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**TRANSCRIPT OF PROCEEDINGS**

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O/N H-1050321

**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**

**9.37 AM, TUESDAY, 30 JULY 2019**

**Continued from 29.7.19**

**DAY 40**

**MR P. GRAY QC, counsel assisting, appears with MS E. HILL and MS E. BERGIN  
MS A. MULDOWNEY appears for Annie Hayward**

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

MS BERGIN: May it please the Commission. There are two preliminary matters,  
one of which arises from yesterday. We seek a non-publication direction be made  
5 over yesterday's transcript.

COMMISSIONER TRACEY: Yes. Well, I understand that those instructing you  
are in the process of preparing that direction, and it will be signed in the course of the  
10 morning.

MS BERGIN: Thank you, Commissioner. Now, the second matter before I call my  
first witnesses is the matter of an appearance on behalf of Carers Victoria.

MS A. MULDOWNNEY: Good morning, Commissioners, I'm Anne Muldowney  
15 from Carers Victoria. I'm the senior policy adviser, representing Annie Hayward  
who is not able to be here today.

COMMISSIONER TRACEY: Very well. Thank you for announcing your  
appearance.  
20

MS MULDOWNNEY: Thank you.

MS BERGIN: I call Donald Geoffrey Laity and Bonney Heather Dietrich.

25  
<DONALD GEOFFREY LAITY, AFFIRMED [9.39 am]

<BONNEY HEATHER DIETRICH, AFFIRMED [9.39 am]  
30

MS BERGIN: Mr Laity, what is your full name?

MR LAITY: Donald Geoffrey Laity.  
35

MS BERGIN: What is your current role?

MR LAITY: I'm a carer. I'm a member of the steering group for the Mildura Carer  
Blueprint and treasurer of the Sunraysia Carers Support Group.  
40

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

MR LAITY: I have.

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

MR LAITY: There is.

MS BERGIN: Operator, could you please bring up WIT.0313.0001.0001. Could I  
5 ask you to please turn the pages over and check that that's a true copy of your  
statement.

MR LAITY: Yes, it is.

MS BERGIN: Do you have any amendments, Mr Laity?  
10

MR LAITY: Yes, do I, if I may.

MS BERGIN: Certainly.

MR LAITY: I would like to amend two dates on item 24 to read:  
15

*During 2005 and 2006.*

MS BERGIN: Thank you, Mr Laity. Is that the first – a variation of the first four  
20 words which currently read:

*During 1995 and 1996 –*

MR LAITY: Yes.  
25

MS BERGIN: Which will now read “During 2005 and 2006”.

MR LAITY: Yes.

MS BERGIN: Thank you, Mr Laity. Are there any other amendments to your  
30 statement?

MR LAITY: No.

MS BERGIN: Is it true and correct to the best of your knowledge and belief?  
35

MR LAITY: It is.

MS BERGIN: Commissioner, I tender the statement of Don Laity.  
40

COMMISSIONER TRACEY: Yes, the witness statement of Donald Geoffrey Laity  
dated 23 July 2019 will be exhibit 7-9.

45 **EXHIBIT #7-9 WITNESS STATEMENT OF DONALD GEOFFREY LAITY  
DATED 23/07/2019 (WIT.0313.0001.0001) AND ITS IDENTIFIED  
ANNEXURES**

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

MS DIETRICH: Bonney Heather Dietrich.

5 MS BERGIN: What is your current role?

MS DIETRICH: My current role is that I'm employed as the coordinator of the Mildura Carer Blueprint.

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

MS DIETRICH: I have.

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

MS DIETRICH: It is and I think it is all correct and there's no amendments.

20 MS BERGIN: Thank you, Ms Dietrich. Operator, could you please bring up document WIT.0314.0001.0001. I understand it's true and correct on the basis of your knowledge and belief.

MS DIETRICH: Yes.

25 MS BERGIN: I tender the statement of Bonney Heather Dietrich dated 25 July 2019.

COMMISSIONER TRACEY: Yes, the witness statement of Bonney Heather Dietrich dated 25 July 2019 will be exhibit 7-10.

30

**EXHIBIT #7-10 BONNEY HEATHER DIETRICH DATED 25/07/2019  
(WIT.0314.0001.0001) AND ITS IDENTIFIED ANNEXURES**

35 MS BERGIN: Mr Laity, you were a carer for 20 years.

MR LAITY: Roughly, yes.

40 MS BERGIN: I'm going to ask you about your role caring for your mother-in-law, Aileen, and your father-in-law, Frank.

MR LAITY: Yes.

45 MS BERGIN: Aileen and Frank were the parents of your wife, Sherilyn.

MR LAITY: That's right, yes.

MS BERGIN: And they ran a mixed business or a milk bar in Minyip for almost 30 years.

MR LAITY: Yes.

5

MS BERGIN: They lived around the corner from you, Mr Laity, and your wife, Sherilyn.

MR LAITY: Yes.

10

MS BERGIN: Minyip is located between Horsham and Donald which is about 50 kilometres north-east of Horsham.

MR LAITY: That's correct.

15

MS BERGIN: Mr Laity, when did you and Sherilyn get married?

MR LAITY: 1987.

20

MS BERGIN: When did you and Sherilyn start to become a carer for Frank and Aileen?

MR LAITY: Around about 1984 – end of 1984.

25

MS BERGIN: What did your role as a carer for your mother-in-law and your father-in-law initially involve?

MR LAITY: Our role for Frank was probably mainly transport. Having a mixed business in the town, somebody had to stay in the shop, so Aileen was tied up in the shop while we took Frank to medical appointments, doctors' appointments, treatment, that type of thing. So we were, basically, involved in transporting.

30

MS BERGIN: What were Frank's hobbies?

35

MR LAITY: He was a bowler.

MS BERGIN: He was a bowler?

MR LAITY: He was a bowler.

40

MS BERGIN: And tell us what were Aileen's hobbies.

MR LAITY: Aileen didn't really have any hobbies, other than walking the dog after Frank passed away ..... her family life mainly took up all of her time.

45

MS BERGIN: When did Frank pass away?

MR LAITY: 1995.

MS BERGIN: What changes did that bring for Aileen?

5 MR LAITY: Well, at that stage she was living on her own, of course, and she went into a fairly deep depression at that stage.

MS BERGIN: What health diagnosis did Aileen have at about this time?

10 MR LAITY: Apart from the depression she was fine but eventually over the next couple of years she was diagnosed with Alzheimer's.

MS BERGIN: When did Aileen move in with you, Mr Laity?

15 MR LAITY: She moved in with us in 2003 – the beginning of 2003.

MS BERGIN: Why did she move in with you and Sherilyn?

20 MR LAITY: Because it got to the point where she was unable to care for herself or reliably be on her own at that stage. Initially she moved in because she was unwell and we convinced her to extend her stay.

MS BERGIN: How long did she live with you, Mr Laity?

25 MR LAITY: Four and a half years.

MS BERGIN: What was your work at this time?

30 MR LAITY: I was a piano tuner.

MS BERGIN: And what did your role as a piano tuner involve?

35 MR LAITY: Repairing and tuning pianos all over the Wimmera Mallee, so I travelled quite extensively. I would be away anything from – doing local jobs I would be away for the day. If I was going further afield, I could be away for two days up to several weeks at a time.

MS BERGIN: What did you enjoy about your work?

40 MR LAITY: Public contact and the satisfaction of getting something restored back to what it needed to be.

45 MS BERGIN: Mr Laity, what did it mean for your work when Aileen moved in with you?

MR LAITY: Initially, very little because at that stage Sherilyn was able to handle it on her own but as her situation declined, obviously, there was more demands put on me and my work was curtailed because of that.

5 MS BERGIN: How many hours of caring were you providing for Aileen by about this time of 2002 to 2006?

MR LAITY: That's difficult to say because at that stage, as I said, Sherilyn was doing most of the supervising rather than caring. Aileen was able to cope on her  
10 own but, you know, she needed to be supervised in case anything went wrong. That was basically the answer.

MS BERGIN: What did you assist Aileen with?

15 MR LAITY: Ultimately – well, at that stage only with transport. Again, we were the local taxi, but eventually in the lifting and that sort of work became my help there. Sherilyn did most of showering and, you know, that sort of work like the more personal caring. But the lifting and that type of thing became too heavy for her.

20 MS BERGIN: Mr Laity, as your caring role for Aileen increased including lifting, what did that mean for your work as a piano tuner?

MR LAITY: Ultimately, I was unable to do anything for probably 12 to 18 months so I was home all the time.

25 MS BERGIN: Were you in a full-time caring role?

MR LAITY: Well, it would be a full-time caring role, yes.

30 MS BERGIN: Mr Laity, at this time Aileen had a home care package.

MR LAITY: Yes.

MS BERGIN: You mention in your statement that the only value – these are your  
35 words:

*The only value Aileen got out of her home care package was respite care.*

40 Could you describe your experience of respite care received through the home care package while Aileen was at the facility in Horsham in 2005 and 2006.

MR LAITY: The facility in Horsham was absolutely brilliant. It was short-term, weekend respite, which was long enough for us to draw breath and, you know, get a lot of benefit from it. It was also where Aileen was totally comfortable. So we could  
45 enjoy our time off because we knew that she was well cared for and that she was happy in the surroundings that she was in. They cared for her over there. They would take her out on trips. They had board games and stuff like this to keep them

amused. It was a situation where the carer-patient ratio was literally two carers to four inmates – four residents. So, you know, there was plenty of time to care for the residents and make sure that they were well looked after.

5 MS BERGIN: You mentioned the staffing arrangements, Mr Laity. Was there consistency in the staff?

MR LAITY: We basically had the same staff every time we went over. So the staff was familiar to Aileen, she knew them from last time. The residents that she met  
10 over there, basically came back the same times as she did. So she was going into a very, very familiar area, which she was happy with.

MS BERGIN: And why was that continuity important for Aileen?

15 MR LAITY: It was, yes.

MS BERGIN: Was it important because as her dementia progressed she became confused?

20 MR LAITY: Yes. Yes.

MS BERGIN: How was the respite care paid for, Mr Laity?

MR LAITY: Some of it was paid for by the package, the Commonwealth package.  
25 DVA covered quite a lot of it. If we managed to get more respite than was covered by those two sources, then it was covered by her pension.

MS BERGIN: How did you book the respite care?

30 MR LAITY: Initially, we got on to it through the memory clinic at the hospital down there. They offered us a spot in the residential care there. And from there on we just kept booking on every six weeks or as often as we could possibly take advantage of it.

35 MS BERGIN: What did that mean for you, Mr Laity, the regular respite for Aileen?

MR LAITY: It meant that I was able to catch up on things that needed to be done at home and I could relax without the pressure of having to worry about caring and what was going on, you know, with Aileen.

40

MS BERGIN: What did it mean for your wife Sherilyn?

MR LAITY: A tremendous break from her responsibilities as, yes, care and nursing, shall we say. She was able to get away with girlfriends, have some time out and get  
45 right away from the situation, so that she could draw breath and recharge the batteries.

MS BERGIN: How did Aileen look at her experience of respite care?

MR LAITY: Over at Horsham, she was going on holiday; she was going away for a holiday for a few days and thoroughly enjoyed the holiday and came back quite  
5 happy about it.

MS BERGIN: How long did you continue – you and Sherilyn, continue caring for Aileen, Mr Laity?

10 MR LAITY: We were caring for her about four and a half years after she moved in, until eventually she went into hospital for care there for a short time and moved on to a nursing home from there.

MS BERGIN: And how long was she in a nursing home for?  
15

MR LAITY: About four months.

MS BERGIN: Was it her preference to stay at home with you and Sherilyn.

20 MR LAITY: Yes, yes. Very much so.

MS BERGIN: Was the respite care an important element of that arrangement?

MR LAITY: It was to us. It was definitely important to us.  
25

MS BERGIN: How would you have managed or would you have been able to manage caring for Aileen without respite?

MR LAITY: We probably would have managed. It would have been extremely  
30 difficult and extremely trying. But by virtue of the fact that we wanted to keep Aileen in a family situation for as long as possible we certainly would have done it, yes.

MS BERGIN: You note in your statement, Mr Laity and you said just a moment  
35 ago that about the final four months of Aileen's life were spent in an aged care facility. After Aileen passed away in 2007, after such a long period, four and a half years of you and your wife caring for her, how did you and Sherilyn recover?

MR LAITY: Probably very slowly. It probably took me the best part of 12 months  
40 to get back to speed again. Sherilyn would have taken much longer than that. I would say that it would have taken between 18 months and two years for her to build up again after the long period of caring. It has a fair toll on the carer and it's now 12 years since Aileen passed away, Sherilyn's sleep patterns still haven't returned to normal, you know, at this stage. So the effect is long term.

45 MS BERGIN: Mr Laity, what supports would assist you and Sherilyn during this recovery period?

MR LAITY: Probably time and support – well, shall we say carer support continuing after the death of the person involved. Continuing to mix with people who have common interests and understand what you’re going through or what you’ve been through.

5

MS BERGIN: Thank you, Mr Laity. Ms Dietrich, you are also a carer.

MS DIETRICH: Yes.

10 MS BERGIN: You care for your mum, Beryl.

MS DIETRICH: Yes.

15 MS BERGIN: And she lives in Mildura; you live not too far away from her in Irymple.

MS DIETRICH: It’s about 15 minutes away.

20 MS BERGIN: And you visit her about every day around your work commitments; is that right?

MS DIETRICH: That’s right.

25 MS BERGIN: What does caring for your mum involve?

30 MS DIETRICH: It’s that checking up, making sure that she’s okay. And I think I’ve thought a lot more about it since, with the Royal Commission. A lot of it is to do with how I feel about Mum and what I would like for me, but it is about making sure – she has no other siblings around here, or no other siblings anyway, and as she gets older a lot less friends. So you need to have that connection to just life in general.

MS BERGIN: How do you support your mum?

35 MS DIETRICH: Company, shopping, every weekend we have a Sunday where you go in and you do all the, you know, basic housework, change the sheets, put the bin out and all those sorts of things, just for a coffee, do things that Mum wants to do, a lot like that. Doctors’ appointments are really important because she forgets things, so you try and put those around different – where my work commitments are, so to  
40 make sure that – just general, I think, yes.

MS BERGIN: Ms Dietrich, you said that it’s about making sure she – because she has no other siblings around here, as she gets older she has less friends, and you need to have that social connection.  
45

MS DIETRICH: Yes.

MS BERGIN: Is isolation an issue?

MS DIETRICH: I'm actually probably pretty lucky because we've got some friends for Mum and that's the informal supports that actually help Mum with – to get to  
5 different things, but it is a real issue for a lot of carers, yes.

MS BERGIN: Perhaps we will come back to that topic while I'm asking you about your role at the Carers Hub.

10 MS DIETRICH: Okay.

MS BERGIN: Mildura is a regional area; you mentioned that your mum has informal support from the community. How does that work?

15 MS DIETRICH: And that's being in the country, I think it's knowing your neighbours, Mum goes over to the corner store every day to get the paper and things like that, so she has got a connection now with the woman who works there. She will ring her most nights to check that she's okay, but that also relates to the person  
20 that lived in the unit next to Mum died without anybody knowing for a while so it's that checking, you know. And the neighbours at the front will come and do things if I've got to go away for a weekend or something, yes.

MS BERGIN: Ms Dietrich, you also have a daughter, Erin.

25 MS DIETRICH: Yes.

MS BERGIN: What are your feelings about your daughter becoming a carer in the future?

30 MS DIETRICH: I don't want it to happen. I suppose because Mum looked after Nan before she died. Nan lived with Mum for about 12 years and I did a lot of the respite for her so Mum could go away and do things. Mum was an only child. And I think maybe now that's why I get tired, and I don't want Erin to have to do that.

35 MS BERGIN: What is it like when you feel tired?

MS DIETRICH: You want to cry. There are days where you just feel so tired. You just – it's not that you don't – you know, like, and I know that when Mum does die I will be devastated, but there's some days where you just go, "I don't want to do this  
40 anymore, I just want to stay home". And even when you stay home you're still connected to the buzzer and everything, so when you go away, at work, I've always got Mum's pager and things like that. So sometimes it is just really hard.

MS BERGIN: Ms Dietrich, how does the pager work?  
45

MS DIETRICH: Mum was assessed by ACAS because she had lots of falls and things like that. So we've got a pager – probably, I don't know what you call it now.

And it's connected – Mum has to press it every morning or if she has a fall or anything, she has got that access and it goes straight through to Melbourne and then I'm there as a phone number that they connect. Amongst that we've set up a spare key outside and let them know so there's a number that they can get in, so if the  
5 ambulance needs to come if I can't get there, so you've done all the preventative work and hopefully you won't ever need it and it's all there. And it's just constantly with you.

10 MS BERGIN: Do you worry about your mum?

MS DIETRICH: Yes.

MS BERGIN: What are your fears for her?

15 MS DIETRICH: Because she is an only child, she doesn't have the siblings where anybody will be around. As she gets older, like I said, her friends, a lot of them have died and I'm really lucky that a lot of my friends and Mum's friends' children who are all around our age understand that and support each other, but it's that loneliness. I feel guilty if I go away.

20

MS BERGIN: How do you get a break, Ms Dietrich?

MS DIETRICH: You just make sure you have things in place, you know, the neighbours, "I'm going to be away, can you check" – "If, by chance, it does rain in  
25 Mildura, could you get the papers for Mum so she doesn't go over? Could you call in?" You make sure that there's enough supermarket stuff done before you go away.

MS BERGIN: Ms Dietrich, it sounds, from what you've said, that your Mum gets a lot of support from her neighbours. In the statement you mention that people don't  
30 like asking for help in the country. Why is that?

MS DIETRICH: Because we're supposed to do it. And a lot of people – and it may be in the city too, but a lot of people do the caring role without realising that they are the carer. They're just the daughter or the mother or the sister or the brother or  
35 whatever, and it's just one of those things. You just do it because it's family.

MS BERGIN: What is the perception of being a carer in Mildura?

MS DIETRICH: I think it might be changing now, because we're doing a lot more  
40 advertising and we're doing things, like – I actually think the hub has done a lot of awareness and we are getting more and more people actually saying they are carers, but it's still word of mouth, you know, to say, "Are you a carer?" I know I spoke to somebody in a shop one day and it's not about aged care, but they had children at the special school, and I said, "Do you think of yourself as a mum or a carer?" And she  
45 went, "No. I'm just a mum". But if you looked at it, every parent at the special school is a carer. And as they get older they're going to be ageing carers too,

because a lot of those children have – you know, have intellectual disabilities that will need to be cared for.

5 MS BERGIN: Now, Mr Laity, I'm going to ask you and Ms Dietrich some questions about the Carers Hub. You first became involved in Carers Victoria in 1993, when you were caring for your father-in-law, Frank.

MR LAITY: That's right.

10 MS BERGIN: You commenced your role on the steering committee of the Carers Hub in 2016.

MR LAITY: Yes.

15 MS BERGIN: That was when you moved to Mildura?

MR LAITY: Yes.

20 MS BERGIN: Mr Laity, could you please describe your role on the steering committee of the Carers Hub?

MR LAITY: The hub was formed to provide an information centre and, shall we say, a venue for carers where they could come and gather together. This was the result of the Mildura Blueprint, which was – it was, again, the result of a carer, well, meeting, shall we say, in 2015 conducted by Carers Victoria in conjunction with Bendigo Health. This meeting with the carers of the district for this forum virtually was to find out what would make caring easier in Mildura? What did the carers need to help their caring role? And from that forum, a committee was formed to draw up a blueprint and try and find some way of easing the work and the lack of communication, shall we say, between carers and the facilitators up here.

35 So I – and I wasn't on the initial committee; I came on later on when they required more carers to be involved in it, and I was brought in at that stage. So it's basically an advisory committee looking at how the blueprint can be implemented and how changes need to be made to the blueprint as time evolves. The blueprint is a living document that basically changes as the needs change within the district. So the steering committee is basically an advisory committee to facilitate that. The hub, it was found, was going to be the answer to a lot of the problems of the district, where information could be spread out amongst the carers of all carer groups.

40 And it evolved – it became an education facility, where carers could be brought up to date on issues like making wills, powers of attorney, how to handle carers, how to handle a carer role, how to look after the people that they were caring for and how to try and reduce stress. Apart from that, it became a meeting place for carer groups, including the Sunraysia Carer Support Group, and a drop-in centre, basically, for carers when it's open. Carers can drop in – well, the average attendance when the

hub is open, we're looking an average attendance of 30 people per day, which is a big demand on the facility and certainly justifies its existence.

5 MS BERGIN: Mr Laity, who else is on the steering committee with you?

MR LAITY: We have service providers, council representatives, Carers Victoria is represented, and carers and carer groups.

10 MS BERGIN: And how often does the steering committee meet, Mr Laity?

MR LAITY: Every couple of months.

MS BERGIN: Ms Dietrich, you were first involved in the Carers Hub as an employee when it opened in July 2017?

15 MS DIETRICH: That's correct.

MS BERGIN: And you were involved two days a week initially?

20 MS DIETRICH: Initially. It's now reduced to one day a week.

MS BERGIN: And why has it been reduced to one day a week?

25 MS DIETRICH: Funding. That's basically what it was. From what I understand and what understand is that the Carers Hub was opened by Carers Vic in conjunction with Bendigo Health Group, who paid for the rent. And now there's, you know, the cost of ongoing rental and wages that are making it difficult. So we've been extended till December this year, one day a week.

30 MS BERGIN: Ms Dietrich, what does a typical day look like at the Carers Hub?

35 MS DIETRICH: I'm not sure there is a typical day. I went in this morning to do stuff early and the computer won't work, so that sort of mucks you up, but usually you would – and a lot of work is done at home, I've got to say, because you just don't have time to do it in there. It can be carers turning up just for a coffee, and it's not just for a coffee because there's always a reason. You know, they need that support and things like that. I do a lot of the organisation for the carer support group meetings, you know, so organising the speakers and things like that.

40 I've now set up a system where any information I get goes out to all service providers and a list of local carers, so you're actually – you know, that point where you can distribute. There might be a phone call there that you've got to answer about counselling. It could be anything. We've also – I've set up – we have a young woman that comes in and we will do teaching digital literacy, which is a real  
45 problem up here because you've got a lot of people that are not literate with all the new technology. And, actually, literacy is a problem too because of our local area, where you've got – a lot of older people would have left school early and done

manual work, so now they've got all the musculoskeletal damage and can't work and do all those things and can't fill out forms, whatever.

5 It might be somebody who comes in, wants a referral, wants some information. It could be, "How do I access Centrelink? What do I do?" "Where do I go for support?" Which is getting harder to get carer respite. There's very limited respite, as such, in town. I've always – I've helped with food vouchers, I've helped with energy relief. And we actually had a success with one of those. Somebody, when we followed up – they got a new fridge out of it. The company decided that their  
10 electricity was being used by an old fridge. So that was really good. So you actually get – there's not a typical day, as such.

MS BERGIN: Ms Dietrich, Mr Laity mentioned that there's an average of 30 visitors a day at the Carers Hub. How would you describe the demographic?  
15

MS DIETRICH: Most of the demographic would be the older people, but it's actually changing now because of the NDIS. There's a lot of carers coming in that feel like they are being left out because of the changes to that, and that's not aged care but it is the NDIS, so that sort of thing, yes. And also we do have, you know,  
20 because of it being rural, we do have a lot of CALD clients too, that's coming more. And the other thing of that, too, would be that the Mental Health Carers Group has now just closed because of the NDIS; the local agency that did that is not doing it any more, so we're providing that.

MS BERGIN: So in addition to the mental health group, are there other groups that meet at the Carers Hub?  
25

MS DIETRICH: There is; they're mainly for younger groups, you know, the autism and ADHD and things like that. Yes.  
30

MS BERGIN: Do you have some regular visitors at the Carers Hub, Ms Dietrich?

MS DIETRICH: Yes. Yes. And a lot of that is just sometimes carers just need to talk. You know, it's just that having somewhere to go and having that understanding  
35 – and I think that's where my experience as a carer, too, actually helps. Yes.

MS BERGIN: When you say sometimes carers just need to talk, what do people need to talk about?

MS DIETRICH: How they're feeling, how they're tired. And it's normal. And, you know, like, a lot of, you know – there is a group of women that care for their partners, husbands, who may have had medical issues or strokes or, you know, early stage of dementia and things like that, and they need to talk to somebody that understands that, will not judge them, because if they say to their children, you  
45 know, like, "Dad's driving me mad", you know, "I can't get out. I can't do that", they will go, you know, "But aren't we lucky we've still got him?" So I've actually

set up a group of women that meet independently of the group. So it's just that understanding of, you know, people need to talk to somebody that understands.

MS BERGIN: How important is that group to the women involved?

5

MS DIETRICH: I think it's really important. Very important. And I know last – they met last Wednesday and I was in at the office talking to you guys and shouldn't have been there, and a woman came in that was – her husband has just been diagnosed in early stages Alzheimer's and I took her to the group and I got a thing saying, "Fantastic. Thank you. They were really supportive. It was really good. Please include me in everything else." Yes.

10

MS BERGIN: What other feedback do you get from carers, Ms Dietrich?

MS DIETRICH: That the hub is providing a service that they need. It's providing education– which is one of the things I did when I first got there, and it was for me to navigate how the carer support – should I keep talking? What I am doing?

15

MS BERGIN: You're welcome to keep talking, Ms Dietrich.

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MS DIETRICH: Sorry. They navigate what they need. And a lot of the things that they organised – they said they needed information. And Don talked about – we've had the Murray Mallee Community Legal Service come in and talk about advanced care directives and enduring power of attorneys. We've got next – no, in September, we've actually got a lawyer coming to talk about how to make a will, what you need to consider. It's not giving – you know, like, not trying to sell them to go there, but it's to give them advice on how they do it. You know, it's what they need for community safety. It's about what services they can access. We've run mindfulness for relaxation and things like that, when I've been successful with getting local grants and things like that.

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MS BERGIN: Mr Laity, how is the Carers Hub funded?

MR LAITY: Initially, it was the – Bendigo Health initially paid the rent for the first two years. Remembering this was initially a two-year project. It was a project to see if it was going to work, see, you know, how it was going to fare. So it was funded for the first two years by Bendigo Health, as far as the building was concerned, and Carers Victoria funded the balance, I understand, through a charitable trust grant.

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MS BERGIN: What is the term of the current funding arrangement for the Carers Hub?

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MR LAITY: The initial funding expired on 30 June. It was looking at the possibility of closing down at that stage, and the State Government granted \$20,000 for its continuance until the State budget and Federal budget were announced, to see if there was funding in there. That \$20,000, by cutting the opening days back to one day a week, allow us to continue until the end of this year.

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MS BERGIN: What does the funding cover?

MR LAITY: Covers the salary of Bonney, office rental and overheads, as in stationery, power, phone, internet, that type of thing.

5

MS BERGIN: You mentioned this briefly at the outset, Mr Laity, but I want to ask you for a bit more information about why the Carers Hub opened in Mildura.

MR LAITY: Carers Victoria were doing a series of forums around the state, trying to determine what carers' needs were in various areas. One of those forums was held here in Mildura. That was held on 12 August 2016. Pardon me while I refer to notes. And that was when it first started. The issues that were raised at that forum then formed the basis of the blueprint which continued on from there, and the hub was a part of the solution to the problems that were seen by carers in this area. A number of the problems were probably a lack of communication and connection between service providers, professionals, that type of thing. So people weren't referred easily to where they could find assistance and support.

MS BERGIN: Was there a lack of information in the community at that time about aged care services, Mr Laity?

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MR LAITY: About all services. Yes.

MS BERGIN: What did that mean for the community?

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MR LAITY: It made it very difficult for people to find where they could source help, and anybody moving into the district, of course, was really struggling because it was a matter of finding out where to go to get the medical supports that they needed.

30

MS BERGIN: Was it sometimes the case that supports were available, but the community wasn't aware that - - -

MR LAITY: Yes.

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MS BERGIN: - - - the supports were available?

MR LAITY: Yes. Yes. Quite a lot of, just, as I said, lack of information.

MS BERGIN: What's your view about whether carers hubs are useful in Mildura?

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MR LAITY: What's my - would you - - -

MS BERGIN: How useful is the Carers Hub in Mildura, noting those problems?

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MR LAITY: To people who are in a caring role, incredibly useful. You know, it's a wonderful support organisation; there's no two ways about it. And now it's being

recognised not only by the community, but the professionals are now referring people to the hub for support and information. So it's now being recognised – in the country areas you really have to earn your stripes, and that takes time, but now the confidence is there in the organisation that the professionals are referring people to the hub.

MS BERGIN: What's your view about whether carers hubs in other regional or rural towns would be useful?

MR LAITY: I think it would be very, very useful. I think it's something that could be used, certainly, in rural and remote areas. It gives them a contact point that is often lacking. It's something that I would like to see spread right across the state and the major towns.

MS BERGIN: Operator, could you please bring up tab 1 in the general tender bundle. Mr Laity, when you talked about the blueprint, is this a copy of the blueprint?

MR LAITY: That is a copy of the blue print. Yes.

MS BERGIN: Operator, could you please bring up a copy of tab 2 of the general tender bundle. Mr Laity, could you talk us through the evaluation that was done of the Carers Hub and the blueprint?

MR LAITY: February this year we had a professional consultant come in and do an evaluation, independent evaluation of the hub and the progress that had been achieved. That is a summary of the evaluation there on the screen at the moment. And, yes, we were very, very happy with the positive outcome that we had found in the evaluation, that the work that had been put in had obviously been effective and had been recognised by the people who were involved in the evaluation.

MS BERGIN: Ms Dietrich, why has the Carers Hub been successful in attracting carers to attend when it's open?

MS DIETRICH: I don't know.

MS BERGIN: Unfair question?

MS DIETRICH: Probably because we provide a service of what they want. You know, it's being able to be there. I suppose, too, I've been back in Mildura for 24 years so I've – and as a social worker you've developed a lot of contacts in community agencies so on – I've been able to use that knowledge to get services and know where to go so people, when people find out that you can actually help them they will keep coming.

MS BERGIN: How do you support carers that may have problems with literacy, for example?

MS DIETRICH: That could be just printing off a Centrelink form or anything – completing a form for them and doing that, actually going with them to an appointment. I’ve been to a few – Centrelink is an issue with a lot of carers in trying to get things through. I’ve helped them complete an appeal process so they can get it reviewed, you know, things like that. So it’s their – just literacy but the computer  
5 literacy is a real issue and with the focus on everything now going digital and everything on computers, it’s going to be – I think it will be an issue for a lot of carers in rural areas.

10 MS BERGIN: What difficulties do you observe for people that may have literacy or computer literacy challenges, what difficulties do you find they have with My Aged Care, for example?

MS DIETRICH: Just trying to access it for a start off. You know, going to  
15 complete the My Aged Care if they haven’t got a GP or someone that can do it. The ACAS service in Mildura does the assessments and personal knowledge of these assessments and things like that, they were really good. So there is help that way as well, too, that ACAS will help.

20 MS BERGIN: You mentioned at the start that you were having some problems with your computer today. How do you go about – is that the only computer in the office?

MS DIETRICH: Yes.

25 MS BERGIN: So how do you go about getting information about My Aged Care for a carer if the computer is not working?

MS DIETRICH: Sorry, I should have said that, no, we have got a couple of second-hand computers from Carers Vic that are there for carers to use. Mine, and I can use  
30 that but the connection somewhere has just changed between my laptop in Melbourne. I will sort it out when I get back.

MS BERGIN: I think we’re all familiar with those computer problems, Ms Dietrich. What’s your view about whether carers hubs in other regional or rural towns would  
35 be useful?

MS DIETRICH: I think a carers hub as such would be really good and – I know that the cost, you know, of keeping them running and operating these things and I think there needs to be a lot more consideration on whether they could work in conjunction  
40 with another agency, you know, like co-locate in Mildura. You’ve got the Cancer Resource Centre, you’ve got the SIRS information. There’s a lot of people around that would be competing for funding and I think maybe they could look at doing it a lot better, but definitely the Carers Hub is, they need an information session where carers can go.

45 MS BERGIN: Yes. Mr Laity, how does the Carers Hub work with Carers Victoria?

MR LAITY: It works very well with Carers Victoria. The Carers Victoria obviously are funded and managed and basically the policy of the Carers Hub, so there's no problem there. We work very well with Carers Victoria, and certainly are grateful to Carers Victoria for the support that we've had over the last two years.

5

MS BERGIN: Is there a Carers Victoria representative on the steering committee?

MR LAITY: Yes.

10 MS BERGIN: Does the staff member attend the bi-monthly meetings that you mentioned?

MR LAITY: Well, yes. Bonney attends the meetings and the meeting is frequently chaired by Annie Hayward from Carers Victoria who comes up for the meetings.

15

MS BERGIN: I just want to ask you both about some of the issues that you've mentioned that carers commonly experience. Starting with you, Ms Dietrich, what is your view about whether or not stress is an issue for carers?

20 MS DIETRICH: Sorry?

MS BERGIN: What's your view about stress as an issue for carers?

25 MS DIETRICH: Yes, it's a real issue. It is a real issue. And people cope with it in different ways. Some of the carers, it's about the caring role. Some of it can be that they actually have to give up employment to do what they want to do so they're actually coping with the anger of doing that and the frustration of doing the caring role and it actually takes it away from the relationship role. So they become the carer not the partner, and it becomes difficult for a lot of people. Counselling is sometimes  
30 difficult to access. There's limited counselling. Once again there's funding, so you're trying to find out where you can go to get support for the carers which I think, once again, it's important for people to be able to come in and talk to someone.

35 As a social worker I know I've got the skills to do it but it's actually not part of the blueprint but it's a very important part of it that gets overlooked a lot of the time.

MS BERGIN: Mr Laity, what's your view about stress as an issue for carers?

40 MR LAITY: Stress has a huge emotional cost to the carer. It builds up and very quietly drags the carer down. It becomes – you know, they go through a stress of grief, a sense of loss, frustration, and even failure at recognising their inability to achieve anything for the person that they're caring for, that they can't cure or restore the health or the normality of the person for whom they are caring. And this in itself is a huge frustration and a huge source of stress for the carer when they see so much  
45 work being put in and so little frequently achieved as a result of that work.

MS BERGIN: Ms Dietrich, what's your view about the issue of isolation for carers in Mildura?

5 MS DIETRICH: There would be a few aspects of that. Isolation is from services as well. They often get isolated from family and friends because if they can't get the respite, to – for the person they care for, that means they're not able to get it to go out and socialise and do things like that, and then that's going to lead to depression and lots more issues, health issues for the carer.

10 MS BERGIN: Mr Laity, what are your observations about isolation as an issue for carers in Mildura?

15 MR LAITY: Isolation is part of the deal, I guess, by virtue of the fact that when you're caring for somebody 24/7, you don't have time to socialise, you have time for work, that's it. You are totally tied up in your caring role and even when you're out, you're still conscious of what's going on at home and it's a matter of do what you need to do like shopping or whatever, and get back to the person that you're caring for.

20 MS BERGIN: Mr Laity, how can distance be a particular issue for carers in Victoria – in Mildura?

25 MR LAITY: Well, we're a self-sufficient little cell in this area. To travel anywhere is a huge commitment. So your social activities are limited to what's in – literally in Sunraysia. If you want to go anywhere, you've got at least 100 kilometres of travelling to the nearest significant town and that significant town is probably fairly small too. So Sunraysia has to be totally self – self-contained in its own services and its own social activities.

30 MS BERGIN: Mr Laity, you mention in your statement about your experience with Frank when you received a call at midday one day from a hospital in Melbourne. What happened there?

35 MR LAITY: We were waiting for a bed for Frank to have bypass surgery in the Royal Melbourne. We weren't aware when this would happen, it was a matter of wait for a phone call. So midday on this particular day, we got a phone call from the office at the Royal Melbourne advising that a bed was available and could we be down in the Royal Melbourne in two – by 2 pm. Giving us two hours to travel 350 kilometres, pack the car and make the trip, which was obviously impossible. This  
40 was eventually extended until 10 am the next day which was achievable but people in the city areas, we've found, and other people have found as well that people in the city don't recognise the distances that are involved in travel and the commitment that's needed to get people down to Melbourne hospitals for treatment.

45 MS BERGIN: Ms Dietrich, what are the benefits of being a carer?

MS DIETRICH: Okay. The care – the benefits of being a carer is that you actually are doing something that – for the person that you love and care about. It gives – you know, like that’s a trick question. It’s one of those things that at the end when, you know, like and I often think about when Mum dies that will be – I will know that I  
5 have done everything that I possibly could to help her and be where we could, and that sort of stuff, but the benefits of being a carer is that you do get to know the person you are caring for. You will get to know all their idiosyncrasies and all those sorts of stuff and maybe just to repay back what you got as a child.

10 MS BERGIN: Mr Laity, how do you see the benefits of being a carer?

MR LAITY: Just that. The satisfaction of knowing that you’ve done everything that you can.

15 MS BERGIN: Mr Laity, you mentioned earlier in your evidence that there’s now – now that the Carers Hub has been opened for three years - - -

MS DIETRICH: Two.

20 MS BERGIN: For two years. Thank you for correcting me, Ms Dietrich. You’re receiving more referrals from sources such as GPs.

MR LAITY: Yes.

25 MS BERGIN: Can you tell us how that’s working.

MR LAITY: Well, people are arriving, if you ask how they heard about the hub which is obviously a point of interest they tell you it was suggested by the doctor that we come down and see you about whatever issue was bothering them.

30 MS BERGIN: What are your observations, Ms Dietrich, about cross-border issues with primary health practitioners such as GPs?

MS DIETRICH: Lack of GPs in this area is the main observation. For cross-border  
35 issues, respite is one of the things, trying to get respite, for GPs to be able to refer somewhere to get respite. There is limited respite beds available in most nursing homes, and there is a nursing home over in New South Wales. It’s called Murray House at Wentworth and you can often get – people can get a bed there at times, you hear, but I understand there’s only one or two doctors that can actually refer to the  
40 New South Wales issue. Personally, anybody that comes into the service, if doesn’t matter where they live, we will help them to their best advantage.

MS BERGIN: Mr Laity, you mentioned the respite care facility in Horsham that was very helpful for Aileen when you and Sherilyn were caring for her. Is there a  
45 facility like that in the vicinity in Mildura?

MR LAITY: Not that I’m aware of.

MS BERGIN: Mr Laity, if you had a rainfall tomorrow of funding for the Carers Hub, what uses would you put it to?

5 MR LAITY: Well, I would love to see the hub open five days a week. I would like to see the services extended to – accommodation services extended to other carer groups that could meet there. You know, if we've got permanency of residency then we can offer that to other groups to – as a meeting venue. I would probably like to see pop-up hubs established from time to time in the outlying areas, like to Gol Gol, 10 Wentworth, Red Cliffs, Merbein and even as far as Robinvale and Ouyen where we could then contact carers who are unable to come into the office in Mildura. There's a lot of opportunities for growth in the area and development of the hub's usefulness if the funding is available. The only restriction that we've got is literally funding.

15 MS BERGIN: Mr Laity, what would a pop-up hub look like?

MR LAITY: Accessing a vacant shop for the day, advertising that we were going to be there. It would obviously necessitate the employment of a full-time staff member that they could get out and do these things. You're not going to do it when Bonney, for example, is employed one day a week. But it would – it would mean that the 20 staff member could travel out to other areas and provide a service from a, you know, a rental shop for the day. And this could be done on an ongoing basis, for example, once every three months, the – a pop-up hub could be established down there to continue the service to that area.

25 MS BERGIN: Ms Dietrich, I'm coming to the end of my examination. Is there anything that we haven't covered that you wanted to say to the commissioners that we haven't already covered in your evidence?

30 MS DIETRICH: Probably, when I think about it later on. At the moment, it would be just the importance of a Carers Hub for people – for carers. Whether it's me, someone else or whatever, on whatever area, it is really important for carers to be able to know that there is somebody or some place that they can go to, where they can get information, education, support, whatever it is they need. Because every carer is going to be different. Every need is going to be different. So they just need 35 to have a place where they can go and feel comfortable, feel that they can say what they want to say without being judged.

40 MS BERGIN: Mr Laity, is there anything else you wanted to say to the commissioners that we haven't already covered in your evidence?

MR LAITY: Probably not. Only to express the concern again that – for a need for face-to-face contact with carers, that peer support can't really be done by online means. The need for personal contact is always going to be there. You can't replace 45 personal contact. And that's one of the things that we really need the funding for, is to maintain personal contact between carers, so that they use it as their – shall we say their social outlet, as well as their support.

MS BERGIN: Commissioners, that concludes my examination.

COMMISSIONER TRACEY: Thank you. What is the hub used for on the four days of the week that you're not using it?

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MS DIETRICH: Nothing.

COMMISSIONER TRACEY: It just sits there? And is – well, does that mean that you are paying rent for one day and the owner is getting nothing for the rest of the week?

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MS DIETRICH: Yes. It's a bit - - -

MR LAITY: Sometimes there are – other groups meet in there. Like, some of the carers groups meet in there when the hub is not open. We've had, I think, craft days down there too, when the hub wasn't officially open. So it does get used, but not regularly. And, yes, this could be, certainly, advanced by the introduction of other groups in – other carer groups in, for example, the Dementia Australia, Heart – they – you know, Diabetes Australia, these specialised groups could possibly transfer and meet in our – the facilities that we've got. But without permanent, regular funding, you know, then it's not likely to leave where they are at the moment to use our facilities.

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COMMISSIONER TRACEY: Yes. It just seems to be a great pity that if there are other community organisations that would have similar needs to bring people together at the hub, that - - -

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MR LAITY: The only - - -

COMMISSIONER TRACEY: - - - arrangements can't be made that so that - - -

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MR LAITY: Well, the only thing that - - -

COMMISSIONER TRACEY: - - - you all get the benefit of it.

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MR LAITY: The only thing that's stopping us at the moment is security of funding, Commissioner.

COMMISSIONER TRACEY: And where do things stand in that regard? I know you've told us that you're funded till the end of this year, but that was pending state and federal budgets; they've both come and gone. What hope have you got of the project continuing into 2020?

40

MR LAITY: The state government have allocated funding on a grant basis, where you apply for grants for it, with a maximum of \$20,000 per annum, which we will be applying for. The budget for the hub is – for the annual budget, would be around about \$66,000 a year to open two days a week, with paid staff. So the \$20,000 is

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going to be a fair bit short there. We're waiting at the moment for the funding to be announced from the Federal Government through the regional support partner – partnership that's being announced. We have no idea at the moment how that's going to be handled.

5

That's supposed to be announced within the next few days, but that's still, you know, coming, shall we say. So the balance of the funding for that at the moment is unknown. Grant funding is possibly available through trusts and that type of thing but, again, it's short-term and it takes an awful lot of time to – doing the applications and that sort of work for grants. And that falls on the shoulders, basically, of carers who are already caring for people 24/7 and are time-poor.

10

COMMISSIONER BRIGGS: I might pick up the line of questioning about the financing. In the evaluation which we saw on the screen earlier on, it makes clear that the formation of the NDIS and some changes to mental health funding have meant that some support services that might otherwise have been there for carers in those fields have disappeared. And you gave in your evidence, Ms Dietrich, that you're seeing some of those people come to your services. Is it that consumer directed care means that supports that might otherwise be available in the community for carer groups are no longer available? Is that your evidence?

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MS DIETRICH: That would be what we're finding out. The NDIS is all about the person with a disability, and it's very hard for the carers to actually get any support in that. So yes. There is.

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COMMISSIONER BRIGGS: Okay. So the government, through the Department of Social Services, has introduced, I think, the Carer Gateway and is introducing this thing called the – let me get the word right. The – it's a marvellous title, something like the Integrated Carer Support Scheme, or something of that nature. Is that made up of officials or does it involve support for community groups such as your own?

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MS DIETRICH: No. The Carer Gateway and things like that are directly on computer.

35

COMMISSIONER BRIGGS: Right.

MS DIETRICH: And it's – that's where the issue is. A lot of people don't know how – don't have the ability to access it, don't know how to access it and it's just not that personal.

40

COMMISSIONER BRIGGS: And the Integrated Carer Support Scheme, is that also on computer? I thought they were going to have representation across the country in various regions.

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MS DIETRICH: I'm unsure on that one. Sorry.

COMMISSIONER BRIGGS: Okay. We will follow that up in, I think, questioning, likely tomorrow. The question for me is the different relationship model. A relationship with officials versus a relationship with community groups and carers such as yourself. And your evidence – you can correct me if I’m wrong – is that a  
5 community-based group is more likely to be a group that carers themselves can relate to; is that right?

MS DIETRICH: Do you want to – there – you have the carer support group that actually provides some peer support, which is really good. I think – and in a  
10 previous life I ran a mental health carers support group, which actually had folded because it was left for the carers to run. And once, you know – if you’re a carer, you – often things will happen, somebody gets sick, some – whether it’s the person they’re caring for and the carer themselves, so if we – you don’t have, actually, any support for the carers, they will often just dissolve.

15 COMMISSIONER BRIGGS: Yes. I get that. So fundamentally, you’re looking for a model that has a mixture of both government support and some kind of structure, or support from an organisation such as Carers Australia or Carers by state, together with a paid worker of some kind or more, and – but grounded in the community?

20 MS DIETRICH: Definitely.

MR LAITY: That would be – yes. That would be the ideal that we’re looking at, and that’s what we’ve experienced over the last two years.

25 COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising?

30 MS BERGIN: Nothing arising. Thank you, Commissioner. If the witnesses may please be excused?

COMMISSIONER TRACEY: Yes. Of course. Thank you both very much for coming and telling us about the hub and the wider activities that go on there, and we  
35 certainly wish you well. It sounds as if you’re well and truly assured of continuity into the coming year. And the major issue, I think, is going to be how much additional funding can be provided, with a view to expanding your excellent activities. And we are very grateful to you for coming and explaining to us how it works and what needs to be done to make things better. Thank you both very much.

40 MS DIETRICH: Thank you.

45 <THE WITNESSES WITHDREW [10.45 am]

COMMISSIONER TRACEY: The Commission adjourn until 11.15.

**ADJOURNED**

[10.45 am]

**RESUMED**

[11.19 am]

5

COMMISSIONER TRACEY: Yes, Ms Bergin.

MS BERGIN: I call Nicole Louise Dunn.

10

**<NICOLE LOUISE DUNN, AFFIRMED**

[11.20 am]

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

MS BERGIN: What is your full name?

20 MS DUNN: Nicole Louise Dunn.

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

MS DUNN: Yes, I have.

25

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

MS DUNN: Yes, there is.

30 MS BERGIN: Could you just confirm by turning the pages that it is your complete statement.

MS DUNN: Yes, it is.

35 MS BERGIN: Thank you, Ms Dunn. Do you have any amendments to your statement?

MS DUNN: Yes, I do. To insert after paragraph 4:

40 *I work in the emergency department of a hospital in Melbourne as a physiotherapist and care coordinator. Since the passing of my nana, I also work privately in aged care consulting.*

MS BERGIN: Do you have any other amendments, Ms Dunn?

45

MS DUNN: No, I don't.

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

MS DUNN: Yes, it is.

5

MS BERGIN: I tender the statement of Nicole Louise Dunn dated 19 July 2019 subject to one amendment.

10 COMMISSIONER TRACEY: Yes, the amended statement of Nicole Louise Dunn dated 19 July 2019 will be exhibit 7-11.

15 **EXHIBIT #7-11 AMENDED STATEMENT OF NICOLE LOUISE DUNN  
DATED 19/07/2019 (WIT.0312.0001.0001) AND ITS IDENTIFIED  
ANNEXURES**

MS BERGIN: Ms Dunn, you became a carer for your nana, Roma Dunn, in 2015.

20 MS DUNN: Yes, that's correct.

MS BERGIN: And at this time you were 32.

25 MS DUNN: That's correct.

MS BERGIN: And Roma was 83.

MS DUNN: Yes.

30 MS BERGIN: She was living in the Macedon Ranges.

MS DUNN: She was, yes.

35 MS BERGIN: You were living in Melbourne.

MS DUNN: Yes.

MS BERGIN: You moved in with nana in the Macedon Ranges in 2015.

40 MS DUNN: She actually moved to Melbourne. Our family home is in Melbourne, and I moved into her Melbourne home.

45 MS BERGIN: You cared for her for two and a half years until she passed away on 6 April 2016.

MS DUNN: Approximately two years, yes.

MS BERGIN: Operator, could you please bring up the photograph at RCD.9999.0122.0002. Ms Dunn, what does this photograph show?

5 MS DUNN: So this is a photograph of my nana and I. It was taken in April of two thousand and – sorry, January of 2017, about three months before she passed away. It's taken in the front yard of our family home in Melbourne which is where I cared for her and it's probably my favourite photograph because it wasn't until I saw this that I realised how similar we were, the family resemblance and we have the same smile.

10 MS BERGIN: Operator, could you please leave the photograph on the screen while Ms Dunn gives her evidence. Ms Dunn, have you brought another symbol of your grandmother with you today?

15 MS DUNN: Yes, I have.

MS BERGIN: What's that?

20 MS DUNN: I've brought a bracelet of hers that has been given to me and I always wear it if I just want extra support and for anything important. So it's important to have today.

25 MS BERGIN: Thank you, Ms Dunn. Why did you decide to become your grandmother's carer?

30 MS DUNN: I guess I never consciously made a choice to be a carer. It was more something that came about. She was diagnosed with pancreatic cancer in April of 2015 and it seemed like the natural thing to do would be to look after her. She had a terminal diagnosis and I knew she would decline quite quickly and need a live-in carer.

MS BERGIN: At this time just prior to 2015, could you tell us about your grandmother and her independent life.

35 MS DUNN: Yes, I guess my grandmother was what you could only describe as being fiercely independent, so she was managing two properties, one in semi-rural Mount Macedon in Victoria and one in Melbourne. She was doing absolutely everything for herself, driving – she was driving her friends around. She was managing quite a large property, tending to the gardens, catching up with her friends.  
40 There was nothing she couldn't do.

MS BERGIN: Tell us about the health event that increased your nana's health needs.

45 MS DUNN: It was very unexpected. She had two weeks of abnormal bowel movements, went to a doctor, went to an emergency department, and was effectively diagnosed with pancreatic cancer. It was a terminal diagnosis and she was given a

prognosis of one year to live, and she could only have treatment which was palliative chemotherapy, so the cancer itself and also the treatment led to her health declining.

5 MS BERGIN: At about this time, how often did you visit your grandmother?

MS DUNN: Prior to her being diagnosed?

MS BERGIN: Yes.

10 MS DUNN: We would kind of catch up every couple of weeks or so. We would always have family events and so there would always be something on amongst the family. We would all catch up as a family as well as with my grandmother.

15 MS BERGIN: Who are the other members of your family?

MS DUNN: So my grandmother has two children: my father Andrew, my aunty Karen; there is myself and other grandchildren. Yes, it's quite a small family.

20 MS BERGIN: Ms Dunn, what were her care needs after the diagnosis?

MS DUNN: So initially the care needs were more around arranging her treatment, so we were needing to decide where she would have chemotherapy because she had been living in Mount Macedon, 45 minutes out of Melbourne, so we would need to relocate her to Melbourne and I was needing to relocate to her home, and then we were trying to coordinate where she would have chemotherapy, who her new GP would be, trying to set up those appointments, blood tests. And then after that it was trying to work out, well, what help and support would we need. Initially, she was managing reasonably well in a physical sense after the diagnosis.

30 MS BERGIN: When did you move in with your nana?

MS DUNN: Immediately. So she spent two weeks in hospital after she presented to an emergency department, and I spoke with her while she was in hospital and I recognised, with my health background, she would need someone to live with her. I made the suggestion that I would like to do it, and I moved in almost immediately after she came home.

40 MS BERGIN: How did you assist your grandmother with navigating the aged care system?

MS DUNN: I pretty much did it all. So I guess having a background in health care I was very fortunate in that I knew the avenues of support for her. That was not something my grandmother was aware of. So I actually arranged it all for her. I completed the referrals myself, completed the paperwork myself. I spoke to all the service providers, doctors, nurses, and took her to all of the appointments.

MS BERGIN: When you first moved in with your grandmother what did you notice about how she might have changed?

5 MS DUNN: I guess the first subtle signs was that she was probably more fatigued than what she normally would have been. So this is a woman who was chopping wood on her property, you know, the week she was diagnosed. And then I guess starting chemotherapy, you can be really quite fatigued after treatment such as that, and also with the cancer. So that was quite unusual for her that she would need to rest during the day or that I might have been doing some of the other things around  
10 the house that normally she would have done without even thinking about.

MS BERGIN: Were you working full time at the time that you moved in with your grandmother, Ms Dunn?

15 MS DUNN: Yes, I was full time.

MS BERGIN: And how many hours of caring were you doing for your grandmother at the same time?

20 MS DUNN: I would estimate between 25 to 30 hours a week, there were certainly periods of time where that certainly escalated. I guess in the beginning where you're needing to initially establish a new health care support service for her in aged care and then at times of deterioration that would also decrease.

25 MS BERGIN: How did you go about setting up the home?

MS DUNN: We arranged some rails. So I arranged for an occupational therapy home visit through our GP. So we set up a care plan and we arranged for a private occupational therapist to come to the home because we needed to get rails installed  
30 on the stairs at the front door and also in the shower.

MS BERGIN: How was this funded, Ms Dunn?

35 MS DUNN: We funded this privately.

MS BERGIN: And you mentioned that at this time you were working full time and also caring for your grandmother up to 25 hours or more a week. What was the impact on your work?

40 MS DUNN: I guess there's quite a lot of stress that can be associated with being a carer and then I guess you may be coming to work not completely your fresh self. I think there can be a lot of carer fatigue and working in health care I've then got to be in a work situation where I keep needing to give more of myself to the patients that I also treat. So there's a lot of, I guess, fatigue in that regard. I was also being  
45 contacted a lot at work by service providers.

So they tend to ring during business hours. And when I had breaks at work they weren't really breaks because I would be needing to call them back. Inevitably, you miss a call; you've then got to call them back. You might not get onto the person you need. You try to speak with someone else. And maybe you need to try again  
5 later in the day, to reach the person who originally left a call for you.

MS BERGIN: Ms Dunn, how did you manage appointments, such as for chemotherapy, associated with your nana's care after she was diagnosed?

10 MS DUNN: With some difficult. It wasn't just arriving for the chemotherapy; there was some work we had to do beforehand. So we needed to get a blood test completed prior to the chemotherapy being done, a couple of days beforehand, to make sure she was well enough to tolerate the chemotherapy; that meant we had to have enough pathology slips from the doctor. It needed to be worked out who could  
15 get her there. I couldn't do it every single time, with work, so I did have family assisting me if I couldn't take her. And my aunty, in particular, provided a lot of assistance. It would then be about half a day to get her into the hospital. We were taking her into a hospital in the city. And by the time you take somebody into the city who might have mobility problems or you're trying to get parking and then  
20 you're trying to get someone in, they need to be monitored before and after. It's easily half a day just for the chemotherapy itself.

MS BERGIN: What was the impact on your social life and your sport, moving in with your grandmother?  
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MS DUNN: I guess, socially, that changed quite a lot. I'm probably at an age where, I guess, what my friends were doing was quite different to myself, in that they had a lot of freedom and could socialise quite regularly whenever they wanted. A lot of that, really, stopped for me. My caring responsibility came first. That was more  
30 important. I couldn't really see it another way. So, really, my dedication was in looking after my nana, not so much socialising with my friends. It was something that I wanted to do, but also needed to do.

MS BERGIN: Once you moved in with your grandmother, how did you manage the increased workload?  
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MS DUNN: I guess there came a point where I knew something was going to give and a change had to be made. It was something that I spoke with my boss about early on, and the conversation I had with him was that I really needed to reduce work  
40 because I couldn't be a full-time carer, which is what it was turning into, and also work full-time. So work had to reduce. I reduced to four days a week.

MS BERGIN: What supports were available for you during this time?

45 MS DUNN: I did access some supports through my workplace, through the Employee Assistance Program, to get some counselling, because it was a very unexpected and shocking diagnosis. It was not something that we could foresee, and

I found the diagnosis quite difficult to deal with. So having some counselling around that was particularly helpful. I did access – try to access some financial assistance through Centrelink; I applied for a carer’s supplement, but that was declined.

5 MS BERGIN: What did the assessment for the carer’s supplement involve?

MS DUNN: It involved asking almost like a tick-box style of questions, “Can she walk on her own or does she need assistance? Can she shower and dress on her own or does she need assistance? What other activity of daily living could she do on her own or needing assistance?” It asked a bit about her memory. It asked a little bit about – if there were any behavioural issues, like agitation and things like that.

10

MS BERGIN: Did it include her prognosis?

15 MS DUNN: I believe we – it was written in the document or the family doctor put some evidence of that in the document, but I don’t believe it was considered.

MS BERGIN: What’s your view about the assessment process, having gone through this with your grandmother?

20

MS DUNN: Yes. I mean, I guess the difficulty that we experienced is she’s a lady who wants to do what she can for herself. She wants to be independent. She doesn’t want to be dependent on someone, so she was trying to do all she could initially. And the assistance, initially, that was needed, which was when I made the application, in a physical sense wasn’t too much. It was more the coordination, but she rapidly deteriorated. And within one – you know, within a year of applying for a carer supplement she was in an aged care facility, requiring 24-hour care, and I don’t think that was taken into account.

25

30 MS BERGIN: By this time, had you been living with your nana for two years?

MS DUNN: I had been living with her since her diagnosis in April 2015. I had been living with her for maybe three or four months prior to making the application. I had lived with her previously in my younger years.

35

MS BERGIN: Okay.

MS DUNN: For periods of time.

40 MS BERGIN: How long did you live with your nana for before she moved into the aged care facility?

MS DUNN: I cared for her at home for 18 months. So she outlived her prognosis, which was – we were blessed.

45

MS BERGIN: What was the impact on your life choices during these 18 months?

MS DUNN: I don't know whether I really considered my life choices, to be honest. I would say I didn't consider them, because that was not what was important to me. What was important to me was providing care for someone else, particularly because I knew the time I had to do that would be limited. So I – I didn't consider my own  
5 life choices. So it meant that if my social life was to be impacted, so be it. If work was impacted, so be it. Even if my own health was impacted, so be it.

MS BERGIN: During this 18-month period when you were living with your nana, how did you get a break?  
10

MS DUNN: Family. Family was a really big support to me. I was very fortunate in that all of my family were very supportive and all of them tried to help out when they can and when they could. Like myself, they were also all working full-time. I did seek some in-home respite and some support through Carers Victoria, which was  
15 wonderful and of great assistance.

MS BERGIN: How many hours respite did you get a fortnight during that period?

MS DUNN: Through Carers Victoria, we qualified for four hours a fortnight. And we paid privately to supplement that, just so I could have a little bit more of a break because, I guess, four hours – it's half a day. By the time you get someone who's quite fatigued or not in good health ready, they might go out, and by the time they come back it's not – four hours is probably not four hours.  
20

MS BERGIN: Ms Dunn, how did you find information about supports that were available to carers?  
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MS DUNN: I was very fortunate because I have a background in health care; that was something that, from a professional sense, I was already aware of. So I was very  
30 lucky. I don't know where I would have started otherwise; I really don't.

MS BERGIN: How did you find out about the treatments that your grandmother would be receiving?

MS DUNN: So that was something that probably was quite foreign to me. My background is not in oncology. My understanding of chemotherapy and palliative care is – would be that of anyone else, really. And we found out about that from the medical professionals, so from the family doctor and also from her oncologist that she was referred to.  
35

40

MS BERGIN: What supports would have been helpful for you at this time, Ms Dunn?

MS DUNN: I think, I guess, perhaps being offered some pre-counselling around chemotherapy, around palliative care before those services are needed would have been really helpful, I think. Just – if you can have some idea of what might happen or what might you expect and how that might impact you, that would have made it so  
45

much easier. It's really shocking when a doctor says to you, "We think we should get the palliative team to come and speak to your nana at home", and that was, really, the first I had ever had any contact with that on a personal level. And I think some pre-counselling would have been helpful.

5

MS BERGIN: How did you feel, moving in with your grandmother and caring for her?

10 MS DUNN: It was probably a bit mixed. On one hand, we've always just been so close and always got along so well, so it was – it was great to be living with her again. But on the other hand, there was another reason for doing that. It wasn't planned. It wasn't something by choice, and I was moving in with her because she had a terminal diagnosis and that was incredibly devastating.

15 MS BERGIN: How did you feel, then, when she moved into the aged care facility, after you had been living with her for 18 months?

20 MS DUNN: I think that was probably another point in time at which I grieved. I probably grieved as much at that point in time as when she passed away. I was just so used to having her there every day. I was so used to doing everything for her and then it was just so quiet. Yes.

25 MS BERGIN: What are your favourite memories about when you lived with your nana?

MS DUNN: Her cheekiness. You wouldn't think a woman of 83 could be so cheeky, but I tell you what, she can. She just – you know, wonderful positive outlook on life. Just so giving, so loving. Yes. Full of fun.

30 MS BERGIN: Ms Dunn, you're one of our youngest – or you are our youngest carer witness in this hearing in Mildura.

MS DUNN: Yes.

35 MS BERGIN: Is there a normal carer, in your view?

40 MS DUNN: No. I was quite shocked to hear that I would be the youngest person speaking. I couldn't understand that. I know other people my age who are carers and I was – I really couldn't understand that at all. It's been a comment that has been said to me before, "Oh, but you're not a normal carer", or, "You're not a typical carer", and I couldn't understand what people meant by that. Am I meant to be caring for a parent rather than a grandparent? Or am I meant to be older? Or was this meant to be a planned thing that would just conveniently fit into my life? Or am I meant to be someone that's retired or already a – working as a stay-at-home mum, 45 so I'm already in that role? I just couldn't understand it at all.

MS BERGIN: How did you recover after your role as a carer ended, when your grandmother passed away?

5 MS DUNN: I guess it took a while to recover. There was obviously a natural grieving process that you go to – you go through, and it’s another point in time in which you’re just constantly adjusting again. And you somehow have to just get back to the normality of life, as if nothing happened. So it was difficult. It was emotionally quite difficult to do.

10 MS BERGIN: Did you resume at five days a week in your work?

MS DUNN: No. I continued at four days a week. I just felt that would be best for me, in terms of where I was at with things.

15 MS BERGIN: You mentioned that your respite was fairly limited, with family members assisting from time to time during this period. How did you manage that?

MS DUNN: Could you repeat the question? Sorry.

20 MS BERGIN: How did you manage the limited – having limited access to respite?

MS DUNN: We had to pay for it was the answer. There wasn’t going to be more avenues. And if we wanted more help, we had to pay for it. And paying for it in the private sector is quite expensive; it’s around about \$55 an hour. Anyone on a  
25 pension will not have the means to afford that.

MS BERGIN: How did you find the services that were available to you?

MS DUNN: The services were wonderful. The quality of care that we received in  
30 home was fantastic. Until particular, the respite and the carer that we had – that provided that was just so dedicated. And she was, really, about not just giving myself a break, but giving my grandmother quality of life. So doing the things that she enjoyed doing, keeping her active. I have no doubt those kinds of things prolonged her life beyond what it should have been.

35

MS BERGIN: How did you find the information services that were available to you?

MS DUNN: Difficult. So I guess one example – I was aware, as a health care  
40 professional, that I could access support through a carer support service. And even with that, I sort of got the run around a bit on the phone because I called up Carers Victoria and they said, “Oh, we’re the state-wide service”, and I thought, “Okay. Well, I obviously should be ringing some other service”. And then I did phone another service and then they said, yes, they are the state-wide service but they also  
45 support carers in the western region of Melbourne, which was where we lived.

So I think you can still have difficulty with the system even if you have knowledge of the system and it doesn't take away the fact that you need to constantly advocate for someone and for the help that they need. I applied for a personal alarm. Again, I was denied for that so the personal alarm – the safety alarm which my grandmother would wear as a button around her neck, so if she fell – which she did have falls while I was at work, she could at least seek emergency help and, again, I was told I wasn't eligible because she – I lived with her even though I was working.

10 MS BERGIN: What information would have been useful for you at this time?

MS DUNN: I think the – the main thing that I really wanted was someone to talk to, so some support as a carer. That was something that I was able to access through Carers Victoria eventually, but there was a wait time. We waited about two to three months to get that, and it might not seem long but when someone has a – a very terminal diagnosis, that waiting time is suddenly magnified. So I think, really, that early intervention would have been really helpful as a carer to know what to expect in the health sense of chemotherapy and treatment and also that counselling side of it.

20 MS BERGIN: How did you get information in the absence of support?

MS DUNN: Google. So I was researching quite a lot on the internet. I spent one – two hours one day researching day centres, so if my grandmother wished to go to a day centre, I would know exactly which one would be the best one for her in our area, so it was lots of online research.

25 MS BERGIN: You mentioned, Ms Dunn, that you have chosen to continue working four days a week. Tell us about how you spend your time now, split between your various employment forms.

30 MS DUNN: So at the moment I guess I'm – I've returned to catching up with friends. I continue to play sport, so I'm playing netball and I was playing football again as well, AFL. So these are really the things that are important to me and I find it really important now to give back as a carer, given I've been through this journey and have come out on the other side of it.

35 MS BERGIN: How is your work going now, Ms Dunn?

MS DUNN: It's busy as emergency departments are, but work is going really good. It's nice to feel comfortable working back in that space again.

40 MS BERGIN: What benefits came from being a carer?

MS DUNN: There were a lot of benefits that I got. It really brought my grandmother and I closer together in terms of our relationship, just the silly little things you do day to day that you get to see and you get to experience in caring for someone, and that's, you know, something I look back and I treasure. I'm really proud of being a carer for her, and it's given me a different outlook on life, so I really

appreciate the little things in life and I'm, you know, very lucky that – that at my age I can really realise what's truly important and it's not the materialistic things, it's the time that you have with people.

5 MS BERGIN: How has your experience as a carer affected your choices about your work?

MS DUNN: I guess after my grandmother passed away, I did make a choice that I would also like to do my own consulting work. I've dedicated that work to her  
10 because I want to work with other carers and I want to create options out there for people to find a way through the system when they can't with what's already available.

MS BERGIN: How do you find that work that you've chosen to do?  
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MS DUNN: I love it; I absolutely love it. I feel that I'm absolutely a better clinician from being a carer. I can just relate to people on a completely different level and see what they're going through and where they're at. And that brings me back to where – where, when I was a carer and I think back to the things that I went  
20 through. So the ability to relate to other carers has just been wonderful.

MS BERGIN: Ms Dunn, that comes to the conclusion of my examination. Is there anything that you wanted to share with the Commissioners about your experiences as a carer?  
25

MS DUNN: Yes. I mean, I guess I find the aged care system to be very reactive in a sense. We wait for someone to be unwell. We wait for someone to end up in a hospital. And then someone comes along and says have you thought about aged care and what help is out there. I just feel it really needs to be flipped on its head. The  
30 one constant in everything is that we are all ageing, so if we know we are all ageing, why aren't we having these discussions about aged care and how the system works before people need it. I think we need to be more proactive in the way we respond to aged care.

35 MS BERGIN: Should the focus be on both their carer and the aged care recipient?

MS DUNN: Absolutely. I think if the recipients were more informed of how aged care services worked and what is available prior to needing them, it would take a lot of the carer burden off because from my experience, I spent so much time speaking  
40 to services and arranging services and that was because my grandmother was not aware of how to do that or what was available.

MS BERGIN: Thank you, Ms Dunn. That concludes my examination, Commissioners.  
45

COMMISSIONER TRACEY: Thank you. Ms Dunn, can I take you away from caring for a minute. Did I rightly understand that you have also got experience in the aged care sector as a physiotherapist?

5 MS DUNN: Yes, I've worked in the aged care sector as a physiotherapist and also a care coordinator. That entails myself sorting out social problems for people both – predominantly recently in the emergency department setting.

10 COMMISSIONER TRACEY: That's within hospitals, not in aged care residential facilities?

MS DUNN: Not in aged care residential facilities, no, it's been more home-based outreach support, so supporting older people at home or in an emergency department.

15 COMMISSIONER TRACEY: Yes. And could you tell us how that linkage is forged. Do I take it that an aged person presents at an emergency department with, perhaps, a broken limb or something of that kind, and after discharge there needs to be follow-up and that's organised through the hospital?

20 MS DUNN: Yes. Very much so. So the common presentations would be a fall resulting in an injury or a fracture, and then there is a need for help that perhaps wasn't there and an individual needs assistance to arrange such help. Where I also see more and more presentations where people have just gradually declined at home, where there hasn't been an incident and someone has continued to decline at home to  
25 the point of needing to come into an emergency department which could have been avoided purely because they've not known how to get help or that's not been offered.

30 COMMISSIONER TRACEY: And your home visits are sponsored by the health service, not as part of an aged care package?

MS DUNN: Part of the hospital. It's hospital-funded.

35 COMMISSIONER TRACEY: Yes. And is that a common practice in major hospitals, to have this outreach service?

MS DUNN: In metropolitan hospitals it is. It's predominantly an emergency department-based service. The hospital I work for has a continuing link to the community. In other hospitals, they may run as separate services, the emergency and  
40 community support.

COMMISSIONER TRACEY: And I take it that the alternative to you looking after somebody at home following an accident would be that they would have to be either still in hospital or in a rehabilitation facility.

45 MS DUNN: Correct, or sometimes emergency respite or an aged care facility is arranged, yes.

COMMISSIONER TRACEY: Yes. And in your experience, do people prefer to be looked after at home, rather than at one of these other types of facility?

5 MS DUNN: Yes. Across the board, older people want to be at home. They don't want to be somewhere else. They want to be where it's familiar to them and they're comfortable.

10 COMMISSIONER BRIGGS: It's just a short question that follows on from your witness statement, Ms Dunn, and you talk there about the problems with having to go through the same information with assessment and so on time and time again. And we've heard that in other evidence before this Royal Commission. My question is a general one and I'm not sure I can put it properly, but I will have a go. If there were a universal tick box that said: I'm the carer for this person, I have authority to take decisions for this person. And that that was to be shared around both the government and the supportive care services, do you think that would be attractive to people or would that be an infringement of their privacy?

20 MS DUNN: I can only speak for myself but that would have been wonderful to have had. It would have saved a lot of duplication, yes.

COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising?

25 MS BERGIN: Nothing arising. Thank you, Commissioners. If this witness may please be excused.

30 COMMISSIONER TRACEY: Ms Dunn, thank you very much for your evidence. As was mentioned during your evidence you are indeed the youngest carer that we have encountered and your selfless care for your grandmother is a wonderful testimony to you and the support system that you have within your family. Thank you very much for sharing it all with us.

35 MS DUNN: Thank you.

**<THE WITNESS WITHDREW [11.56 am]**

40 MS BERGIN: Ms Hill will take the next witness.

COMMISSIONER TRACEY: Thank you. Yes, Ms Hill.

45 MS HILL: If the Commission pleases, I call Catherine Thomson.

**<CATHERINE MARY THOMSON, AFFIRMED [11.57 am]**

**<EXAMINATION-IN-CHIEF BY MS HILL**

5 MS HILL: Please feel free to take a seat, Ms Thomson. Ms Thomson, may I ask you to state your full name.

MS THOMSON: My name is Catherine Mary Thomson.

10 MS HILL: What is your role, Ms Thomson?

MS THOMSON: I'm a research fellow at the Social Policy Research Centre at the University of New South Wales, Sydney.

15 MS HILL: Accordingly, you're based in Sydney.

MS THOMSON: Yes.

MS HILL: And you've just finished your PhD.

20 MS THOMSON: Yes, I've just received my marks and I'm very happy.

MS HILL: What was your thesis on?

25 MS THOMSON: My thesis was on the direct cost of care for Australian carers.

MS HILL: With your work at the Social Policy Research Centre at the University of New South Wales, you work alongside others.

30 MS THOMSON: Yes. I work along – I work in a team with Dr Trish Hill and Dr Myra Hamilton but the centre has a broader perspective where we look at issues around welfare and evaluation of government programs, and we do look at things such as care and disability, family and communities, poverty, policy design and evaluation.

35 MS HILL: Together with Dr Hill and Dr Hamilton, the three of you prepared a joint paper for the Aged Care Royal Commission.

MS THOMSON: Yes, we did.

40 MS HILL: The joint paper has in fact been prepared for the purpose of this hearing in Mildura.

MS THOMSON: Yes, it has.

45 MS HILL: Operator, could I ask you to please display document ID WIT.0286.0001.0001. Ms Thomson, is that the joint paper that you've prepared together with Dr Hill and Dr Hamilton displayed with the monitor in front of you?

MS THOMSON: Yes, it is.

MS HILL: Commissioners, I tender the joint paper of Dr Hill, Dr Hamilton and Ms Thomson.

5

COMMISSIONER TRACEY: Yes, the joint paper of Drs Thomson, Hill and Hamilton dated 22 July 2019 will be exhibit 7-12.

10 **EXHIBIT #7-12 JOINT PAPER OF DRS THOMSON, HILL AND HAMILTON DATED 22/07/2019 (WIT.0286.0001.0001) AND ITS IDENTIFIED ANNEXURES**

15 MS HILL: As the Commission pleases. Ms Thomson, in broad terms, who are carers for older Australians?

MS THOMSON: So in broad terms, carers are people who provide unpaid support to people with disabilities, who have chronic illnesses and who are frail due to  
20 ageing. There is a – there's other more specific definitions from the Australian Bureau of Statistics where it encompasses that, but there is a definition of primary carers who are the carers who provide the main sources of support to those people.

MS HILL: How do people become carers?  
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MS THOMSON: There's a range of ways people become carers but it's usually – it can be a slow process as somebody gradually ages. It can be the onset of a traumatic event, such as a brain injury. It can also be as a result of a stroke or a chronic illness, and usually carers – most often they're in, already in a pre-existing relationship. So  
30 sometimes it can be difficult to define when that – when they become a carer.

MS HILL: In the experience of your research does it go beyond being the spouse, being the eldest daughter?

MS THOMSON: Primary carers are predominantly spouse carers and daughters, sometimes sons if there are no daughters. But there are a range of secondary carers and they might be other – other children, other siblings or they can be brothers or sisters of the person with a disability or who is ageing. And sometimes it's friends, close friends and also it can be a neighbour.  
40

MS HILL: Why do people end up as carers?

MS THOMSON: There are a range of reasons why people take on a caring role. Sometimes it's – and often it's to do with a pre-existing relationship and it's out of  
45 love and they want to take care of the person, their family member. Sometimes it can also be about there's no alternative to them taking on the caring role. They're not – there aren't other relatives or supports around, informal supports around that

they trust. There can be a lack of services. And, also, sometimes it's about family obligations and gendered ideas about who should take on a caring role.

5 MS HILL: The Commissioners have heard evidence in Mildura from people who are caring for their loved ones who describe that it's almost as though they're caring for a child when they're caring for their older spouse or older partner. Is caring for an older person different to caring for a child or caring for someone who has a disability?

10 MS THOMSON: There are some similarities in terms of you have to look after somebody and provide them with – sometimes you have to cook for them, clean for them, you have to bathe them. But the difference between caring for a child and caring for somebody with a disability or who's ageing is that caring for a child usually follows a natural progression and they will, in the end, become more  
15 independent and go on and have their own lives, whereas – and it's mostly a positive experience.

Whereas caring for somebody who – who's declining in their cognitive ability or who's becoming more frail, not that it's not always happy but – but the nature of the  
20 relationship changes and so there's this, like, a decline and so that's not really associated with – people aren't generally happy about that. But also the needs of those people and the support that you give is often unpredictable so you can't – you can't know exactly what's going to happen in terms of the types of support you're going to provide, unlike with a child as – as they develop.

25 MS HILL: Ms Thomson, can I ask you just to keep your voice up slightly.

MS THOMSON: Sorry.

30 MS HILL: Thank you. Could I ask you to draw out what the positive impacts are for those that are carers.

MS THOMSON: Carers often gain a lot of benefits from caring, so they can gain skills in terms of managing very complex relationships and service systems. They  
35 also – they also can – it's also a positive experience in terms of providing a loved one with the care that they need and knowing that you're providing the best sort of care that you can and you're allowing that person to remain independent and to remain at home, which is what they – they want to do.

40 MS HILL: What is the impact of employment for carers?

MS THOMSON: So from the research that we've done, it's very clear, and other research, it's very clear that caring can have a negative impact on employment. Carers have a lower employment rate than non-carers, they're often employed part-  
45 time rather than full-time, and the other problem with employment is that they're often employed in precarious work arrangements because it gives them access to more flexibility and more control over their – over their working hours.

So for carers in employment, it's often very difficult to juggle both the caring responsibilities and their employment responsibilities and what happens is many of them reduce hours of work. They don't take on additional responsibilities. They don't have access to promotions because they're not taking on – they can't do  
5 additional training and so forth. And then the following consequence for that is that their income rates are lower, so then – and that has a negative impact on their current financial security but also their longer term financial security in terms of retirement savings and income.

10 MS HILL: In consideration of that financial impact, can I take to you page 19 of the joint paper.

MS THOMSON: Yes.

15 MS HILL: At page 19 about part way, in the middle of that first paragraph, the joint paper describes that:

20 *As women undertake the largest share of unpaid caring work women disproportionately experience the financial impacts associated with caring. This is compounded for carers who also take on child care responsibilities throughout their lives.*

In consideration of that aspect of the joint paper, what does that mean for the financial consequences for who is undertaking the care?  
25

MS THOMSON: Yes. So for women, we often talk about caring being a dynamic process, that you can move in and out of different caring situations so – and for women sometimes the disadvantages associated with caring can start when they have children because they are taking time out from the labour market so that can have  
30 impacts on their career progression but also financially in terms of contributing to their retirement income. And then – then they have another impact later on in life and sometimes at the same time as when they're providing care for children – called the sandwich generation when they're providing care for smaller children and caring for parents.

35 Again, they have to take time out of – they may have to take time out of the caring – out of the labour market and again that can affect their income, current and future. And it also has another impact on their – their ability to progress through promotion, do training, work full time, so all of those things have a sort of a cumulative effect on  
40 their ability to save for the future, for their retirement.

MS HILL: How can carers' participation in paid work be supported?

45 MS THOMSON: So there's a number of things that would support carers to participate in employment. Firstly, and I know that other people have talked about this and it's not just about employment, it's about general awareness of what carers are doing, the – the barriers that they face, and the important role that they play

within society, so that workplaces as well as colleagues are aware of the need to support carers.

5 So within workplaces, the research that we've done shows that workplaces that have a carer-friendly culture, meaning that they – carers are supported, they have access to flexible work arrangements, they can take leave, they have either unpaid or paid leave, they have a supportive management, that facilitates carers participating in employment.

10 And also access to services has been shown to support carers' employment, but currently with the changes in the way the service systems, both the aged care and the carer support system is heading – the changes – the way that the systems are heading it's very difficult for services to support carers to work. So if – if the service system was designed to help carers participate in employment, then I think that would  
15 facilitate women remaining in, or maintaining employment.

MS HILL: And are those mechanisms currently available to employers and employees?

20 MS THOMSON: So within the workplace, carers have the right to request or work – carers have the right to request flexible working arrangements. Although there's – employers don't have to do that if they can give reasonable grounds for them – if they can argue a case as to why that shouldn't be – why the carer shouldn't access that. So it's there but it can be denied.

25 MS HILL: At pages 6 through to 9 of the joint paper, there's a reference to a bundle of legislation - - -

MS THOMSON: Yes.

30 MS HILL: - - - in respect of carers. What role does legislation have in supporting carers?

35 MS THOMSON: I think legislation is important. The Carers Act is an important piece of legislation in terms of raising awareness of carers, however, it doesn't have legally enforceable mechanisms to allow carers to have access to an assessment or services which is different to other countries, for example, in England. I – but I don't think that legislation is the only thing. I think legislation should be there but it also has to do with a cultural change within society about acknowledging and recognising  
40 the value of carers.

MS HILL: Do you consider that the recognition of carers in Australia has faced challenges?

45 MS THOMSON: I think that – that it hasn't gone far enough so, as I said, the – the Carers Act doesn't have any legally enforceable rights to an assessment or to services. So in terms of strengthening the legislation, I think that – that would be a

good thing. But I don't know whether there's enough support yet for such a change. So that's why I think it's important to have a cultural change within society and – and people have talked about, here, about raising awareness of carers and what they do and the important role that they play within society.

5

MS HILL: In your research, has – do you find – have you found whether the shift to consumer-directed care has seen a change in the role of the informal carer?

10 MS THOMSON: So the – the shift to consumer-directed care in itself, I think, is a – a positive thing so that care receivers or older people have more control over the sorts of services and the types of services and the way they're provided. I think that's a positive thing, but what has happened is that the focus on the older person has meant that there's less of a focus on the carer.

15 And I – I think both a focus on the carer and the older person is important because they both have needs and one shouldn't be prioritised over the other. So – and what's happened with carers and respite is that it's assumed that the person accessing support through the consumer-directed – through the package, those services will give the carer a break, but that isn't necessarily the way that carers need or want to  
20 have a break from their caring role, sort of indirectly through the services that are received by the older person or the person with a disability.

MS HILL: What is the role of respite, in caring for the elderly?

25 MS THOMSON: So, currently, the respite is designed to give carers a break from the caring role. And that's really important, that they receive a break. Caring can be quite stressful; it can have health impacts. And we know that carers have lower levels of social and emotional wellbeing. They often prioritise the health needs of the person receiving support than their own needs. So getting a break from the  
30 caring role and the stresses associated with caring is very important. And carers can access different types of respite, which is useful. But many carers can't access a type of respite, the long – they might need a longer break, so that the respite they get at the moment is often short – short break, and that doesn't necessarily give them a long enough break. And also respite, as it currently stands, can't assist carers to  
35 participate in employment because it's not a long enough period of time.

MS HILL: Ms Thomson, in your research you've described the paradox of respite. Can I ask you to explain that to the Commissioners?

40 MS THOMSON: So that references a report by Hill and Brodaty, and it was looking at the social and emotional needs of carers. And they – in that report, they talk about the paradox of respite, in that carers rate their satisfaction with respite as high, but then many of them don't access it, so there's a paradox there. If it's – if they're so  
45 happy with it, why wouldn't they access it more?

But also respite can – if it's provided in certain ways, can – once the person goes into respite, it can actually – when they come out, it can create extra burdens for the carer,

particularly for people with dementia, when they go into residential respite, if the residential respite isn't of high quality or isn't meeting their needs, when the person comes home they can be quite disorientated and it can take a while for them to settle back into their routine at home, so that creates additional stress for the carer.

5

MS HILL: In a setting of consumer directed care, is it possible for respite to both provide a break for carers as well as benefit the care recipient?

10 MS THOMSON: It can, if the carer is involved in the planning of the needs of the person with – the older person. So if the carer needs are taken into account in that assessment, it can do that.

MS HILL: Are carer needs taken into account in assessments?

15 MS THOMSON: Well, evidence from the Carers New South Wales survey – they did a survey of their members. And it's not a representative sample by any means, but what – what the results from that survey indicate is that carers' opinions are taken account of in that assessment, but their needs aren't. So their opinions about what the care recipient needs are taken into consideration, but the carer's own needs aren't taken into consideration.

20

MS HILL: How can the carers' needs be taken into consideration?

25 MS THOMSON: Within that system – within that assessment process, carers could be asked what sort of break they need, so that then, perhaps, the services that are supporting the care receiver can be designed so that they both meet the needs of the carer and the care recipient. So, for example, perhaps the carer needs more than two hours off because what can you do in two hours if – you know, if you don't live close to anything, if you've only got a two-hour break when somebody is coming in to provide physiotherapy, that doesn't really give you a break. So that if you can sort of

30

– if you can bring together some of the services that the care receiver is accessing, then that might give – in a block, then that might give the carer an adequate break.

35 MS HILL: You're aware of the Carer Gateway that's being introduced? What do you understand the role of the Carer Gateway to be?

40 MS THOMSON: The Carer Gateway is designed to enable carers to access information about the services that are available to them and information about income support, and it's designed to streamline the process of accessing that information.

MS HILL: And do you consider that a gateway such as that will support carers in receiving the assistance that they need?

45 MS THOMSON: The Carer Gateway has the potential to support some carers with accessing information, carers who are very familiar with online – accessing information online. But not all carers can do that and some of them might find it

quite challenging going through that interface. And I think it's important that access to information isn't just through one mechanism, because carers have different needs. There are carers from different cultural backgrounds who might not respond well to accessing information over the internet. They might want a more personalised  
5 approach. So I think it's important to – and also people who – where English isn't their first language might find – also find that quite challenging. So I think it's important to recognise that carers have different needs and, therefore, access to information and services has to – is better provided by a variety of ways.

10 MS HILL: Are you able to give some examples of what those ways could be?

MS THOMSON: So I think people attending a community centre might be one way to do that. Because I know that there are some centres where you can go and meet up with other carers. That's one way that carers who I've spoken to get information  
15 – is from other carers. So having access to carer support groups is a way where carers can gain information, and that can be an informal carer support group but it can also be a more supported carer support group where they had a worker who assists them with accessing information that they need. Going – just having access to information at that community centre about income support, because that can be  
20 quite challenging for carers to access, to go through the Centrelink process to access benefits. But I think the more personalised approach and meeting other carers and also have been access to workers that they can speak to face to face.

MS HILL: What is the impact on carers on their social and emotional wellbeing?  
25

MS THOMSON: The research shows that carers – although carers can gain some benefits from providing care – and the research shows that carers have much lower social and – social and emotional wellbeing compared to non-carers, they're one of the lowest – have one of the lowest levels of social and emotional. That can be due  
30 to isolation, so for some carers their social activities constrict and their access to friends also is affected. So – and if they leave work, that can also be another point where their social activities are constricted. And isolation can lead – it often can lead to depression and, also, they tend to not consider their own health because they're prioritising the health of the older person, or they don't have time to attend to their  
35 own health needs.

MS HILL: What does the role of community support services for carers have in those circumstances?

40 MS THOMSON: Well, community support services can give carers access to social activities. So there have been – there are services that provide both carers and the older person with social activities. So that can be – and carers have talked about in the research that we've done – have talked about they don't want just time away  
45 from the older person or the person that they're caring for, they want to do activity with them. So there have been some services where they organise holidays for both the care receiver and the care recipient – caregiver with – and workers go along with those. They can do outings and things like that. But also carers want access to high

quality services that they can trust, so that, then, they can have a break and not worry about the person while they're away, which is important, so that they can actually really have a proper break from the caring role.

5 MS HILL: The Social Policy Research Centre has done some work on social inclusion. Could I ask you to explain to the Commissioners what is meant by social inclusion?

10 MS THOMSON: Social inclusion is about giving people the ability to participate in a range of activities. So things like employment, social participation, also having a voice, and there are policies – there are groups of people that find it difficult to participate in certain areas of life. So social inclusion is about designing services that support people's inclusion, no matter what their background.

15 MS HILL: What is known about when carers access support for themselves?

MS THOMSON: Sorry. Could you explain that a bit more?

20 MS HILL: What is known about when carers will – will draw upon the services – support services within the community?

25 MS THOMSON: Carers often access services at a point when they've been caring for a long time. And that's – that relates to what I was speaking about before, that caring can often occur quite – the taking on the caring role can occur quite slowly and it can be a result of somebody who is slowly declining, either physically or cognitively. So sometimes it's difficult for carers to recognise that they actually are a carer.

30 And if they don't see themselves as a carer, then they don't think to access services that are for carers. But once something happens, either their health becomes too much for them to provide care or something happens to the older person, they might go to hospital and they become introduced to a system where they – at discharge, there are things put in place to help them support the person who is coming home or themselves when they go home. And once they're identified as a carer, they're more  
35 likely to access those services.

MS HILL: What's known about those carers who aren't accessing services?

40 MS THOMSON: That's a difficult question, because sometimes they're hidden. But - - -

MS HILL: What do you mean by hidden?

45 MS THOMSON: Well, they're not picked up in statistics because they don't identify as a carer, so they're not collected — the way we calculate the number of carers is through the census and through ABS surveys. And if you don't identify the carer, then you're not going to check the box to say that you're a carer. So we can't

know that you're a carer. But there are other ways to sometimes identify them. If people indicate that they're providing support in – with particular activities, if – yes. So that's a main way. So the hidden carers are sometimes younger carers who might be caring for a grandparent or a parent, an older parent. There can be people from  
5 different cultural backgrounds, so – yes.

MS HILL: How do carers identify themselves as carers?

10 MS THOMSON: It's often as a result of some sort of crisis and then not being able to manage, and being quite desperate and then going on the internet and trying to find help that way. But it can also be, perhaps, when they give up work and they realise that they can apply for Centrelink. They might be eligible for a carer payment and so that's when they think, "Well, I'm a carer", but it can also be when a service –  
15 when the providing – when the person with – the older person is receiving a service and then that service might come in and say, "Well, you're actually providing all this care. There are these other services that are available for you".

MS HILL: Is there a role in community health services or in other services in supporting the self-identification of carers?  
20

MS THOMSON: In New South Wales I think we have, at the discharge planning, there is a check box for the identification of a carer. So I think definitely when people are being discharged from hospital, if they identify that they're a carer, that the person is being discharged to a home with a carer, that's one way to identify  
25 carers and get supports in that way. Training for allied health professionals about the caring role and the support of carers might be another way to identify carers and also GPs. GPs are a key way for carers to be identified if the – if the GP knows about carers.

30 MS HILL: To your understanding, are GPs currently supported to understand how to identify carers?

MS THOMSON: I think there is some training but the training could be more widespread and also it could be incorporated into degrees. There could be a module  
35 within a – when people are training as a doctor – to become a doctor, there could be an aged care module which talks about these issues as well as carers.

MS HILL: Ms Thomson, to your research does a focus on carer burden – carer needs ultimately detract from the needs of a care recipient?  
40

MS THOMSON: There – there is a line – there is an argument, particularly in England with the disability rights perspective, they argue that focusing on carer and carer needs detracts from there being – them being seen as independent and they're viewed as – as creating a burden on the carer. My opinion is that that is – that can  
45 be true, but I also think that there are people who want to be cared for and who want to provide care, and caring occurs within relationships and the focus – it's important to focus on both the needs of the person with the disability or the illness or who's

ageing as well as – as the carer. I don't think there should be one or the other. I think it's important to focus on both of them because many people want to remain at home. The only way that they can remain at home is through the support they provide, the support that's provided by the carer, but also the care recipient wants to be cared for by their – their relatives.

MS HILL: Is it possible to overcome carer burden?

MS THOMSON: If carers are provided with the support that they need, you could alleviate some of the burden. But some of the – some of the carer burden is an emotional burden which is to do with watching a loved one decline physically or cognitively. So some of that is an emotional burden that won't be alleviated by supports. But having adequate high quality supports for the person that they're caring for as well as themselves would alleviate some of that burden.

MS HILL: Do we need to rethink how we identify carers, what the role of carers are?

MS THOMSON: It's important to raise awareness of carers, so that society generally recognises them and also so that at an individual-level carers recognise what they're doing as important and valuable. And it's also important to have carers supported adequately.

MS HILL: We know that older people want to stay and age at home. What needs to be done in the immediate term to sustain carers in that role?

MS THOMSON: The provision of services for both the older person and the carer that are high quality, meet their individual needs, and that are affordable.

MS HILL: And for you, is it a question that more research needs to be done to understand carers' needs, or can policy be implemented now that will consider that?

MS THOMSON: There has been a lot of research done about carers' needs over the years and a lot of it says similar things about the importance of care, the value of caring, and the barriers that they face. The only – the thing I think would – that is needed is it's a different policy environment now. So we probably need to look at what these policy changes that are – that are occurring in both the aged care system, the NDIS and the carer support system, we need to look at how that's going to impact on carers.

MS HILL: Why was it important to you to come along and give evidence today?

MS THOMSON: Well, I've been – I've been researching care – carers and aged care for 20 years. I – when I first started at the centre, I worked on a longitudinal study that looked at a group of people who have been – older people who had been discharged from hospital and they either had a physical or a cognitive disability and they had a carer or not a carer, and that longitudinal research showed that those that

had a carer were much more likely to be able to remain at home. So that created an interesting need to look at caring and the importance of carers, plus it's also to do with women and the position of women.

5 So I feel very strongly about that, and also I've had a personal experience in – I cared  
for my older parents for eight years and I can – sort of living my research which is  
interesting, but I can see that the service system is quite difficult for carers to  
navigate and from a personal level, even I found it difficult to try and organise  
support for my parents, even though I – I'm very – I'm educated and I know a lot  
10 about the system.

So I can only imagine what it's like for other people who don't have that level of  
knowledge or education to try and navigate that system. So the research that we do  
is trying to raise awareness about how the service system can be improved for a  
15 range of people. Not just carers and I think that's important, that the systems talk to  
each other because caring is in a relationship, the – the things that are implemented  
in the aged care system has an impact on the carers and the carer system and also the  
– the policies and programs that is are implemented, for example, the NDIS has an  
impact on carers and older people. So I think it's really important that these service  
20 systems are thought of holistically and prioritising the needs of a range of people.

MS HILL: Commissioners, that concludes my examination of Ms Thomson.

25 COMMISSIONER BRIGGS: I think it's nearly Dr Thomson now.

MS THOMSON: Almost.

30 COMMISSIONER BRIGGS: You've given some very interesting and important  
evidence, indeed, through the joint witness statement as well. I want to turn, I think,  
to your issue of very difficult to navigate the system, even for somebody who's well  
informed and we heard earlier evidence from Ms Dunn on a similar thing. Is it  
because so many parts of this system are fragmented? Is it because we have a federal  
system and a system of services provided through a host of different for profit, not-  
for-profit, charitable and so on, services? So really my question is, is it the nature of  
35 the system and how it works; that's the issue. Or is there something more  
fundamental about individualised support for carers to help them through the system  
or both?

40 MS THOMSON: I think it's both. I think it – the system is fragmented and I know  
that the policies that are being implemented now are designed in some ways to  
address that, but the system is still fragmented. But, equally, I think it's also about  
resources. If you have a system that are trying to manage a very finite bucket of  
money with a high level of need, then it's – it's not going to work as effectively as it  
could.

45 So I think I was saying before that the system, going through the gateway, will suit  
some people and they will be able to navigate that – that gateway quite effectively

because they're used to doing that, but for some older people and maybe some young people, they don't have the confidence or the ability to read all the information.

5 That's why I think it's important to have various ways to enter the system. So a more personalised way through, you know, the carer hub, the community support centres, because it is a complicated system. So having somebody who can help you navigate that system I think is important.

10 COMMISSIONER BRIGGS: The other question I want to ask about is – is around the new carer gateway. The way governments tend to work is when in doubt you change an arrangement, so you might split the Carer Gateway in half and give half of it to aged care and that it will, you know, you think for a while you had fixed it but then there's bound to be some overlaps between the mental health side of that and perhaps the disability side, as we know already, because aged care services look after  
15 some people with disabilities even to this day. So the question is, in this day and age, with systems interoperability that is quite feasible, why can't we, at least for those people who are computer literate, manage to have this system work as an effective gateway to supports for carers?

20 MS THOMSON: I can only speak from – personally, I haven't done research on this. It's possibly due to the way the different systems have been set up historically, and they're not used to sharing information and working across different silos. So the only way to address that would be by trying to get those different departments to speak to each other, and that idea of holistically looking at a care relationship,  
25 because people don't exist in isolation. They interact on many different levels with different people and so these systems need to recognise that.

COMMISSIONER BRIGGS: Yes.

30 COMMISSIONER TRACEY: Anything arising, Ms Hill?

MS HILL: No, Commissioners.

35 COMMISSIONER TRACEY: Dr Thomson, we've heard a lot of anecdotal evidence in these hearings but your research and that of your colleagues that you've drawn together in the paper confirms much of what we've heard and puts it on a much firmer base when it comes to us making recommendations so we're indebted to you for that, and if you would be so kind as to pass on our thanks to your colleagues when you return to Sydney.

40

MS THOMSON: I will do that. Thank you.

45 <THE WITNESS WITHDREW

[12.43 pm]

COMMISSIONER TRACEY: The Commission will adjourn until 2 o'clock.

**ADJOURNED**

**[12.43 pm]**

5 COMMISSIONER TRACEY: Anything arising, Ms Hill?

MS HILL: No, Commissioners.

10 COMMISSIONER TRACEY: Dr Thomson, we've heard a lot of anecdotal evidence in these hearings but your research and that of your colleagues that you've drawn together in the paper confirms much of what we've heard and puts it on a much firmer base when it comes to us making recommendations so we're indebted to you for that, and if you would be so kind as to pass on our thanks to your colleagues when you return to Sydney.

15 MS THOMSON: I will do that. Thank you.

**<THE WITNESS WITHDREW**

**[12.43 pm]**

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COMMISSIONER TRACEY: The Commission will adjourn until 2 o'clock.

**ADJOURNED**

**[12.43 pm]**

25

**RESUMED**

**[2.02 pm]**

30 COMMISSIONER TRACEY: Yes, Mr Gray.

MR GRAY: Thank you, Commissioner. Commissioners, our next witnesses are a panel of experts, I call Dr Meredith Gresham, Dr Lyn Phillipson and Associate Professor Suzanne Hodgkin.

35

**<SUZANNE PATRICIA HODGKIN, AFFIRMED**

**[2.03 pm]**

40 **<LYN JANELLE PHILLIPSON, AFFIRMED**

**[2.03 pm]**

**<MEREDITH DELL GRESHAM, AFFIRMED**

**[2.03 pm]**

45

MR GRAY: Members of the panel, I will ask you to verify statements that you've made for the Royal Commission first, and we will start with you, Dr Gresham.

Operator, please bring up WIT.0284.0001.0001. Dr Gresham, what's your full name?

DR GRESHAM: Meredith Dell Gresham.

5

MR GRAY: Have you made a statement for the Royal Commission?

DR GRESHAM: I have.

10 MR GRAY: Do you see before you on the screen a copy of the first page of the statement?

DR GRESHAM: I do.

15 MR GRAY: And with reference to the entirety of the statement, to the extent that it states facts, to the best of your knowledge and belief are those facts correct and are the opinions stated in the statement opinions that you truly hold?

DR GRESHAM: That is correct.

20

MR GRAY: I tender the statement.

COMMISSIONER TRACEY: Yes. The witness statement of Meredith Dell Gresham dated 19 July 2019 will be exhibit 7-13.

25

**EXHIBIT #7-13 WITNESS STATEMENT OF MEREDITH DELL GRESHAM  
DATED 19/07/2019 (WIT.0284.0001.0001) AND ITS IDENTIFIED  
ANNEXURES**

30

MR GRAY: Dr Phillipson, I will ask you to verify your statement. Operator, please bring up WIT.0287.0001.0001. Dr Phillipson, what's your full name.

35 DR PHILLIPSON: Lyn Janelle Phillipson.

MR GRAY: Have you made a statement for the Royal Commission?

DR PHILLIPSON: I have.

40

MR GRAY: Do you see on the screen before you a copy of the first page of the statement?

DR PHILLIPSON: That is the statement.

45

COMMISSIONER TRACEY: And with reference to the entirety of the statement, to the extent that it sets out facts, to the best of your knowledge and belief, are they

correct, and to the extent that it sets out opinions, are they opinions that you truly hold?

DR PHILLIPSON: They are.

5

MR GRAY: I tender the statement.

COMMISSIONER TRACEY: Yes, the witness statement of Lyn Phillipson dated 19 July 2019 will be exhibit 7-14.

10

**EXHIBIT #7-14 WITNESS STATEMENT OF LYN PHILLIPSON DATED 19/07/2019 (WIT.0287.0001.0001) AND ITS IDENTIFIED ANNEXURES**

15

MR GRAY: Associate Professor Hodgkin, I will ask you to verify your statement. Operator, please bring up WIT.0285.0001.0001. Associate Professor, what's your full name?

20

ASSOC PROF HODGKIN: Suzanne Patricia Hodgkin.

MR GRAY: Thank you. Do you see on the screen before you, a copy of the first page of a statement that you had made for the Royal Commission?

25

ASSOC PROF HODGKIN: I do.

MR GRAY: With reference to the entirety of the statement, to the extent that it sets out facts are they, to the best of your knowledge and belief, true and correct, and to the extent that it sets out opinions are they opinions that you do hold?

30

ASSOC PROF HODGKIN: They are.

MR GRAY: Thank you. I tender the statement.

35

COMMISSIONER TRACEY: The witness statement of Suzanne Hodgkin dated 22 July 2019 will be exhibit 7-15.

**EXHIBIT #7-15 SUZANNE HODGKIN DATED 22/07/2019 (WIT.0285.0001.0001) AND ITS IDENTIFIED ANNEXURES**

40

MR GRAY: Thank you, Commissioner. Dr Gresham, I will start with a brief introduction of you, if I may. Until recently, you've been director of research at HammondCare's Dementia Centre and you're a senior consultant in HammondCare's Dementia Centre; is that correct?

45

DR GRESHAM: Correct.

MR GRAY: You're a post-doctoral research fellow at the University of New South Wales. What is the focus of your research effort over many years now?

5

DR GRESHAM: Much of my research has focused on improving the life of carers and working with people living with dementia in terms of reabling and improving their quality of life.

10 MR GRAY: Thank you. And currently you're engaged in a study to improve the design of post-diagnostic support of people living with dementia and their carers; is that correct?

DR GRESHAM: That is correct.

15

MR GRAY: And your presently relevant expertise and experience relates to carers of people who are living with dementia; is that so?

DR GRESHAM: Correct.

20

MR GRAY: Thank you. Dr Phillipson, I will next make a brief introduction of you, if I may. Your PhD related to factors influencing the use of respite by carers of people with dementia; is that correct?

25 DR PHILLIPSON: That's correct.

MR GRAY: Since 2016 you've had a National Health and Medical Research Council – Australian Research Council fellowship; is that so?

30 DR PHILLIPSON: That's right.

MR GRAY: What's the focus of the research called for under that fellowship?

35 DR PHILLIPSON: So I've been looking at the experience of consumer-directed care of people living with dementia and also of their carer's experience of that program.

MR GRAY: Yes. And is consumer-directed care the policy that's been implemented in relation to home care packages?

40

DR PHILLIPSON: That's right. It's been introduced into the home care packages program that the government has signalled its intent that that model could be expanded into other programs.

45 MR GRAY: Thank you. And Associate Professor Hodgkin, may I make a brief introduction of your research and back ground. Your current role is Deputy Director of the John Richards Centre for Rural Ageing Research at La Trobe University

ASSOC PROF HODGKIN: That's correct.

MR GRAY: Your background qualifications are in social work; is that so?

5 ASSOC PROF HODGKIN: Yes, I have a Bachelor and a Master's in Social Work.

MR GRAY: Your research focus is in particular in rural settings; is that right?

10 ASSOC PROF HODGKIN: Yes, it's in relation to mainly community care and how community dwelling people access the supports and services that they need to continue to live in rural communities.

15 MR GRAY: Thank you. Could you please just give the Commissioners a brief outline – we will come to it in more detail in a minute but some brief detail now of the Australian Research Council project ASPIRE and the scope of that study, the rural areas that it covered.

20 ASSOC PROF HODGKIN: Yes, so that study set out to look at how rural people – how services and supports combine to make rural people's living experience better. And we did some mapping in relation to carers in that project and in relation to, you know, who was doing what for who, so we will talk about that later but that was the main focus of the project.

25 MR GRAY: And were there six rural areas chosen to be as representative as possible; is that right?

30 ASSOC PROF HODGKIN: Yes, there were. We chose six rural regions across Victoria and Queensland and we – they were – three of those in Queensland included mining towns, areas like Nanango which had some difficult socio-economic disadvantage and Stanthorpe which was a much more affluent area in Queensland. So we were trying to get very diverse communities. And the same with Victoria, we had the alpine region in Victoria which is where I currently live. It's quite affluent in many ways. We had Yarriambiack which is around this area and we had Yarram, so very different communities – rural communities.

35 MR GRAY: Thank you. Commissioners, the format this session will adopt is that I will pose questions for the panel and the panel will address that question. There will be a brief discussion about the various responses that have been provided to the question, and then we will move to the following question. If you at any point wish to ask questions, please do so as we move through the topics. The first topic is who is the carer. Members of the panel, in considering this question, I ask you to consider both the conceptual framing to the question, and any practical issues that arise with respect to recognition of carers, both in terms of their self-recognition and social recognition. If we could start with you, Dr Gresham, who is the carer?

45 DR GRESHAM: First, I think it is really important that we recognise that each and every carer in Australia is unique. They are living and caring in unique

circumstances within diverse service landscapes, if we want to call it that. Every carer brings a unique set of strengths and limitations to that caring relationship and we will be discussing that, I think, as the panel goes on. Carers come from many different roles, many carers are spouses or care partners, or partners, I beg your  
5 pardon. Many carers are siblings. We've heard from a granddaughter today. Some are children, granddaughters, relatives and friends. Some carers come to a caring relationship very willingly. They do it through love and devotion.

10 Other carers will come to a care relationship and have it thrust upon them when there is no alternative. There are carers who will recognise themselves as carers as such, but there are many people who will actually also be what we call hidden carers and these are people who either don't recognise themselves as carers or are in some way hidden to the system. These might include people who are geographically isolated, people of specific sexual orientations whose relationships may not be recognised.  
15 Some people might be not recognised because of cultural or gender expectations or stereotyping. We've also heard today, and I think it's important that sometimes children are carers of parents. Some carers cohabit with the person they are caring for, others do not. But I think it is extremely important to recognise that carers who do not self-identify as a carer are at a particular disadvantage. Why would you avail  
20 yourself of carer services if you don't consider yourself a carer?

MR GRAY: Thank you. Associate Professor Hodgkin, perhaps with your background and expertise in rural settings in particular, who is the carer?

25 ASSOC PROF HODGKIN: We – when we were doing what we call the ASPIRE study, which was funded by the Australian Research Council, we actually asked a series of questions. So it was 265 older people who we did a telephone interview with, and we asked them a series of questions about – we asked them, first off, to name the closest 15 people they could think of in their lives. So we then obtained a  
30 name from them about that person and a relationship and where they lived, how close they lived to them. And then we asked a series of questions in relation to who's doing particular tasks.

35 So a number of tasks which included, sort of, your more instrumental assistance with daily living tasks, to transport tasks, to emotional care tasks, like telephoning them to make sure that they were okay. So we did this kind of – a kind of neat social network analysis of those people. And what we came back to with all of that was that the first person that they named, for those 15, was the most important person in their life. That was the person who did most of the tasks. And they range from –  
40 they were mainly household support tasks.

45 So I guess the second primary carers did things like emotional assistance and helped with home maintenance and so forth. When it came back to looking at the relationship of the person who was doing – that first person, it was always a person who was a family member and lived close by and usually was a spouse or a daughter or a daughter-in-law.

So we were able to track who the key people were. And I think this was important, because in rural communities it can often be assumed that, you know, there's other people who pick up those tasks. So some of those romantic views of rural communities, where we talk about issues around social capital and so forth – and they do. They do pick up a lot of tasks and care tasks, but not those kind of instrumental tasks which are critical to older people staying at home. So they were the carers that we looked at in that study. And we've also – we also looked at another study, looking at that spousal care. So we looked at some of the issues facing spousal carers in rural communities as well.

10 MR GRAY: Thank you. Dr Phillipson, who's the carer?

DR PHILLIPSON: I think I would echo much of what my colleagues have already said, except to say that, you know, this recognition of the fact that people who are carers usually have a pre-existing relationship with the person to whom they now provide care. And so in that context, when people start to identify that maybe they are a carer, it's often because of the nature of that relationship changing, and it's usually in a situation of strain or stress. So where they feel like their own capacity is not sufficient any more to meet the needs of the person – so when we meet a carer who's identifying – a carer, they're usually in that situation where they feel they're no longer able to deliver the needs of that person any more.

The relationship itself may be undergoing change and that has emotional impacts and can be associated with loss and grief, particularly in the situation where someone's caring for a person with dementia. But, yes, just to consider that context of the fact that when we meet a person who's identifying as a carer, it is usually in that context of them needing some practical supports, financial supports. They're being faced with quite complex situations, legal, financial, physical, medical, where they begin to feel that the relationship is not enough to sustain the person's wellbeing.

30 MR GRAY: Thank you. We will come to ideas about preventative interventions in due course, but are you saying, Dr Phillipson, that there's a – the real issue, right at the outset, is concerning self-recognition as a carer itself contributing to problems around getting preventative interventions in place?

35 DR PHILLIPSON: That's right. And often carers receive a message if they're presenting at a health service or I – my experience has been, particularly with carers for people with dementia, where they're actually told, well, the person has dementia and, "When you're not coping any more come and see us, because we've got supports for you when things get tough."

40 MR GRAY: Okay. We will come back to preventative interventions. The next question is how are we to understand the needs of informal carers? Now, in posing this question, I'm not for a moment limiting any of the panel members to consideration of formal assessment processes that government might have. I'm asking you to consider this question from a broad academic frame. How are we to understand the need of informal carers, Dr Gresham?

DR GRESHAM: I think – if I may also expand that out from not just a broad academic frame, but to draw from my own clinical experience. We have discussed the enormous diversity of carers. And that, for me as a clinician, makes assessment of need quite hard. One framework that I have used throughout my career that I have  
5 found helpful is understanding caring style. One particular framework involves considering carers sitting somewhere on a spectrum, from what we call a care provider to a care manager.

MR GRAY: I will just ask the operator to put up your witness statement, Dr  
10 Gresham, at paragraph 17. And if we could just go over the page, please. Over to the next page. Thank you.

DR GRESHAM: There we are. Okay. It's a very simple framework. A care  
15 provider, on one hand, is the sort of carer who will perceive a need and then attempt to meet that need themselves. A care manager, on the other hand, is the sort of carer who perceives, possibly, almost the same need, but will ask who is the best person or service to meet this need? And it may or may not be themselves. People can sit anywhere along that spectrum. The spectrum may vary over time and it may vary with tasks. For example, somebody might be a good care manager about managing  
20 household duties or housework or shopping but be unable to relinquish any personal care tasks. But using that framework, you can identify various caring styles. And that does a couple of things for me.

It allows me to understand carers who will be at most risk, because it's evident that if  
25 you keep actually adding on duties and tasks as a care provider you will reach breaking point at some stage. The other information that actually – understanding caring style helps me work with the carer – is that it changes the nature of how I would introduce, how I would coach the carer in actually effectively using services. And I think that's a key and really important point. Just because we have need X and  
30 service Y, putting the two together does not actually necessarily equal support for a carer. So I think caring style is one way that we can actually help to understand how people work within that caring relationship.

MR GRAY: Thank you. And in understanding caring style, do we understand the  
35 gist of your evidence to be that a particular carer might benefit from some coaching toward being more of a manager rather than a provider?

DR GRESHAM: Correct. It might do, for example, address guilt. Carers often  
40 carry a lot of guilt for a number of reasons. They may feel very guilty about asking for assistance in the first place. So, again, understanding caring style will actually change my role as a clinician in how I will introduce and help that person use a service or a support effectively.

MR GRAY: You've been in the field of carers of people living with dementia for  
45 many years now, if I may say so, Dr Gresham, starting with work in coordination with Professor Henry Brodaty; is that right?

DR GRESHAM: That is correct. Yes.

MR GRAY: When we think about the particular needs of carers of people living with dementia, is this consideration of whether they're taking all of the burden onto themselves particularly acute? In the context of carers who are caring for people living with dementia.

DR GRESHAM: Yes. In many cases, carers caring for a person living with chronic cognitive decline are in a particularly difficult situation. We've heard from other carers today that the fundamental nature of a relationship, a pre-existing relationship, which my colleague has talked about, will change. There is no longer the reciprocity. We've heard from other witnesses today, who have said that carers will often derive benefits from a caring relationship. And it's often that ability, that reciprocity within a relationship that you can derive satisfaction for; a person being cared for is grateful for the assistance being received and they are able to thank a carer. Often, that reciprocity completely breaks down in dementia and it can be a very lonely existence for a carer.

MR GRAY: Thank you. Dr Phillipson, how are we to understand the needs of informal carers?

DR PHILLIPSON: I think the system has tended to understand them in a very practical sense. You know, the person that they're caring for might need assistance with dressing or bathing and perhaps that's becoming too difficult, or the person might need supervision so that the person can go out. But, actually, the needs of the carers are not just around those kinds of things. There really is a great deal of expertise that they need to develop to – to provide what can be quite specialised care.

And I think if we think about caring for somebody who's living with dementia, we're talking about the way we might be able to support the simplification of tasks to allow a person to do something which is becoming quite frustrating, how we might use behavioural management sorts of techniques, how we might modify the environment in the home, to make it easier for the person with dementia to function.

The carer often has to become a communication partner for the person and advocate within situations, like medical appointments or even during family visits where people don't understand what the person is trying to communicate or why they might be behaving in a particular kind of way. They have to often take on legal and financial issues which may not have been in their expertise before. So, really, the role of caring actually requires the development of an enormous amount of expertise which creates needs.

I guess, on the back of that, carers have their own health and social and financial needs which existed before they took on the substantial responsibilities of providing care for another. And so in assessing a carer's needs, we must also look to their own health and financial and social, and often other caring and family responsibilities that they're also trying to juggle.

So we have all the needs that we all have for financial security and housing and socialisation and meaningful occupation, then we add the specialised needs that they might need to actually provide the care. And I think, particularly going back to the way we began this conversation, we also have to see the carer's needs for adjusting  
5 to the changing nature of the relationship that they have with the person for whom they're now providing substantial care.

And I mentioned before loss and grief, but there's – there are also other types of adjustments that we know carers can really benefit from, psychological therapies and supports to come to terms, with not just right at the end of the trajectory but during  
10 that relationship as well. So there are a complex set of needs.

MR GRAY: I will just ask the operator to put up your witness statement. And, in particular, the passage at paragraph 13 to 18. You make a number of points there on  
15 this topic. One of the issues you refer to is the scope of the National Dementia Training and Study Program.

DR PHILLIPSON: Yes.

20 MR GRAY: What are your views on that?

DR PHILLIPSON: So I guess we've recognised the complexities that are associated in providing good quality care for people with dementia and the fact that even health professionals and paid care workers really benefit from training around this – this  
25 role. And – but the Dementia Training and Study Program does focus on paid carers and on health professionals. It doesn't include unpaid carers as one of the target audiences.

There is a National Dementia Support Program, which does provide very limited  
30 amounts of education around dementia for people with dementia and their carers, but they tend to be targeted towards the beginning, when the person receives their trajectory – their diagnosis, and don't really meet the needs as – as the person with with dementia's condition changes.

35 So it's just an interesting situation that we have recognised the complexity of this care and invested a lot of money into a program that's very needed for health professionals and formal paid carers but haven't actually developed a similar program which recognises that informal and family carers are actually providing the vast majority of care for people with dementia who are living at home.  
40

MR GRAY: And if we move from the topic of training and education of carers to practical supports that would, for example, allow them respite, the programs that the Commissioners have heard about under which those sorts of assistance can be subsidised include the home care package and the Commonwealth Home Support  
45 Program. Those are assessed by ACATs or Regional Assessment Services. Do you have any views about the adequacy of the scope and character of the assessment that occurs when it comes to considering the needs of carers, caregivers?

DR PHILLIPSON: So I think in the transition toward consumer-directed care and with an increasing focus on the older person and the person living with the disability, I think there has been some loss of the – of the focus and the comprehensive assessment of carers' own needs in this context. I think if we take something like  
5 respite services, really if a carer is going to attend training or, you know, a seminar to help them understand the – how to better care or provide care or some sort of legal appointment to come to terms with power of attorney, all those sorts of things, none of those programs are actually accessible unless there is the provision of planned respite services.

10 And so there is a real interrelationship, not just between respite as a provision of direct – service of direct benefit for the carer having a break to maybe attend to their own social or health needs but actually to their ability to access other support services that exist.

15 MR GRAY: I will ask the operator to put up tab 44 of the tender bundle. This is a document which is a tool referred to in the assessment directions and guidelines for ACATs and RASs; it's called the national screening and assessment form. It does refer to carers. I will ask the operator to go to page 4, it's 0003, native page 4. And  
20 there's a page dealing with carer. Do you have any comments on that page? It's – I suppose it does encompass the carer.

DR PHILLIPSON: So that particular page that's up is just the identification of whether there is a carer.

25 MR GRAY: Yes.

DR PHILLIPSON: Is that the page you're wanting me to comment on?

30 MR GRAY: Does that prompt an adequate assessment of carer's needs?

DR PHILLIPSON: So I think there's the next page after that also - - -

35 MR GRAY: Page 6, called sustainability of caring relationship.

DR PHILLIPSON: Within the national screening assessment form there is an identification that there is a primary care relationship and then the next is an assessment of whether that relationship is under strain.

40 MR GRAY: So that's page 0005, native page 6. We will go to that page, please, Operator.

45 DR PHILLIPSON: So whilst obviously I think it's very important for us to recognise whether a relationship is under strain, some of what I've already shared shows the complexity of the needs of carers in terms of the kinds of education and support that they might need to care well and maintain that caring relationship before it gets under strain. And also their own kind of health and financial situations as

well. So to me, to leave the assessment of carers just at that level of is this in crisis, is this carer kind of at breaking point really does show a problem with the system if our goal is to be maintaining people to live well at home, and also to maintaining the wellbeing of carers as part of that situation.

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MR GRAY: Thank you. Any other comments from the panel, any questions from the Commissioners? I will go to the next topic. Our next topic is in a way an addition to that topic that we've already raised about assessing needs. The next topic is what are the ameliorating and aggravating factors which affect the wellbeing of the carer, the sustainability of the caring relationship, ameliorating and aggravating factors. Associate Professor Hodgkin, I will start with you, if I may. What are the ameliorating and aggravating factors?

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ASSOC PROF HODGKIN: My evidence is about rural areas. So I think there's three key things that I would like to raise and the first of those is in relation to the limited service delivery in rural regions and we've just recently completed a project on consumer-directed care. And, you know, it raises – consumer-directed care assumes that there's markets in rural areas where, you know, they're very limited and there's very limited services on offer, and one of the things that we did find was that older people and their carers, on the face of it thought that they had some choice in choosing programs that – or services from providers who are located, you know, 300 kilometres away and then that - - -

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MR GRAY: I will just ask the operator to put up your witness statement.

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ASSOC PROF HODGKIN: Yes.

MR GRAY: WIT – perhaps you've already got it, Operator, at paragraph 16 to 19. Thank you. Pardon me, Professor, please go on.

30

ASSOC PROF HODGKIN: Yes. So there's this assumption that there are markets, they were choosing sometimes s providers who are 300 kilometres away and then only seeing their case manager, you know, once for a 12-month period. And what – when we question older people and their carers, they had – most of them had drifted back to a rural and regional provider because they acknowledged at some point that even though the services were maybe more limited, that at least they were getting comprehensive care, and that it was kind of more integrated care that they were getting from their existing providers.

35

And there's, in rural areas, you know, there is that sense that older people do get looked after in particular areas because the service system knows them so well. So while there's limitations in services, there's some trade-off for rural people as well in having that limitation in some ways. I think the second major issue is in relation to rural isolation and travel, so across all of our studies this has come up consistently time and time again, that tyranny of distance and people having to travel first off. Say for instance a carer and the person they care for might live in, say, Mount Beauty which is one of our alpine areas. There's first that trip just to the service centre

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which might be in Myrtleford which is a trip across the mountains, it's not an easy trip. There's always difficult geographies in rural areas to get by and that's just to get to their local service.

5 If they have to go to a metropolitan service, often they're several hundred kilometres away. It's all about transition, the cost, the fatigue cost in having to navigate all of this, you know, having somewhere to stay when they're down in metropolitan areas is, you know, quite difficult for a lot of people. The third key issue relates to, I  
10 guess, population ageing and in rural communities where we see a lot of in-migration of older people into rural communities as they get older, but also an out-migration of younger people from those communities for education opportunities, for employment opportunities, and what this means is that an older person is left with limited care options in that sense.

15 So unless you've got a spouse living with you or a daughter or a son who lives close by, you can be quite isolated and our ASPIRE study did pick this up that those people who really – so men, older men living in rural communities whose spouse may have passed away, didn't have children, were really the people most at risk of not getting any – they didn't have any carer. So then their relationship to formal  
20 services, you know, there's that reliance then on what is technically a limited sort of service system. Those are three key things that I would raise.

MR GRAY: Thank you. Just picking up the first of them concerning limited service delivery and the challenge to the assumptions that seem to underpin  
25 consumer-directed care.

ASSOC PROF HODGKIN: Yes.

MR GRAY: You talked about the trade-off being that the rural communities might  
30 be – my words – closer knit communities and there might be some benefits from that. How do you see that playing out in terms of the appropriate model for a rural community. Is it a competition-based model or is it more of an integrated model for the particular community?

35 ASSOC PROF HODGKIN: Yes. I really don't believe that competition-based models work in rural communities. What we see – and we work with a number of providers in our areas, is that they have to work together to offer the gamut of services that older people need. So they are constantly brokering services off each other. It's a sort of a furphy, I think, that competition adds to better service delivery  
40 for rural people. It doesn't. And they really – my experience of all – all the rural providers that we've dealt with, they really do go to extraordinary lengths to look after the older people who they take on as their – as their clients so - - -

MR GRAY: Thank you. And on your third point, if I just ask the operator to move  
45 to paragraph 29 of your statement. You bring out a telling point in your statement concerning the migration point that you've made.

ASSOC PROF HODGKIN: Yes.

MR GRAY: And the conundrum, or the dilemma that arises from the fact that, I  
5 think according to your ASPIRE study, you're really looking at family members  
being primary carers.

ASSOC PROF HODGKIN: Yes.

MR GRAY: And yet the younger generation of family members are the ones who  
10 are likely to be moving out.

ASSOC PROF HODGKIN: Yes. And when we – the study I referred to earlier, the  
spousal care study which is being conducted by a PhD student of mine, she found  
15 that of all the spousal carers and their partners, there were no adult children available  
to provide any care. So there was enormous pressure on those spouses to do it alone.  
I think that's one of the key issues in rural communities is that there's not often other  
people around and not other services around to sometimes pick up that slack. So –  
and then there's obviously there's older people out there who are not getting much of  
anything so – which is a bit of a concern, not carer support nor family support - - -

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MR GRAY: Yes. Are you now adverting to the problem of getting information and  
finding your way around the system as an older person if you're left to fend for  
yourself?

ASSOC PROF HODGKIN: Yes, no, and that's – I was thinking – my father-in-law  
recently said to me, he has got a friend called Brenny who had a stroke and he said to  
me, “Can you get that service I've got for Brenny,” and I said it doesn't work like  
that; he would have to get on to My Aged Care, and I'm happy to help him out with  
25 that. But these are – and he's an older man living in a rural community with very  
30 limited family supports and that requires someone who's just had a major stroke  
who's having trouble with speech to be able to, you know, even think of accessing a  
computer to get onto My Aged Care and do that is quite, you know, baffling.

So yes, you know, there are a number of people who – the navigation of the system  
35 and relying on people who are able to help them in some ways and usually a carer,  
we did find that carers were the ones who, in the consumer-directed care study were  
the ones who were navigating the system, not the older person themselves.

MR GRAY: Thank you. Dr Gresham, ameliorating and aggravating factors.  
40

DR GRESHAM: Certainly. My colleagues have talked about complexity,  
complexity of relationships. Dr Phillipson has actually talked about how services  
and supports tend to get deployed when they're at evident needs and those services  
and supports are often around practical things. It's about practical things like  
45 transport, practical things like showering and so on. I would actually like to unpick a  
little bit more about carer stress and strain and put a different complexion on it. I  
actually believe that with the services and supports we offered, we are reactive and I

think the model at figure 2, paragraph 26 of my statement is a good illustration if we are - - -

MR GRAY: Operator, that's on page 5. Thank you.

5

DR GRESHAM: Page 5. This particular model, I've found it was devised looking at what ameliorates or helps things get better or what exacerbates or aggravates carer stress within dementia, but I also believe the model is transportable to other chronic disease states. I draw the attention of the Commission to, firstly, the middle box.

10

The situation is we have a person with dementia. As dementia progresses the person becomes more dependent upon a carer. The person may also develop – and this is rather old language now because it is an old model – challenging behaviours or changed behaviours or behaviours – psychological symptoms of dementia. This places burden on the carer and in this model burden actually means the number of duties or tasks or the amount of time a carer actually spends supporting the person with dementia.

15

Burden is manifested in carers in a whole range of different ways. We call this caregiver strain, and it might manifest in psychological ways. For example, we know that carers are far more at risk of becoming depressed than other age-matched people. It might manifest in physical ways. Often caring involves helping people physically moving around, getting up and down from chairs, on and off the toilet, in and out of the shower. It may manifest in financial ways, and we've heard that working carers often need to give up work, go to part-time and this may actually cause financial strain.

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25

We've also heard about social strain where family or friends may actually fall away because they don't know how to react to the person with dementia or the carer might self-limit getting people out because they're fearful of how their person with dementia will act or react or they might be embarrassed about what they do. Or the carer might just be too tired to keep up their caring – their social relationships.

30

The left-hand box is – are just examples of factors that might exacerbate or make that carer strain a lot worse. I've already mentioned social isolation. But if the carer has a lack of knowledge, for example, and they don't understand why a person is doing what they're doing – a common example is, I will hear from carers telling me, "He's driving me mad; he's asked the same question 65 times in the last hour."

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They think that the person is being deliberately aggravating when, of course, they're not. Carer health too is not particularly on this list but carer health, depending on their own – the carer's health and wellbeing may actually make the caring situation a lot worse. Poor marital relationships. If you have lived with a very poor marriage, you've even been in an abusive situation, and then your partner develops dementia and you, as I said before, are thrust into that particular caring relationship, it can be absolutely devastating.

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On the other side of this particular model, we know from research, and clinical experience, that there are practical protective factors. The first one, practical support, is the one that we tend to concentrate on when we are thinking about providing services. Practical support, as I said, with showering, with personal care, with transport, with etcetera. But, also, education is protective. For carers to understand what's going on, understand their reactions, understanding that they aren't alone is very protective against carer strain. Good social support. Good education about how I maintain my own social network. Education about how do I go about solving problems as they arise. Where do I go. How do I actually work out – how do I start thinking about solving these particular problems.

There are other protective factors that aren't so evident in there. In the middle box again, if we can reduce dependency in the person with dementia, that will also again reduce burden and reduce strain. A good example is that we now have good evidence that reablement for people living with dementia is as effective, if not better, than the anti-dementia drugs. If we actually look at services that will reduce that dependency, we can reduce carer burden, and therefore the strain that carers are feeling. This particular model allows me to start to think more broadly about how we go about supporting carers in practical proactive ways, rather than what I think we really have is a rather reactive service or set of services and set of ways about assessing carers from the system's perspective.

MR GRAY: I think that's the perfect point to return to Dr Phillipson. Dr Phillipson, is this really an illustration of a point you mentioned a short time ago in relation to the national screening and assessment form? Do you care to comment?

DR PHILLIPSON: It is, and I'm happy if you leave the model up because it helps us to keep speaking the same – same language. I think we really do need to address the exacerbating factors that we can, which is around people's lack of knowledge and skills, and some of the psychological interventions that we know can improve people's ability to cope, even if we don't change the practical circumstances, and think about how a system is actually also emphasising protective factors before things get to that point of stress and strain.

And I think one of the things that's quite interesting about what Meredith has put forward is again those protective factors are usually – they're provided by, again, specialist people with expertise in areas like dementia care, by psychologists, by occupational therapists and unfortunately really we don't see health professionals featuring as much in the system that we funded at the moment.

We have a health professional assessment with the ACAT and then we have a system that funds supports by a poorly paid, poorly trained, unqualified workforce, so it's unlikely that in the delivery of those everyday practical supports that carers or people with dementia will get this sort of reablement and education and support, psychological training that they actually need to live well.

MR GRAY: Thank you. And in referring to that workforce, are you referring to the vocational education and training – well, partially VET qualified workforce in aged care facilities or are you referring - - -

5 DR PHILLIPSON: So my – I’m most familiar with the community setting again.

MR GRAY: The community setting.

10 DR PHILLIPSON: So a lot of the carers, the paid carers that are providing care in there will not have had dementia training.

MR GRAY: Thank you.

15 DR PHILLIPSON: They might have a VET qualification in aged care but the amount of dementia training within those qualifications is very small.

MR GRAY: Thank you for clarifying.

20 DR PHILLIPSON: Even health professionals have very little education around dementia hence the need for the dementia training programs, Dementia Training Australia which targets people both at that paid carer level as well as at the health professional level, yes.

25 MR GRAY: Thank you. That leads naturally to my next question which is going to be on interventions. Unless the Commissioners – I will move to that question. Dr Phillipson.

30 DR PHILLIPSON: Did you also want me to talk about the exacerbating factors around the knowledge about the system as well? Does that - - -

MR GRAY: Please do and then we will go to interventions after that.

35 DR PHILLIPSON: So in Meredith’s model we can see there that having a lack of knowledge is really quite significant to being a factor that exacerbates things and you asked me to refer to the study that we had recently done around the services and resources that we were able to identify that were available to carers and older people, to support their decisions in the consumer-directed care system.

40 MR GRAY: Well, let’s put that up now. We can also, when we come to the question about any systemic defects, go to it there.

DR PHILLIPSON: We can leave it till then; I don’t mind.

45 MR GRAY: Perhaps we will address it then.

DR PHILLIPSON: Sure.

DR GRESHAM: Interventions.

MR GRAY: Interventions, I'm going to ask you, Dr Gresham to address this first and then Dr Phillipson and Professor Hodgkin, perhaps if you could address it third.  
5 Not necessarily limited to those topics that the panel has already opened but thinking as broadly as you wish, in light of the identity of the carer, the way we should think about their needs and what are the ameliorating and aggravating factors in trying to meet those needs, what are effective interventions? Now, there might be many, but if you wish to focus on those that you regard as key interventions, please do. And we  
10 will start with Dr Gresham.

DR GRESHAM: Thank you. We have an extensive literature over about the last four decades on interventions for carers for people – caring for people living with dementia. One of the problems with that particular literature is it is very difficult to  
15 synthesise all of those interventions into something that resembles a silver bullet and there was a well-publicised – I think it was a Productivity Commission report released this year that was unable to say that there was effective interventions for carers of people living with dementia. I beg to disagree.

20 I think what we have heard here today and on this panel, the extreme heterogeneity of carers, of the people that they are caring for, and the situations in which they are caring, there is no single intervention that will be good for everybody.

We need to be flexible. We need to be individualised and we need to be multi-  
25 component. The two large research projects that I have been involved in across my career were multi-component interventions and that's where you have a whole lot of different strategies combined into the one intervention, which means that they will speak to a variety of carers. The two projects I have been involved in, the first one was run in the mid-1980s at Prince Henry Hospital, spearheaded by now Professor  
30 Henry Brodaty. I coordinated that project. We ran a 10-day residential comprehensive intensive carer training program with a person who was caring, and the person with dementia; both came and lived in. We delivered everything that we could that would support a carer, both now and in the future from diagnosis to death, and even beyond.

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MR GRAY: Dr Gresham, I will just ask the operator to put up Dr Gresham's statement from paragraph 39. Thank you. Please go on, Doctor.

DR GRESHAM: Okay. What we found in that particular project in the mid-1980s  
40 was that we improved quality of life of the carer, we improved the health and wellbeing of the carer. We reduced the behaviour and psychological symptoms of the person with dementia. And we delayed significantly the time until the person was admitted to a nursing home. We looked three years after that program, Brodaty and Peters did a cost analysis. That was an expensive program to run. It was run in  
45 an acute hospital. It would never occur nowadays. But they were able to demonstrate a saving of \$8000 – this is in 1991 figures – over three years, even

though it was a very expensive program to run. We were able to – sorry, I will backtrack there.

5 The actual program left such an impression on me and it was – I felt such an important piece of work that right throughout my career I felt we have to replicate this. In the mid – around about 2010, I was lucky enough to be awarded an Aged Care Service Improvement in Healthy Ageing Grant. We updated and condensed the program into a week-long program and ran it again as an intensive comprehensive residential training program for the care couples, the person with dementia and the carer, in a residential aged care setting.

15 What we found were very similar results. We increased the amount of time that the carer was able to keep their person at home. We improved the number of needs that carers had unmet so they improved. We decreased absolutely significantly the number of behavioural concerns that we had. And we were able to demonstrate, through financial modelling done by Flinders University, considerable savings. Those particular savings, which I will present, if I may consult my notes here.

20 MR GRAY: Paragraph 40.

DR GRESHAM: Yes. I mentioned that we demonstrated in the 1980s a saving of \$8000 per couple over three years. We costed out the program we ran just a couple of years ago. Again, it was an expensive program to run at around about three hundred and – \$3700. Preliminary modelling done by Flinders University demonstrated that we were able to recoup those costs to health and aged care systems over just five months. Flinders also extrapolated this economic modelling over a five year period and were able to come up with the results that for carers who had received comprehensive multi-component training proactively – I will emphasise that point – had a cost to system of about \$121,000 compared with carers who did not receive training, and cost to system was around about \$230,000.

35 This highlights for me, and I will echo the sentiment of – of one of the previous witnesses who said we've really got to turn the way we think about supporting carers on its head. When you have a diagnosis of dementia, there may be years, a decade or more before the person with dementia becomes functionally dependent enough to qualify for services. Over that period, where does a carer go? What – what supports do they get?

40 My colleague has mentioned things like coping with grief. When you are diagnosed, the carer is being told your life will never be the same ever again. You are gradually going to lose this person little by little. Where do they go to for support? There is no roadmap, there is no trajectory, and it's the luck of the draw whether you've got a darn good doctor or health professional to coach and monitor you through that journey.

45 This sort of program, I believe is incredibly important to actually get in earlier in the disease trajectory. As Dr Phillipson was saying, we've got to get in and coach and

help carers understand where they go to, how we support them, think about those right-hand protective factors on that model there. We've got to get in and boost our carers' ability to be able to support the people that they want to support, and people who are being cared for want to remain at home.

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MR GRAY: Thank you, Dr Gresham, a couple of quick questions if I may, just before I go to Dr Phillipson. Firstly, the Flinders modelling that's updated the economic cost saving information that you extracted in paragraph 40 of your statement, at what stage is Flinders University's report, are we able to obtain that?

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DR GRESHAM: I did actually ask. They are in the process of writing that up. The information has been presented at the Royal Australian and New Zealand College of – Royal – sorry, I can't remember – Geriatric Conference in New Zealand so the material has been actually published in the conference proceedings but it's still under review and currently being written up. So it's preliminary financial information but it certainly is overwhelmingly positive.

15

MR GRAY: Thank you. And the second point was could you please explain to the Commissioners what form of residential aged care setting is optimal for this program? And you referred to the modern incarnation of this program as the Going to Stay at Home program. What form of residential accommodation is optimal?

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DR GRESHAM: Correct. The program was actually run in a HammondCare cottage and this form of residential aged care service are small domestic cottages or homes that have a limited number of beds, a kitchen, laundry, all the features that you will find in an ordinary home. So I was able to actually utilise a cottage as it was built before permanent residents moved in. We had eight bedrooms, all of that as I said, the normal domestic services, so it was in a home-like residential atmosphere. HammondCare has continued to run sporadically, I would say, the Going to Stay at Home project and they have actually utilised respite cottages - - -

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MR GRAY: Paragraph 43, please, Operator.

DR GRESHAM: - - - as a small homely domestic environment in which the carer and the person with dementia will come in and attend that program. I also failed to say that while the carer is receiving their training program, the person with dementia also has their own program. It will vary from being an active respite-type program with pleasurable activities and outings, will also include an element of brain training, for example, for the person with dementia or small group discussions about how dementia, memory loss, confusion has actually affected them. But each program will be tempered to cater to the particular needs of the group that has come in.

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MR GRAY: Is there government subsidy for programs that have a reablement, a proactive preventative element to them like this?

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DR GRESHAM: Largely I would have to say no. I would actually also defer to my colleagues with greater knowledge in that area. Again, it is that gap between

diagnosis and often that assessment of functional dependency that will provide when services become available so - - -

5 MR GRAY: You refer in paragraph 43 to a study currently under review for publication noting the disproportionate use of cottage respite over residential respite suggesting it is preferred by carers. Are you able to expand on that?

10 DR GRESHAM: Certainly. My colleagues at HammondCare interviewed 126 carers which for a qualitative study is an enormous number of people. These were users of cottage respite and a large proportion had actually used residential respite and cottage respite.

MR GRAY: Just pausing there, residential respite being in an RACF.

15 DR GRESHAM: Correct.

MR GRAY: Residential aged care facility.

20 DR GRESHAM: Correct.

MR GRAY: Usually of course much larger than a cottage setting.

25 DR GRESHAM: Yes. Cottages being a small – generally only a few people receiving respite at the same time and in residential care often people having to fit into an institutional routine. What we found through that study is that carers overwhelmingly preferred cottage respite. They felt that the flexibility of cottage respite allowed them, for example, to introduce respite care to their person with dementia on a gradual basis.

30 They could go there for the day, have afternoon tea, get to know the environment, go for a night, go for a couple of nights until the actual cottage became a known environment. What I think, probably rather unscientifically, but a very interesting finding nonetheless was as part of that interview process, the interviewers asked carers, did cottages help you keep that person at home for longer?

35 On average carers responded yes, it did, and were able to even quantify that in months. And were able to tell us on average they kept their person at home for 12 months longer than they otherwise would because they had that flexibility of having various lengths of breaks when they needed it. Key to that for me is that again it's proactive. It's not about having respite when you are overwhelmed and exhausted and then somebody says we will give you a month's respite or two weeks respite. When you do that, quite often the carer has been so enmeshed in their caring role, when you actually pull those people apart, both of them suffer tremendous separation anxiety.

45 And we've heard at this Commission on carers that some carers really don't cope. The anxiety can overwhelm people with dementia, can cause them to be placed on

additional medications, can cause their function to actually decrease. It can be a really negative experience, but again, cottages provide that much more homely flexible environment, can really cater for individual needs.

5 MR GRAY: Dr Phillipson, in your statement, you've referred to the importance of a flexible analysis of all of the different respite options that are available for the particular caring relationship, sometimes called the dyad, I understand. Please don't limit yourself to that point but if you could please speak to the interventions that you see as key?

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DR PHILLIPSON: So I would have to say that similar to Meredith, the actual evidence around the benefits of respite interventions, when we do things like systematic reviews is inconclusive. And that's partly to do with the heterogeneous thing that we call respite. You know, respite could be for some people a stay in residential care, it could be an in-home support, it could be somebody attending a day care program. And really, you know, the – an analysis of the literature I think would be more accurately that most of the time carers are receiving too little respite and too late.

20 So I think really when it comes down to respite, the thing that we can consistently say in the research across the last 15 to 20 years is that it is consistently identified by carers as one of their greatest unmet needs, and that's from all the population surveys that we do and all the smaller studies that we've been able to do with research funding. So when we talk about the kinds of respite that make a difference to people, 25 it is around that flexible system where we can actually come in and respond to the needs both of a carer and of a person themselves, and their interest. So things like in-home respite, being available at the time when a carer might actually have an appointment on short term or perhaps in the evening or perhaps overnight, things like that.

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MR GRAY: So in-home respite in that context means what in practical terms?

DR PHILLIPSON: In-home respite means somebody coming in and actually having a meaningful interaction with the person who's remaining at home while the carer perhaps goes and attends to something in their own – of their own needs or another responsibility that they have. So provision of care in the home. We know, really, across the trajectory that often when people are physically well and able, they might tend to focus on or benefit from respite services that are out of the home when they can get out and move around in the community and things are a little bit more physically easier. 40

And then as the person functionally deteriorates getting out can be a burden in and of itself, so services in the home can make a big difference to a carer being able to attend to some of their own needs and to have a break, or even to attend the sorts of supports that we're talking about, their own counselling or an education session to understand more about how they can provide care. 45

And then we have the residential options and I would say consistent with the research that Meredith has talked about, that in the studies that I've done, both during my PhD and subsequent to that, carers have expressed a preference for cottage respite because of the home-like environment and the relational nature of what happens there. However, cottage respite is often not very available for people and it's often only for short-term breaks, maybe two or three nights, whereas residential respite care can be available for longer periods and there are real issues with access to both cottage respite and to residential respite in aged care facilities as well.

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10 MR GRAY: Thank you. There are some aspects of the assessment of the needs of carers, I might take you back to. Is it the case that until the introduction of CDC, there was under consideration a continuation of what was a specific carer directed funding package, which was a continuation of a previous program? Is that right?

15 DR PHILLIPSON: So when we trialled consumer directed care in Australia for older people with complex needs, there was a parallel trial of consumer directed respite care packages. Is that what you're - - -

MR GRAY: Yes.

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DR PHILLIPSON: - - - talking about? So there – I guess in that trial there was an acknowledgement that both people, the older person and the carer, might benefit from a budget to spend on services to meet their different needs. And the evaluation that was done by KPMG around - - -

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MR GRAY: Tab 13 of the tender.

DR PHILLIPSON: - - - that trial was very positive about the benefits of consumer directed respite care packages and giving carers access to a budget for the purchase of respite services.

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MR GRAY: If we go to page 4 – beg your pardon, native page 4 – CDRC is defined at a later page as consumer directed respite care. And if we look at the second paragraph, there seems to be a conclusion expressed about consumer directed respite care. Is this the element of this study that you're referring to?

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DR PHILLIPSON: So I think in my submission I raised this point because in the context of many studies that I've been involved in, over the last 10 or 12 years, carers have consistently identified that they don't have the resources that they need and the access to respite services that they need. And, certainly, with the introduction of home care package budgets, that seems to continue to be the case. So in a recent survey that we did with carers in the Illawarra, where we studied them over time, their need for – their unmet need for respite increased from 69 per cent to 78 per cent between 2016 and 2017, which was during that transition.

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And, certainly, in my study of home care packages, I really can count on one hand the number of times that I have seen dollars allocated from within a person's home

care package to the provision of respite services for a carer. That's partly to do with the budget limits, but I wanted to raise attention to this particular program because when the CDC trial happened, we trialled both of these packages and yet we only introduced the package for the older person themselves and for the services for the older person.

MR GRAY: And I was just trying to find the year in which this study was done. Do you recall?

DR PHILLIPSON: KPMG? I think the report came out in 2012.

MR GRAY: Thank you. So the sequence of events was CDC was trialled in 2012, was then introduced progressively in around 2015.

DR PHILLIPSON: 2013 was the first - - -

MR GRAY: 2013.

DR PHILLIPSON: First – earliest introduction.

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MR GRAY: Thank you.

DR PHILLIPSON: Yes.

MR GRAY: And then it became, in effect, mandatory for new packages in 2015, and then was – and then it has become the norm for home care packages since that time; is that right?

DR PHILLIPSON: So probably the other big change happened in 2017, because before that we were in a bit of transition, where services were still holding the budget for people's packages. And in 2017 the budget was allocated to the person, who then chose the service. So that was the last change that happened with the – with the way the program rolled out.

MR GRAY: Thank you. And winding the clock back before the very first introduction in 2013 - - -

DR PHILLIPSON: Yes.

MR GRAY: - - - two forms of consumer directed care were trialled.

DR PHILLIPSON: That's right.

MR GRAY: And one of them was specifically directed to the needs of carers for respite; is that right?

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DR PHILLIPSON: So providing both the older person, so consumer directed care, a budget for services that the older person required, and CDRC, consumer directed respite care, a budget for the carer to purchase respite services that they needed.

5 MR GRAY: Yes. And were the findings of the study in relation to consumer directed respite care positive?

DR PHILLIPSON: Yes. They were. In fact, in some ways they were more positive than the finding for CDC for the older persons themselves.

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MR GRAY: And is it known generally why consumer directed respite care wasn't implemented?

DR PHILLIPSON: Well, not to me. No. I mean, I have to say consumer directed care – I wouldn't want to say that there are not problems with that particular system for older people in general. We know internationally the evidence suggests that older people, whether they're an older person with service needs or a carer – an older carer themselves actually finds some of the burden that goes with the management for resources and organisations of services difficult. I think the point I'm trying to make is the allocation of resources specifically towards addressing the carer's own needs, as opposed to just the needs of the older person and expecting that the secondary benefit will be sufficient enough to meet the carer's needs.

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MR GRAY: Thank you, Dr Phillipson. Professor Hodgkin, could I ask you about interventions but, in particular, to focus on whether there are interventions we should be think about when the caring relationship comes to an end?

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ASSOC PROF HODGKIN: Yes.

MR GRAY: And that might be, for example, because the person receiving care dies.

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ASSOC PROF HODGKIN: Yes. So we've just recently conducted a study on palliative care, regional – rural service delivery of palliative care. And, you know, the – this particular service runs as a consultancy service only. So those who are providing palliative care in the home get what's called a consultancy service, where somebody comes out and says, "You can ring this number if you have any trouble". So there's – isn't actually any palliative service, as such, attached to that. And those people, people that we interviewed that that study – and it was conducted by an ex-honours student of mine, Naomi Mason, and I collaborated with her on that study.

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They were just – they talked about lots of things, like going into the battle – into battle with – with the health care system just to – to get basic services and help and so forth. So one of the things that we discovered along that route was that they were meant to – people who were recently bereaved were meant to get a follow-up phone call from this particular service to see how they were doing. And we've discovered through those interviewed that very few people had actually been phoned. Instead, people were phoned, you know, by other services to, you know – basically, who

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weren't aware that that person that they were caring for had deceased. So they were following up on issues to do with their care, but it was - - -

MR GRAY: What was the effect on the caregiver - - -

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ASSOC PROF HODGKIN: Yes.

MR GRAY: - - - on the former caregiver of being reminded of that?

10 ASSOC PROF HODGKIN: Devastating. Really devastating that they got a – you know, get calls after the fact, you know, for follow-up. And they talked about being in the void after their loved one had passed on, not knowing – you know, had some services going but suddenly there was nothing and no follow-up bereavement call. And those sorts of issues to do with, you know, finances, wills, sorting out property,  
15 you know, a number of things that happen after a person dies that – that you've cared for, that just weren't followed up on.

So we are at the moment, Naomi and I, looking at a study where, first off, we – the first stage is actually doing a comprehensive audit of files in relation to what happens  
20 when – for a carer when an older person dies. So that's taking – we've just got to fix for that, and that's taking place. But the next intervention we're hoping to get funding for is to actually look at developing what we're calling a toolkit, but a – what it means is a number of resources that are going to be available to the carer once, you know, their loved one has passed on, which gives them some clues into what they do  
25 about a number of those practical issues that happen after a bereavement, so - - -

MR GRAY: Dr Gresham, I know I've already asked you some questions under this topic, but I do want to come back to you on this idea of what happens to the carer after the caring relationship comes to an end, in the more social context. What about  
30 social re-engagement? What about re-employment, if the person is of working age? Do you have any comments to make?

DR GRESHAM: Briefly. I have mentioned before that caring relationships can extend over many years, even decades. Over that time, generally with chronic  
35 diseases, the carer becomes more enmeshed, more involved in the day-to-day care of that person. As they become more involved, more of their own employment, their social interests, their friends, their hobbies will often fall by the wayside. After that person either is admitted to care or has died, it can take many, many months for the person to start picking up the pieces of their life.

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And often, their social networks have actually moved on. They're no longer engaged with those networks. The employment that they had before may no longer be there for them. They may have lost skills. So for a person to re-engage with social and employment and other life activities can be a challenging and daunting task. And  
45 especially as carers will often be absolutely exhausted at the end of their caring career, it can be a very difficult transition back into finding their own identity and their own life.

MR GRAY: Do any of the panel members know of government-funded programs in that space?

DR GRESHAM: No.

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MR GRAY: Before I leave that topic, are there any further contributions from the panel members or any questions from the commissioners? I will go, then, to what does the system leave unmet? What are the key unmet needs? What are systemic defects that panel members identify? And, again, I will ask you to limit your responses to those things that you regard as keys issues in this regard. I will start with you, please, Dr Phillipson. Could I ask the operator to display tab 20. Beg your pardon, paragraph 20. Paragraph 20 of Dr Phillipson's statement. Paragraph 20 seemed a logical place to begin, because that information we've already heard some lay evidence – some direct evidence about people feeling, in effect, lost and alone. But I'm not seeking to limit you to that response at all, Dr Phillipson. What are the key unmet needs and systemic defects, in your opinion?

DR PHILLIPSON: So, I guess, going back to Meredith's model again on that left-hand side, we talked about people, you know, having information and ability to act on that information. And when I first started to study this new consumer directed care, home care package, I really wanted to think, "Well, if I was a carer or somebody trying to navigate this system, what information and supports are actually available to me out there to understand what it is that I can access?" And so we did quite a systematic search. We looked at the first 100 pages that came up through Google to identify nonpartisan information that was out there to inform home care package choices.

MR GRAY: Can I just ask you to pause there for just a moment? Operator, please display RCD.9999.0150.0001. Thank you. Dr Phillipson.

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DR PHILLIPSON: So what we found in that study was that most of the information – well, the information that is available is all on the web, or obtainable via a My Aged Care phone line. So that requires a certain degree or ability to – to communicate via a phone line. And I would – I guess I would use a similar situation to anybody who has ever tried to call a Centrelink or a telephone company or an energy company to what sometimes that experience can be like, if you're looking for information. The printed information that we were able to locate, you're required very high literacy. So, you know, third year university level education to – to really understand the ramifications of what a consumer directed care package was.

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We found it very difficult to identify training opportunities for people who thought this is too hard for me to, you know, to understand this information, where could I go for training or support. There were some original courses that were funded by the government right at the introduction of the system by COTA but they don't exist anymore. And, you know, I guess our conclusion was that, really, in terms of the accessibility of the information and the nature of the information that was available

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that it wasn't really suitable for a population, if we think about the Australian population who is multicultural, and ageing with cognitive impairment.

5 MR GRAY: If I could ask the operator to put up page 0017 at the foot of the page under the heading Conclusion and Implications for Research and Practice.

DR PHILLIPSON: So if we go to the situation of people with dementia where we may be looking at people that might need supported decision-making to be consumers of care, or even substitute decision-making really there was very little  
10 information there to support carers that may be acting in that kind of role. So really in introducing a consumer-directed care model our conclusion was that the government, whilst it had intended to introduce choice, hadn't really established the preconditions for what we understand people need to exercise choice, which is  
15 accessible information, and also information about the kinds of outcomes that might arise if we make different decisions that we might see in decision-making tools in other situations when people maybe are making health care decisions.

So there really does seem to be a disjunct between the provision of choice within a system and the kind of supports that the government has made available to a very  
20 vulnerable population to actually make the most of these choices.

MR GRAY: I want to ask you about the study that you then did taking this concept into the particular topic of accessing respite care.

25 DR PHILLIPSON: Yes.

MR GRAY: Operator, please display tab 29 of the general tender bundle. And Commissioners, the last document that I mentioned will be added to the tender  
30 bundle. I won't make a separate tender of it now. This document at tab 29 – I should have said the document that was displayed was the article Consumer-directed care for older Australians: Are resources identified on the web adequate to support decisions about home-based care packages, 2019. The next article at tab 29 is Knowledge, help-seeking and efficacy to find respite services: an exploratory study in help-seeking carers of people with dementia in the context of aged care reforms.  
35 Dr Phillipson, what was the approach in this study?

DR PHILLIPSON: So we looked to recruit a baseline of carers in the Illawarra Shoalhaven-region where I've done a lot of study to try and understand what the help-seeking to respite services was going to be like in the context of the system  
40 transition and we were also looking to establish a baseline for an intervention that we ended up running around whether we could improve knowledge and help-seeking and access to respite services for carers of people with dementia. So in the context of this study I guess we see a case study of the situation that I was talking about before, where whilst the vast majority of carers who responded to our survey, so 86 per cent  
45 of our carers told us that they had sought out information about respite service, the majority of those, so 73 per cent reported an unmet need for respite services, and they were really relying very much on their personal networks and sometimes, you

know, they could be professional people like general practitioners or maybe other carers or other older people that they knew or family members, to try and find information about the sort of care that they could get.

5 MR GRAY: Operator, please call out and zoom results and conclusions in the abstract.

10 DR PHILLIPSON: So in the context of that study, some had talked to us about their contact with My Aged Care. So often they would ring as an advocate for the person who they were caring for to say they were interested in support services and that they needed help and that the My Aged Care helpline would say to them, well, that person has to get on the phone, the care is for them, and so they have to, you know, be able to identify their needs and that they want support. And this was, in the context of  
15 this study, carers of people with dementia who often become quite confused in that situation and really they weren't given very much help through that helpline unless they were able to establish that they had a legal guardianship or carer advocate relationship with that person.

20 So really our carers – the carers that were successful at finding services had to find or access information through four or more services before, or sources, before they were successful in actually getting the support that they need. And I think that shows you the kind of labyrinth that sits behind even the My Aged Care gateway, if people get through that – that first system. And, you know, the way that the respite services have been divided up between the different programs, the aged care programs and  
25 the new Carer Gateway and the old care link and care respite centre means that all sorts of respite system services actually sit within different programs, so you've got to navigate different systems to access them.

30 MR GRAY: I want to ask you about that. Operator, please put up Dr Phillipson's statement at paragraph 25. Here, you make the additional point you were just beginning to speak to about there being a separation – separation between – well, it's not exactly in that paragraph, sorry, but - - -

35 DR PHILLIPSON: I think there is a diagram in the article, too, if you wanted to go to that. Yes.

MR GRAY: Thank you.

40 DR PHILLIPSON: I can talk to it while you - - -

MR GRAY: Yes. It's actually paragraph 26 of your statement, not 25, if we call out paragraph 26. And perhaps I will take you back to the diagram in the article in just a minute. Could you please explain to the Commissioners what this separation  
45 between different systems is?

DR PHILLIPSON: So I guess if we think about the nature of respite services, so funding for planned respite services fits within the Commonwealth Home Support

Program which is a program which has been designed predominantly to assess the needs of older people for supports and, as we've heard before and discussed, isn't at the moment really conducting a very comprehensive assessment of carers' own needs within – for people with more complex needs, the home care packages program, the  
5 allowance for respite services within that program suggests that carers, if their needs for respite aren't met within that program, could access Commonwealth Home Support Programs as a substitute or as an adjunct to the home care packages program.

10 But our experience on the ground is that that doesn't happen very often and often the costs of those are quite prohibitive because carers might be charged the full fee for accessing a CHSP program rather than a subsidised fee if it was a service that was being delivered through the CHSP. And also often that can be quite difficult if  
15 people have a single home care package provider and they're trying to access a CHSP service that is actually funded or run by another provider there can be some difficulties in negotiating that situation.

MR GRAY: Operator, please display paragraphs 27 and 28 at the same time.

20 DR PHILLIPSON: The residential aged care respite program requires an ACAT assessment in urgency respite up until this point has required an assessment by the care link and carer respite centre which is another gateway and – but I do understand that the new Carer Gateway will be able to provide people with information and assessment and access to emergency respite when that service is introduced in  
25 September. However, they don't have - - -

MR GRAY: I will just stop you there if I may, Dr Phillipson

30 DR PHILLIPSON: Yes.

MR GRAY: If we go now back to Dr Phillipson's article at tab 29, in the second page there's a schematic describing that division you've just explained.

35 DR PHILLIPSON: Yes.

MR GRAY: And so there's a different pathway depending on whether the carer is seeking to plan in the medium or long term. That's the My Aged Care gateway. Or whether the carer is facing an unplanned emergency in which case currently and up to date the carer has had to go to the Department of Social Services care link and  
40 carer respite services; is that right? And now those services are going to be replaced; is that right?

DR PHILLIPSON: So my understanding is that the emergency respite services will be part of what the new Carer Gateway will provide access through – through the  
45 RDP, the regional providers, however, the Carer Gateway does not have funding for planned respite services so if care is needed planned respite to attend psychological services or a carer education program or any of those things the new integrated

support plan for carers does not hold the funding for planned respite services, it sits back within the Commonwealth Home Support Program.

5 MR GRAY: So how does it work in practice if a carer needs those counselling sessions and so it's not an emergency, but those counselling sessions are accessible through the carer gateway operated by Department of Social Services, is that right?

10 DR PHILLIPSON: Well, we're waiting for the new system to start. I guess the equivalent would be the education sessions that might be being run, have been previously run by care link and care respite services and even some of the carer – state-based carer organisations. A lot of those programs, carers have struggled to access or even dementia education programs through organisations like Dementia Australia, they've had trouble accessing those programs because they've been able –

15 unable to access the planned respite they need to get there.

MR GRAY: So in practical terms if I'm a carer caring for a loved one 24/7 and I desperately need counselling and education, assuming I know about the Department of Social Services Carer Gateway, I might find out about some useful counselling programs offered in my locality and I might see when the times are and I might be put in touch with them, but I can't say it's an emergency so I can't ask the care link and respite service for – to come in and look after my loved one while I go to that session. It's planned respite. So what do I have to do then?

25 DR PHILLIPSON: So if - - -

MR GRAY: If I can't get out of the house without obtaining some respite care; what do I do?

30 DR PHILLIPSON: That's right. So if you are caring for somebody who had a home care package you could try and negotiate some extra care but if the budget is exhausted then that might be difficult. You might have to forego another service that week, you know, the person might not have to have their shower so you can go to your education session and a lot of carers aren't prepared to put their own needs in front of the needs of the person so - - -

35 MR GRAY: And who do I speak with to try to obtain that help. Is it the Carer Gateway?

40 DR PHILLIPSON: Well, it would have to be with the home care package provider of the person you're caring for.

MR GRAY: Yes.

45 DR PHILLIPSON: Or there is that – there is that allowance within the home care packages guidelines that say if a carer does have additional needs that aren't satisfied within the home care package, they can access Commonwealth Home Support Program activities in the short term to help them, which may be possible. But you

can see the kind of situation and the efforts that this carer who's under strain, who has particular needs is having to go through just to organise for themselves to be able to access a program to help them care better or get psychological services. So it's – it seems to me to be a bit of a fatal flaw that our new Carer Gateway has not been  
5 provided with sufficient funding to actually support the planned respite services that carers will need to access what could be quite valuable services for them.

MR GRAY: Thank you. Now, just while we're on the topic of that additional assistance that might be available under either the home care package or the  
10 Commonwealth Home Support Program, could you just expand on that again?

DR PHILLIPSON: So within the home care packages guidelines there is a statement or a clause that says if a carer's need for respite, and I'm – I don't know if you can bring up the actual word, but there is that sense again of strain or stress or if  
15 they're really – you know, can't cope without some extra respite, that they can access - - -

MR GRAY: Tab 55, please, Operator.

20 DR PHILLIPSON: They can access some other supports through Commonwealth Home Support Program.

MR GRAY: If we go to tab 55, this is the Commonwealth Home Support Program manual, is this the document that sets the rules for eligibility for CHSP grant –  
25 grantees - - -

DR PHILLIPSON: Providers of those services.

MR GRAY: - - - providers who have received grants - - -  
30

DR PHILLIPSON: That's right.

MR GRAY: - - - under the program - - -

35 DR PHILLIPSON: Yes.

MR GRAY: - - - to provide subsidised assistance to people?

DR PHILLIPSON: Yes.  
40

MR GRAY: If we go to page 70, native page 70, in the heading Access and Interactions there's a section dealing with the interaction between home care packages and Commonwealth Home Support Program. In native page 70. On native  
45 page 70.

COMMISSIONER BRIGGS: While that's being brought up, might I ask whether you think the story you just told is an unintended or an intended consequence of the establishment of the new system?

5 DR PHILLIPSON: I think it was probably unintended. So as part of an aged care service grant that I was involved in a few years ago, we did some interviews with service providers and policy makers. And in the context of that – those interviews, this whole idea about the complications that had arisen from taking on aged care reform but leaving carers till later, and the unintended consequences of that leaving, 10 you know, the new carer program without any money for planned respite, I can – I can only reflect on some of those – those comments.

I would say it's probably an unintended consequence. And, I think, probably in response to the government trying to address what they see as the very substantial 15 needs of our growing ageing population, they were really looking for any way that they could to boost the budget within the Commonwealth Home Support Program.

So there would be money moving from a national respite carer – for carers program, which used to exist into that program, certainly would have provided some more 20 resources within that – that program as well. The big problem is the separation of those systems and – and them not seeing those – that relationship and the needs of that relationship as being both interdependent and independent, and, really, that's the challenge that we're talking about, that the needs of one can't be seen without, you know, looking through the lens of the other as well. And yet they have both got 25 different needs, so, yes, I would say it was an unintended consequence.

COMMISSIONER BRIGGS: But one that needs to be dealt with, because ideally you would have a system where both the carers' framework and the other side, administered through the Health Department, could draw down respite care services 30 as and when required?

DR PHILLIPSON: Well, the whole idea of a consumer directed care program and people with complex needs was to give people more control and choice over what they were using their services on. 35

COMMISSIONER BRIGGS: Yes.

DR PHILLIPSON: So the idea that we're saying, "Well, you've got this budget but, actually, if it's not enough to meet your needs" – and that has been a big problem 40 with the home care packages budget, that they have not been adequate to meet the higher order needs of the person that is living with needs and – and I've been studying quality of life of people with dementia and home care packages over the last four years as well, and those budgets are not meeting their needs for meaningful activity and social participation, let alone meeting the needs of carer for respite. So 45 to call that choice and control, but you've got a package and it doesn't meet your needs, then you had better go back and negotiate with another program which could meet your needs and a whole set of other service providers and, "If you want an

assessment, go to a Carer Gateway”, it doesn’t feel very much like choice and control to me.

COMMISSIONER BRIGGS: Or user-friendly.

5

DR PHILLIPSON: No.

COMMISSIONER BRIGGS: Thank you.

10 MR GRAY: Dr Phillipson, can I just ask you to address that issue that arose from some of our earlier testimony? You referred to a means by which under the Commonwealth Home Support Program there could be access to some additional funding for respite. Have I found the right reference? Near the foot of page 70. Operator, please go to the third – about the second-last full paragraph on the margin:

15

*There are four defined circumstances.*

And call out that text and the rest of the page. And then, over the page, points 3 and 4.

20

DR PHILLIPSON: Yes.

MR GRAY: Now - - -

25 DR PHILLIPSON: That’s what I’m referring to. And there’s a similar kind of paragraph within the home care packages guideline as well that says if there’s an identified need for carer respite then the carer – the person should be able to access services back in that other direction. I would say to you again that on the basis of studying the dyad that is receiving home care packages, I really have only seen that  
30 situation be offered to people at quite high cost. So cost recovery, rather than a subsidised. So one of the carers that comes to mind immediately, before they went from – they transitioned from CHSP to a home care package – were paying \$8 a day for a day respite program. And if they wanted to use that program once the person transitioned to a home care package, it was going to cost them \$80. So that cost was  
35 prohibitive.

MR GRAY: So just pausing there, there’s an important point to be brought out here. If a person is in receipt of services from a provider that receives grants under the Commonwealth Home Support Program, that program is subsidised on a block-  
40 funded basis and the particular receiver of those services, the recipient of those services, only contributes a small amount towards the services they receive?

DR PHILLIPSON: They usually pay a subsidised fee.

45 MR GRAY: And this is, of course, the program, CHSP, that is described as entry-level and low-level?

DR PHILLIPSON: That's right.

MR GRAY: If, however, the care recipient suffers a deterioration in their condition such that they need higher-level care, they're meant to be progressed into home care package?  
5

DR PHILLIPSON: That's right.

MR GRAY: However, when they get to home care package, the rules change.  
10 Under CDC and the other rules of the Home Care Package Program, they have to be charged on a full cost recovery basis; is that right?

DR PHILLIPSON: Well, I think there's all sorts of models that are working, and there's very little transparency out there around what these people are paying and –  
15 you know, if you're doing research it's quite difficult to work on that out, in terms of when you're making that choice. But all that I can say is in my experience of working with carers and people who have been on a home care package, that that has been their experience; that they've been told that because they're receiving the funding as at – as an allocated budget, that that is their subsidy, and that they pay and  
20 purchase services, then, at a full cost recovery amount.

MR GRAY: And when it comes to respite, in your statement, you're saying that that tends to be only, in effect, purchased out of a home care package when other needs have been met. And it's at this far higher cost to the care recipient and their  
25 carer - - -

DR PHILLIPSON: That's right.

MR GRAY: - - - than under the CHSP.  
30

DR PHILLIPSON: Yes.

MR GRAY: Even though the home care package is meant to be addressed to people at higher need - - -  
35

DR PHILLIPSON: Yes. Yes.

MR GRAY: - - - than the Commonwealth Home Support Program is.

DR PHILLIPSON: The fee that people may be paying for their – any of their services within the home care package would be far – often far greater than what they were paying for it if they were receiving, for instance, personal care assistance through the Commonwealth Home Support Program. That's the way the system works.  
40

45 COMMISSIONER BRIGGS: Sorry. Dr Phillipson, would you agree that this paradox of fees runs quite contrary to the Medicare system? So the health system,

where the sicker you are the more likely the services are to be packaged around you and available free of charge?

5 DR PHILLIPSON: So one of the principles of consumer directed care was supposed to be about enabling choice and increasing transparency. But it has certainly brought a lot of complexity for people, in terms of making choices, often without any sense of what those costs might be to them. And, I think, for the people that I have been conducting research, it has been a great shock to them that in  
10 transitioning from the Commonwealth Home Support Program to their Home Care Package Program they may, in fact, get less care and pay more for it. And one of the principles of CDC has also been around that – the idea that if people have the means to pay for their care, then they should be doing so. So there’s the old sliding scale fee and income testing. That can be very stressful for people to go through as well.

15 MR GRAY: And that’s a layer of complexity that doesn’t apply to the Commonwealth Home Support Program either; is that right?

DR PHILLIPSON: Mmm.

20 MR GRAY: And in the context of all of that explanation – thank you very much for explain that in detail. In the context of all of that, when we come to the points at the bottom of page 70 of the Commonwealth Home Support Program manual, there appears to be, in limited circumstances, the ability of the carer and the care recipient who are in receipt of a home care package – in some circumstances, where the home  
25 care package has been fully allocated and exhausted, the ability to get some respite under the Commonwealth Home Support Program. However, it’s limited, is it? What are your remarks about this?

30 DR PHILLIPSON: Well, the language there tells us very much that it’s emergency and short-term. But, again, I would say that in the practice of it the costs of that have been prohibitive for many people. Like, the paying for the cottage respite, for instance, you know, eight or nine hundred dollars for a few nights, whereas they might have used it before as CHSP clients – it might have cost them \$150 or something even less. There seems to be more problems if the home care package  
35 provider is a different provider to the CHSP employer. There seems to be a little bit more flexibility when the CHSP service is being delivered by the same package that the person happens to have. Yes. But that’s more a matter of, kind of, convenient circumstances than a feature of the system working well, I think.

40 MR GRAY: Thank you. Could I just ask you now about one other issue that came out of your testimony, which was your reference to the Commonwealth Carelink and Respite Centres being replaced? And you said, “Yes. There’s a plan on foot, under which they will be replaced.” Could I ask the operator to bring up tab 38. Is it this  
45 program, the Integrated Carer Support Service, that is providing for the replacement of the Commonwealth Carer Respite Services?

DR PHILLIPSON: So, again, I'm going to say this is on the – on the best nature of my – my research and trying very hard in developing respite coaching modules for carers to take to understand how the system works. It is my understanding that Commonwealth Care Respite Services, their functions have been diminishing and decreasing, and all they're currently left with at the moment is the emergency respite, and that the provision of emergency respite services will be taken over by the new regional carer delivery hubs within the integrated carer support services.

MR GRAY: Thank you. So if we – Operator, please go to tab 37.

DR PHILLIPSON: But this – none of this starts until September. And I rang my Carelink and Care Respite Centre in our local region last week again and she said they still don't know who will be taking over their – the contract for that service in September. So they're just taking the calls for emergency respite and they're not sure who will have the – will be the successful provider of those services.

MR GRAY: Thank you. If we go to page 0019, second paragraph, if we call that out. It says here in this paper – described as a draft on the regional delivery model, that there are:

20 *Currently more than 100 organisations –*

etcetera, funded as Commonwealth Respite and Carelink Centres. They're the centres to which you refer, which still have the emergency respite function, are they?

DR PHILLIPSON: That's right.

MR GRAY: And, in effect, they're being wound down. Is that the – is that your understanding of - - -

DR PHILLIPSON: Well, my understanding is that the current services that they're providing around the delivery of emergency respite services will be taken over as part of the new integrated carer support services that are provided by the regional delivery paths.

MR GRAY: Yes. And according to your inquiries, it's still uncertain exactly what shape that will take?

DR PHILLIPSON: It may be known to the Department, but it wasn't known to the current organisation who runs the Commonwealth Respite and Carelink Centre in our region.

MR GRAY: Yes. So, Operator, please go to the heading Proposed New Model. And if we call out down to option A and option B, we understand, Commissioners, from a paper provided by the Department of Social Services, that for some 18 or 19 areas there's an – expressions of interest or tender process underway in relation to those areas. We will be taking this up with a witness from the DSS tomorrow.

DR PHILLIPSON: Can I say I think that makes sense that that's where those services should sit. The big limitation that I see for the new model is that they haven't got a bucket of money to support carers to access planned respite service that is would allow them to actually take advantage of the new services that would be on offer.

MR GRAY: Thank you. Well, thank you very much, Dr Phillipson, for your evidence about those complexities in the system. I now want to ask Professor Hodgkin what are, from a rural perspective, some key deficits or defects that you perceive in the system, as it stands.

ASSOC PROF HODGKIN: Okay. So in our consumer directed care study, we – when we went – when our research officer was going out to see some of the community-dwelling older people in rural areas, they were totally confused about what package they were on. They had – they had had the paperwork in front of them and asked the research officer, “Can you make sense of it?” Because she wasn't there as a clinician, more as a researcher, said, “Well, I can't really have a look at that documentation”, but they were some of the issues in relation to not understanding what their package is, what they could spend their funding on.

And from the provider's point of view, and picking up what Dr Phillipson was saying, you know, the – they were recommending with older people to stay on their Commonwealth home support package than accept a level 2 home care package because it wasn't going to – it was going to cost them more money – you know, full cost recovery for some of the services that they had been getting prior to that. So the providers were – you know, there were some encouragement or at least tutoring of the older people in relation to, “Don't accept that at the moment”.

And when we looked at the figures – so this was for a north-east region and there was five of these in Victoria and five providers. Overall, there was, you know, 1800 people on Commonwealth home support package. And then when we looked at the HCP packages, there was, like, 150 or 60. So there's this huge discrepancy. So somewhere, rural people are not being able to access these packages. The providers talk about their frustrations about not being able to obtain level 3 or level 4 packages for their clients and – and saying, obviously, the level 2 aren't sufficient at this period of time.

So there's all those issues, and then that affects all the things that we've discussed today in relation to, you know, respite and carer education and, you know, a number of things that a carer might be able to get out of the package that at the moment they're accessing through the Commonwealth home support package instead. So there's – the other thing I think is in relation to education of carers. And I hear my two colleagues talk about – and I'm, you know, envious that these sort of – some of these programs exist, because they certainly don't in rural areas, so – you know, they're – and I think I have enjoyed my time here, giving evidence here, because it makes me understand in some ways how limited – having heard the discussion, it's

even more limited in rural areas, and it's quite concerning, I think. So – yes. There's that.

5 MR GRAY: Thank you. Dr Gresham, I will skip you for the purposes of this topic and I will go to our final topic and ask for, in effect, a wrap-up from each of our panel members concerning what they see as key recommendations they would make to the commissioners. Key reforms that are needed. And, again, we can't cover everything, but I will start with you, Dr Gresham, with the key unmet needs that you think should be met with a recommendation of some kind.

10 DR GRESHAM: Thank you. Very briefly, I would very much advocate for proactive intervention for carers, rather than – what we have is largely a more reactive set of services and supports. Family or informal caregivers are the backbone of aged care support in this country. And we need to recognise that. We need to  
15 recognise the pivotal role that family caregivers play and we need to provide those family caregivers with the right sort of support at the right time. In terms of practical recommendations, 30 years ago, when I started in this area, the sentiment from carers was that they would get a diagnosis and the diagnostician, the specialist doctor, would say to them, “Go home and manage as best as you can and start looking for a  
20 good nursing home.” The tragedy is that I still hear that today.

We need a pathway. We need a supported pathway for carers of people with chronic diseases to get on so they have some person they can contact. They have some  
25 inkling of what's next, where do I go. It is clearly outlined – a pathway is clearly outlined in the Australia Dementia Clinical Guidelines, I think 90 to 100 of the guidelines, a recommendation, is about a pathway and a pathway is not rocket science.

30 The second recommendation I think we need is that we cannot expect carers to choose, to decide on their own care unless they are provided with the information, education and support to understand what are the ramifications of the choices that they make. The third thing that I really advocate, that I think is so important is we need to start thinking about not reactive services for the older person themselves but  
35 looking at proactive reablement type of services to help lessen the impact of chronic disease on family caregivers. I think I would like to finish with an old adage that an ounce of prevention is worth a pound of cure and I think in this instance it's highly relevant. Thank you.

40 MR GRAY: Thank you, Dr Gresham. Associate Professor Hodgkin, key recommendations; what needs to be done?

45 ASSOC PROF HODGKIN: I think, if I look across regional areas, the system is very fragmented and limited. So limited and fragmented. And I think one of the things that – one of the most basic things that I think needs to happen is that in any kind of – if we're seriously talking about person-centred care in these models, the carer has to be included in that, and across all the studies that we've conducted there seems to be limited acknowledgement of how crucial the carer is in all of this, and

how they need to be consulted, they need to be considered as part of the care team and they often aren't. And in our – the spousal care study that we conducted, it was often at the end when the carer went up to the care team afterwards and said “Can I have a quiet word?” and that quiet word was about, “I’ve got some issues that I need to discuss. That’s a good plan but you haven’t talked to me about it, you haven’t included me.”

So I think it even gets back to that basic thing of thinking about how crucial the carer is, consulting the carer, making sure that they’re part of the care team and I’ve been scratching my head to come up with some models of service delivery that are integrated in rural areas and have been looking to kind of the Netherlands and talking to them about some of the projects they’ve got going. And one of them is called the sustained research project which is - - -

MR GRAY: Operator, paragraph 55.

ASSOC PROF HODGKIN: Yes, which is a project which is being conducted across several European nations where they – countries, where they actually are, the sustained group are looking at person-centred care and models of person-centred care and – the best models and then testing those out and then coming back with some key recommendations going forward. So there’s a number of innovative projects there, such as Care Works Berlin which is really aimed at – and I’m with Dr Phillipson here, I’m much more in the community care space but it’s much more at looking at improving community care through highly integrated services. So I visited this not so long ago when I was in Europe and think some of the ways forward might be with these other international countries which have – have had similar issues and problems with what they call the cash for care programs that are in operation, so yes.

MR GRAY: Thank you. Dr Phillipson, what needs to be done?

DR PHILLIPSON: So I think in the long term, this separation of carer from older person is – is – has really kind of been highlighted as problematic. So I really do think that in the end we need a system that assesses comprehensively the needs of the dyad and provides coordinated care that meets those needs because there can be a lot of overlap and there’s a lot to be gained through the delivery of services that are needing the needs of both at the same time. And an enormous amount to be lost through the separation and duplication and burden that goes with navigating systems that don’t – that, you know, kind of see you as somehow separate and I do think that that is a philosophical issue. I think that that has come in through this introduction of consumer-directed care and the atomisation of people as individuals with particular individual needs that need to be – need to be met.

I think, really, we’ve highlighted the fact that people actually don’t just need information but they actually need advice and supports to make good care decisions. And I think particularly in complex situations, you know, like people living with dementia we’ve got lots of evidence around things like dementia link workers

working, there's programs again in the Netherlands like the Buurtzorg nursing programs that show that highly targeted interventions that are delivered by health professionals, they might be more expensive in the short term but in the long term they provide much greater benefits for carers and for people with dementia over their journey. And again that's quite relational care and again it's about access to health professionals who can provide that – that training and support and – and that both carers and people with dementia need.

And we have things like breast care nurses but we don't have dementia link workers, care nurses that are actually supporting people through this very complex journey. So the health professional sort of end of the system seems to be around assessing eligibility. So we will employ health care workers to make sure people are eligible for the programs but then we won't provide people with anything but information, we won't provide them with that advice that they need to make good decisions as their situations change as well. So access to health professionals who can provide advice over the trajectory from diagnosis to end of life care.

And obviously I'm going to say we need more funding to actually address carer needs and that includes proper funding, access to funding to allow the purchasing of respite services and other services that actually promote carer recognition. We need to take seriously the Carer Recognition Act and to be making sure that that has legal and financial things associated with recognising the social and health and economic participation in rights that carers have to good services and supports.

MR GRAY: On the funding of respite there's a suggestion in the government material that the Royal Commission has received for this hearing that funding reform in relation to residential or respite should await the outcome of the residential care resource utilisation classification study, now called the AN-ACC. And it should be a reform that is in effect put on pause until the outcome of that study is known. What do you say to that?

DR PHILLIPSON: So we haven't really focused on residential respite in aged care facilities at all and there are big problems with people being able to access those services. They're predominantly being filled by aged care organisations by people as a transition into permanent care and people that need access to residential aged care beds for true short-term respite with the intention of moving back into the community find it very difficult to access care when they need it at appropriate – at times and the appropriate sorts of facilities.

The waiting for the AN-ACC results and the RUCs won't help the model of residential respite. That study – residential respite funding was out of the scope of that study. We really need an independent review of the models and the sustainability of residential respite care. Waiting for that study, it wasn't – the study didn't include the data collection of people and the care needs of people that were there on respite stays. Its focus was on funding for permanent residents.

MR GRAY: So your evidence is we shouldn't be waiting for the outcome of the RUCs study.

DR PHILLIPSON: No, I think we need a separate study.

5

MR GRAY: Thank you.

DR PHILLIPSON: And it would be good, actually, to see the way that that kind of model works or, you know, in concert with other kinds of residential stay like cottage because we know that there are preferences and both of those models can be used for different things so it would be good to see a study that was looking at access and funding for both of those things, I think.

10

MR GRAY: Thank you. Commissioners, those are my questions for the panel.

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COMMISSIONER TRACEY: One thing seems clear from your evidence and wish lists, and that is the current system has to be amended such that everything involving aged care, including the interests of the carers need to be brought under the one umbrella, and regulated by one institution in a coordinated fashion. But there still have to be rules. There will still have to be forms or still have to be log-ons on computers or whatever it may be. Now, there are going to be a lot of people, particularly as the next generation that is familiar with computers and dealing with these sorts of matters online who will be able to cope with that, or they will have family members or good friends who can do it for them.

20

25

But if they are going to make informed consent, or choices, the sources of information that are presently available don't seem to be sufficient, and I would be interested in your comments as to whether there ought to be, in addition to the options that are currently there, a body of people distributed around the country who have the requisite knowledge, who are available for one-to-one consultation, not necessarily in a Medicare office or somewhere like that, someone who would, if need be, go to the person's home because it's simply not feasible for them to come out, and provide that information on a one-to-one basis.

30

ASSOC PROF HODGKIN: One of the things that we've been looking at, that we trialled in Wangaratta is a – an information hub where older people could go and volunteers help with access onto My Aged Care and take them through a number of key things. I think this morning they were talking in the Carer Hub, it was a similar sort of organisation, so I'm thinking about rural areas where it's difficult for people to get to. So that has been quite successful. The only problem has been that it's been run by volunteers who have been left, you know, to their own devices and that's not a good – that's not good for the volunteers that they're not supported as such.

35

40

But those sorts of models I think in rural communities do work, where there's good information hubs available and people, older people can access them and not feel quite so isolated and some of the carer hubs that they were talking about, some of the speakers, we've had similar speakers come and there have been a huge success,

45

talking about wills, talking about My Aged Care, talking about transportation and how you access transportation, talking about respite care so that these kind of key hubs in regional areas I think have some promise going forward.

5 DR GRESHAM: This sort of information can also be delivered in small groups. We found throughout the Going to Stay at Home program that if all carers could actually take on new information they needed opportunities to ventilate, to tell their story in a safe psychological environment. It was only after that happened that they realised that yes, there were people who were in their same situation, they were not  
10 alone, that they were able to actually take on new information.

What we found is even with that one week program, the nature of information, the problem solving and the other activities, we had set carers up well for the rest of their caring journey to be able to utilise services and supports in a way that was going to  
15 be effective for themselves. So I think there are a number of delivery mechanisms but I think what Dr Phillipson said is people do need that interpersonal relational way of working, certainly for this generation we have now and certainly over the, you know, foreseeable decade. It's very important.

20 DR PHILLIPSON: I think there could be ways we could equip places that people go already, like the practice nurses could actually – it's not just information people need. It's actually support to go through the process and so we hear stories all the time of, you know, people, you know, graduate carers who now help other carers who say bring in your paperwork, I will help you do it in small group kind of settings  
25 or practice nurses in GP surgeries kind of helping people do the paperwork. I know that sort of providers of culturally and linguistically diverse services they've really just taken on this extra responsibility to help people just to fill out the paperwork because that's what's required.

30 I mean, we've got a navigator trial at the moment. The system we've invented is so difficult to navigate we've now got to fund an alternative navigator trial for vulnerable groups and the system was to fund care for vulnerable groups. It's a really strange situation to be in. But I would say your idea of shopfronts and outreach services is a good one, but not just for information, for the actual support to  
35 do it and the expert advice to say to people, you know, on the basis of your aged care assessment, which was done by a multidisciplinary health care team, these are what we actually recommend, because that's where people also fall down.

40 What do I do now I've got all these services calling me and I don't know who they are, and which one will be best. People actually often need some expert advice, not just a fact sheet of information because remember they're under stress, they're under strain, they've only sought help because they're finding their situation extremely difficult.

45 COMMISSIONER TRACEY: Well, they've first got to know that help is available.

DR PHILLIPSON: Yes.

COMMISSIONER TRACEY: And that requires advertising presumably in local press and particularly in rural areas, but you will have heard the evidence today about how the Mildura Carers Hub works, and it's struggling at one day a week at the moment, but if that were to be a five day a week operation - - -

5

DR PHILLIPSON: Yes.

COMMISSIONER TRACEY: - - - then it would meet the sort of model you have in mind.

10

DR PHILLIPSON: That's right. But older people are already going to council services and local doctors' surgeries and all of these sorts of things. So even being able to find a model to extend the services – of places people are already going to access help and support would be another way of thinking about it.

15

COMMISSIONER TRACEY: Each of you, if I may say so, with respect, have an enormous volume of knowledge about how the present system works and, more importantly, doesn't work, and is unlikely to work in the future, even with proposed modifications. May I ask, have any of you been consulted by government department policy advisers about the sorts of matters you've given evidence here today about?

20

DR PHILLIPSON: So I've had some contact with the carer policy department. So when we ran a trial around respite coaching for carers of people with dementia I sent them an email to say we've just done this, these are things we learnt about them. So I went and visited and shared that information and have had a bit of contact in the way that they're thinking about the coaching program. That was a few years ago now. And I also was recently on a dementia in the community policy think tank kind of event that happened in Sydney. They've been my two experiences, yes.

30

COMMISSIONER TRACEY: But none of you were consulted, for example, as to the proposal that we see developing the integrated carer support service regional delivery partners.

35

DR PHILLIPSON: Not beyond the actual carer coaching experience that I had.

COMMISSIONER TRACEY: Mr Gray, anything arising?

MR GRAY: No. Thank you, Commissioner.

40

COMMISSIONER TRACEY: Well, we're enormously grateful to you. The session has gone on a lot longer than was scheduled and I'm very glad about that because we've learned an enormous amount of information. We thank you for coming here and sharing it with us. And we will do our best to absorb it all and you have the comfort, when you read out your wish lists, that the transcript was operating and we have it in black and white. Thank you very much.

45

DR GRESHAM: Thank you for the opportunity.

COMMISSIONER TRACEY: The Commission will adjourn until 9.30 tomorrow morning.

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<THE WITNESSES WITHDREW

[4.27 pm]

10 **MATTER ADJOURNED at 4.27 pm UNTIL WEDNESDAY, 31 JULY 2019**

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