MR GRAY: Thank you.

MR SOTIROPOULOS: So there is a difference between the planned and the emergency respite.

40

MR GRAY: I want to ask about what happens when the carer gets in touch with the Carer Gateway seeking counselling, or education or other social support services, but they can't get out of the house; they're a 24/7 carer. So, in effect, respite needs to be coordinated with the ability to make access meaningful for that carer. What happens then?

45

MR SOTIROPOULOS: If it's an emergency respite situation, if the carer must get out of the house?

5 MR GRAY: No, if it's not an emergency but the carer is trying to line up a program of counselling or education or social connectivity through Carer Gateway. I understand those are the sorts of services - - -

MR SOTIROPOULOS: That's correct.

10 MR GRAY: - - - which the Carer Gateway refers a carer to.

MR SOTIROPOULOS: That's correct.

15 MR GRAY: Is that right?

MR SOTIROPOULOS: Yes.

20 MR GRAY: So – and that's great. But to make that practically meaningful for the carer, a 24/7 carer, how are they going to work out or ensure that they can actually get to those appointments, those programs at various points in the future in a planned manner?

25 MR SOTIROPOULOS: So – so at present, the carer could come through either the – the online webpage or through the 1800 number and the requirement there would be that the – the carer would be – the relevant service providers would be identified that could support the carer, and beyond that I don't have – I don't have the knowledge to be able to explain any more detail than that.

30 MR GRAY: Okay. So it's then up to the carer to pick up the phone to those service providers and see if that information about respite being available was accurate and make their own arrangements. Is that right?

35 MR SOTIROPOULOS: It's not nationally consistent. I think some service centre – some carer Commonwealth respite and care link centres would provide a little bit more support than that, but it's not a nationally consistent approach. Some would – would provide greater assistance to the care err and maybe make contact with the carer's behalf, but in other instances it could be up to the individual themselves to make contact with the relevant providers.

40 MR GRAY: Would the carer directed respite package pay for that respite? Assuming they can arrange it, assuming – having received that information about available respite beds over a certain period into the future and having made contact with those aged care providers and tried to secure those nights, or days, who pays for it? Does DSS pay for it?

45 MR SOTIROPOULOS: It could be paid – it could be paid for out of the – out of the targeted respite packages.

MR GRAY: That DSS administer.

MR SOTIROPOULOS: On a short-term basis. That's correct.

5 MR GRAY: On a short-term basis and subject to that \$3000 cap that's coming in.

MR SOTIROPOULOS: That's right, and there is some flexibility there too.

10 MR GRAY: And if it's, as I said, cottage respite, and if you agree with me that it's – just for the sake of this question, that cottage respite is expensive, there's – on a full-cost recovery basis, it seems to be as much as \$700 on Ms Buffinton's evidence, it's not going to really – you're not going to be able to obtain much - - -

MR SOTIROPOULOS: No.

15

MR GRAY: respite.

MR SOTIROPOULOS: And that's where the emphasis would be on, on getting that carer in touch with the right service providers or the My Aged Care system to ensure that the longer-term requirements are actually addressed.

20

MR GRAY: So, Ms Buffinton, I think I need to ask you about this, and we might be getting to the territory where Mr Murray can join in. I don't know. But we've got here a situation where the carer desperately want to avail herself of the programs that are offered by the Carer Gateway, counselling, education, support, just the sort of things that we know - - -

25

MS BUFFINTON: Yes.

30 MR GRAY: - - - can have a preventive effect and, in sheer human terms, we should be supporting that, we all agree, and indeed it makes sense for the sustainability of the my age – of the aged care system as well. Now, my proposition to you is that it's unclear how My Aged Care fills that need or meets that need when the carer needs some regular planned respite for a few days here and there on into the future without, in effect, huge private cost. Are you able to explain what happens at the point Mr Sotiropoulos left off?

35

MS BUFFINTON: Yes. So the My Aged Care gateway and the Carer Gateway are closely linked. In fact, I sat on the foundational committee using our experience of My Aged Care in the formation of the Carer Gateway. So typically if you ring the Carer Gateway, one is – the services you were describing which was the counselling and those direct supports to the carer, but one of the things that on the Carer Gateway they would be asking, "Has the person you've been – you're caring for, have they been assessed for a sort of aged care? So have they got through a RAS or an ACAT? Have they got assessment?" "Yes, they have", or, "No, they haven't." So a suggestion that we can pass you through to the aged care gateway to get that sort of screening prior to doing an assessment for that broader aged care.

45

MR GRAY: So it sounds like it's not terribly clear what happens. Maybe the person gets referred to assessment by a RAS, maybe they get referred to assessment by an ACAT and they have to go through a process of demonstrating that the person they're caring for meets those assessment criteria that I took you through. And if
5 that happens, as I was suggesting to you, the focus of that assessment material is not on the needs of the caregiver, the informal caregiver, but it's on the needs of the care recipient. And when it comes to higher levels of care under HCP, unless there's, in effect, a threat to the sustainability of the carer relationship in the immediate term, they're unlikely to be recommended for higher levels of HCP on the basis of strain to
10 the career. That's right, isn't it?

MS BUFFINTON: So positively, they're – come into My Aged Care. If we understand they're under strain, typically people coming in making their first calls don't come into the system in an acute environment, but if they do, we arrange to get
15 a high priority assessment that can be done within a couple of days. And if the carer relationship is under strain or non-existent due to the hospitalisation of the carer or the passing of the carer, we can arrange a high-priority home care package as well.

So what I'm trying to get across is we are actually all working to the one – to the one
20 purpose, which is to make sure that the person being cared for and the carer is well looked after. We acknowledge that it doesn't always work as well as it could, and that's part of what a Royal Commission is shining the light on, but I certainly wouldn't want to leave the impression that the system is broken. We've put a lot of work, a lot of co-design, we do a lot of work with Carers Australia, Dementia
25 Australia in designing our approach at each step of the way and we do take feedback and continually to improve the system.

MR GRAY: Just picking up the point about high priority that's important because we know that there are very long waiting lists for home care packages, even
30 assuming you get through the assessment process. The Royal Commission has heard evidence that at levels 3 and 4 there are waiting lists in the order of two years before you get an assignment of that higher level home care package; is that right?

MS BUFFINTON: At the medium priority.
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MR GRAY: At the medium priority. So high priority is important. If you get high priority what's the waiting list around the country?

MS BUFFINTON: For a - - -
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MR GRAY: I beg your pardon; what's the waiting time in the national - - -

MS BUFFINTON: So we can get somebody attached to a level 2 package within a week or two. We can get them attached to a level 3 package, which if they're
45 assigned or assessed level of care is a level 4 that they could be attached to a level 2 within a week or two, that they would get a level 3 package within two months and they would get a level 4 package within five months.

MR GRAY: There's still quite long times at level 3 and 4 of three or five months. I will ask the operator to put up tab 3 of the general tender bundle. These are the – this is the guidance document on high priority. That's right, isn't it, Ms Buffinton?

5 MS BUFFINTON: That's correct.

MR GRAY: And I mean, you didn't say otherwise but this is for when carer arrangements are already unsustainable or at crisis point, isn't it?

10 MS BUFFINTON: And so this could be because they've been in a carer relationship, they've already been attached to care and now that something has changed in the carer relationship, or they have come in and already it's in crisis because we do know a lot of carers, rightly or wrongly, even if they do know that
15 they feel that it's their role to look after the individual and so sometimes they come in – by the time they do actually or their families support them in ringing, they are in a crisis.

MR GRAY: We know that, we've heard that evidence.

20

MS BUFFINTON: Yes.

MR GRAY: But it's no answer to the propositions I'm putting to you that reform is needed to be more preventative, more proactive and intervene earlier to say, well, a
25 lot of carers don't understand that. You've got to extend outreach to those people, don't you?

MS BUFFINTON: Yes, and what I think we've said is we agree, we think we can improve. We've got – moving from the role that DSS are playing from being more
30 in an emergency situation to far more turning that round to being in an outreach education, we've both agreed I think that that early intervention is the better way to go.

MR GRAY: And the policy settings that underlie the home care package program
35 are a long way from being preventative or encouraging the use of regular short-term respite to sustain the care relationship over the long course, aren't they? They're all about immediate threat to the sustainability of care relationship and they're not about long-term preventative measures, do you agree with that?

40 MS BUFFINTON: I do not.

MR GRAY: Well, I suggest to you further that on the evidence in your own witness statement, flexible cottage respite, for example, is very, very expensive when it's
45 paid for out of a home care package. That's true, isn't it?

MS BUFFINTON: Cottage respite, when it's paid for by government, I have acknowledged is about \$700 a night. Whether it comes through Commonwealth

home support or home care packages, the cost to the Commonwealth or the taxpayers is around about \$700 a night, it's exactly the same price.

5 MR GRAY: I'm asking about the cost to the home care package held by the care recipient. If the home care recipient wishes to obtain cottage respite, they're going to be charged full cost recovery under the rules of the home care package program; is that right?

10 MS BUFFINTON: Yes.

MR GRAY: Save for in certain limited circumstances.

15 MS BUFFINTON: Yes, because they've already – their subsidy has been paid – let's take a level 4 home care package, they've been given \$50,000 of potential subsidy, whereas as we know, under Commonwealth home support, the individual is given no subsidy. They get access to that same \$700 a night bed. It's costing the same price, but it's - - -

20 MR GRAY: It's costing the Commonwealth the same but the home care package holder is perceiving a \$700 hit to their home care package account if they choose to try to obtain cottage respite - - -

25 MS BUFFINTON: You could say that about all the care under the – the whole concept is that you now know that you've got \$50,000 and you've got choices in how - - -

MR GRAY: I'm just asking whether you agree with the proposition that I just put.

30 MS BUFFINTON: You used the word "hit".

MR GRAY: Yes.

35 MS BUFFINTON: So you draw down on that package so one way we pay a subsidy to the individual to draw down on; the other in Commonwealth home support we provide that funding through a grant to the - - -

40 MR GRAY: The reason I asked it that way is that I suggest to you that there's a distorted incentive involved here and that home care package holders are disincentivised from obtaining flexible respite in the form of cottage – overnight cottage respite for short periods, one and two day periods because they will perceive a very large subtraction or debit or hit from their home care package account. Do you agree with that?

45 MS BUFFINTON: I – I acknowledge how they can perceive that, yes.

MR GRAY: And yet we know from the evidence, we've heard a lot of evidence that carers, that is, informal caregivers, prefer cottage respite because it's available in

short amounts, one, two or three nights, and it can be planned out over a long period. You don't have any basis for disputing that, do you?

MS BUFFINTON: No, I don't.

5

MR GRAY: Residential respite, on the other hand, which is the program that has its own freestanding subsidy attracted to it, we've heard evidence this morning from the provider panel that their preference is to offer or encourage residential respite in at least two week blocks. Did you hear that evidence this morning?

10

MS BUFFINTON: I'm aware of that evidence.

MR GRAY: Residential respite in a residential aged care facility is not well adapted to regular long-term short bursts of overnight respite, for that reason. Do you agree with that?

15

MS BUFFINTON: Yes.

MR GRAY: And part of the reason for that is that a residential aged care facility incurs quite a lot of upfront administrative costs around care assessments and it's a more institutional and a large-scale facility and it's just harder and more expensive for residential aged care facilities to take on short-term respite residents. Do you agree with that?

20

MS BUFFINTON: Well, it actually, interestingly, I think depends on the style of residential care, because more recently, and Mr Murray can discuss this further, is the innovation that's coming into residential care, rather than a very large bricks and mortar building, there is many providers now offering effectively clusters which might be four, five, six rooms with a single kitchen, across a facility made up of 10 or 12 different clusters as part of what is actually residential. So that gives them the flexibility to offer classic permanent residential or more of a cottage or if, in the future where there may be less demand with aged care with sort of, after we go through the baby boomers to actually offer different types of care. So there's a lot of innovation coming into what is residential rather than the classic cottage versus the bricks and mortar - - -

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MR GRAY: At present, the residential respite program is overwhelmingly going to be taken up in larger scale residential aged care facilities which are not well adapted to providing short one, two or three night stays and are going to prefer, as we heard from the provider panel, at least two weeks as a means of trying to recover some of their upfront administrative costs. Do you agree? I will ask Mr Murray – do you agree Mr Murray?

40

MR MURRAY: That's certainly what we've heard from providers and what ACFA heard in their consultation as well.

45

MR GRAY: So respite care, Mr Murray, means:

...residential care or flexible care as the case requires provided as an alternative care arrangement with the primary purpose of giving a carer or a care recipient a short-term break from their usual care arrangement –

5 and I'm quoting from the definition in the Aged Care Act.

MR MURRAY: Yes.

10 MR GRAY: You're very familiar with that, I'm sure.

MR MURRAY: Yes.

15 MR GRAY: The thrust of the ACFA report's relevant concerns was that – well, one of the thrusts for their concerns was that there are strong indications that the residential respite subsidy program is increasingly being used for purposes other than that dominant purpose. For example, for the purpose of a transition to permanent residential care; correct?

20 MR MURRAY: They certainly identified that's what they referred to as try before you buy arrangements seem to be coming more widespread in the sector. That's not necessarily to the exclusion of someone who might be using it for that purpose, also using it for a short-term standard respite care break.

25 MR GRAY: Because somebody might not have actually made their mind up.

MR MURRAY: That's right, yes.

30 MR GRAY: That's fair enough but for people who are along the lines of some of the evidence we heard from the providers, in a transitional phase where they're getting their affairs in order and there will be a transition to permanent residential care, that's not respite, is it?

35 MR MURRAY: So again it will depend on whether there is also a purpose to give the short-term break and - - -

40 MR GRAY: If there isn't a purpose of returning to some other in-home care arrangement which has been departed from just temporarily, but actually the care recipient or the carer knows that home care has become unsustainable and this is now a move to permanent residential care and is just a stepping stone to permanent residential care, that's not respite, is it?

45 MR MURRAY: If the pure purpose has nothing at all to do with providing a short-term break that could well be the case. Again, it would be difficult to determine that when you've got the carer and the carer simply could have different motives and it would be hard to determine that on each individual case.

MR GRAY: It's hard to determine it, but ACFA inferred that about a third of people are actually going straight from respite – residential respite in an RACF into permanent residential care.

5 MR MURRAY: That's correct.

MR GRAY: So a fair number of that third are probably just using it as a stepping stone, would you agree with that?

10 MR MURRAY: Quite possibly. There's always been a reasonably significant amount of people that have moved straight from respite into permanent but that number has increased over recent years.

MR GRAY: The fact that it's increasing is a cause for concern for this reason, isn't it; the reason is that residential respite has a certain amount of money allocated to it, through the budget processes, and it has a certain purpose for which that money is allocated and that's to provide respite. Do you agree with that?

15 MR MURRAY: Well, certainly, the provision of respite care is for short-term care. That's the primary purpose, yes.

MR GRAY: It's a very important purpose for the reasons I actually asked Ms Buffinton about right at the start and I think Mr Sotiropoulos also agreed, that is, an ounce of prevention is worth a pound of cure. If you can get some sustainability of the informal caring relationship out of respite, then all other things being equal, you tend to, in fact, save the aged care system some money. No cost benefit analysis being done to determine exactly how to calibrate that amount but in principle that must be so.

25 MR MURRAY: Yes, I'd agree with that.

MR GRAY: And although no cost benefit analysis has been done, what has happened is that a certain amount of money has been put aside by policy makers for the use of respite which has an important role in ensuring sustainability of the aged care system.

30 MR MURRAY: Yes.

MR GRAY: And what's happening here is in increasing numbers, the money that's been set aside for that purpose is leaching away to be used as a stepping stone for another purpose.

MR MURRAY: I wouldn't necessarily agree that it's leaching away, as you put it. As I mentioned before, it is not clear and it is very hard to get to that issue as to whether someone also has a purpose of using this for short-term respite care. It is also the case that there has been quite significant growth in respite care usage over

recent years and only part of that could be explained by these types of try-before-you-buy arrangements.

5 MR GRAY: I want to ask about whether there's more than just try before you buy at play here, but actually whether there's a disparity in the compensation or the subsidy that's available to the operator of the residential aged care facility that might also be in play, because this is another concern of ACFA, isn't it?

10 MR MURRAY: Yes.

MR GRAY: If we go, please, Operator, to – back to tab 26, the ACFA report, and we look on page 0126, native page 25 at 2.1. You would be very familiar with all this, Mr Murray, no doubt and your statement refers to the ACFA report.

15 MR MURRAY: Yes.

MR GRAY: This chart – correct me if I'm wrong, but it seems to be showing that what's happening is that even if you take into account all of the potential supplements that are available for residential respite, they're not actually now
20 matching what the RACF operator could expect to get from allocating the relevant bed to a permanent residential resident, assuming they get a reasonable amount by way of accommodation payment as well. Is that a fair description of what the chart shows?

25 MR MURRAY: Yes, in general. Yes. Of course, each individual circumstances will be different, and you've got the maximum ACFA rate there. Some would be on a lower ACFI rate, for example. So it would depend on the individual circumstances. But in general, the chart does show your proposition that if you receive the maximum funding under ACFI, that would be higher than the maximum that a respite person
30 would receive.

MR GRAY: Now, we've prepared a chart based on information received from the department. Have you had an opportunity to consider the charts that were provided earlier in the day?
35

MR MURRAY: Yes, I have seen those charts.

MR GRAY: So – thank you. If the operator would please bring up tab 68. And does tab 68 consist of two pages? It's RCD.9999.0152.0001. If we go first to page
40 0002, this is another depiction of data about the maximum respite payments that are available if they're all combined, compared with permanent residential payments, and the green add-ons in the columns on the right-hand side are the accommodation elements.

45 MR MURRAY: Yes.

MR GRAY: And they're showing, in effect, the same thing as the proposition I advanced a short time ago.

MR MURRAY: Yes.

5

MR GRAY: If we look at the longitudinal graph that's on page 0001, we get a picture of the trends. Have you had a moment - - -

MR MURRAY: I have had a moment, yes.

10

MR GRAY: - - - at some point during the day to consider this longitudinal chart?

MR MURRAY: Yes, I have.

15 MR GRAY: Did you see anything objectionable about the methodology employed?

MR MURRAY: There probably would be the need to refine this chart if you're trying to draw that comparison between, you know, mainstream the residential care and the respite. The reason for that is the green – the green line there, which is the average basic – effectively, the ACFI subsidy for permanent residential care, that's appropriately reflecting what has happened in terms of the growth of ACFI, so that's fine from that point. But it's important to note that in terms of the ACFI subsidy, it will be growing from two purposes. One is because of annual indexation applies to those subsidies, and the other is because of changes in claiming behaviour from providers. And what we have seen over time is a fairly reasonably significant increase in providers claiming higher rates of ACFI than the lower rates.

20

25

So that has increased the – the gradient and the growth rate of that line as well as indexation, whereas, in contrast, the lines there you were showing for the respite subsidy, they will be only showing the indexation impact. And what the ACFA report noted also is that in respite, there has been a shift from low-level respite to more high-level respite. So you would need to take that into account to probably get a more like for-like comparison of the respite rate growths to the ACFI rate growth.

30

35 MR GRAY: Well, let's take the high-level, high-care respite subsidy. This is, in effect, looking at that those elements of the subsidy that are intended for the – intended to meet care costs. Correct?

MR MURRAY: Yes.

40

MR GRAY: And let's just take the orange line, the higher one, because ACFA has concluded and has depicted in the graph in the ACFA report that there's a marked increase in people receiving residential respite care at the high level rather than the low level and the low level is tailoring right off.

45

MR MURRAY: That's correct.

MR GRAY: So let us assume that the residential aged care facility, approved provider can expect remuneration, in effect, subsidy to meet care costs of a residential respite resident at the orange line.

5 MR MURRAY: Yes.

MR GRAY: Make that assumption. The green line is not ACFI at the highest level; it's average ACFI.

10 MR MURRAY: Yes.

MR GRAY: It's the average ACFI level of subsidy over time depicted from year 2006/7 to 2017/18; correct?

15 MR MURRAY: Yes.

MR GRAY: What this chart is showing that under a combination of the very two factors you mentioned, indexation and basically case mix or increasing acuity claimed under ACFI, that the green line depicting the average remuneration or subsidy that an RAC operator gets from a permanent resident has increased and increased to the extent that it has overtaken the amount that's set aside for care needs of respite residents back in 2009/10; correct?

25 MR MURRAY: Yes.

MR GRAY: And that's an apples and apples comparison because the ACFI – the green line, the ACFI figure is intended to meet care costs.

30 MR MURRAY: Yes.

MR GRAY: And the orange line is intended to meet care costs.

MR MURRAY: Yes.

35 MR GRAY: So, in fact, at some point back in 2009/10, the rest – the basic care fee for respite, residential respite was failing at the high level to keep track with the average remuneration or subsidy available to an RACF operator for a permanent resident.

40 MR MURRAY: Yes, and, as I mentioned, that is partly driven by the frailty growth, but yes, that analysis.

MR GRAY: And there's indexation of both of them - - -

45 MR MURRAY: Correct.

MR GRAY: - - - on the whole.

MR MURRAY: Yes.

MR GRAY: There's been – there was a freeze at one point on ACFI.

5 MR MURRAY: Yes.

MR GRAY: But let's say there's indexation on both of them. So we're not talking about inflationary effects. We're talking about a mix in acuity needs or in acuity and care needs that is driving the growth in the green line - - -

10

MR MURRAY: Yes.

MR GRAY: - - - and in the claiming behaviour that responds to that.

15 MR MURRAY: In the green line it is certainly the claiming behaviour which is driving the

MR GRAY: The orange light, residential respite subsidy has no provision for being increased with increasing acuity of residential respite applicants.

20

MR MURRAY: Not above the high-care line, as you've said, yes. The low care would shift as there's been a move between low and high, but that's correct.

25 MR GRAY: And this has created a distortion, or an absence of neutrality at least, in the subsidy that's available for caring for a residential respite on the one hand as opposed to a permanent resident on the other, hasn't it?

30 MR MURRAY: Yes, certainly. And as the other chart's highlighted, and ACFA has highlighted this again, that the – on average, there is a higher payment for a permanent resident, and the chart shows that, than a high-care respite resident.

MR GRAY: And why didn't the department do something about this in 2009/10? Was the department paying attention to the data?

35 MR MURRAY: So there has been a fair bit of focus on the – the ACFI growth line and, as you've noted yourself, there was concerns that that growth was higher than what government considered was sustainable. And as you can see in the chart itself, there have been high gradients and then low gradients as government has reacted to those measures to adjust the growth in ACFI subsidies - - -

40

MR GRAY: Sorry to interrupt you. My question was not well-framed. Why hasn't – why didn't the government do something about the fact that the residential respite subsidy had fallen behind the average ACFI level back in 2009/10?

45 MR MURRAY: I can't really comment on 2009/10. I wasn't - - -

MR GRAY: All right.

MR MURRAY: - - - in the department or where - - -

MR GRAY: Well, it's then got worse, hasn't it, because even if you add on all of the supplements – there are two extra supplements.

5

MR MURRAY: Yes.

MR GRAY: There's an accommodation-related supplement and there's a smaller supplement called the incentive supplement.

10

MR MURRAY: Yes.

MR GRAY: You explained these in your statement. Even if you add those on – and we're no longer comparing apples and apples because there are add-ons that you get under ACFI as well that would take ACFI - - -

15

MR MURRAY: Yes.

MR GRAY: - - - even higher. But even if you add those on, you only get to the red line and, in fact, the average – and I stress – the average ACFI subsidy level is now over and above what an RACF operator can get at best for a residential respite resident, even with the additions of the two supplements that I've mentioned.

20

MR MURRAY: Yes, that's correct.

25

MR GRAY: So this is a significant disincentive to an approved provider using a bed for respite as compared with using it for a permanent resident, isn't it?

MR MURRAY: Well, I guess it's important to understand what the costs of providing that care for the respite care recipient would be to come to that firm conclusion.

30

MR GRAY: Well, on any view, even if you don't take into account the additional upfront administrative costs that, say, Mr Midgley was referring to when he was explaining how expensive it is for Chaffey to provide residential respite beds in his evidence today, but they're doing that at a loss, in effect. I think he at one point said perhaps for marketing purposes, if you like, but they're running at a loss when they provide residential respite and they're doing it to help the community. Remember that evidence?

35

40

MR MURRAY: I wasn't here to hear that evidence - - -

MR GRAY: All right.

45

MR MURRAY: - - - but I've heard it relayed. So I will make the point that I accept – I accept all those propositions you've put. There is also an argument – and again it's an issue where probably further work needs to be done to understand the true cost

in this area – that you may often find that a mainstream permanent resident may have higher costs because they have reached a stage in their frailty decline where they need higher care than perhaps somebody who is still able to stay in the home and have occasional sort of respite care. But nevertheless, certainly the – there is a
5 difference between those funding levels, and the Aged Care Financing Authority identified that as something that was worthy of further consideration, and the department agrees with it.

MR GRAY: You agree with it and you agree with it in your statement, but you say
10 not now. You say let's wait until the resource utilisation classification study, now called ANACC, has been concluded and there's been reform to a funding model to permanent residents. Is that right?

MR MURRAY: So - - -
15

MR GRAY: That's a fair summary of your evidence, isn't it?

MR MURRAY: I guess the position I would put is on balance it would make sense
20 to consider whatever changes we do do to the respite funding system at the same time as we consider changes to the mainstream system. The mainstream system has already gone through a ruck study. They've already put out a consultation paper and received feedback on that. So that is quite well advanced consideration.

And if we're looking at a system that is going to be sustainable and equitable and as
25 neutral as possible going forward, it would make sense, looking at the long term, to consider how we move both the respite system and the residential system together so we get a – sort of a holistic perspective, and some of these concerns that have been put forward about differences and lack of neutrality can then be properly considered together.

30 MR GRAY: The ruck study and now its incarnation, being run under the stewardship – the trial being run under the stewardship of the University of Wollongong - - -

35 MR MURRAY: Yes.

MR GRAY: - - - the ANACC don't encompass residential respite within their scope
at all, do they?

40 MR MURRAY: No, but that is partly the point. What they did actually comment on was that there would be some benefit in doing a further study to get a better understanding of the respite costs.

45 MR GRAY: So let's get this straight. You're saying that reform of this funding distortion, this disincentive to approved providers making beds available for residential respite purposes, should await the resolution of policy decisions around permanent residential funding models; is that right?

MR MURRAY: So I'm saying that on - - -

MR GRAY: Even though the study on which that's based didn't consider residential respite.

5

MR MURRAY: What I am saying is that on balance it would make sense to consider how we move the respite funding system at the same time as we consider how we move the residential care funding system - - -

10 MR GRAY: If we do that - - -

MR MURRAY: - - - rather than have them out of - - -

15 MR GRAY: If we do that, it will be years before this distortion is corrected; do you agree with that?

MR MURRAY: It will take some time to change, develop the form, so I guess one of the considerations though is we want to get those long-term settings right and there is, I guess, a timing issue as to how we bring these things forward together. Ideally you would do them together. One consideration government could consider is whether it was able to move on some elements earlier than others, but still if you're looking at the long term trying to get everything sustainable going forward it would make sense to consider them together.

25 MR GRAY: I suggest to you time is of the essence; an ounce of prevention now is worth any amount of cure later. We've got a scarce resource. It's the energy and the willpower and the – the emotional resources of our informal carers, and we have to act to help them now in whatever way we can and that means not waiting for several years before the RUCS AN-ACC process is completed. What do you say to that?

30

MR MURRAY: I would say I think with everything in aged care there are whole lots of parts to the moving puzzle. I still think it is important that we do work out how we integrate how we move forward on those things. Now, it could be government could consider a staged approach to how it does certain reforms and that could allow some parts to move forward but still if we are trying to look at the long-term picture and get everything sustainable and properly balanced. It's not that we would – government can consider these things, of course, there's a difference between something can be implemented and brought forward.

40 It's also of note that, as I've mentioned before, respite care usage has been increasing so it is not as if there is a decrease in respite use, it is increasing throughout - - -

MR GRAY: That might be attributable to try before you buy, mightn't it?

45 MR MURRAY: It can't be fully attributed to try before you buy. The growth has exceeded – the growth in those – the move from short-term respite into permanent.

MR GRAY: It might be attributable to increasing acuity, people wanting to stay at home longer and the caring relationship reaching the unsustainable levels that actually permit, under the assessment processes, respite to be made available.

5 MR MURRAY: There are a range of considerations that could be influencing that, yes.

10 MR GRAY: It wouldn't be a difficult thing to have an interim adjustment made to the subsidy levels, the subsidy formula for residential respite which would track with the ACFI curve, the green curve on this graph. It would be an easy thing for the department to do that, provided government agreed to implement such a change.

15 MR MURRAY: Certainly, changing the rates is an easy thing to do, and it comes with a cost to government which they would have to consider but changing the rates itself is simple.

20 MR GRAY: Now, I need to wrap up, but I need to ask a few final questions. Ms Buffinton, I was going to ask you some questions about home care package. There is one loose end from the home care package hearing in March that I do need to follow up on. In March you were asked by Dr McEvoy QC about people who had died waiting for a home care package during the extensive waiting period that applies, particularly at the higher levels of need for home care packages. And Dr McEvoy quoted in his closing figure, a figure as high as 16,000 people who had died waiting for a package. And we heard again as recently as Monday of this week from Ms
25 Barbara McPhee that her mother died waiting for a home care package level 3 to 4.

30 You were asked about whether this was under active – some sort of active consideration by the department back in March. Are you able to provide the Royal Commissioners with any interventions to prevent notifications of assignments being conveyed after the death of the applicants for these packages?

35 MS BUFFINTON: Yes, we have been in contact with the Department of Human Services and we are in the process of coming to some final conclusions to make sure our systems – if somebody tells a part of government that we will all be aware of that, that will reduce – so certainly if something happens within a couple of weeks sometimes our systems aren't notified but all our systems will be notifying each other, so that if you've told the Department of Human Services, the Department of Health system will also be known so that we can reduce those unfortunate letters that have been going out, sometimes many months after the passing so, yes.

40

MR GRAY: So you can't give a guarantee that there's a system in place that would prevent it happening within a couple of weeks at present but you can guarantee that there is now a system in place that will stop it happening at any longer period than that; is that right?

45

MS BUFFINTON: That's correct. And it's just purely, by the time that centre is alerted and it goes into the system and that information is shared, I'm just saying I

can't guarantee that there will be no letters. Once somebody has alerted us, it may take a short period of time, but the very unfortunate examples where our systems weren't talking and therefore we had people getting sometimes nine, 10, 12 months after the passing, us sending out those letters, we're ensuring that that doesn't happen.

5
MR GRAY: Thank you. Commissioners, that concludes my examination of this government panel. Subject to any questions that the Commissioners have for the panel, I can proceed to now closing.

10
COMMISSIONER BRIGGS: Just one question. With that adjustment, Ms Buffinton, does that mean that the cost of providing home care packages to the people who are on the waiting list for level 3 and level 4 reduces from the 2.5 billion, I think you said last time, because those people would be removed from the list?

15
MS BUFFINTON: I think what counsel was describing that we had an unfortunate situation where people were giving advice to possibly Centrelink and that they had passed away and we were continuing to write to them, in terms of the number of people who are on the waiting list, you know, it continues to be substantial and the investment required to bring that down, as we discussed two or three month wait, still remains at that figure.

20
COMMISSIONER BRIGGS: Thank you.

25
COMMISSIONER TRACEY: Nothing arising?

MR GRAY: No. Thank you, Commissioners.

30
COMMISSIONER TRACEY: We thank you all for your evidence and you're excused from further attendance.

<THE WITNESSES WITHDREW

[3.52 pm]

35
COMMISSIONER TRACEY: Yes, Mr Gray.

40
MR GRAY: Commissioners, the evidence in Mildura has painted a picture of inadequate and belated government action to address the needs of informal carers of older Australians. The future of the current reforms to address these needs is uncertain at best and seems likely to deliver little systemic improvement in the areas of greatest need, particularly around those preventative matters that I've just been adverting to. While carers have told the Commission about the benefits of caring, such as establishing a strong bond with their loved one and a sense of purpose, carers have also described feelings of exhaustion, isolation, grief and sometimes frustration and anger. And I'm reminded of the evidence of Mrs Cameron about the nadir of her experiences in trying to deal with the system.

The Commission heard that opportunities to participate in paid work are impacting when a caring role was undertaken and carers' own health and social needs can be compromised. Informal carers of older Australians should have an easily understood accessible comprehensive system of support services geared to preventing them from
5 being harmed by the burdens of care that occurs. At a policy level, the system seems likely to continue on the trajectory of reacting to piecemeal needs that arise when caring relationships have already begun to become unsustainable rather than adopting a preventative approach oriented to equipping carers with the skills for the long journey ahead. Something needs to be done from the start and to be
10 accompanied by a regular flexible respite along the journey.

At a more operational level, the design of the support services for carers is in a transitional phase. It remains to be seen how well linkages between constituent elements of the framework will perform. And the evidence of Mr Sotiropoulos is
15 relevant in this respect. I will now proceed to address you on seven key themes which have emerged from the evidence during this hearing:

- (1) pathways, information and navigation;
- (2) the disconnection or potential disconnection between the carer system and the aged care system in delivering effective support services to carers;
- 20 (3) assessment of carer needs in the aged care system;
- (4) the somewhat reactive policy setting behind respite, that is, that it's reacting to needs when it's too late to achieve those preventative purposes, and the need for a reorientation of respite to a more preventative and reabling design;
- (5) aged care subsidy program defects and distortions when it comes to delivering
25 care that will sustain the informal caring relationship, especially regarding the home care package program;
- (6) the distortion of incentives regarding the funding model design for residential respite care, a matter that I was asking Mr Murray about a minute ago;
- (7) distortions in the system regarding other more flexible forms of respite that
30 might support a more preventative reabling approach such as short-term and regular cottage respite.

These are not abstract topics. They have a real life human impact. During this hearing, we've heard of terrible hardships which have been borne with incredible
35 fortitude. There was no pathway or education for Rosemary Cameron when her husband, Don, was diagnosed with Lewy body dementia. This had a real impact on her. In time, she was pushed to the brink of despair, feeling utterly abandoned. Mrs Cameron somehow had the strength to survive, being repeatedly rejected for meaningful respite by the aged care system and the mental health system and left to fend for herself in caring for Don.
40

In a less dramatic but just as profound manner, Dot Holt's story is also a story of the ineffectiveness of the systems that are set up to help her. Dot struggled for years on night shift without much by way of effective or reliable respite in caring for her mother, Dorothy, whom she had taken into her home in Mildura. In their own way, each direct experience witness told a story of hardship and fortitude, many of them conveying the sense that they had struggled on alone and without adequate support from government services. Could at least some of this suffering been avoided; yes, it could have. And with more care in the design of the systems intended to support informal carers and older Australians we can do better.

So I will turn to this topic of pathways, information and navigation. Many informal carers see themselves as fulfilling a family role and will not consider the need to seek help or the availability of various forms of assistance until the strain has told on them so greatly that it's too late to be of much good in sustaining their caring work. We know from the data that despite the availability of support services the overall proportion of carers who use them tends to be low and even then that use is often delayed to a critical juncture or crisis point.

Ms Barbara McPhee then gave evidence that she also didn't know where to go to seek help for her mother and father as their health declined. Ms Elaine Gregory gave evidence that had her mother's aged care assessor provided information about services available to assist her in her caring role she would have engaged with carer support services sooner. Returning to Mrs Cameron's evidence on this topic, she referred to making a telephone call in about 2014 to DBMAS, the Dementia Behaviour Management Advisory Service. At transcript 3883, line 30, I then made the suggestion that DBMAS commenced later, perhaps in 2017. I need to clarify that suggestion I made. True it is that in October 2016 Dementia Support Australia provided a nationally consistent approach to the provision of dementia behaviour management advisory service.

However – and this is the important point – even before that time there were services available in the various states under the banner DBMAS. The programs relating to dementia support are described as at 2015 in a report by KPMG which we've added to the tender bundle at tab 67. Earlier, more preventative intervention to help carers is a matter of common humanity and it also likely sustains the caring relationship which is of benefit to the system. It delays or prevents altogether entry into permanent residential care so why aren't we doing more in this regard or at least to understand the costs and benefits so that a proper policy can be formulated in this regard?

More action is needed to publicise the availability of support for informal carers of older Australians and to allow carers to identify as carers. An important way of achieving this, especially in rural and regional areas, will be to support community-based organisations, possessed of local knowledge, in their endeavours to publicise and reach out to those who need assistance, including those who may not even yet realise that they have that need.

Commissioners, you've heard evidence about the Mildura Carers Hub from those who work there, volunteer and carers who call into the hub who have a cuppa and a chat. The hub is a critical resource for carers in Mildura. It affords the chance for the carer to debrief and to share their experience with other carers. The need for
5 community support services is particularly acute when it comes to dementia because of its progressive nature and its effect on the condition of the care recipient and the indirect effects of this on the carer, who becomes trapped and isolated in the 24/7 interminable cycle-of-care burden.

10 Next, I will turn to the topic I mentioned of the disjunction, or the potential disjunction between the carer and aged care systems. Relevantly, there are two distinct systems in existences and there are uncertainties about the extent of the linkages between them. The gateway and the system for carers to access education,
15 counselling and support services is the Department of Social Services Carer Gateway and the newly emerging Integrated Carer Support Service. This system is distinct from and administered by a different department from the gateway and the system intended to facilitate planned respite, which is My Aged Care. My Aged Care is, of course, administered by the Department of Health.

20 For many informal carers, they cannot leave the house and so cannot access carer support services from DSS's gateway unless they're able to coordinate planned respite with an available opportunity to attend Carer Support Services. But they have to go to My Aged Care for that. And it's, at best, uncertain the extent to which they
25 get any assistance in doing so. Mr Sotiropoulos indicated that there's a process of indication of where respite beds might be available, and perhaps contact details given, and that might be the extent of it.

Emergency respite is different. As Mr Sotiropoulos explained, the availability of emergency short-term respite is coordinated through the Carers Gateway and the
30 newly emerging ICSS, the Integrated Carers Support Services. However, by definition, it's emergency respite. That's inadequate to achieve anything in the preventative vein. By the time the carer relationship is in crisis, it's too late for educative measures and carer supports to have a sustaining effect. We're already in the phase of crisis management by definition.

35 Both in terms of the manner in which the aged care system assesses the need for respite – and I took Ms Buffinton to the assessment documents which suggest that prevention is not the focus of that assessment process – and in terms of the economics of the subsidisation of respite, the current philosophy behind making
40 respite available is that it's made available when the caring relationship is approaching the breaking point. But as I've said, respite should be supported at much earlier stages in small and regular amounts to encourage long-term sustainability. And that, the My Aged Care system, does not achieve.

45 I will next turn to that third topic of the inadequacy of assessment of care and need. The aged care system is geared toward treating the recipient of care as the client or the consumer, to use the expression that's often heard, under the model of Consumer

Directed Care, and does not adequately address or assess the needs of their informal carers, or holistically assess the needs of the care dyad, that is, the relationship between caregiver and care recipient, treating those two as a pair.

5 Rather, the carer is treated as someone who helps achieve an outcome for the care recipient. And, in fact, looking at that assessment documentation, that's treated as an offsetting factors which might tend to reduce the level of need that's assessed. Certainly, the caregivers' needs are not the focus of attention until it appear that is they can no longer help achieve the overall outcome of caring for the care recipient,
10 and that's far too late.

I next go to that topic of the care for – beg your pardon, Commissioners, the need for a preventative and also a reabling orientation and approach. The aged care that's subsidised through the main programs direct to sustaining people who age in their
15 own homes, Commonwealth Home Support Program and Home Care Package, CHSP and HSP, are not well-oriented to meeting the needs for carers, especially the need for early regular planned respite of short duration. At the entry level, as it's described, CHSP may do so. But at the paradoxically higher levels of need, HCP is certainly not geared to doing so.

20 Data is not even collected about the extent to which HCP is used to purchase respite services. There's a glaring omission in the data, and it deprives the government of a sound empirical basis to make policy decisions in this area. This point alone is revealing of government neglect in focusing on the needs of carers. These forms of
25 respite provided under subsidy, including the other important form of respite, residential respite, are not accompanied by government incentives to achieve reablement and improvement of the condition of the care recipient.

Now, I didn't have time to ask the government panel about this, but, Commissioners,
30 you heard evidence, emphatic evidence from the providers' panel earlier today on this point. There's just simply nothing available in the funding and the staffing ratios that result from the funding to achieve a restorative approach, even in residential respite care. There doesn't seem to have been any attention given to designing a
35 system of incentives for this to occur.

Next, I will go to the topic of the program deficits in sustaining the informal caring relationship with a particular focus on home care package which is subject to Consumer Directed Care, so called CDC. Yesterday we heard from Dr Lyn Phillipson from the University of Wollongong that an unintended consequence of
40 Consumer Directed Home Care has involved focus on the care recipient missing an opportunity to linking family and friends to appropriate supports. Dr Phillipson also gave evidence that funding for respite is rarely allocated to a home care budget because services are directed to the care recipient and they're exhausted or fully allocated in achieving that.

45 The panel of expert witnesses yesterday drew your attention to the funding arrangements associated with each program. The CHSP is block-funded and delivers

subsidised respite programs. These same services may be accessed with a home care package but at full cost recovery, and I was asking questions of Ms Buffinton about the consequences of that. It creates a system of disincentives against the holder of a home care package accessing those sorts of services. The evidence suggests that this
5 can have real impacts on the ability of care recipients who are on home care packages and their carers to obtain affordable and appropriate and regular and flexible respite.

I will go to the second-last topic, which is the distortions and potential disincentives in residential respite care. The economics of residential respite care subsidy are badly distorted. I asked Mr Murray about this. He doesn't disagree. Perhaps he wouldn't agree with the word "badly", but he agreed that there's a distortion and he agreed that ACFA had found there's a distortion. That distortion is probably, in my submission, discouraging the supply of residential respite care for the true purpose
10 for which it's intended. The costs and benefits to an approved provider of making beds available for respite are no longer anything like neutral with making the same bed available for permanent residential care.

For several years, the subsidy for residential respite care has not kept pace with increases in resident acuity, as shown by the increases in ACFI revenue available from permanent residential beds, tracked on that graph that I took Mr Murray to. Until reformed in a manner that restores a true incentive to approved providers to make beds available for genuine respite, subsidy funds set aside for respite will leach away for non-respite purposes. The first stage of permanent residential care is not a
20 respite purpose.

The use of subsidy intended by government for respite for the purposes of subsidising the first stage of residential care means that the intended amount of supply for respite has been constrained and is not available to the extent it should be. Reform to address this distortion should not await the outcome of ACFI reform through the RUCS and AN-ACC study and the processes which I asked Mr Murray about, which will clearly take years. The need for action is far more pressing. We heard this morning from the providers, including in great detail from Mr Midgley, as to the losses being sustained by Chaffey on an ongoing basis by the provision of
30 respite, and you can infer that other approved providers are in a similar position.

Finally, incentives for more preventative and reabling approaches. As I said a moment ago, there are no incentives for flexible form – flexible forms of preventive – beg your pardon – for preventative and reablement measures to be combined with
40 flexible forms of respite or for those preventative and reablement measures to be deployed in residential respite contexts.

In summary, far from residential respite being the opportunity for reablement that it should be, the Commission has heard concerning evidence that residential respite is identified by academics, and I refer to Monash University – the report of Monash University in the Sydney hearing in exhibit 371 as a source of risk for residents, and there's a perception that respite can result in deterioration of the condition of the
45

5 person who goes into respite. Doesn't always happen, but it can happen, and you've heard evidence, compelling evidence from Ms Kay Gray and from Mrs Cameron of cases where that occurred during the course of this hearing, that is, you've heard the evidence during the course of this hearing that that occurred in the case of spouses of those two women.

10 In line with the recommendations of Dr Gresham, there should be reablement and upskilling programs offered to the care recipient and the carer respectively in conjunction with respite care. This is what will best sustain the care dyad. A philosophy of preventing strain on carers before it approaches unsustainable levels protecting them from that strain is the appropriate approach. And it's not the appropriate approach to continue on a policy trajectory of merely providing for a minimalist respite program reacting when it's too late because the care relationship's becoming unsustainable and in the immediate term, to use the languages of the assessment documentation, it's necessary to consider the needs of the carer at that late juncture.

20 In order for a reorientation to a preventative approach, amongst other things, there must be a pathway laid out immediately upon any diagnosis of dementia. We've heard compelling evidence about the particularly acute needs that arise in the case of dementia. And similarly, pathways need to be laid out that are unique to the particular care dyads and the particular conditions that have been addressed. Reablement has to be a focus that continues all the way through the home care pathway. Commissioners, those are the submissions of counsel assisting.

25 COMMISSIONER TRACEY: Thank you, Mr Gray. Mr Kennett, you and Mr Dighton are excused from further attendance until your clients' interests become the interests of the Commission again. I would like to place on record the Commission's gratitude to the professional and support staff who have sustained us in setting up and maintaining our presence here in Mildura, and to all the local people who have assisted and contributed to the work of the Commission during the time that we have been here. The Commission will adjourn until 5 August at 9.30 am in Brisbane.

35 **MATTER ADJOURNED at 4.15 pm UNTIL MONDAY, 5 AUGUST 2019**

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