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TRANSCRIPT OF PROCEEDINGS

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**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

10.04 AM, MONDAY, 29 JULY 2019

Continued from 17.7.19

DAY 39

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

COMMISSIONER TRACEY: I start by acknowledging the Latji Latji people who are the traditional custodians of the land on which we meet today. I would also like to pay my respects to their elders past and present and extend that respect to other Aboriginal and Torres Strait Islander people present. Yes, Mr Gray.

5

MR GRAY: Thank you, Commissioner. Commissioners, I appear with Ms Erin Hill and Ms Eliza Bergin. On behalf of the counsel assisting team, I wish also to acknowledge the traditional owners of the land on which we meet. This hearing is being held on the lands of the first peoples of the Millewa-Mallee, the Latji Latji, Ngintait and Nyeri Nyeri people and we wish to acknowledge them as traditional owners. We pay our respects to their elders past and present and Aboriginal elders of other communities who may be here today.

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The focus of this hearing is on the role played by family and friends as informal and unpaid carers of older Australians. This care is often but not exclusively given in their own homes, shared with the person they care for. There are many such people, particularly spouses, who do not identify themselves as carers but who do, objectively speaking, have a demanding primary care role. During this hearing, with due deference to the preferences of these people to characterise their roles how they wish, we will use the term “informal carer” for them. We will also use informal carer to distinguish family and friends providing care to older Australians without pay from those who are formally employed or who volunteer within the aged care system.

20

Over the next three days we will inquire into the challenges faced by informal carers, the support services that are supposed to be available to them, and whether there are improvements needed in facilitating access to those services, and in the quality of those services. We will also focus on the provision of respite care within the aged care system which is important to the sustainability of the informal care relationships. We know that most people want to remain in their own homes as they age and not receive care in a residential facility. Taking just one example from the evidence already received by the Royal Commission, a survey by the Combined Pensioners and Superannuants Association in 2015 indicated that 95 per cent of people wanted to receive care in their own home.

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Informal carers are acknowledged in the Statement for Australia’s Carers scheduled to the Carer Recognition Act 2010 of the Commonwealth. Principle 7 of the statement calls for carers to be considered as partners with other care providers in the provision of care acknowledging the unique knowledge and experience of carers.

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These family and friend carers and the vital care work they do may be hidden from public view, but they are important to the sustainability of the aged care system for reasons I will turn to shortly. Providing care for an ageing family member or friend can bring personal rewards and satisfaction. It is a choice that many people willingly make but it comes at a cost.

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It can have detrimental effects on the health and wellbeing of the carer; the physical, psychological and financial impacts can be significant. Over time, not only might the carer be affected but so might the quality of care that their loved one receives. If informal care becomes unsustainable permanent entry into a residential aged care facility will probably result at significant public cost. Family and friends of older people have already appeared throughout the Royal Commission hearings to tell us of the experiences of their loved ones. Many have incidentally also explained the challenges of accessing and managing formal services as well as the financial, social and emotional toll that a caring roll can have. In this hearing those matters will be central.

What are the data on informal carers in Australia? In 2015 almost 2.7 million Australians identified themselves as informal and unpaid carers; that's 12 per cent of our population. Of those around 420,700 are primary carers of people over the age of 65 and this may be an underestimate because it depends on the respondent to the survey self-identifying as a carer. Many carers are themselves older Australians. The data suggests that spouses or partners are the most likely people to be providing care to an older Australian followed by daughters. Gender equity remains an issue in caring roles. While there has been some increase in the population of men in caring roles, caring is primarily done by women.

In 2015 female carers made up 68.1 per cent of all primary carers. The societal impact of caring as a gendered issue has been well documented in terms of pay equality, employment opportunities and the mental workload burden. In 2015 Carers Australia commissioned Deloitte Access Economics to research the economic value of informal care in Australia. The study concluded that informal carers provided an estimated 1.9 billion hours of care in 2015. This is equivalent to each carer providing 673 hours per year or 13 hours per week. We also know that Australia has an ageing population. In the last 40 years the number of Australians aged 85 years and over increased significantly in absolute terms and as a share of the Australian population from 0.6 per cent in 1978 to 2.0 per cent in 2018.

These demographic changes result in more people who are likely to need care. However, the number of people able to provide this care is anticipated to rise at a much slower rate because people are having fewer children, there are increased rates of divorce, increased participation of women in the labour force and more single person households. So there is a very real challenge in supporting a growing number of people choosing to age at home with decreasing numbers of family and friends able to provide care. There are a range of services that the Australian Government subsidises to assist people who take on a caring role in support of an older person. These services come in the form of respite care, training and counselling.

There is also financial support. These services and support are delivered through three Australian Government departments: Health, Social Services and Services Australia respectively. For veterans and their dependants, the Department of Veterans Affairs can also provide support and assistance. The Commission has received submissions and heard evidence about the difficulties of navigating

different complex systems that are designed to support them and the person they care for. This can act as a barrier to accessing important services that sustain the caring relationship. We will hear more evidence about such issues over the coming days.

5 During this hearing, there will be a particular focus on respite care. Respite care is an alternative care arrangement that provides a carer or a care recipient a short-term break from their usual care arrangement. From the carer's perspective there may be many reasons for respite, such as giving them time to attend to leisure activities and their own needs and to meet other responsibilities in their lives. There is an element
10 of ambiguity in the concept of respite. Is it a service for the recipient of care or the caregiver? It should, of course, benefit both and be for the overall enhancement and sustainment of the care relationship.

15 In technical terms, however, the way the need for respite care is assessed may not adequately reflect this. The focus of the Royal Commission is on aged care that is subsidised by the Commonwealth and so we will not be inquiring in depth into respite services funded by State and Local Government. Relevantly, respite care is subsidised through the Commonwealth Home Support Program, the Home Care Package Program and through residential aged care facilities. Home care packages
20 and residential aged care are delivered by providers approved under the Aged Care Act to recipients assessed as needing those services, and Commonwealth Home Support Program services are delivered by service providers who have received grants under that program to recipients, that is, the services are provided to recipients assessed as needing those services.

25 There are various types of respite services available which I will now outline in turn. Residential respite is the most widely used form of respite, with 2522 facilities across Australia providing this service in 2017/18. It is available only for approved care recipients which means older people who have been assessed by an aged care
30 assessment team, or an ACAT, or an aged care assessment service in Victoria, an ACAS, as needing residential respite care and who are then approved as recipients of this form of Commonwealth-subsidised aged care under the Aged Care Act. They are entitled to 63 days of subsidised residential respite care in a financial year if they can find a service with a vacancy, with the possibility of extensions of up to 21 days
35 at a time. The use of residential respite is increasing. The number of residential respite days used in 2017/18 was two million, an increase of 120,000 days from 2016/17.

40 The Commonwealth Home Support Program, often called CHSP, funds provision of services to people needing low level or entry level care assistance so that they can keep living independently at home and in the community. Providers under this program may offer short-term flexible respite, such as day centre programs, in-home respite or cottage-based respite. 556 providers delivered respite to 46,098 people in
45 2017/18. Providers are permitted to offer these services to recipients assessed by a regional assessment service or an ACAT or an ACAS as needing those services. Various respite services are also at least theoretically available through the Home Care Package Program. Home care packages are often called HCPs.

First, the person's care needs are assessed by an ACAT or ACAS and they may be approved for a home care package in one of the four applicable levels of need. The waiting time for assignment of such a package, however, is very long, particularly at the higher levels of need. Assuming a package is eventually assigned to the

5 recipient, the recipient chooses a service provider approved under the Aged Care Act to provide home care, and the recipient can spend the funds allocated in the home care package by obtaining care from other service providers if they so direct. This is so-called consumer-directed care, often called CDC.

10 Respite-related services can be accessed through funds allocated to a recipient's home care package budget although in practice it seems that tends to happen if any funds are left over after meeting other needs identified in the package. In the event that no funds are left but a need for respite for an informal carer arises – say, on an emergency basis – there may be scope to get access to services funded by CHSP, the

15 Commonwealth Home Support Program. We will explore this during the hearing. The Department of Health does not hold data that can identify whether or the extent to which home care packages are used to purchase respite care. This is a glaring gap in the data.

20 In addition, short-term and emergency respite can be accessed currently through the Commonwealth Respite and Carelink Centres. These are soon to be subsumed in the rollout of the Department of Social Services integrated carer support service from September 2019. The Department of Social Services is responsible for providing other services for all informal carers in Australia, including those caring for older

25 Australians and people with disabilities. These are delivered through the Carer Gateway. The gateway is designed to link carers to services, including education, counselling and advice. Respite services, on the other hand, are available through the different My Aged Care portal administered by another department, Health. The evidence suggests that there may be ineffective coordination between the two.

30 A report by the Aged Care Financing Authority in Act 2018 on respite in Australia outlined the multiple concerns of people who access aged care respite services. These include difficulties navigating the My Aged Care system, inadequate attention to the carer's needs, reduced availability of respite, difficulties faced by people with

35 additional needs, for example, culturally and linguistically diverse people, Aboriginal and Torres Strait Islander people and people living with dementia and the out-of-pocket costs associated with respite care. There are also expert and anecdotal indications that residential respite is too often perceived as a negative and even a risky experience. You will hear more about these issues during the hearing.

40 The evidence will suggest that opportunities are being missed and reform is needed particularly reorientation towards reablement of the elderly person using respite and coordination with provision of support services to enable carers to benefit. Despite the availability of government-funded support services in Australia, the 2015 Survey of Disability, Ageing and Carers reported that 58.9 per cent of primary carers

45 surveyed did not receive assistance from organised services within the previous six months. Of those surveyed 35.1 per cent were not satisfied or were unsure about

their satisfaction with a range of organised services to assist with their caring role, and 25.4 per cent were unaware of the range of services available.

5 A large proportion of primary carers, 86.2 per cent, had never used respite. Of those, 55 per cent said they did not need respite and 10.8 per cent said the care recipient did not want respite. But this still leaves a large number of people who would like respite but have never had it, and it also raises questions about why a very large group of primary carers do not wish to try it. Could this be because of concerns about its efficacy, its quality or even its safety? In the coming days we will hear
10 from a number of such carers who will tell the Commission about their experiences accessing and navigating government-funded systems designed to support them and their experience in accessing respite services.

15 Four expert witnesses will share and discuss their research on the significant contribution and challenges faced by unpaid and informal carers. They are Catherine Thomson of the Social Policy Research Centre at University of New South Wales; Dr Meredith Gresham, also of UNSW and senior research consultant to HammondCare's Dementia Centre; Dr Lyn Phillipson of the University of Wollongong; and Associate Professor Suzanne Hodgkin of the John Richards Centre
20 for Rural Ageing Research at La Trobe University. A panel made up of representatives from four aged care providers will be asked to share their perspectives on the issues associated with providing quality respite care in a regional area.

25 We will also be hearing from the Department of Health on the ways in which respite care is structured and funded, and the Department of Social Services on their carer support services. Our focus in this hearing is on access to the support services that should sustain the caring relationship, not on the system of government payments available directly to primary carers through Centrelink. Informal carers may be
30 eligible for the carer payment, carer allowance and carer supplement. Further detail about services to support carers is available in Background Paper Number 6 which has been prepared by the Office of the Royal Commission for this particular hearing. It is available on the Commission's website.

35 Mildura is a highly appropriate setting for the themes for inquiry in this hearing. It is a regional hub in Sunraysia with a population inside the city as recorded in the last census in 2016 of 32,738 and, of course, the surrounding regions are much more populous. Mildura has an ageing population. In 2016 people aged 65 years and over made up 19.1 per cent of its population compared to 15.7 per cent of the Australian
40 population over 65. And people 85 and over made up 2.7 per cent of the population here, compared to 2.1 per cent of the Australian population. Mildura also has a higher population of people who identify as Aboriginal and Torres Strait Islander than the general population, 4.6 per cent compared to 3.3 per cent.

45 The area also has a high population of veterans, with the most recent data showing there are 679 Department of Veterans Affairs clients, including 338 veterans here. Mildura provides an opportunity for the Commission to examine the experiences of

carers in a regional area with high demand for aged care. Unique to many regional centres, Mildura has a dedicated carers hub. The Hub, as it's known was established in 2017 and connects carers with support and information and provides a meeting place for carers and care support groups. The Hub is currently funded to open on
5 Tuesdays. In 2016, the carers hub of Mildura worked with Carers Victoria to develop the Mildura Carer Blueprint. The blueprint was developed by carers, service providers and Carers Victoria.

10 A range of concerns for carers in the Mildura regional were identified. These included carers feeling unsupported and isolated, lacking awareness, and access to appropriate services, and difficulties dealing with dementia in the home. Tomorrow, we will be hearing from the project coordinator for this blueprint and the Mildura meeting place, Bonney Dietrich together in a panel with carers hub volunteer and steering committee member, Don Laity. In a moment we will commence hearing
15 from today's witnesses, but first I will ask the operator to display the index for the tender bundle of documents to which we intend to take witnesses during the hearing, consisting of 65 tabs. Commissioners, I tender the tender bundle according to the index.

20 COMMISSIONER TRACEY: The Mildura general tender bundle will be exhibit 7-1.

25 **EXHIBIT #7-1 MILDURA GENERAL TENDER BUNDLE**

MR GRAY: Thank you, Commissioner. Today, the Commission will hear first from Elaine Gregory who will tell the Commission about her experience caring for her mum here in Mildura. Ms Gregory took on a caring role while she had four
30 teenage children. Ms Gregory will tell you of the impact of the caring role on her wellbeing, including on her ability to work, along with the difficulty in accessing support services and the importance of those support services. We will then hear from Dorothy (Dot) Holt about her experiences caring for her mother, also named Dorothy in Mildura from 2004 to 2016. Ms Holt was working as a night shift RN in
35 Mildura through much of that period. Even with her personal involvement in the aged care system, her experiences of getting access to necessary services including respite were very arduous.

40 Next, we will hear from Rosemary Cameron, the carer for her husband Don Cameron who lives with Lewy body dementia and in April 2016 moved into a residential aged care facility. Prior to this move Ms Cameron cared for Mr Cameron in their home in the Macedon Ranges and accessed mainstream respite care and specialist mental health residential respite care. Ms Cameron will tell you about the exhaustion associated with caring for someone with challenging behavioural symptoms of
45 dementia and the desperate need for respite. She will also describe to you the trauma she and her husband experienced with respite services who were ill-equipped to

manage Lewy body symptoms, and the challenges of advocating for her husband. She will tell you about her volunteer support group and their vision.

5 The Commission will then hear from Joan Rosenthal who cares for her spouse, Ian, living at their home in Sydney. Ian, a retired doctor, suffered a spinal injury following a fall in 2015. Ms Rosenthal will speak about the grief and loss that comes with caring for a disabled partner and the impact on her own wellbeing. Ms Rosenthal will also tell you about the financial impact of caring as well as the difficulty in planning respite. This afternoon the Commission will hear from Barbara
10 McPhee AM. Ms McPhee will tell you about her experience with caring for her parents in a regional town in New South Wales, including issues of waiting for home care packages, the quality of respite care and the services and difficulties faced by Ms McPhee when navigating the aged care system.

15 The final witnesses today will be Shontia Saluja and Lynette Bishop, vice-chair and chair of the Victorian Committee for Aboriginal Aged Care and Disability who will discuss the particular challenges faced by older Indigenous Australians and their carers in accessing aged care services. We will invite any legal representatives appearing today on behalf of parties granted leave to announce their appearances as
20 and when relevant witnesses are called, rather than doing so now. Ms Hill will now call our first witness.

MS HILL: If the Commission pleases, I call Mrs Elaine Gregory.

25

<ELAINE MAREE GREGORY, AFFIRMED

[10.30 am]

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<EXAMINATION-IN-CHIEF BY MS HILL

MS HILL: Good morning, Mrs Gregory.

35

MS GREGORY: Good morning, Erin.

MS HILL: Mrs Gregory, could I ask you to please state your full name.

MS GREGORY: Elaine Maree Gregory.

40

MS HILL: And what is your age?

MS GREGORY: 59.

45

MS HILL: Where do you live?

MS GREGORY: In Mildura.

MS HILL: On 18 June of this year, you attended a community event with the Aged Care Royal Commission in Mildura, didn't you?

MS GREGORY: Yes, I did.

5

MS HILL: And as a result of attending that day, you then prepared a statement for the Aged Care Royal Commission.

MS GREGORY: Yes, I did.

10

MS HILL: Operator, could I ask you to display document ID WIT.0315.0001.0001. Mrs Gregory, do you see a copy of your statement dated 25 July 2019 on the monitor in front of you?

MS GREGORY: Yes.

15

MS HILL: Are there any changes you would seek to make to that statement?

MS GREGORY: No.

20

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

MS GREGORY: Yes, they are.

MS HILL: Commissioners, I tender the statement of Elaine Gregory.

25

COMMISSIONER TRACEY: Yes, the witness statement of Elaine Maree Gregory dated 25 July 2019 will be exhibit 7-2.

30

**EXHIBIT #7-2 WITNESS STATEMENT OF ELAINE MAREE GREGORY
DATED 25/07/2019 (WIT.0315.0001.0001)**

MS HILL: As the Commission pleases. Mrs Gregory, is Mildura home?

35

MS GREGORY: Has been for about the last 40 years.

MS HILL: And you live in town with your husband, Geoff?

40

MS GREGORY: That's right, yes.

MS HILL: And you've got adult children?

MS GREGORY: Yes, I have.

45

MS HILL: And is it fair to say that you're a proud and busy grandmother?

MS GREGORY: Very busy, yes.

MS HILL: So Mildura has been home for the past 40 years. Where did you grow up, Mrs Gregory?

5

MS GREGORY: I grew up in Walpeup, 130 kilometres away, yes.

MS HILL: And you were one of five siblings growing up?

10 MS GREGORY: That's right, yes.

MS HILL: And your parents ultimately settled in Walpeup.

MS GREGORY: That's right. Dad had always lived in Walpeup, yes, on the farm.

15

MS HILL: How did your mum and dad meet, Mrs Gregory?

MS GREGORY: They met at a kitchen tea, I think it was, at a dance years ago, yes.

20 MS HILL: And your dad grew up on the farm. Did your parents ultimately end up being farmers?

MS GREGORY: Yes, they did. Yes.

25 MS HILL: What did they farm?

MS GREGORY: Wheat and sheep.

MS HILL: And is that farm still in the family?

30

MS GREGORY: Yes, my twin brothers of 57 still farm it.

MS HILL: What was life like growing up in Walpeup?

35 MS GREGORY: Fun, yes. Best life ever on the farm, yes.

MS HILL: And why was that?

40 MS GREGORY: Just relaxing, yes, and it was sort of a special – Dad's family had actually settled there, I think it was in 1912 or something, purchased the farm and cleared a lot of it.

MS HILL: What was your relationship like with your dad over the years?

45 MS GREGORY: Very close to my father, yes.

MS HILL: And if I can ask you about your mum. In your statement, you refer to a story where at one point your mum was nursing a kangaroo.

5 MS GREGORY: That's right. The mother had died, so we reared this baby kangaroo, yes.

MS HILL: And do you recall when that was?

10 MS GREGORY: Be over 40 years ago, yes.

MS HILL: And why did you pick that story to tell the Commissioners?

15 MS GREGORY: Just something I remember with Mum having the pillow case in front of the wood fire and she would hold it out, and it would just hop itself into it, yes.

MS HILL: And you've provided the Aged Care Royal Commission with a few photos, haven't you?

20 MS GREGORY: I have, yes.

MS HILL: Operator, could I ask you to display document ID, EGG.0001.0002.0001. Is that a picture of your Mum and Dad?

25 MS GREGORY: That is, yes, taken the night of their 50th wedding anniversary.

MS HILL: And why did you pick that photo?

30 MS GREGORY: It was a special night for them because we had a big dance there at Walpeup for them, yes.

MS HILL: Operator, could I ask you to display now document ID EGG.0001.0001.0002. Could I ask you to describe that photo, please.

35 MS GREGORY: That was taken Christmas Day – sorry, Christmas Day 2005, two days before Dad had been diagnosed with leukaemia.

40 MS HILL: Now, Mrs Gregory, your parents ultimately moved from Walpeup to Mildura, didn't they?

MS GREGORY: Yes, they did.

MS HILL: And do you recall when was that was?

45 MS GREGORY: Goodness. 2004, I think it was, he was diagnosed with lymphoma.

MS HILL: And is that why they ultimately moved?

MS GREGORY: That's – yes, to be closer to Mildura for all the doctors and medical reasons, yes.

5 MS HILL: And, eventually, did your parents end up moving next door to you and your family?

MS GREGORY: They did. Dad was in Melbourne for six months with his treatment, but he got too sick, so they sort of ceased it, and they moved back to Mildura, into the flat across the road. And then the house next door become
10 available, so they rented that and then they actually bought it.

MS HILL: Yes. And your father passed away in 2006; is that right?

MS GREGORY: Yes, he did. Yes.
15

MS HILL: How was your mother after your father's death?

MS GREGORY: Lost, yes. But it was probably good she had been in Mildura for sort of 12 months and had started a bit of a life for herself there, here in Mildura.
20

MS HILL: When you describe your mother as "lost", what do you mean by that?

MS GREGORY: Well, she had lost her soulmate. So they sort of looked after each other, yes.
25

MS HILL: And what did you do at that time?

MS GREGORY: Well, the 12 months Dad was here I was sort of caring for him, helping, and then I just took over caring for Mum.
30

MS HILL: What sort of things would you do for your mother?

MS GREGORY: Took her to all her appointments, pretty – all her shopping because she didn't have a licence. So it was pretty well I had to do everything for her.
35

MS HILL: Did it feel like you were doing a lot for your mum at the time?

MS GREGORY: Yes, because I had to sort of reach out then and find – go to Veterans and cancel everything of dad's as well, yes, because he was a returned soldier, so yeah.
40

MS HILL: What else was happening in your life at that time?

MS GREGORY: At that stage I had sort of four, as you said, teenagers, nearly teenagers, children, and running our own lawn mowing business, paving.
45

MS HILL: Did you share the load with siblings or any other family?

MS GREGORY: No, not really. No.

5 MS HILL: Was that an option for you?

MS GREGORY: They just didn't seem to take an interest in anything with her.

10 MS HILL: Why did it fall to you to care for your mum ultimately?

MS GREGORY: I suppose you live next door to her and someone's got to look after her at the age she was.

15 MS HILL: Mrs Gregory, in your statement, you say:

If I wasn't going to care for my mum, then no one else was.

MS GREGORY: Yes.

20 MS HILL: Why did you feel you had no choice?

MS GREGORY: Well, there's – I didn't know what was out there or anything for help. So you just - - -

25 MS HILL: And did you receive any?

MS GREGORY: Not really, no. No.

30 MS HILL: You referred to the people that you had to contact after your father passed away. When you first started caring for your mum - - -

MS GREGORY: Yes.

35 MS HILL: - - - what organisations did you need to contact?

MS GREGORY: Probably just the everyday – just – our mum was on Centrelink but Dad was with Veterans, so we sort of had to transfer Mum across. And it was just reaching out to everything, trying to get help for her in the home and everything.

40 MS HILL: And what was that like for you?

MS GREGORY: Frustrating. Even if you sort of went to the doctors there was no advice given to you from them for support.

45 MS HILL: And that's something you talk about in your statement, isn't it?

MS GREGORY: Yes. Yes.

MS HILL: And in your statement you describe the role that the GPs could have had in helping you care for your mother. What role in particular are you referring to?

5 MS GREGORY: Just the caring or just the everyday – just sort of everything probably, yeah. I was lucky my daughter was – worked with the aged Aboriginals, so she sort of guided me and her boss guided me a little bit into the aged side of things.

10 MS HILL: In your statement you describe that you had no pathway to follow at this particular time. What do you mean by that?

15 MS GREGORY: I just – I had no idea which way to go for getting anything organised, her Safety Link for if she had a fall. You sort of had no idea what way you should be going with anything.

MS HILL: What did you want from a pathway?

20 MS GREGORY: Probably someone to speak to you and guide you and sort of sit you down as a support worker and sort of say, “Well, this is an avenue to go down for everything.” But you were sort of following it yourself or trying to talk to someone.

MS HILL: You refer to having to contact Veterans’ Affairs a moment ago.

25 MS GREGORY: Yes.

MS HILL: Why did you need to contact Veterans’ Affairs?

30 MS GREGORY: To try – well, I had to let them know Dad was deceased and to try and get Mum onto the War Widow, because Dad had a gold card, and to work our way to into putting Mum onto it.

MS HILL: And what happened when you contacted Veterans’ Affairs?

35 MS GREGORY: Well, we had – I had been taking Dad in there, and they were to put him on a – more of a disability pension. And when we actually went in there and made an appointment, nothing – it was still sitting there. It had never been processed. So then we had to go through to prove that Dad had actually passed away from the effects of the war, which was back to the 1940s, yes.

40

MS HILL: And what was that experience like for you?

45 MS GREGORY: Alan Wilson, president at the time, he was very good, actually. He was the one that pushed it, got it moving for us to prove that Dad did die of the war effects.

MS HILL: And he was president of the Returned Services League.

MS GREGORY: He was back then, yes. Yes.

MS HILL: Mrs Gregory, do you remember how you felt when you first started caring for your mum?

5

MS GREGORY: You just sort of step into the role, I suppose, because Dad was given two days and he survived two weeks. We had him home for 24 hours before he passed away. But you just step into that role, because Mum was – she was, what, 83 or 4. Well, she was past all those – working out all those avenues.

10

MS HILL: And you've now had the opportunity to reflect on what it was like for you at the beginning of caring for your mum. What do you think about what you were doing?

15

MS GREGORY: Yes, I don't think I realised how it was 24/7. You – it was just constant all the time with working out what avenue, and each day there seemed to be – there would be another issue. So you would be chasing up another avenue of things.

20

MS HILL: And what kind of issues would come up for you?

MS GREGORY: Probably just working out what – for her packages and everything like that, and you had your Safety Link and getting someone in to do a little bit in the house for her. And then I sort of got Sunassist on board to volunteer to come and pick her up one day a week to take her somewhere so I didn't have to take her.

25

MS HILL: And how did you come to have contact with Sunassist?

MS GREGORY: Just made the phone call, saw the – I think probably an ad in – or someone I spoke to, and made the phone call, and they came around and assessed Mum.

30

MS HILL: And were you referred to Sunassist by a particular person, or was it through word of mouth or - - -

35

MS GREGORY: I think just word of mouth, I think. You saw the ad somewhere or something, yeah.

MS HILL: And what sorts of things would Sunassist do for you at the beginning?

40

MS GREGORY: Well, they would sort of come and pick Mum up one day a week and take her to the RSL. I think it was on a Wednesdays. They'd pick her up and take her to the Laurel Club that was on.

45

MS HILL: And when your mum was at the RSL, what would that mean for you?

MS GREGORY: I could – often I could go to work that day with my husband, yeah, because then I didn’t have to be back at 1 or whatever to pick her up to bring her home again. Yes.

5 MS HILL: And what sort of work were you doing with your husband?

MS GREGORY: Lawn mowing and paving. Pretty hands-on, yes.

10 MS HILL: Were you working much at this time overall?

MS GREGORY: Well, the days I could work, otherwise my husband went on his own to do the work.

15 MS HILL: And if Sunassist were coming about once a week, does that mean - - -

MS GREGORY: It was only once a week to start with is all they could do, yes. And then we gradually went to two and then three days a week, which took a lot of the workload off me.

20 MS HILL: And what did that mean for what you were able to do during that time?

MS GREGORY: Could go to work, yes. Mum – she liked to go out, which was good. That was – which I encouraged for her to go out, but she had to rely on me for the first few – probably 12 months nearly.

25 MS HILL: In your statement you describe the experience of having your mother assessed - - -

MS GREGORY: Yes.

30 MS HILL: - - - with an ACAT. What would your mum do when the ACAT assessment took place?

35 MS GREGORY: Well, she knew she was coming so she would have the house clean. Everything was done, so everyone thought, “Oh, she’s coping so well.” But then I never actually sat down with the lady that would do the – the ACAT lady. I would be probably at work or something and – so you never actually spoke to them and they asked you how did you – how were you coping with it all.

40 MS HILL: So were you involved in the ACAT at all or - - -

MS GREGORY: I knew when she was coming. Probably once I might have sat in, but other times I was at work.

45 MS HILL: Do you think you should have been involved?

MS GREGORY: I think so. A bit of support to actually say to you, “How is Mum going and coping with everything?” Because they can keep their house clean if they really want to and you’re not there doing it, yes.

5 MS HILL: Why was it important – or why is it important for you to have been asked whether you needed support at that time?

MS GREGORY: Well, probably just a bit – support – I was sort of – I got to the stage with Mum, I – you’re beginning to think, “Oh my goodness, if she would just
10 pass away it would all be over.” And I knew that wasn’t the right attitude to have with it all, so I knew that I needed – just needed someone to come and say, “Hey, is everything all right with you?”

MS HILL: And how does it feel reflecting back on how you felt at that time with
15 your mum?

MS GREGORY: Probably angry and frustrated. Now looking back, and especially when you read through a lot of it, you realise, “My goodness. How did I get through all that?”
20

MS HILL: How did you get through all that?

MS GREGORY: You just kept yourself going. You knew you had to. You didn’t have a choice.
25

MS HILL: If I can return to the ACAT assessment. If you had been able to be present when that assessment was taking place, do you think you would have felt comfortable to say that you needed a hand in front of the assessors and your mum?

30 MS GREGORY: Probably not in front of Mum, probably I wouldn’t have, because then you feel like you’re a bit of a failure because you’re not coping with what you’re doing. You should be able to cope with it all.

MS HILL: In what circumstances do you think you would have felt comfortable to
35 have that kind of discussion?

MS GREGORY: Either if I sat with the ACAT lady or somebody else was there as a support person for you, to come in and just check on you.

40 MS HILL: And did you have the opportunity to do that at any stage?

MS GREGORY: No. No.

MS HILL: What was the impact of caring for your mum on your relationship with
45 your mum?

MS GREGORY: With – well, with – trying at times, and we sort of – we had always clashed – clashed in a way. I think if I said “black”, she would say “white”. But you just went in and done what had to be done. And I suppose next door, you could just come and go. You would nick in and check her three or four times a day and do what you had to do for her. But you got – I probably didn’t show it in front of her, but I would go home frustrated, frustrated and just think, “Oh my gosh. Why is it me all the time?”

MS HILL: And how would you manage that frustration?

MS GREGORY: Probably took it out on my husband and children.

MS HILL: And how were your husband and your kids during this time?

MS GREGORY: Well, my husband was probably frustrated because I wasn’t there to help him work, whereas I was lucky my children were very good with my mother, especially my older daughter. She would take – she would go and do things with Mum for me or take her somewhere in the car.

MS HILL: What was the experience of caring for your mother like, if I could ask?

MS GREGORY: Draining, very draining, frustrating, yes. But then I’m glad I did it, yes. I sort of wouldn’t change it, but a bit of support would have been good.

MS HILL: What was the hardest thing for you during this time?

MS GREGORY: Probably the hardest thing for me was time for myself, probably. You sort of – you were 24/7 with Mum in case she had a fall. You had to have your phone with you and you really couldn’t go anywhere or do anything. You had to be close by to – if you got that call from Safety Link that she needed you.

MS HILL: And when you were referring to Safety Net, what are you referring to in particular?

MS GREGORY: Safety Link. It’s – either they wear on their wrist or a neck thing, and if – and she pushes the buzzer and it alerted them in Bendigo that she’d had a fall or she needed help. So then they’d ring me to go over and check on her day or night.

MS HILL: So how did you cope in circumstances where you’ve described being on call effectively 24/7?

MS GREGORY: Well, if I couldn’t be around, one of my children – sort of had to make sure they were around with their phones.

MS HILL: In 2006, Mrs Gregory, you got involved with Carers Victoria, didn’t you?

MS GREGORY: Yes, I did. Yes.

MS HILL: How did that come about?

5 MS GREGORY: I can't remember where I saw the ad or anything. I just got myself out there. I knew I needed help to talk to someone. I think it was through Bendigo Health first, and I just reached out and made a phone call and started attending their meetings at the time, which was only once a month anyway.

10 MS HILL: How did you know that you needed help?

MS GREGORY: When I started thinking, "If Mum would only pass away, everything would be better." The frustration of it and, yes, 24/7 on – you're on call.

15 MS HILL: And you describe going to meetings at first once a month.

MS GREGORY: That's all there was, yes.

MS HILL: What would happen at those meetings?

20

MS GREGORY: You would have a cuppa and a chat with someone else that was – a lot of the others – I was one of the younger ones involved. A lot of the others were caring for their partners, so they were older people, yes.

25 MS HILL: And what did that mean in terms of your continued involvement with Carers Victoria?

MS GREGORY: It was just an outlet for me to realise there's other people in the same sort of caring role and they feel the same way as I do.

30

MS HILL: In your statement you talk about the Mildura Carers Hub.

MS GREGORY: Yes.

35 MS HILL: What is the Mildura Carers Hub?

MS GREGORY: The Mildura Carers Hub, probably the last two years it's – we've grown. We actually now, some of us ladies meet up once a month and go somewhere for a cuppa on our own, attend the meetings and then we sometimes have
40 workshops as a guidance for the aged or dementia or anything like that. It's just a get-together for us all to sit and have a chat.

MS HILL: And what kind of things are the other people that you meet there and connect with dealing with?

45

MS GREGORY: A lot of them are caring for – it might be children, even adult children or their partners, yes. And some of them it's their parents.

MS HILL: And how would you describe your level of involvement at the hub?

MS GREGORY: Well, I've just been made vice-president of the support group, so, yes, got very involved, especially the last 12 months.

5

MS HILL: And how are the workshops that you've described organised?

MS GREGORY: Through Bonney Dietrich. She sort of does them with the carers.

10 MS HILL: And how do they work? Does someone come along?

MS GREGORY: Yes, yes, come along there, usually to the hub, which was two days a week but we've just had our funding cut back to one day a week.

15 MS HILL: Before that funding cut, how often would you attend the hub?

MS GREGORY: It'd be once or twice a week. I would pop in just for a cuppa, to see Bonney or someone, yes.

20 MS HILL: And why do you access it at those times?

MS GREGORY: Well, it was only open Tuesday, Wednesdays. So I'd, sort of, pop in one day or two days. You'd just pop in for a cuppa and a chat with someone.

25 MS HILL: The fact that it's now only open once a week - - -

MS GREGORY: Yes.

MS HILL: - - - what does that mean for you?

30

MS GREGORY: Well, the other – was it last week or the week before? I couldn't get there Tuesday, so I missed out on popping in there at all. So then you sort of have to wait until the next week to see anyone.

35 MS HILL: What's the role, Mrs Gregory, of the hub in the community of Mildura?

MS GREGORY: Just an outlet for us – the carers to pop in and touch base and see how each other are coping. You might be good, but then there's someone else that is in there that needs a bit of a pick-up and encouragement.

40

MS HILL: Your mother's now in residential care, isn't she?

MS GREGORY: Yes, she is.

45 MS HILL: When did she go into care?

MS GREGORY: Three years ago. So it must be May 2016.

MS HILL: How was the decision made to put your mum into residential care?

MS GREGORY: Well, I sort of made the decision. I'd had her in and out of respite off and on, and her eyesight – she has nearly lost her eyesight, and she was at the
5 stage of turning on the wrong hot plates and smoke alarms were going off and – yes.

MS HILL: How did your mum feel about going into residential care?

MS GREGORY: I was the worst person in the world when I said there was a spot
10 for her, yes.

MS HILL: And how did that make you feel?

MS GREGORY: Terrible. I think her words were, she rang – “Well, I will ring all
15 the other siblings.” And I think her words to them was, “Oh, did you hear the bombshell? I'm going into care.”

MS HILL: And what did you do?

MS GREGORY: Well, I actually rang a couple of them and warned them that Mum
20 will probably ring, and so they encouraged her. And by that night she sort of said, “Oh, all the others reckon it's a great idea.”

MS HILL: And how is your mum now?
25

MS GREGORY: She loves it, yes.

MS HILL: Has your mum being in residential care seen a change in the amount of
30 care of the amount of things that you do for your mum?

MS GREGORY: I still do a fair bit for her, appointments and things, but - - -

MS HILL: What sort of things do you do aside from appointments?

MS GREGORY: Last week she had to have her – go and have her eyes checked.
35 So I had to take her to the eye specialist. I'm there probably every second day. I'm involved with the activities and some of her clothes that she doesn't want them to wash, I – good ones, I take them home, buying a few groceries for her and just sort of every – things that the home sort of don't do for her.

MS HILL: What activities are you involved in?
40

MS GREGORY: Well, we had the fete last Friday, so I was involved with the
45 committee, and I go in and help with activities. And my husband drives the bus for when they have outings.

MS HILL: And have you been able to get back into working?

MS GREGORY: No. My husband has actually retired. He's had a quadruple bypass five years ago, so he decided to – I do – sorry, I do three hours a week of cleaning now, but that's all at this stage.

5 MS HILL: And as far as what you're doing for your mum in residential care, do any of your siblings help you out with that at all?

MS GREGORY: Not really, no. My brothers do a little bit. One of my brothers does all the financial side of the stuff for me. But other than that, not much, no.

10

MS HILL: You've given evidence this morning about how you put your mum into respite care a couple of times before she went into permanent residential care.

MS GREGORY: Yes.

15

MS HILL: How did that come about?

MS GREGORY: Well, I was going away and I just – I didn't know what I was going to do with Mum because no one else offered to take her. So I just went and looked into – she had been to a couple of – she went to Regis for a weekend and then Jacaranda at Redcliffe, and then I got her into Prince's Court Homes, just went in there and asked them about booking her in for respite.

20

MS HILL: And was that how you organised it?

25

MS GREGORY: Yes. And you sort of had to do it a month, two or three ahead to get her in there.

MS HILL: And how long would your mum go into respite for when she was there?

30

MS GREGORY: Two weeks at a time, yes.

MS HILL: What do you say the point of your mum being in respite at that time would have been?

35

MS GREGORY: For myself, just to give me a bit of space and to – just even if we wanted to go – I used to only do it when we were going away, and then in the end I done it a couple of times when I was at home to give me space at home so that you could do the things you wanted to do or work at home.

40

MS HILL: Was it always available, respite, when you needed it?

MS GREGORY: Not really, no. I had to book ahead.

45 MS HILL: And how often – how much in advance would you need to book ahead?

MS GREGORY: Probably two or three months. If I knew we were going somewhere, then I would sort of go in well ahead to book it in advance.

5 MS HILL: And how was the amount of time that your mum spent in respite decided?

MS GREGORY: They only do two weeks at that stage, yes.

10 MS HILL: And did that amount of time work for you and your family?

MS GREGORY: Yes. Yes. Yes.

15 MS HILL: Now, you mentioned in evidence that about five years ago your husband, Geoff, had a quadruple bypass.

MS GREGORY: That's right, yes.

MS HILL: How is Geoff now?

20 MS GREGORY: He's good, yes. Yes, just can't lift or anything. Yes.

MS HILL: Were you able to access respite – you were caring for your mum, weren't you, when this happened?

25 MS GREGORY: Yes. Yes. No, I had to ring my brother an hour and a half away and he – because we had to – I had to drive to Melbourne, and we met him on the road and he drove up to actually pick Mum up and take her back to the farm for me because – no way I would have got her in for respite.

30 MS HILL: And how did all that come to be?

MS GREGORY: In what way, sorry?

35 MS HILL: Were you ultimately able to organise all that?

MS GREGORY: Yes. Yes.

40 MS HILL: Looking back at your time when you're caring for your mum full-time, when she wasn't in residential care - - -

MS GREGORY: Yes.

45 MS HILL: - - - what would you have needed to be able to sustain your caring role for your mum?

MS GREGORY: More support, I think, and probably with your doctors, the GPs, just – I took Mum every month, but there was never any suggestion to me that – did I

need any more support or what was available. You sort of went out and found it yourself.

5 MS HILL: And does the support that you're receiving now through the carers hub, is that the sort of support you were looking for?

10 MS GREGORY: Yes, definitely. Yes. And unless you know someone that's been through it, then you can actually – I can guide someone and say to them, "Well, try this." But I didn't know of anybody then, so I was just reaching out in all avenues that I could find.

15 MS HILL: And is that your experience now, that you talk about how you cared for your mum, how you supported your mum, through accessing those services at the hub?

MS GREGORY: Yes. Yes.

20 MS HILL: In your statement, you describe that communication is key when it comes to carer support. What do you mean by that?

MS GREGORY: Probably more the communication from your GP, the doctors, a bit of advice that there is a support group – this support group out there for you to – and for them to guide you in your – the Safety Link and everything in those avenues.

25 MS HILL: And do you have a view that being based in Mildura meant that you had certain support services that were or were not available to you?

30 MS GREGORY: Probably there wasn't, probably, because a lot of Mum's Veterans' phone calls were to Bendigo – to Veterans' in Bendigo, so there was sort of no one here in Mildura. So you'd have to make that phone call to Bendigo to go through Veterans'.

MS HILL: Commissioners, that concludes my examination of Mrs Gregory.

35 COMMISSIONER TRACEY: Thank you. Mrs Gregory, was the first occasion where you had interaction with a government agency when you decided that it was necessary for you to take on the caring role for your mother, the arrival of the assessment team?

40 MS GREGORY: Sorry?

COMMISSIONER TRACEY: I will break that up a bit. The point arrived where you felt that you had to take on the caring role for your mother.

45 MS GREGORY: Yes. Yes.

COMMISSIONER TRACEY: What I'm asking you is after that event occurred, you had interaction with a government agency.

MS GREGORY: It would have been Centrelink to start with, yes.

5

COMMISSIONER TRACEY: Yes. And was that agency the assessment team who
- - -

MS GREGORY: They - - -

10

COMMISSIONER TRACEY: The people who were assessing your mother for an aged care package.

MS GREGORY: Yes. She was already on an aged care – the aged care package, and Dad was on the veteran affairs one.

15

COMMISSIONER TRACEY: All right. And what I want to ask you is at that point, you were obviously in need of advice about the support services that were available for your mother and for yourself.

20

MS GREGORY: Right. Yes.

COMMISSIONER TRACEY: Was any of that information provided to you by the people in the assessment team?

25

MS GREGORY: No. No.

COMMISSIONER TRACEY: Were you referred to any other agencies that might be able to help you in that way?

30

MS GREGORY: No. I sort of just went – we went to Veterans' with Dad's – for Dad's things and then they said, "Well, try putting her – getting her the War Widow." So we sort of just went through Veterans' Affairs. It was just through them. No support.

35

COMMISSIONER TRACEY: Well, would it have helped you – I suppose the answer to this question is probably obvious, but I will ask it anyway. Would it have helped you if they'd been a bit more proactive and given you referrals to - - -

MS GREGORY: Yes. No, definitely. Yes.

40

COMMISSIONER TRACEY: - - - agencies that could have assisted you?

MS GREGORY: There's sort of no support out there at that stage then, no, so it would have helped me a lot to know which way to go.

45

COMMISSIONER TRACEY: Yes. Well, we're very grateful to you, Mrs Gregory, for sharing your story with us. It is one, on your part, of great care and love for your mother, and the burden was great and perhaps it needn't have been so great. And your evidence has assisted us in being able to make recommendations about how
5 other people might be assisted in the future - - -

MS GREGORY: Yes, that'd be good.

COMMISSIONER TRACEY: - - - in getting care that is there that they often don't
10 know about.

MS GREGORY: No, I think you've got no idea what's there. No.

COMMISSIONER TRACEY: Thank you.
15

MS HILL: Commissioners, before we break for the morning tea adjournment, I note that the second photograph of Mrs Gregory is not referred to in Mrs Gregory's statement. If I could formally tender or have document ID ECG.0001.0002.0001 included as part of the exhibit 7-2, which is Mrs Gregory's statement.
20

COMMISSIONER TRACEY: Yes, certainly. It will be incorporated in that exhibit.

MS HILL: As the Commission pleases.

COMMISSIONER TRACEY: The Commission will adjourn for 15 minutes.
25

<THE WITNESS WITHDREW [10.35 am]

30 **ADJOURNED** [10.35 am]

35 **RESUMED** [11.26 am]

COMMISSIONER TRACEY: Yes, Ms Hill.

MS HILL: If the Commission pleases, I call Dorothy Holt.
40

<DOROTHY FRANCES HOLT, SWORN [11.27 am]

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

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

MS HOLT: Yes, Dorothy Frances Holt.

5 MS HILL: And you've asked me to refer to you by Dot today.

MS HOLT: Yes, I have.

MS HILL: Dot, how old are you?

10 MS HOLT: 67.

MS HILL: And you are retired?

15 MS HOLT: I am retired.

MS HILL: What did you used to do for work?

MS HOLT: I was a registered nurse.

20 MS HILL: And how long were you a registered nurse for?

MS HOLT: Nearly 50 years, and 25 in aged care.

25 MS HILL: Did you enjoy that work?

MS HOLT: Yes, I did enjoy it.

MS HILL: What about that work did you enjoy?

30 MS HOLT: When I went back to aged care – and it was a conscious decision because I loved it – you actually got to deal with the people and I loved the caring role.

35 MS HILL: Where are you from, Dot?

MS HOLT: Originally, Melbourne, then I moved to Mildura, and now South Australia.

40 MS HILL: When were you in Mildura?

MS HOLT: From about 2001 till 2015.

MS HILL: And you got in touch with Aged Care Royal Commission and said that

45 you wanted to tell your story, didn't you?

MS HOLT: I did.

MS HILL: Why did you do that; why did you want to tell your story?

MS HOLT: Because I think aged care is an area which needs a lot of looking at, and there's a lot of work needs done to it.

5

MS HILL: And in addition to that experience working as a nurse, you've had experience caring for your mum as well, haven't you?

MS HOLT: I did. I had Mum for 12 years.

10

MS HILL: You've prepared a statement, haven't you?

MS HOLT: I have.

15 MS HILL: Dated 23 July 2019.

MS HOLT: Yes.

MS HILL: Operator, could I ask you to please display document ID
20 WIT.0336.0001.0001. Do you see a copy of that statement on the monitor in front of you?

MS HOLT: Yes, I do.

25 MS HILL: Are there any changes that you want to make to that statement?

MS HOLT: No.

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

30

MS HOLT: They are.

MS HILL: I tender that statement, Commissioners.

35 COMMISSIONER TRACEY: Yes. The witness statement of Dorothy Frances Holt dated 23 July 2019 will be exhibit 7-3.

40 **EXHIBIT #7-3 DOROTHY FRANCES HOLT DATED 23/07/2019
(WIT.0336.0001.0001)**

MS HILL: As the Commission pleases. So in 2001 you moved to Mildura.

45 MS HOLT: Yes.

MS HILL: And in 2004 your mum moved to Mildura as well, didn't she?

MS HOLT: She did, yes.

MS HILL: How did that come about?

5 MS HOLT: Mum had been unwell and my father had just died in Melbourne, and I noticed that she wasn't very well and she had also started having fainting attacks. She was under investigation for some – to find out why she was fainting and her blood count was low and she needed more care. My aunt had taken her from where she was living and started it all again so I said to my sons, "Get her, put her on a
10 plane and send her up here".

MS HILL: How did that all that go?

15 MS HOLT: Aunty wasn't very happy.

MS HILL: How did your mum feel about coming - - -

MS HOLT: Mum was happy to come.

20 MS HILL: Do you recall how old your mum was at that time?

MS HOLT: About 83.

25 MS HILL: And you've described your mum as having episodes of fainting. What was her health like overall at that age?

MS HOLT: Overall her health was good but what she had was an acute duodenal ulcer that was bleeding so she was fainting because her haemoglobin had dropped.

30 MS HILL: And once your mum is living in Mildura, what was your role with your mum?

35 MS HOLT: Well, initially we thought it was just get her back to health and she could go back to Melbourne but as she was with us, we were finding she wasn't – I would leave her out sandwiches and a thermos of tea to drink during the day while I had been asleep, and she wasn't drinking the tea and she wasn't eating. Then we started noticing she was forgetting more stuff, so the decision was made then not to go home.

40 MS HILL: You were working at this time?

MS HOLT: Yes.

45 MS HILL: So once you had made that decision to keep your mum in Mildura what did you do then?

MS HOLT: I just kept on going. I kept on going to work and kept on looking after Mum.

5 MS HILL: What sort of things would you do for your mum?

MS HOLT: You could take her shopping with you. She was still very mobile so we got her into the aquatic centre and she was doing exercises twice a week, so you'd take her to those. And she just really came along with us wherever we went.

10 MS HILL: Was she living with you at this time?

MS HOLT: Yes, she was, the whole time.

15 MS HILL: Who else was living there, Dot?

MS HOLT: At that stage my husband.

MS HILL: Did your mum and husband continue to live with you?

20 MS HOLT: Mum did, my husband didn't. He left – he went in about 2010.

MS HILL: Now, you've provided a photograph to the Royal Commission of your mum, haven't you?

25 MS HOLT: Yes, I have.

MS HILL: Operator, could I ask you, please, to display document ID RCD.9999.0134.0001. Is that a photo of your mum?

30 MS HOLT: Yes, it is.

MS HILL: And you and your mum share the same name, don't you?

35 MS HOLT: We do.

MS HILL: Does she go by Dot also?

MS HILL: No, she's Dorothy.

40 MS HILL: Why did you pick that photo?

MS HOLT: I took that one specially, actually, on, what, Friday a week ago. We had her out to have her hair done so she looked good.

45 MS HILL: How is your mum going at the moment?

MS HOLT: Yes, doing well, except for the disaster yesterday when the tooth fell out.

MS HILL: What happened yesterday?

5

MS HOLT: We got a phone call when we were here saying Mum has lost a tooth and the nursing home were in a bit of a panic.

MS HILL: And so what did you do?

10

MS HOLT: I rang them back and said, "Don't worry. Just look – just watch her and then I will take her to the dentist when we get home."

MS HILL: Is that kind of contact a typical kind of experience for you, Dot?

15

MS HOLT: Yes, it is, they're very good.

MS HILL: You and your mum have together written a description about your mum's life, haven't you?

20

MS HOLT: We have.

MS HILL: And you've included that in your statement at paragraph 11.

25

MS HOLT: Yes.

MS HILL: Would you like to read that out?

MS HOLT: Yes. I'll read it out. Well, we just say there this was done in preparation for Mum's funeral with Mum.

30

My mum Dorothy Joyce Ashton was born –

do I give the date? Yes:

35

...on 28 October in 1921 in Brunswick, Melbourne. Set out below is an extract of writing my mum has provided to me about herself.

Education: from 1927 to 1939, I attended St Peter's Girls School, Murrumbena, Victoria from prep to leaving as in year 12. I was a prefect in my final year, school captain. I also was captain of the school basketball team. I played goal shooter and sang in the school choir. It was at school when I was in year 1 that I met my lifelong friend, Evelyn. Ev was in prep. Our friendship remained active until she died in 2004. After I left school, I worked for my father as a telephonist on his ambulance business. I married William Jack Hocking on 27 May 1944 when I was 22 years old. In the early days we would play tennis at Evelyn's father's house. Jack and I played competitive tennis.

45

We lived in Melbourne while the girls were young and at school. Jack had butchers shops which kept me and him busy. I helped him in these.

5 *Married life was not easy and is not something I choose to talk about. Jack was a violent, bad-tempered alcoholic. I was subject to his rage on a daily basis. I learned over the span of my marriage to remain quiet and unobtrusive. In 1995, I chose to leave the marriage. I disappeared from everyone for three months. The only people who knew where I was were my dear Evelyn and my*
10 *19 year old grandson. From that time until 2004, I lived in Carlton at Princes Hill Village. While I lived there I ran the kiosk, walked every day and read.*

15 *In 2004 I was not well, and I was put on a plane by my grandsons and flew to Mildura. For the next 12 years I lived with Dot. We stayed in Mildura until 2015 when we moved to Mount Pleasant.*

And from that, you understand Mum's a very quiet, unassuming lady.

MS HILL: Why was it important to share that about your mum?

20 MS HOLT: Because it's for Mum who was the real person, because Mum now isn't who she was, and that's the person that I look after.

MS HILL: When your mum first moved to Mildura, you were working.

25 MS HOLT: I was, yes.

MS HILL: What would your average day or night involve?

30 MS HOLT: Usually I worked night duty which made it easier. I would – well, if I hadn't worked, the first night back you would just get up in the morning, have a rest in the afternoon, and go to work at 11 o'clock, come home, set Mum up for the day and then go to bed and have some sleep. But then every time you woke up, of course, you would check on what she was up to and that just continued through.

35 MS HILL: What was your average week like?

MS HOLT: Average week. Weekdays, Monday to Friday would just be normal; you would do your household things. You would do – take Mum initially, take her to the swimming pool, do the exercises, do your shopping, anything you had to do
40 and really just – it was like looking after a child.

MS HILL: Why do you say that?

45 MS HOLT: Because she didn't do anything for herself. She wouldn't get up and initiate having a cup of tea or initiate eating a meal. You'd have to just put that all for her, and just keep her eating it.

MS HILL: Were you able to work full time?

MS HOLT: No.

5 MS HILL: How frequently were you working?

MS HOLT: I was working five nights a fortnight.

10 MS HILL: Looking back on at now, how do you feel about how you were caring for your mum at the time?

MS HOLT: Look, I think it was all right. It ended up it wasn't all right, it wasn't a good experience when I was still working. It was just too hard but then that was taken out of my hands anyway, so - - -

15

MS HILL: Was your mum assessed for an ACAT?

MS HOLT: She was and I've got it down here, several times. When did we - - -

20 MS HILL: Were you involved?

MS HOLT: I made a point of being around when they were done.

MS HILL: How did you do that?

25

MS HOLT: Just being in the house and usually, if I could, in the room with her when she was being assessed.

MS HILL: And were your mum's care needs and your care needs considered?

30

MS HOLT: Mum's were but there was very little interest in what I might have needed or what it was like looking after her because everything is focused on the client.

35 MS HILL: Were you able to explain to the assessor what your needs were as a carer?

MS HOLT: No, I didn't really get the – no, I didn't. But I made sure they knew that Mum really wasn't aware of what was going on.

40

MS HILL: Do you think your needs should have been considered?

MS HOLT: Yes, I do. You would cope better if your needs were looked at.

45 MS HILL: What was the impact of your caring for your mum on your overall wellbeing?

MS HOLT: In the end it wasn't a good impact at all. I had had – I had been sent to Melbourne and had to have some stents done because I had spent a little time in hospital. And that was really hard, and I don't think – I don't know whether – just my blood pressure was then out of control and with the stress and all that stuff going on, it just wasn't controllable.

MS HILL: Were you receiving any support at this time for caring for your mum?

MS HOLT: When we were in Mildura, she was going to day care one day a week and there was a two hour stint every Wednesday when somebody would come in.

MS HILL: And when you refer to day care, what are you referring to?

MS HOLT: She would go there, they would have morning tea, do some activities. I don't think there were a lot of activities done. She would have a rest in the afternoon and I would pick her up at 3 o'clock.

MS HILL: How did you balance your own health needs with the care of your mum?

MS HOLT: It just went around what Mum's needs were, and if I needed to go – well, once – when I had to go back to see specialists, that's when we would – not the early respite but I sent her off, I think, once for respite, otherwise we would take her with us.

MS HILL: Did your mum ever take up a home care package or anything like that?

MS HOLT: No.

MS HILL: And why was that?

MS HOLT: Mum wouldn't have understood what they were saying about the costs and what they involved, and they were expensive, and I could have done the work myself and I wasn't going to spend Mum's money on stuff I could do. I could do the washing, I could do the cleaning. I did my housework anyway, and we were also told because it wasn't Mum's home it didn't really apply for us because it was my home.

MS HILL: Did you pursue that further?

MS HOLT: No.

MS HILL: Over the course of the years that you were caring for your mum, did you receive any financial support at all?

MS HOLT: Only in the form of some carer allowance and then after I finished work, of course, I qualified for the carer payment.

MS HILL: What financial support would have assisted you in caring for your mum at this time?

5 MS HOLT: Probably the biggest help would have been if the carer payment was somewhere equal to what you were earning beforehand because, like I said in my statement, my income dropped a lot.

MS HILL: And what did that mean for you?

10 MS HOLT: I could still meet my mortgage and I could still pay my bills but the rate I was paying my mortgage off really slowed down.

MS HILL: Were you aware of any services for carer support at this time?

15 MS HOLT: No. Not while we were in Mildura, no. When I moved to Mount Pleasant, after I had finished work, then I became aware of it.

MS HILL: And Mount Pleasant is in South Australia.

20 MS HOLT: South Australia.

MS HILL: Did, when you met with the ACAT assessors, have any discussion with them about carer support services?

25 MS HOLT: No, they never mentioned it.

MS HILL: Did you seek out any support for yourself?

30 MS HOLT: No, because I thought the support you got was the time that Mum was away at day care, or when you got the two hours a week, that that was your support, and that was all directed at Mum's needs that, you know, we can come in and we can do a friend sit with her for a couple of hours but that was all Mum-focused stuff. None of it was actually saying, "We could give you this, or you could have this service".

35

MS HILL: Is that something you would have liked?

40 MS HOLT: It would have been terrific, yes. I had one episode where I couldn't get someone to look after Mum for a weekend when I was working and I went through a support agency, worked all the shifts over Easter, and that cost me over \$1000 which was a lot of money for four days.

MS HILL: You've described in your statement your mum's experience of dementia. What is your mum's experience of dementia?

45

MS HOLT: Are you meaning how demented? Mum has got significant memory loss. She has lost none of her cognitive skills, so she can still dress herself, still feed

herself. Most of the time she will still tell you when she wants to go to the toilet but she remembers nothing, and I think that's possibly part of the dementia but I think a lot of it's probably choice.

5 MS HILL: And does she know that you've come along to give evidence today?

MS HOLT: Yes, but she – I told her, I told her and I told her that the photo was coming down and she laughed and said, "That's good," and five minutes later I said, "Now, what did I get you to – what did I tell you about?" "I don't know."

10

MS HILL: And how does that make you feel?

MS HOLT: It's sad because you've lost her – you lose her a couple of times, but I knew that.

15

MS HILL: How - - -

MS HOLT: It doesn't make it a lot easier, though.

20 MS HILL: How are you able to understand your mum's experience of dementia?

MS HOLT: I can't understand what it's like for Mum now. I know what it was like when her memory was starting to go, where she knew she was forgetting things and the frustration she would go through because she couldn't remember. But then she said, "Oh, it's easy just to say, 'I can't remember'." So she stopped worrying about it.

25

MS HILL: And did you require any support or were you able to obtain any support to assist you in understanding your mum's dementia?

30

MS HOLT: There were courses, little short courses offered in South Australia – certainly not here – that would go through explaining, but I sort of felt I had a reasonably good understanding because I've already done quite significant post-grad study into dementia. Very different when you're the one looking after the person, it's your person. But you still had the issue if the person was at the house, where did – how did you go to these courses? But I went to one after Mum went into permanent care, and that answered a lot of questions and made me feel better.

35

MS HILL: And how did you find out about those?

40

MS HOLT: Through the group in the Barossa Valley – and I've got people. I'm forgetting their name. They would constantly send messages – or not messages. They would send fliers out. Because Costas had already used these services before, he was still getting all the mail so he could feed me - - -

45

MS HILL: And who's - - -

MS HOLT: - - - the information.

MS HILL: Who's Costas?

5 MS HOLT: My friend sitting over there.

MS HILL: And Costas has had his own experience of - - -

10 MS HOLT: Yes. Yes. So he was still getting all the information from the care support.

MS HILL: You've described using respite with your mum.

15 MS HOLT: Yes.

MS HILL: What was the purpose of putting your mum into respite?

20 MS HOLT: The first time, I think it was purely because I just needed a break, which I didn't get anyway, but that was – and that was okay. There was one episode in Mount Pleasant where I was going away for a couple of weeks, for – purely for a holiday. Then a week – we were going to my granddaughter's 16th birthday in summer and outside, so it was not appropriate to take Mum. And most of the time I would take Mum with me. And then there was a week when I needed to go back to Melbourne to specialists, but that week was hideous.

25 MS HILL: When - - -

MS HOLT: It was four weeks.

30 MS HILL: When you say you didn't get a break, what do you mean by that?

MS HOLT: A break?

35 MS HILL: You said the first time you put your mum - - -

MS HOLT: Yes, because we were leading up to accreditation at work, so I spent every day at work.

40 MS HILL: How did you feel about putting your mum into respite on those - - -

MS HOLT: I hated it and didn't want to do it. Just did not, because nobody was going to look after her as well as I could, and I think all carers probably feel the same way. And you're entrusting people you love to somebody you – people you don't know.

45 MS HILL: Did you, at any point, have a positive experience with respite?

MS HOLT: The first one in Mildura was quite positive. I think I said that in my statement, because the staff knew me. She was where I was working. Staff knew me, they knew what I liked and didn't like, and they knew what I wouldn't tolerate. And there was a degree of respect there, so they would go along with what you
5 wanted. And the three weeks in Mount Pleasant was really good.

MS HILL: And what made those three weeks really good?

MS HOLT: Mildura because I also could see Mum, and I knew they were sort of
10 keeping on what I was doing at home. Mount Pleasant was really good because there were emails flipping between us when I was away, and I knew how Mum was going. And I assumed that they were telling Mum – and I think they probably did – where I was and what was going on. So there was still some contact.

15 MS HILL: Looking back, what did you need from your mum's time in respite?

MS HOLT: Probably rest, but the reassurance that she was okay and that she was being looked after properly. And my big things were I needed to know she was being taken to the toilet, that her hair was combed and that she was still being the
20 same person that she was.

MS HILL: And what do you consider your mum needed from her time in respite?

MS HOLT: Mum at that stage just needed somebody to make sure she was treated
25 with respect and her dignity was okay. She wouldn't ask for anything. Too quiet to ask for anything. So her meals – and that her routine was left alone and did what she would have normally done.

MS HILL: You describe in your statement that at the end of 2015 your mum's care
30 needs ultimately changed. And is that when you moved to Mount Pleasant - - -

MS HOLT: Yes.

MS HILL: - - - in South Australia.
35

MS HOLT: Yes.

MS HILL: What was happening at that time?

40 MS HOLT: Mum's needs were – she was getting more difficult to – she was getting more difficult to get her to drink and to eat. It was becoming a full-time job doing that. She needed stimulation that I couldn't give her because it didn't matter what I gave her to stimulate her, it didn't work. She needed more outside involvement.

45 MS HILL: And were you still working at this time?

MS HOLT: By that stage, no, I had to – I retired in July 2015.

MS HILL: And had you planned on retiring at that time?

MS HOLT: No. No.

5 MS HILL: And was your mum's health a factor in your decision?

MS HOLT: Partly Mum and my health. I had just had the stent done, and I was sort of advised, "Look, stay – it would be really good if you considered staying home now." And I weighed it up and I thought, "Yeah, I think I'm better off staying home with Mum too", because she was needing a lot and I needed not to go to work by then.

10

MS HILL: How would you describe your experience of caring for your mum and yourself at that time?

15

MS HOLT: Hard. It never stops. It's just consistent and your whole day is around the person you're caring for. Well, in my case, Mum was anyway, that everything I did was around what she did and what she needed and if she did – if I didn't give her a drink and remind her to drink it, she wouldn't drink it. If you didn't put her food in front of her and remind her to eat it, she wouldn't eat it. And the only thing she would really do was ask you to go to the toilet. So you sort of were trying to stimulate her and keep her going all day.

20

MS HILL: Over the course of the years that you were caring for your mum, are you able to describe what the impact of that was on your family life, relationships that you had?

25

MS HOLT: I'd put some of it down to the marriage breakdown but not all, because you didn't – certainly didn't have a social life by then. You couldn't go anywhere and there was a degree of, "Well, you don't go anywhere with me any more." I've got, by this stage, like, a 90 year old mother sitting at home, "No, I don't go with you." But the other part was also just him. The kids, we didn't – I didn't see as much of the kids because they were all in Melbourne and you weren't going to be driving to Melbourne all the time. That was a bit difficult, but that was the choice I'd made by moving out of Mildura, really.

30

35

MS HILL: What did you do if you wanted to go out or spend time with your kids in town?

MS HOLT: Take Mum with me. You would hop in the car, you'd go. I'd mix it around initially, mix it around doctors' appointments or other things I needed to do in Melbourne, and you would – I would have to, in that case, book a motel or a caravan park because the accommodation at the kids' places wasn't good enough. They had stairs and stuff like that, and you'd just take her with you.

40

45

MS HILL: As your mum's health deteriorated - - -

MS HOLT: No, Mum's health is still fine.

MS HILL: And as you get to the end of 2015 and you describe that her care needs have changed and you're doing more for her, what did you ultimately end up doing?

5

MS HOLT: Mum had been sick. She had been admitted for a chest infection and it was really taken out of my hands because Mum's needs were getting greater. She got a little bit aggressive, which was probably her dementia affecting her. And the local – our local doctor said, "She's not going home. You will not be taking her home." But she came home for two weeks and then she was in. I didn't like it, but I had a blood pressure that was not doing what it was meant to do.

10

MS HILL: So in 2016, your mum moved into residential care.

15 MS HOLT: Yes.

MS HILL: And what sorts of things do you do for your mum these days?

MS HOLT: Take phone calls about falling-out teeth. We – I visit her every day except like now when we're away. Every day around meal times, I made sure in summer it would be over evening meal. Hairdressers once a month. Then we take her out to the hotel and take her to lunch. Dentist every couple of months. Hearing aids will be coming up soon. We will take her to Mount Barker, another town about 50 kilometres away, to have her hearing done. So you just do all that sort of stuff.

20

MS HILL: How does it feel to be away from your mum at the moment?

MS HOLT: I don't like it. It's hard, but you've got to – I'm getting better at it, that you can just step back and say, "Well, she's going to be okay for a week." But I still don't like it.

30

MS HILL: Looking back at your time caring for your mum, what support have you received over the years that's worked well for you?

MS HOLT: The carer support that I got once I moved to South Australia was invaluable because it was time – they came in for – at 4 o'clock one Wednesday a month and had until midnight that night to go out and just do whatever you wanted to do. So you actually could go back to having a bit of a life.

35

MS HILL: And how did you get that support?

40

MS HOLT: Again, it goes back to Costas, who had the contact with the Carers Link.

MS HILL: What did you need to be able to support your mother over the time?

45

MS HOLT: Well, I think it was more the support for me. I mean, I had the skills to support her, but you needed someone to support you because it is hard work, and it's emotionally hard work and physically hard work. But there's nothing there that comes in so sort of say, you know, "Are you okay?" And there would be days when you'd probably pretty safely get a, "No, I'm not." But there was nothing there.

MS HILL: How can carers be encouraged to care, to be in their caring role?

MS HOLT: More support for the carer on that purely carer angle. I mean, you've got to have the care for the aged person in the first place, but to just focus on the carer to Like I think I said in my statement, the people from Barossa Valley would see you walking through the town and they would stop and pull up and say, "How are you?" Or they'd pick the phone up and ring, "How are you going? Is it going all right? Do you need anything?" And that's the stuff that you need. And you could wish to have family support, but you're not going to get it. And I think it's just the availability and more education as to what's available because you just don't get told, and I felt like a fool because I should have known.

MS HILL: Commissioners, that concludes my examination of Dot.

COMMISSIONER TRACEY: Thank you. Ms Holt, one of the things that we've got to consider is the availability of respite and other services in rural areas. I just want to ask you a little bit about your experience of obtaining respite care for your mother when you needed it. Was it easy? Was it difficult? How many institutions did you have to choose from with a view to finding a place for her?

MS HOLT: Well, while I was in Mildura, you had quite a few, but, obviously, I was only going to let her – I was only going to put her where I knew the staff. That for the first lot of respite was quite easy, but then I needed respite in 2015 and couldn't get it. And I wanted to plan a holiday. I wanted to have a break and was told within Mildura, "You can take it when it's available but, really, basically, unless somebody dies, you won't get you any", because at that stage there were no respite beds. Well, we had none where I was working.

In South Australia, locally, I spoke to the hospital there, they said, "Book your holiday. Just go. We will put her somewhere. She will be in this building somewhere." So that was really great. The week I needed, that was reasonably easy but it wasn't a great experience, and the last time she had respite I only wanted a week to go to Melbourne, come back and pick her up and was told, "You can have four weeks or nothing." So that used up half - - -

COMMISSIONER TRACEY: And that was in South Australia.

MS HOLT: That was in South Australia, yes.

COMMISSIONER TRACEY: Yes. And what about when it came time to place her in full-time care? Were you able to exercise choice as to where she went, or were you limited by the availability of beds in particular places?

5 MS HOLT: No, there was – there was the choice. I think she – well, I don't know, because she went to the local nursing home, which is a five-minute walk from home, and - - -

COMMISSIONER TRACEY: Is it attached to the local country hospital or - - -

10 MS HOLT: Hospital, yes. Yes.

COMMISSIONER TRACEY: Yes.

15 MS HOLT: So you're talking a really different situation in a really small community, and the beds come available pretty often. And if you didn't have spare beds, their acute section is not all that busy so they could slip somebody into an acute bed.

20 COMMISSIONER TRACEY: And she has received good care there?

MS HOLT: Yes. Yes.

COMMISSIONER TRACEY: Thank you.

25 COMMISSIONER BRIGGS: Dot, thanks for your evidence. You mentioned earlier on that very little attention was paid to your needs as the carer. We're interested in understanding where the right places for intervention to address carers' needs might be. Should it be when they're assessing your mother through the
30 ACAT? Should it be at your doctor's surgery? Should it be in a hub, like exists at Mildura? Should it be through Centrelink? What do you think? It can be all of those.

35 MS HOLT: Now, in my particular case, through the doctor would be pretty – it would be a rare thing because Mum would have only been at the doctors every three months or six months for new scripts, and a lot can happen in that time.

COMMISSIONER BRIGGS: Yes.

40 MS HOLT: But, again, lucky because it was because of our local doctor that she ended up going into permanent care, because he was also treating me. So that's – I don't think it's a fair thing to put on the doctor, though, because they might not be treating both. You need things like the carers hub. The one in the Barossa Valley is really good. They're not a huge group but they really are. They're focused purely
45 on the carer, and they were good. And I think that's where it needs to be. Certainly not through Centrelink.

COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising out of that, Ms Hill?

5 MS HILL: No, Commissioners. May this witness be excused.

COMMISSIONER TRACEY: Yes, certainly. Thank you, Ms Holt, for your evidence.

10 MS HOLT: Thank you.

COMMISSIONER TRACEY: It has been very helpful to us to understand how things work in rural communities. And your experiences I think are probably typical of many people - - -

15

MS HOLT: I think so. Yes.

COMMISSIONER TRACEY: - - - who have problems caring for elderly relatives, and we're very grateful to you for taking the time to travel and give us your evidence. Thank you.

20

MS HOLT: Thank you.

25 <THE WITNESS WITHDREW [12.02 pm]

MS HILL: Commissioners, Mr Gray QC, will call the next witness.

30 MR GRAY: Commissioners, I call Rosemary Cameron.

<ROSEMARY JEAN CAMERON, AFFIRMED [12.03 pm]

35

<EXAMINATION-IN-CHIEF BY MR GRAY

MR GRAY: Mrs Cameron, what's your full name?

40

MS CAMERON: Rosemary Jean Cameron.

MR GRAY: And what area of Victoria do you live in?

45 MS CAMERON: I live in the Macedon Ranges.

MR GRAY: How long have you been living there?

MS CAMERON: Around 34 years now.

MR GRAY: Where were you originally from?

5 MS CAMERON: I was originally from down in the suburbs of Melbourne, down near Maribyrnong.

MR GRAY: You're here today to tell the Royal Commissioners about your husband, Don.

10 MS CAMERON: Yes, that's right.

MR GRAY: When did you first meet Don?

15 MS CAMERON: I first met Don when I was 12 years of age and we were at a youth group together, and by about the age of 14 we started to go out to movies and whatever and been inseparable ever since then.

MR GRAY: And you say in your statement you've had a wonderful marriage with Don over many years.

MS CAMERON: Yes, very lucky.

MR GRAY: I'll ask the operator to bring up a reasonably recent photograph of Don.

MS CAMERON: Yes.

MR GRAY: RCD.9999.0122.0001. When was that photograph taken?

30 MS CAMERON: That was taken in 2013, I think. 2013.

MR GRAY: And when that photograph was taken, was Don already showing signs of - - -

35 MS CAMERON: Yes. He - - -

MR GRAY: - - - dementia with Lewy body symptoms?

MS CAMERON: Yes. His dementia was starting to really settle in a lot, his anxieties. That was the last time – Don was actually president of Clan Cameron, Victoria, so – or Australia, actually, and based in Victoria, and we used to go to this function every year and Don would liaise with all the other presidents of all the other clans and we would have a wonderful day. But on this particular day, by the end of the day it got the better of him and he was very confused and disorientated, so that was the last outing to that function.

MR GRAY: Tell us a little bit about Don. What did he do for a living?

MS CAMERON: He was a mechanical and structural engineer. We ran our own business, consulting engineering business for about 25 years, and he worked in heavy-lifting equipment, mainly cranes. He designed a lot of the big container cranes at the docks and smaller cranes as well, and so his day was, yes, consulting on standards and repairs and that type of thing.

MR GRAY: And he was very active in the community, I understand.

MS CAMERON: He was very active in community. He loved – Don was full of life, he just – there wasn't enough hours in the day for Don. He just loved everything and he – yes, he loved to do – we did Scottish country dancing together. Don was part of many community groups and he loved Australian history and his Scottish background. He was born in Scotland, came here at the age of 4, and he – he used to actually do history talks. He would be invited by community groups to give talks on the local history in particular, and he would take with him a suitcase full of hats and wigs and moustaches and bonnets, you name it, and he would tell the local history, and with each character he would become that character. So Don was just – he was great fun to be around. He was full of life.

MR GRAY: You've got children together and some granddaughters, grandchildren.

MS CAMERON: Yes, we have four children together. One child deceased after birth and our other – eldest son passed away 2017, and we have two grandchildren, two granddaughters.

MR GRAY: Tell us - - -

MS CAMERON: Sorry.

MR GRAY: Tell us a bit about what Don used to do at the Olympics, at the time of - - -

MS CAMERON: Well - - -

MR GRAY: - - - the Olympics for your granddaughters.

MS CAMERON: Don loved doing so much with the grandchildren and children. He was very hands-on, you know, bringing our children up. And we would have the grandchildren every second weekend. He would drive all the way to Ballarat and pick them up and bring them home. And during one of the Olympics he decided we would have our own Olympics. He couldn't take the children to the Olympics but we would create our own.

We live on 18 acres, and so Don spent all week and he would set up all sorts of events. He would use hay bales and there would be, you know, hay bale hurdle-jumping, and he would collect dry cowpats and there would be, you know, discus-throwing and there would be, you know, a course in and out the brown cows and

back to the big gum tree, who got there first, and there was all these type of races, so we had our day with the Olympics and he made medals for them, chocolate coins with ribbons on them and they would be presented and I would present them as they had the different hay bales, all the different sizes.

5

So Don was into everything, and he would take part in these races and clumsily fall over before the winning line so the children could win. So he was – yes, he was full of fun. Full of fun.

10 MR GRAY: Operator, please bring up WIT.0309.0001.0001. Mrs Cameron, you've made the witness statement for the Royal Commission.

MS CAMERON: Yes, I have.

15 MR GRAY: Do you see in front of you the first page of that witness statement?

MS CAMERON: Yes, I do.

MR GRAY: Do you wish to make any amendments to it?

20

MS CAMERON: No. No, I don't.

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

25

MS CAMERON: Yes, to the best of my belief.

MR GRAY: Commissioners, this witness statement - - -

30 COMMISSIONER TRACEY: Thank you.

MR GRAY: I will just find the date for it, but I tender it.

35 COMMISSIONER TRACEY: The witness statement of Rosemary Jean Cameron dated 26 July 2019 - - -

MR GRAY: 2019, yes. Yes, Commissioners.

40

COMMISSIONER TRACEY: - - - will be exhibit 7-4.

**EXHIBIT #7-4 WITNESS STATEMENT OF ROSEMARY JEAN CAMERON
DATED 26/07/2019 (WIT.0309.0001.0001)**

45

MR GRAY: Thank you, Commissioner. Mrs Cameron, in the witness statement you describe a number of aspects of the journey you've had in caring for Don from the time he began to show symptoms of dementia with Lewy body symptoms.

5 MS CAMERON: Yes.

MR GRAY: And during a period of two years or so, you cared for him as best you could in the home with periods of attempts to get respite.

10 MS CAMERON: Yes.

MR GRAY: And where is Don now?

15 MS CAMERON: Don's in a residential facility, but it's a mental health facility for people between the age of 16 – 65 years of age, and for people who have behavioural symptoms with dementia or mental illness.

MR GRAY: I want to take you back to the beginning of this journey in about 2006, you say in your statement, at paragraph 7, when Don was approximately 60 years of age. He began showing some symptoms that concerned you. What - - -

MS CAMERON: Yes.

25 MR GRAY: What were his symptoms?

MS CAMERON: Because Don was so quick-witted and quick-minded, I started to notice that he was hesitating on making decisions or problem-solving, and it was just a slowness or he would start questioning me on little things that once upon a time he took in his stride. So there was subtle things at first, and probably nobody else would have noticed them but me, and then slowly I noticed a – like, a slight depression creeping in.

35 MR GRAY: Mrs Cameron, if you could please keep your voice up a little, that would be wonderful. Thank you. As time went on, did you notice those symptoms deteriorating?

MS CAMERON: Yes, yes. They definitely did. They – he was having more difficulties managing in our – in our business, and at that stage I worked for a group of doctors and a psychiatrist and I found that it was very difficult to see him struggling. So I retired from the group of GPs and just kept up the part-time work for the psychiatrist and eventually left that as well because it was just a little difficult for him to manage all that he had to manage.

45 MR GRAY: And you sought diagnoses in 2010; is that right?

MS CAMERON: Yes. Yes, I had actually sought – I had been to GPs and I'd asked, you know, what was going on. We tried to find what was going on, why his

mood was changing and why these things were happening. And constantly I was told that he was just suffering from stress. There wasn't anything else offered to me. And over that time we did try some natural things like acupuncture and various things, and it did improve his health but his symptoms were deteriorating. And it
5 was a health practitioner – a natural health practitioner that said, “Look, how about you get a referral to a neurologist?” And that's what I did at that time.

Unfortunately, the neurologist cleared Don and said he didn't have dementia. I think Don was pretty cluey and followed – you know, passed the questions. So he really
10 was cleared again. We were no better off at that stage.

MR GRAY: So at about this point with that uncertainty, what was the impact of this on you?

15 MS CAMERON: Well, I really didn't know where to go with that. You know, when you've got health practitioners saying to you that, “It's only stress”, and, quite clearly, Don wasn't the type to suffer stress, I really didn't know where to go with that. I'd never known anyone with dementia before. I'd never dealt with anyone with dementia. There was occasionally a sneaking thought coming in there, but then
20 when the professionals were telling me that that wasn't so, then I had to try to accept and do the best I could.

MR GRAY: Can you tell the Commissioners about what led to the diagnosis in 2013 – early 2013, was it?

25 MS CAMERON: Yes, it was early 2013. I had been concerned about Don's social interaction with others because he was becoming more withdrawn. So I phoned the local community health centre just to ask if there were any activities that one could undertake with a bit of memory loss or difficulty integrating in mainstream groups, because Don had always been socially active and I felt it was important for him to
30 keep this up. They invited me to come down to the group, and they were actually the people who were involved with the local nursing home as well. And when I went down there they said, “Well, we will just do a bit of an assessment just to see where he stands with things”, and – and it was at that time they suggested that we try to
35 obtain an appointment at the Memory Clinic in Bendigo.

MR GRAY: And what was the outcome?

40 MS CAMERON: From the Memory Clinic? They determined Don had Lewy body dementia with possible Parkinsonian symptoms as well.

MR GRAY: And not only based on what you might have been told then but taking into account all the knowledge you've acquired since then, what is dementia accompanied by Lewy body's? Is that a particular form of dementia?

45

MS CAMERON: It's – yes, there's over 100 different types of dementia and Lewy body is one of them, and it comes with symptoms of hallucinations, paranoia, anxiety, agitation and aggression. As it deteriorates, the aggression comes in more.

5 MR GRAY: So is it fair to say that this is a particularly challenging and difficult diagnosis?

MS CAMERON: Yes, it's one of the more challenging dementias to deal with.

10 MR GRAY: Yes. Now, I want to ask about what happened after that diagnosis or what didn't happen. You say in your statement – this is at paragraph 17 – that in effect, you were left walking out of the clinic blind as to what to do next.

MS CAMERON: Yes. They were very nurturing and understanding there and they
15 took time with Don and they took time with me to just talk about what, you know, dementia was, but there was no pathway there. You walked out of there thinking, "Well, I now know what we have to deal with", as in that it's a diagnosis, but there was no referrals, there was no pamphlets, there wasn't anything to help me to know. You're out the front door. And they did explain that's the reason they were there, for
20 diagnosis, and they didn't have any further reason to contact after that. But there was really nothing to know where to head. I had no idea what to do from there.

MR GRAY: So did you just return home and keep trying to care for Don as best
25 you could?

MS CAMERON: Yes, I did. I – I had joined a carers group, a very small, new
carers group, and, really, anything I learned was through there. I really didn't –
didn't know what else to do. I thought we had always done everything else together
and I thought, "We can do this together as well"

30 MR GRAY: Is that the Woodend Lifestyle Carers Group?

MS CAMERON: It is, yes.

35 MR GRAY: And you refer to that in some detail towards the end of your statement, and I will be, certainly, bringing you back to that topic.

MS CAMERON: Thank you.

40 MR GRAY: Apart from getting some help and support through contacts with that group, were you essentially on your own? Is that how you felt?

MS CAMERON: Yes, very much.

45 MR GRAY: What was the impact on you?

MS CAMERON: Well, it was very exhausting. You know, I had always been a very independent person, so I really always thought that I could manage and we could do it day-by-day, but I really was becoming quite rattled with symptoms that I'd never – nobody had ever explained to me and I didn't really know how to cope
5 with and there was no manual that came with it. And I really – it was just each day, just struggle the best – best you could. Don's anxieties meant that he was extremely dependent upon me every minute of every day.

MR GRAY: Can you just explain that a bit further for the Commissioners. Do you
10 literally mean every minute of every day?

MS CAMERON: I do mean every minute of every day, because with Don's anxiety building he – where he was afraid to be alone, the paranoia and the hallucinations, he thought that there was danger in everything he saw, and I guess I was the only – at
15 that stage he still sort of vaguely knew who I was and knew that I was a bit of safety. However, that could split into different fragments as well. Don just perceived everything as a danger. So he was constantly hyper-vigilant. He would, during the day, pull everything out of his cupboard and try to stuff clothes up his jumper or put things down his socks so that he was holding them safe because there was obviously
20 enemy around who were trying to steal his things, and I was one of those enemies at times when he had not realised who I was.

At night, he would strip the things off the bed, so sometimes we didn't even have a bed to sleep in. And when he would lull into a sleep, I would just sleep with my arm
25 across his chest so that if he did stir, I would know because I was frightened of falling asleep because Don would wake and then not know who I was, so I was the person breaking into the house or trying to murder his beautiful Rosemary, as he used to say, that they would try to murder me. So he was constantly – I just constantly had to try to keep him calm and tried to deal with that. And during the
30 day, he just wanted to hold my hand and walk around all the time.

So if I wanted to vacuum, I would be holding Don's hand and vacuuming with the other, and then he would perceive that I was going to electrocute myself or then it might turn into that I was stealing the vacuum cleaner, so there was just constant – I
35 just had to watch him. I never knew – I had to deadbolt the doors often because I tried doing activities with him in the garden to keep him calm and settled, but he would then perceive that somebody was there to murder me. So he would bolt – he was very fit – he would bolt all the way down to the local intersection and try to flag somebody down to say that they had murdered – somebody had murdered me. So
40 there was this constant watching.

So after a while, we couldn't go outside because he would take off so fast. So most of the time I was, yes, locking us indoors. And at night I had to lock us into the bedroom en suite area because if I did fall asleep and he got out, I – there was too
45 many dangers for him. And also I didn't know when he perceived there was the enemy, so he might have taken knives from the kitchen and he may have used them on me. I never really knew what it would be.

MR GRAY: Mrs Cameron, there were some times when there was some aggression; is that right?

5 MS CAMERON: Yes, Don would often try to strangle me or I'd be thrown against a wall. And he didn't know it was me.

MR GRAY: Mrs Cameron, apart from just the obvious exhaustion that must have been entailed by all that, within yourself, how did you psychologically deal with this? Did you develop coping mechanisms?

10 MS CAMERON: I did, yes. I used to – when I got up every morning, I had a motto and it was, “Today I won't take anything personally because it's not. It's his illness.” I would try to, you know, just remember the man he was and he was – his symptoms were developing, but he was still the man I loved. So you cope with that.

15 And Don loved dancing. Pardon me. So one of our coping mechanisms was that we danced. If Don was becoming agitated and I went into waltz hold in front of him and I would start humming a few bars of whatever, he would – he would just settle and we would dance. We were known as the crazy people in our town because if I had to go and shop for food and Don was starting to get anxious, which he always did, I would shop waltzing up the aisle ways, you know. If it worked, you did it. It's survival. You learn to do the things that – if I had to go to doctor's waiting room and Don was agitated, well, I would dance in the waiting room. It was whatever worked. You just learned survival techniques and you learn not to worry about what people are going to say because when it came down to it, not one was there to help.

20 One time in the supermarket, Don started yelling out, “Help, help”, because he was overcome with what was going on, and I managed to settle him slightly by ringing my son and my son spoke to him. When I got to the – I decided to go straight to the register then, and the woman on the cash register said, “So how's your day been going so far?” And I said, “Did you not hear the yelling?” And she went, “Oh.” You know, it was like a shrug of the shoulders and – but nobody came to help, you know. So I just – I just learnt that I was on my own, you know, and I couldn't rely on anyone else to get me through that. It was about – I – I knew Don. It was about pulling in whatever techniques I'd work – learned over the time that would work, and sometimes they did, sometimes they didn't.

MR GRAY: But in around July 2013, in contact with the Woodend Lifestyle Carers Group, there was a suggestion made that you should get help; is that right?

40 MS CAMERON: Yes, yes.

MR GRAY: What came of that? Put up paragraph 18 please, operator, of Mrs Cameron's statement.

45 MS CAMERON: Well, they suggested that there was such a thing as a home care package and that maybe I should see if I was eligible for any help or support through

that, and I did that and had somebody come out to the house and he was assessed for a level 3/4 package.

5 MR GRAY: Just stopping there, is that an Aged Care Assessment Service that came out?

MS CAMERON: Yes, from the ACAS – ACAT - - -

10 MR GRAY: Can you just tell the Commissioners a little bit about that process. For example, were you sitting beside Don during the interview process during the assessment?

15 MS CAMERON: Yes, I was, because I was Don's power of attorney and Don really couldn't give accurate answers to questions at that stage that – that I was – I made sure I was there through the process and tried to answer the questions as best they tried to assess, yes.

20 MR GRAY: And were you the focus of attention during the assessment, that is, your own needs; were they the subject of questions and considerations during the assessment, in your view?

25 MS CAMERON: Not really, no. I don't recall anything being offered. I think they asked me a lot about what Don's capabilities were as in able to shower himself, feed himself, do things like that. But there wasn't really terribly much about what – what I needed to get through. And I think at that stage I probably didn't think to ask because with Don's anxieties, he really – it was a bit more confronting with people coming in and out of the home anyway, that I probably wouldn't have suggested that. But I don't recall anything being asked or offered for my purposes.

30 MR GRAY: And what was the outcome of the assessment? You say in your statement you were – that is Don was found eligible for a home care level 3 or 4 package.

35 MS CAMERON: Yes.

MR GRAY: Was it ever assigned?

40 MS CAMERON: No, it was never assigned. Don went into full-time care in 2015 and I never heard anything more. I was never contacted. So I just assume they took me off the list eventually. I didn't hear anything back from them.

MR GRAY: So over a period of two years after being assessed as eligible for one of these higher level need packages, nothing was assigned to Don.

45 MS CAMERON: No.

MR GRAY: Were you told what the progress of the assignment might be?

MS CAMERON: No, not at any time. I wasn't told of the progress. Toward the – the later stages before Don went into care, I decided to give them a call. It was suggested that maybe I should be re-assessed. It might bring something through faster and they did come out and re-assess and said he definitely was very high care but I still didn't hear anything back on – there was still nothing assigned.

MR GRAY: All right. Now, I want to take up the narrative at paragraph 20 of your statement. You refer there to a first experience of short stay respite care at the beginning of 2014. You speak of becoming exhausted. Can you just tell the Commissioners a bit about your – your state of wellbeing at the beginning of 2014 and what these accumulated experiences had been doing to you?

MS CAMERON: Well, I was pretty exhausted, really not getting very much sleep and Don had been going into some short-stay day respite care at the local facility, just for three hours one day a week. But at – at this stage at the beginning of 2014 we actually had fires in our area and we were asked to leave the area. So Don was pretty bad at that stage and I really had to try to pack up animals and goods and go down to – they sent us down to Gisborne which was the local town, and I was tired and that in itself, trying to get out, because I would pack something up and Don would pull it off and I would put the trailer on and Don would take it off and, you know, it was just hard coping by myself so I was just so exhausted.

And when I did get down to the area that they allocated for us to take our domestic animals, Don was wanting to wander off and I had to stay with the animals and it was a 40 degree temperature and I had decided that seeing as how Don was going to day respite in Gisborne, I would actually ask if I could pop him in there for the day, just while I tried to manage this emergency, but the answer was no. So I had to manage and so I was just becoming so exhausted that I decided I had to try to apply for a couple of weeks respite with a facility about 30 minutes from home.

MR GRAY: Now, in your statement, you refer to that finally coming through in May 2014 after four months on a waiting list.

MS CAMERON: Yes.

MR GRAY: Was that the best you could do after ringing around?

MS CAMERON: Yes, yes.

MR GRAY: A four month wait.

MS CAMERON: A four month wait. There was nothing available at all in the area. They said that they possibly could have had beds out of the dementia section, but Don really needed a secure keypadded area at that stage.

MR GRAY: And then – well, from paragraph 21 – well, at paragraph 21 and 22, if we could bring those up, please, operator. You describe in your statement what

happened during that first attempt at residential respite. Can you tell the Commissioners a bit about that experience?

5 MS CAMERON: Well, I had been allocated a three week respite period and, you know, for me there was just so much to try to do at home in that time. And I decided that I would try to have a bit of a break at home and my children would go in to see Don. But every day they would ring me and the nurse would ring me and say Don has just gone into somebody else's room or he won't come and sit down at the dining table or he's out in the garden and he will not come in. So it was a constant ringing
10 me and I kept saying, "You do understand he has dementia; I mean, you're a dementia specific area, you know, can you not deal with it so I can just have – this is my respite break". And as much as I didn't want to walk away from Don but I expected that they would be capable of doing that.

15 Finally, they were – they said they were at their wits end and she phoned me after the second week and said that she refused to have him there unless he had a PRN medication which is an as needed medication to try to settle him down. Now, with Lewy body dementia I had already been warned that there were so many medications that they cannot have. They have very adverse reactions on and there is very few
20 that are safe to use. So I said to her, who would be prescribing this, she told me that it was a Saturday night and she told me she was getting in a locum to address the situation. I said that I really needed to speak to the locum because unless he was trained in Lewy body dementia prescribing that I wouldn't be happy about that at all. I wasn't going to risk Don's life with that.

25 And she pretty much just said, no, that wouldn't be – excuse me – that wouldn't be permissible, that the locum would prescribe what he felt possible and if I didn't like that, then I could come and get him. So it's exactly what I did. I went and took him home because I just couldn't take the risk on his health. They couldn't manage him.
30 They just didn't seem to know how to manage him and they – they didn't have the expertise to know what they were dealing with either.

MR GRAY: And did the nurse say anything in more detail about the medication that she proposed asking the locum to prescribe?

35 MS CAMERON: No, I don't think she knew what that was going to be. So I think that was purely going to be at the locum's discretion, but the locum would have been a GP and GP – GPs aren't the ones to decide on Lewy body dementia medication. That usually comes from a psychogeriatrician.

40 MR GRAY: Did you have a psychogeriatrician you could take Don to from time to time?

45 MS CAMERON: I had been on the waiting list for an appointment for a long time, and I think it was about an eight-month waiting list, six to eight month waiting list. But when I finally – finally managed to get Don into another lot of respite care, they had a psychogeriatrician attending on that day to see the residents in the facility. So I

was lucky enough for them to fit me onto that list because I – I had been waiting a long time for an appointment for Don.

5 MR GRAY: I will ask you about that now but just in terms of trying to get a psychogeriatrician appointment while you were – while Don was living in the community and you were caring for him at home, that eight month waiting list, is that because you were in a rural area in the Macedon area?

10 MS CAMERON: No, I tried down in Melbourne as well, and the waiting list is just very long.

15 MR GRAY: Now, at paragraph 23 you refer to your experience after this, in effect, refusal to keep Don unless the nursing staff could ask an LMO to prescribe something to settle Don down. You refer to putting Don's name down on respite waiting lists - - -

MS CAMERON: Yes.

20 MR GRAY: - - - at various nursing homes. And, in general terms, what were the waiting lists that were - - -

25 MS CAMERON: Usually around three months. And sometimes after that three months they would say well, we've only got a week there. But the problem was that sometimes I would – because I learned that you don't wait till you need respite, that you – you book ahead so you know you've got a set break in, so you can pace yourself virtually, because you won't get anything at the time. So sometimes I would book it in and it would be three months ahead and then I would get a few weeks just prior to going in and you're hanging on thinking, well, if I just hang on a little longer I'll get that respite. And then they would ring me to say, "I'm sorry, that bed's not available now, we've filled it with a permanent resident so I'm sorry, you know, you can't have that".

30

35 So then you've got to ring again and wait longer, you know, again, so you're put to the back of the list. A lot of the facilities were closing down their respite beds and it was told to me by one facility that really wasn't worth them doing all that paperwork every two weeks. If they did two-week slots for respite, then it was far too much paperwork. If they put a permanent resident into that bed it was easier. So they were stopping their respite beds.

40 MR GRAY: And maybe this is completely hypothetical because it sounds like it was very difficult to get a booking even for a two-week block. And when you did get a booking, it sounds like it was unreliable at times.

45 MS CAMERON: Very unreliable.

MR GRAY: But did you ever consider getting shorter periods of more regular respite?

MS CAMERON: I tried for whatever I could get. Constantly when I phoned – in the early days when I phoned they would just say, “We don’t have anything now, we will put you on a waiting list” and then maybe they would contact you. In the later stages when I would ring and ask for respite, they would ask what type of dementia
5 Don had, and when I would say he had Lewy body dementia, I – several times I heard them say, “We don’t take them”, and it was like he had leprosy or something, you know, as if it was his choice so - - -

10 MR GRAY: Was there anybody you could turn to when you were met with a response like that, because of presumably the special challenges that Lewy body dementia presents? Was there anybody you could turn to? Was there a number then in existence that you could call?

15 MS CAMERON: At one stage through the support group that I was with I was given a phone number for a lady at DMAS which was the – I think that was part of what was Alzheimer’s Australia and I was put through via them, I think, and I did speak to her about the issues and the problem – behavioural symptoms, and she did talk to me about the difficulties but there was never any solution offered. You know,
20 sometimes there were people – when you phone numbers, there was people that would talk to you, but there was never solutions. I was given a 1800 number in case of emergency, and one time after struggling with Don and him trying to strangle me and I, you know, separated myself into another room and I did ring the 1800 number I was supplied and this was in the – you know, the earlier days in, I think, 2014.

25 And the lady on the other end of the phone was – she was lovely, but her solution was, you know, “Try to settle yourself down. Make a nice cup of tea and just see how you go after that.” But there was really nothing as to how to cope with this, who do I head to, who can help me with how to deal with this, what do I do. There was really nothing offered.

30 MR GRAY: You’re not suggesting that that number you called on that occasion was DBMAS, DBMAS having only commenced somewhat later in 2017, perhaps.

35 MS CAMERON: No, the woman I was with, Libby, she was part of what they call DBMAS but I don’t know, I don’t think so. I think the number they have now, the 1800 number now is so much more reliable from what I hear others say and that they have a follow-up time where they actually come and see you at home. There’s a lot more offered I think now but back then there wasn’t really anything offered.

40 MR GRAY: Now, can I ask you about the next course or admission to residential respite which was referred to in your statement at paragraph 25, and it’s around October 2014.

45 MS CAMERON: Yes.

MR GRAY: Could you tell the Commissioners about your experience of just the – what turned out to be a rather short stay in that facility.

MS CAMERON: Yes, I was granted – it was a facility that Don had been going to for a short bit of day care, you know, one day a week. So it was the local facility, they knew Don. And I had managed to book ahead. It took me several months and I managed to get one week which I gladly took. Because they knew Don I thought
5 they would be able to manage him okay, understanding him a bit more. But after three days the nurse phoned me and said that he was behaving badly. Actually on the first day of that respite was when I saw the psychogeriatrician that had attended and he had suggested – suggested that in lieu of, you know, no other help and the type of dementia that Don was experiencing that there was a mental health facility in
10 Bendigo that Don maybe could go to and there would be a wait to get into that but maybe after this short stay at respite care, he could enter into that, you know, maybe three weeks or a month down the track.

But Don had had three days of that short-stay respite, the one week I had he – after
15 three days the nurse phoned and just said how he was behaving badly and she wasn't going to tolerate that so she had ordered an urgent ambulance transport and an emergency admission into this particular mental health facility. So she really sort of jumped the queue instead of the waiting period because she couldn't cope with him.

20 MR GRAY: I want to ask you about the impact on you of hearing that sort of sentiment from a nurse.

MS CAMERON: Yes. Well, it's pretty upsetting because, you know, Don wasn't a
25 criminal. He wasn't choosing to do this. This was his illness. So it's like a cancer patient. They have certain symptoms and, you know, it's beyond their control and so is dementia. And Don had no choice in this whatsoever. So to be told that he was behaving badly, or to be, you know – you know, there were times when I felt that I had the naughtiest boy at school and that he just wouldn't conform – well, he couldn't conform and I felt that she was trained to know better. She was part of the
30 dementia specialised part of the nursing home. So it's hurtful. It's hurtful to see Don treated that way. It's disrespectful.

MR GRAY: And the facility organised the transport, did they, for Don?

35 MS CAMERON: They said they were going to put Don into ambulance transport, but I knew Don wouldn't deal well with that because he got very anxious. So a lovely friend of mine offered to come with me and we – we drove him. One of us – I sat in the back seat with Don trying to manage him and we took him because that was the best and most respectful way to do it.

40

MR GRAY: So can you tell the Commissioners a bit about what your expectations were on arrival at the mental health facility. And, if we could just start with that and the admission process there, and then I will ask you a bit about what happened.

45 MS CAMERON: Well, it was explained to us that this particular facility was there to be able to find medications under a supervised – in a supervised the manner, that would suit Don. And it was going to be in a very slowly, slowly approach, so they

would slowly introduce medication – a medication to him to see how he managed that and he was there – to be there around about a four to six week stay. It could be longer if that was what was needed but it was about tailoring a medication to suit him.

5

And they explained to me that as this couldn't be done in a home-like setting it needed to be under strict supervision and that at the meeting when we first arrived, we were told it would be, as I said, a very slowly, slowly approach on, we would be kept informed every step of the way, that nothing would be introduced to him without clearing it with us first and explain it to us first so that we understood the implications.

10

MR GRAY: I want to ask you about your observations just a few days into this admission at the mental health facility. What were your observations of Don at about that time, a few days - - -

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MS CAMERON: Well, it was pretty horrific. They asked me not to come in for a couple of days so that Don could settle in. When I did go in there Don was really just knocked out. He was in a chair, he was unshaven, he was smelly and he was non-coherent, really. He was just so heavily sedated.

20

MR GRAY: What did you do in response to that?

MS CAMERON: Well, I asked to speak to the doctor because I needed to understand. I was told that, you know, the approach was going to be slowly, slowly and I really needed to know, was this the slowly, slowly approach, and I then realised that at this stage they had not done that. They had not started him on the amount of medication that they had promised they would. They had actually doubled the medication without saying anything to me or starting on a low dose. It just wasn't as planned. So it – yes, it was pretty overwhelming.

25

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MR GRAY: And when you learnt that, what did you say?

MS CAMERON: Well, we agreed that it would be different and we agreed that instead of giving it to – this – this dose to him in the morning because he had a greater risk of falls - - -

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MR GRAY: Was this a discussion with the doctor, Mrs Cameron?

MS CAMERON: Yes, it was the psychogeriatrician, actually, or the psychiatrist that was there. And it was agreed that they would modify it, and if they were going to give him slightly heavier medication it would be more at night so that he would, you know, be able to sleep off most of the effects and they said they wouldn't start any PRN medication, you know, the 'as needed' medication until discussing it with us, but it just didn't happen that way. They just were constantly throwing in a medication. So instead of the scheme being that we just slowly introduce, we slowly bring the amount up, it just wasn't monitored that way. It was inconsistent within the

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day so there was really no monitoring because when extras are thrown in and it's up and it's down, and it's up and it's down, I don't know how the body can find its balance or where it's needed.

5 MR GRAY: What was Don's state the next day when you visited?

MS CAMERON: I found him face down on the floor, out to it. And they – he was so heavily sedated, they had left him in an upright chair in the lounge area and he had just fallen forward out. His face was quite bruised, and he was in a really bad way.
10 And often when I would ask, "Has he had any extra medication?" I would be told that they, no, they didn't think so, that he had just had a bad night, and he was very tired. But then when I would check closer and ask to see what the medications had been I would find that that was quite different, that he had, in fact, had extra.

15 MR GRAY: How often were you visiting?

MS CAMERON: Well, I was going down most days. Sometimes I would have a break and one of my children would go but I was pretty much going every day at that stage.
20

MR GRAY: And Don had previously occasionally had gout; is that right?

MS CAMERON: Yes, in the past he had had gout but it was pretty well monitored or maintained with a good diet and occasionally if it did flare up which was maybe
25 every 18 months, two years, then it was treated with an inflammatory medication, for inflammation, but it was pretty well maintained.

MR GRAY: You knew a bit about the way his gout had been treated in the past successfully; is that right?
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MS CAMERON: Yes. And I knew when he got it I could see what that looked like, you know, the inflammation to the joint and the area and what it was like.

MR GRAY: And about a week after admission to the mental health facility what
35 happened in that regard?

MS CAMERON: He started to get gout. And I only knew this because I used to take Don's socks and shoes off and give him a foot massage to settle him down and I found – he had been limping a bit and I then found that the joint was becoming quite
40 inflamed so that was, I think, on a Thursday of the week and I had asked if a doctor could look at it and prescribe something because I knew how quickly it could flare up and make him so unwell. And I was told that there wasn't an LMO, a GP available until the following Monday, and I had asked could there be something else done because I knew that it was going to flare up and I was told no, that there was no
45 one else available.

MR GRAY: In brief, did you then have disagreement with the LMO who prescribed antibiotics and Don's condition deteriorated very badly so that he was in terrible pain after about 10 days?

5 MS CAMERON: Yes, yes, I did because I knew that antibiotics weren't the medication for gout. And he disagreed that it was gout and his comment was, "Well, we will soon see who's right" but after 10 days Don was in a really bad state so they finally did put him on a gout medication and he did improve after that. But he got very unwell and wouldn't let anyone touch him because he was so unwell.

10

MR GRAY: Without asking about all the other things that happened during this admission, it went for many weeks, what was Don's condition at the end of this admission?

15 MS CAMERON: Well, he was – he was sedated most of the time. He was taking off weight. He was getting very agitated because he wasn't incontinent before he went in and they insisted on putting hospital-type pants on him and tying them at the sides, although they used to lock the toilet so he couldn't even find the toilet or get into the toilet so he was becoming very agitated, so he was starting to become
20 incontinent as well and degraded because he was often soiling himself so he was in a really bad state. His health was going down.

MR GRAY: So just recapping, this was respite – this began with planned respite that you had booked back in July and you had finally received a firm – what turned
25 out to be a firm booking for October 2014 but that respite only managed – the facility only managed to look after Don for a few days and then he was admitted to the mental health facility and by comparison with his condition before he went into the respite in October 2014, he was in a far worse condition coming out.

30 MS CAMERON: Yes, definitely. I actually discharged him to home. I just said he can't stay any longer because what was promised wasn't being delivered. There was no monitoring of medication. When he went in there, I thought finally I've got someone now who's going to tailor something to suit Don. Because that didn't happen and there was no sight of us achieving that when everything was up and
35 down every day and extras thrown in and him being more and more sedated, we were not achieving anything. So after many weeks I discharged him to home.

MR GRAY: Now, in your statement you refer to an improvement while you were caring for him at home after this, and then a decision which came about in, in effect,
40 in early 2015, that you would try respite again, and what was the outcome this time? This is the subject of a long passage from paragraph 40. Paragraph 40 through to forty - - -

45 MS CAMERON: Yes, well, I had been told this time that I would be assisted by a lady from an aged care mental health service in Kyneton that she would actually go and talk to the facility, you know, so that Don could go back in – this was the local facility – so that Don could go back in and with her support talking to staff about

Lewy Body Dementia and Don's trigger points and what would happen, that I should try respite again and this would be – it would be different this time because staff said they now understood the way in which to deal with Don. So Don did go in and he had been there several days of that week and then early on the Saturday morning I
5 got a call about 8 o'clock and the first words I heard were, "Don's out of control, he's threatening to break windows, are you coming to get him or am I calling the police?"

10 MR GRAY: This is after one night.

MS CAMERON: It was after a couple of nights, yes. They had agreed – we had finally had a PRN that was agreed upon when he went in there and the plan was that as soon as they saw Don starting to show signs of agitation, that he would be given this PRN medication – as needed medication, and that would stop any situation
15 escalating. But, unfortunately, he had started – things had started to get a little bit agitated at night before he went to bed, but I later read from the notes that instead of them giving him a PRN medication, they shut him in his room and so he had all night to escalate and so by morning he was pretty vigilant and agitated.

20 So when I arrived at the facility I said not to call the police and I was there within about 15 minutes. And I found Don sitting at the dining room table with all the other residents and he had blood all over him and I asked what had happened. Nobody wanted to tell me. I identified the nurse who had called me and she just told me that I had to go and pack his things and leave, that he wasn't welcome there. And I
25 checked on – over and found a big gash on the back of his hand which was dripping blood. Nobody – they were told – the nurses, the PCAs were told not to discuss anything with me, so I reluctantly took Don to his room, packed his goods, wrapped a singlet around his hand. I was given a bandaid when I asked for something and that wasn't enough so I wrapped his hand, and nobody wanted to speak to me. I just
30 had to – to take him home.

MR GRAY: Mrs Cameron, at paragraph 42 and 43, you do refer to the impact of this on you and on your wellbeing and your state of mind.

35 MS CAMERON: Yes, it was enormous. You know, I just remember feeling so extremely sad for Don, to be almost rejected when he needed help the most. And I think walking out of the facility with Don in one hand and his goods in the other, and I hopped in the car and I thought I can't rely on anybody. I just don't think there's anything out there, and I was so exhausted and I thought I'm failing him as well.
40 And I thought if I can't look after him nobody else certainly is showing me they can do that too, and I just cried silently all the way home so Don couldn't see. And I just thought well maybe I just end it for both of us.

45 You know, I thought maybe I will put the exhaust pipe in the back of the – you know, the pipe, it was just this irrational thought that I can't get any other help and I just don't think – if anything happens to me, I don't know who else will look after

him. Anyway, I slapped myself round the face a bit, pulled myself together and I just got back into the role of looking after Don.

5 MR GRAY: Mrs Cameron, somehow you were able, throughout most of 2015, then to manage looking after Don at home.

MS CAMERON: The best I could, yes.

10 MR GRAY: You say in paragraph 50 that you persisted throughout the year with no options. You then refer to home assistance having been withdrawn; is that right?

15 MS CAMERON: At one stage through the Macedon Ranges Shire, I was offered that – and it was more for company for Don – that a gentleman would come and sit with Don for a short time. In the early days, he would take him down for a coffee to the café so Don had an outing, but then that stopped because of the agitation in the car, but he would come and sit with Don. But then – in a small community, word gets round pretty quick, and once everybody heard that we had been evicted and banished from the local facility, that they realised that there was a danger there.

20 So I was told at first that they could still come, but I had to stay in the room with them. I didn't see any point in that. They were coming so that I could have a little break. That hour and a half could have afforded me time to prepare an evening meal, because I couldn't prepare an evening meal with Don there because if he saw me with a knife, then that was the perception. So there was so many things that I could
25 have done with that time, but then that was withdrawn because Don was deemed unsafe, so people – and they were very apologetic about it, but I was pretty much just told that they can't put their workers in danger, so that was it.

30 MR GRAY: Mrs Cameron, there were occasions – I won't ask you to go into detail about them – when you had further access to mental health unit. That was in March 2015. And then that stay ended in really quite a confrontational interview - - -

MS CAMERON: Yes, it did.

35 MR GRAY: - - - with the LMO, and again you had to take Don out of the unit.

MS CAMERON: Yes, I did. They were sedating him so badly. He was on Fentanyl patches. They said it was for pain, but it wasn't; it was to manage him. They were sedating him.

40

MR GRAY: And you were concerned about the medication regime and in particular the Fentanyl patch, and you had a serious disagreement with the LMO about that.

45 MS CAMERON: Yes, definitely, because they had not told me about it, and then they tried to claim it was for pain. I knew Don wasn't in any pain, and they refused to take them off. And then one of the staff angrily said to me, "Well, I don't come here to be assaulted. How else am I going to manage him?" So then I realised they

were just using them for that. And Don's health had gone down and he was barely coherent at this stage, in a really bad way. I couldn't leave him there any longer.

5 MR GRAY: And then again – and this seems like it was in late May 2015 – you received a booking for a two-week respite stay with a view to a permanent stay afterwards.

10 MS CAMERON: Yes. Yes. Excuse me. There was a lovely – there's a lovely facility in Kyneton and I had put Don's name down on there about a year prior to this with a view for him going there for respite, and they didn't have any – the only time they gave respite was between residents passing away if they had a little gap there before a new one coming in. And they had phoned me and said they had a two-week gap there with a view, if I wanted, for Don to be that permanent resident that would stay. I did explain about to them about Don's Lewy Body Dementia and I had Don's
15 GP talk to them about it and discuss the issues, and they said that they would try. They would see how it went. They'd see how they manage it.

MR GRAY: And the outcome wasn't - - -

20 MS CAMERON: No.

MR GRAY: Wasn't a good one, I understand.

25 MS CAMERON: No, unfortunately not. Look, they were very good and they did keep him there for the two weeks, but, unfortunately, for Don to go in they needed a new PRN medication, otherwise they won't take them in unless they've got something to use if needed. And because Don had been withdrawn off most of the things because they were not working, it was a matter of the GP trying to find something that – she did some research and she thought she had found what would
30 work for Don. They were the only circumstances that Don could go in, as long as he had a PRN medication.

35 But, unfortunately, even though they did keep him for the two weeks respite, he again developed gout while he was in there and the PRN medication was making him more agitated. And then I think when they prescribed prednisolone for his gout, which is a steroid, it seemed to be a clash in medications and Don was starting to punch people. And I could understand their point. They just weren't trained or equipped to look after him. They did try their best, but they couldn't do that.

40 MR GRAY: You tried to carry on caring for Don at home, but by a certain night in early June, I think it was – perhaps it was a day.

45 MS CAMERON: It was the day he came home from that respite. He was so hyper-vigilant and pacey and agitated. It was difficult for my daughter and I to just bring him home, actually, in the car, and all day, he paced and was agitated, and we couldn't settle him down. We had trouble settling down. By night, he was climbing furniture; he was pulling curtains down; he was trying to smash things, throw

appliances, punch us, kick us, whatever. It got to the stage where we knew we needed help.

5 My daughter had to restrain him, which was very upsetting for her. And she called to me to ring triple-zero. It was the only outcome. I think I hoped for ambulance, but I knew in my heart ambulance can't come without police. It has to be a safe situation.

10 Fortunately, a friend of mine – her daughter was a police officer and was on duty that night; heard the call, phoned the police officers that were attending and said, "Please be sensitive. This man has dementia and he's a very good man." So they were very sensitive with him.

15 MR GRAY: And essentially, after hospitalisation and quite a lengthy admission to hospital and a mental health unit, in April 2016, Don has been moved to his current nursing home where he is.

MS CAMERON: Yes, it's a specialised nursing home.

20 MR GRAY: What's your current role caring for Don? What do you do day-by-day?

25 MS CAMERON: I'm pretty hands-on caring still for Don. I found over the time that unless you take a really active role and have really good communication, the care is not the same. I had to learn how to cut Don's hair when he was in the hospital – the mental health facility. They don't have hairdressers there. So I now cut his hair because the hairdresser is, you know, inconsistently there. I attend to cutting his nails because they don't always have time to do that. I do his washing because I don't like all of his washing going into an extra hot tub with everyone else's in the unit. So I do all his washing. And I just attend to all his leisure activities. He gets very little stimulation. The staff just don't have the time to do that sort of thing. So I spend a lot of time reading and music and doing all sorts of activities with him.

35 MR GRAY: How often do you visit Don?

40 MS CAMERON: I go every second day, but if I'm concerned, I'll go in the day between. The facility is over an hour's drive for me. So on the days that I don't go, my children try to go. And we involve Don and they play instruments, so we involve Don with music and instruments and things, and that just adds a bit. Don's in a very peaceful state now. He sleeps most of the time. He hasn't been able to walk for a long time, probably about 18 months, and he has a permanent catheter. So he's pretty confined to a chair. So unless we give him some stimulation – so we – as a family, that's our contribution to Don's care. And it eases the burden from staff. They just don't have the time for that.

45 MR GRAY: Can you tell the Commissioners about the Woodend Lifestyle Carers Group.

MS CAMERON: Yes. I came across the Woodend Lifestyle Carers Group when I saw an ad in the paper in 2013 and they were just a few couples who attended a quick dementia course in Bendigo, and then when it finished they decided they needed to stay together to support one another. And I joined them not long after
5 they'd first formed this group, and we have built up over that time and our philosophy is to be there for the carers, to give support to the carers, to offer social interaction.

10 And by doing that, we support the person with dementia as well because we involve them in part of the session too. We have a session where – we meet twice a month and one of the meetings is purely for carers so that they can – we have guest speakers or they can just talk to one another, just discuss the things that they go through on a day-to-day basis and offer each other support.

15 MR GRAY: Can I ask the operator to put up paragraph 131. You speak there of the impact of caring for somebody who's living with dementia, the isolation, and – these are my words summarising yours - but, in effect, you're saying that this support group is invaluable in providing that social connection to try to overcome that isolation. Is that right?

20

MS CAMERON: It certainly is. We finish up becoming very isolated with someone with dementia because they have antisocial behaviours, you know, with their symptoms and people don't want to know you. You find that most of your friends and even family members disappear because they don't know how to deal
25 with it. And – and as I said, you know, even in town I found people would cross the street rather than come and have to talk to us because they didn't know how to deal with it. So you become very isolated.

30 So to be able to talk to somebody else who is going through a similar – it probably won't be the same, but it could be a similar-type thing, to be able to laugh together or cry together or just share information as to what works and what doesn't and we have contacts and information sessions that we can hand to people when they come. We find it's harder to get men to the group, but we are trying to do more in that area.

35 MR GRAY: In paragraph 133, you refer to one of the projects or initiatives being to provide information to fill that gap that you felt about there being no pathway for referrals - - -

40 MS CAMERON: Yes.

MR GRAY: - - - and help.

MS CAMERON: Yes.

45 MR GRAY: Has that worked?

MS CAMERON: It has, actually. We have people now who – if they hear about our group early enough and come into it, we’ve had people say that they’ve found it a huge help, that they’ve been headed in the right directions. I mean, we’re not professionals in what we do, but we can certainly give them brochures or suggest
5 pathways. And we try to interact with the local medical people so that they can hand out our brochures. We run market stalls and hand out our brochures. We try to make it known that we’re there so that we can be a support - - -

MR GRAY: In - - -
10

MS CAMERON: - - - when somebody needs it.

MR GRAY: Sorry, Mrs Cameron. In paragraph 134, you refer to helping people with grief after somebody has passed away.
15

MS CAMERON: Yes, we found that after somebody with dementia has passed away, the carer often stays on in the group. And so I think that’s part of their grief support, and also they’re invaluable to hand back information and support others in the group, especially if we have a social outing. They can help assist the carers, you
20 know, with the person they’re caring with.

MR GRAY: And another area where the work seems very innovative is The Bracelet Project. What’s The Bracelet Project, at paragraph 135?

MS CAMERON: We found that dementia is often not dealt with well in the community and often people with dementia if they wandered, they would be perceived to either be on drugs or alcohol, and often when they were picked up by police they weren’t dealt with in the best way, the most sensitive way. And particularly we had one man who, when he wandered off, would go and sit at the
30 park and watch the children and was perceived to be a paedophile.

So we decided that if we come up with a bracelet project where we would get a bracelet engraved with a certain identification on it, with permission, with the families, we’d then register that with the local police so that if somebody was picked
35 up with unusual behaviours, they could be identified and then family contacted. We’re struggling a little bit with this. The police really haven’t had the time to get it going, but we’re certainly still pushing with that.

MR GRAY: And we only have a couple of minutes left but, in brief, the Woodend Lifestyle Carers’ Group has been gifted land and has plans to build a centre; is that
40 right?

MS CAMERON: Yes. We’re pretty adamant about trying to get more respite facilities. So we’ve been gifted 10 acres of land and we’re ploughing ahead, raising
45 money and we’re going to be building, firstly, a day-respite cottage. It will be in a farm-style situation. And then we plan to move on to overnight respite stay in the next build and to permanent stay.

MR GRAY: You identify in your statement the need for day respite and flexible respite - - -

MS CAMERON: Definitely.

5

MR GRAY: - - - as a key need, don't you?

MS CAMERON: Definitely.

10 MR GRAY: Pretty difficult to ask you to try to do this, but looking back over this entire journey that you've related to the Commissioners and that you've lived over these years, apart from the Woodend Lifestyle Carers' Group, have you felt there was any support available to you?

15 MS CAMERON: No, not really. No. I didn't really feel that there was much that guided me through it at all.

MR GRAY: And is that group a government-funded group?

20 MS CAMERON: No, we're not. We do all our own fundraising. We have sausage sizzles. We run raffles. No, we're not at all.

MR GRAY: If there's one message or recommendation you would like to leave with the Royal Commissioners about how the very difficult journey that you've been on could be ameliorated for people in the future, what would that message or recommendation be?

25

MS CAMERON: I feel if there were more professional staff in facilities to deal with dementia. I just feel that PCAs, while they have their role, they are not equipped to deal with a lot of the situations that occur. And I think I feel that if I had have had somebody who knew and understood dementia more, if the staffing was adequate and they had their adequate training, things could have been very different, I think. I think I would have got more regular breaks. And maybe the outcome may have been the same, but I think the journey along the way would have been a lot gentler and a lot more easy and certainly not taken such a toll on my health as well.

30

35

MR GRAY: Thank you. Commissioners, those are my questions for Mrs Cameron.

COMMISSIONER TRACEY: Thank you. Mrs Cameron, I've only got one thing I want to ask you about and that is whether there has been a proper medication regime developed which has produced the better reaction from your husband in his new facility?

40

MS CAMERON: Yes, there certainly was. As soon as I got to this new facility, there's a psychiatrist that attends every week and a GP, and we have meetings with them every six to eight weeks. They started him on a new medication that I had never been told about – it wasn't a new medication – and it had a big change in Don.

45

His anxiety levels weren't as great and he certainly settled. But they were also trained to manage his behaviours in other ways. They didn't have to sedate him all the time. Don hasn't had to have a PRN for several years now and to understand the behaviours, to manage them, to deal with them – and the facility he's in is a small
5 facility of 10 people per module, and that smaller regime and the correct medication has made a big difference.

10 COMMISSIONER TRACEY: And is the medication medication that was always available?

MS CAMERON: As far as I understand, yes. I asked 'was it a new one' and he just said, "Oh, some – some don't prescribe it." So I don't – I think – I got the impression that maybe GPs can't prescribe it, but I felt that psychogeriatricians could. But it was never introduced.

15 COMMISSIONER BRIGGS: Thank you very much for your witness statement which we received this morning, so I've been reading it as you've been giving your evidence. It's an incredibly distressing story. The resilience you must have required
20 within yourself to be shuffled around between the aged care system, the healthcare system and so on is extraordinary. How did you manage that? How did you look after yourself? And what's the message about the interface between mental health services, specialists and other geriatricians and psychogeriatricians and GPs?

MS CAMERON: Well, firstly, I think – my father always called me a stubborn
25 person, so I guess my resilience was because I wasn't going to let it defeat me. And also for the person you love, you just – you don't give up, and somehow you're just thinking, "Tomorrow may be better." You just keep going. So I guess that was, you know, where I got my strength and I just somehow got through.

30 I think with the – I had never been told from the GPs that I could be referred to a psychogeriatrician. I didn't really understand that process in the beginning, and it was only that I stumbled across that by getting Don into a day care process that they said that I would probably need to see someone and then I went on the waiting list. So I don't really understand why that referral pathway isn't there. Maybe it is and
35 they just don't utilise it. But I guess I am often amazed at how many doctors really don't know enough about dementia. Yes.

COMMISSIONER BRIGGS: Good point. Thank you.

40 COMMISSIONER TRACEY: Mrs Cameron thank you very much for sharing your long and difficult and selfless journey with us. It's so important that we understand the difficulties that are being faced by families on a daily basis, and you have certainly provided us with a very good example of how the system can fail people and given us some pretty good hints about how things can be improved for the
45 future.

MS CAMERON: Thank you.

COMMISSIONER TRACEY: We're very grateful for you for doing that. Thank you.

MS CAMERON: Thanks very much.

5

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

<THE WITNESS WITHDREW

10

ADJOURNED

[1.21 pm]

15 **RESUMED**

[2.06 pm]

COMMISSIONER TRACEY: Yes, Ms Hill.

20 MS HILL: Commissioners, I call Joan Rosenthal. And I understand that co-solicitor assisting, Ms Amundsen, is present in Sydney to administer the oath.

<JOAN BARBARA ROSENTHAL, AFFIRMED

[2.07 pm]

25

<EXAMINATION-IN-CHIEF BY MS HILL

30 MS HILL: Ms Rosenthal, you're giving evidence by video link today.

MS ROSENTHAL: Yes.

35 MS HILL: If I can just ask you to let us know if at any point you can't see or hear us clearly.

MS ROSENTHAL: Okay.

MS HILL: And could I start by asking you your full name.

40

MS ROSENTHAL: My full name is Joan Barbara Rosenthal.

MS HILL: And you've asked that I address you as Joan today, haven't you?

45 MS ROSENTHAL: Yes, I would be happy with that.

MS HILL: Joan, how old are you?

MS ROSENTHAL: Sorry; 79.

MS HILL: And you're retired, Joan.

5 MS ROSENTHAL: I am but I do work part time. I have a private business.

MS HILL: What sort of work do you do part time?

10 MS ROSENTHAL: I do editing of academic publications like journal articles.

MS HILL: And is that something that you used to do a bit more of before going into that work part time?

15 MS ROSENTHAL: No, the main thing I did before I formally retired was that I was a lecturer in speech pathology at the university and then I retired and then I – I began to be an editor because people asked me to do that and I gradually became more skilled at that, and now that's what my business is.

20 MS HILL: And Joan, you've prepared a statement for the Aged Care Royal Commission.

MS ROSENTHAL: Yes.

25 MS HILL: Operator, could I please ask you to display document ID, WIT.038.0001.0001. Joan, do you have a copy of the statement that you've made in front of you?

MS ROSENTHAL: Yes, I do.

30 MS HILL: In fact, are you able to see a copy of it on the screen in front of you?

MS ROSENTHAL: Yes.

35 MS HILL: And is that the statement that you made for the Aged Care Royal Commission?

MS ROSENTHAL: Yes, it is.

40 MS HILL: Are there any changes you would seek to make to that statement?

MS ROSENTHAL: No.

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

45 MS ROSENTHAL: They are as far as I know.

MS HILL: Commissioners, I tender that statement.

COMMISSIONER TRACEY: Yes, the witness statement of Joan Barbara Rosenthal dated 23 July 2019 will be exhibit 7-5.

5 **EXHIBIT #7-5 WITNESS STATEMENT OF JOAN BARBARA ROSENTHAL
DATED 23/07/2019 (WIT.038.0001.0001)**

10 MS HILL: As the Commission pleases. Is Sydney home, Joan?

MS ROSENTHAL: Yes, born and bred.

MS HILL: Born and bred.

15 MS ROSENTHAL: Born and bred.

MS HILL: Who do you live with in Sydney?

20 MS ROSENTHAL: I live with Ian Hamilton.

MS HILL: And who is Ian?

MS ROSENTHAL: Ian is my spouse.

25 MS HILL: How long have you and Ian been together for?

MS ROSENTHAL: We've been together since about 1983.

30 MS HILL: And Ian is retired.

MS ROSENTHAL: Yes.

MS HILL: And before he retired, what did Ian used to do for work?

35 MS ROSENTHAL: He was a specialist physician and he worked in various capacities in public health occupational medicine and similar activities.

MS HILL: In August 2015, Ian had a fall; is that right?

40 MS ROSENTHAL: Yes.

MS HILL: What happened in August 2015?

45 MS ROSENTHAL: Well, we had been out to lunch with a friend and we were walking back on a small road through to the car. We had had no alcohol at lunch. And there was a slight camber on the road and as Ian stepped forward onto the road he tripped and he fell flat face down, and obviously hit the front of his – hit his face

on the ground and the result of that was that he had two fractured vertebrae in the back of his neck, C1 and C2. And so he was hospitalised and he was – that was August and he was hospitalised there, the first hospital, till about November and then he was in rehab at another hospital until shortly before Christmas.

5

MS HILL: And how old is Ian now?

MS ROSENTHAL: How?

10 MS HILL: How old is Ian?

MS ROSENTHAL: How old; he's 87. Yes.

15 MS HILL: And what does the nature and the extent have Ian's injuries mean for his day-to-day existence?

20 MS ROSENTHAL: Well, he was – he's actually very fortunate that he's able to get around, but he's quite limited. He has poor balance. He walks with the aid of a walking stick or with a – what we call a rollator, other people call it a walker and he needs – he needs help to get about. He also suffers neurogenic pain. He has spasms – painful spasms in his legs particularly, but also in other parts of his body which just come on unpredictably. So he – somebody has to be with him all the time and help him and he – he needs some help with toileting.

25 MS HILL: What's life like for yourself and Ian now?

30 MS ROSENTHAL: Well, it's – we live in our own home where we have lived all the time and that's quite important to – to us. We go out. We usually go out for lunch every day and I drive. Ian doesn't drive anymore. We have 25 step from our house down to the garage and obviously 25 steps back up to the house. So Ian generally manages that about, at lunchtime, once a day. The rest of the time he's entertained by television. We just do things round the house. I also do some of my work in – at my computer, and that's – and when possible, we go out and meet friends. Some friends come to see us and that's – that's what life is like.

35

MS HILL: How would you describe your role to Ian?

40 MS ROSENTHAL: My role. Well, I'm a carer. I'm paid a carer's allowance. I'm – well, I provide his meals at home and I – I look after – he has carers come in every day to shower and dress him. I look after his toileting most of the time and I also fetch and carry where necessary and I keep him entertained in whatever way I can, and we talk about – we have conversations together about all sorts of things.

45 MS HILL: Joan, how would you describe the impact of caring for Ian on Ian, who's receiving the care?

MS ROSENTHAL: Well, it's more the impact – for him it's more the impact of the loss of his – the loss of a large part of his life, really, the loss of his mobility. The loss of his independence. A loss of – a loss of being able to follow a lot of his interests. So what was the question?

5

MS HILL: How would you describe the impact on Ian of being a care recipient?

MS ROSENTHAL: Yes. Okay. Well, he's – partly he's – he's grieving for what he's lost and we both have. We've talked about that. And he's also trying to make the best of what he has got, trying to make the most of his opportunities. There – there are many things that he would like to do and sometimes he tries to do them and then realises he can't. So he's – he's sad about it all. He's sad that this is what – what his life has come to, but he's certainly glad that he's alive. He's never – he has never said, you know, I wish I had died or anything like that.

15

MS HILL: Joan, how would you describe the impact on caring for yourself as the carer?

MS ROSENTHAL: Well, I – I have similar feelings to what Ian has. I – I miss the things I can't do anymore and I regret that – that I'm not able to do those things, and – but I'm pleased that I had the ability to be Ian's carer and to look after his interests and to try and provide what I can to – to make his life more interesting.

20

MS HILL: Why is it important to you and Ian that you're the one caring for Ian?

25

MS ROSENTHAL: Well, he's – he trusts me. He's – he's a person who – who has always been rather suspicious of other people, but he does trust me and he always wants my company and – and he knows that – I guess he knows that I understand most of how he's feeling and what he needs. So he doesn't have to do a lot of explaining to me, although he does like to talk a lot, but he knows that – that I can need his needs.

30

MS HILL: You describe that you can't do the things that – the sorts of things that you used to do. What sorts of things did you used to do?

35

MS ROSENTHAL: Well, he was very keen on – so one example, he's very keen on photography. Our house has stacks and stacks and stacks of slide boxes everywhere, of his photographs from many years. I would hate to tell you how many; I've never counted them. So now he can't hold a camera. He has poor feeling in his fingers, so he can't manipulate the little buttons on the camera, so he's really extremely limited in the type of photography that he can do. For instance, he finds it hard to hold an iPad and photograph with that, which is the – I guess the easiest form of camera. So that's one thing he can't do anymore. He's also very keen on going to the local cricket and that involves getting down to the cricket ground and being able to sit somewhere comfortably for hours if he wanted to and he doesn't have the stamina to do that anymore and he some of the getting about there is a bit difficult for him.

45

So those are examples of things he can't do anymore. He likes to go to – we both like to go to concerts and he loves to hear classical music and for instance yesterday we went to a concert from the Shostakovich quartets and Ian lasted for the first half and for the second half he just couldn't sit there any more. He was too
5 uncomfortable. His legs wanted to move and so he had to leave that concert and go out and we were with another friend and he had to go out and just sit outside where he could walk around. So the things that he would like to do and like to, and things that he want do anymore, those are the things that he regrets very much.

10 MS HILL: And are there things that you're not able to do anymore?

MS ROSENTHAL: Yes. I can't – unless I get respite I can't – I can't go out much. We both used to do quite a bit of birdwatching and we've also been on holidays
15 where we went on birdwatching trips, some of them overseas, like to Malaysia, to India. We can't do that anymore because – for various reasons. And tell me where I'm starting from again?

MS HILL: You talked about how you used to do quite a bit of birdwatching
20 together?

MS ROSENTHAL: Yes. So there's very little of that we can do now. Yes, that's an example.

MS HILL: What do you do, Joan, if you want to go out these days?
25

MS ROSENTHAL: Well, if I want to go out, if I need to go out, and sometimes I need to go out, say, to shop, some of the time he will come with me and he will walk round the supermarket aisle with me but he's beginning to be a bit limited in that but that's what he would do. If I need to go out separately, we have a VitalCall. That's
30 a thing that hangs round your neck, and it's connected to a service that can provide help in case of emergencies. It's something that a lot of old people have.

And Ian has a VitalCall so if I have to go out, I will put his VitalCall on and that means that if anything happened to him, if for instance he tried to get up and he fell,
35 he would be able to press the button on his VitalCall and that would go to an agency and they would then contact him if they could or if they couldn't they would come to the house and try and get in and give him physical help, get him to hospital if he needed to.

That's never happened but that's a mechanism for getting help. Otherwise, apart
40 from that, I put him with – I give him his phone so that he can phone me anytime while – while I'm out, while I'm not home. So that's what I do and I make sure he's in a safe chair and that he has got his roller near him so that he can walk himself around if he wants to.

45 MS HILL: Using today as an example, you've come to the AGS office in Sydney to give your evidence, haven't you?

MS ROSENTHAL: Yes.

MS HILL: And what arrangements did you put in place so that Ian could remain at home while you entered the CBD?

5

MS ROSENTHAL: Okay. Well, we've got – we have one very good friend who is willing to come and be with Ian at times when – when she's able to do it. And it worked out that today was a day it was possible for her, so she has come to our house and she's keeping him company, conversing with him. They're having – I provided lunch so they're having lunch together and so that's – she's going to be there until I come home and that's probably the best sort of arrangement. We also do have carers that stay with Ian. He has two half days and week, two mornings where he – one of the carers stays with him, takes him out and they have lunch together somewhere until I come home.

15

MS HILL: And those carers that come to see Ian during the week, is that part of a home care package or how are those arrangements - - -

MS ROSENTHAL: Yes. Yes, that's part of the home care package. They are – yes, they're from an agency and Ian has a level 4 home care package and they are employed under that arrangement.

20

MS HILL: You've given evidence that after Ian was discharged from hospital in December or the end of 2015 there was a transition to home package that came - - -

25

MS ROSENTHAL: Yes.

MS HILL: - - - from the hospital?

MS ROSENTHAL: Yes.

30

MS HILL: When did you get a home care package after that?

MS ROSENTHAL: Well, I can't remember the exact date but I think it happened fairly soon. He was always – he had always been assessed as suitable for a level 4 home care package but there were no level 4 packages available but we were able to get – I think with almost no break, we were able to move from the transition to home care to a level 2 package administered by one of the local care agencies. And so from there he had a carer come to shower and dress him. I think it was five days a week then.

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40

MS HILL: How long between being on the level 2 home care package did you wait for the level 4 home care package?

MS ROSENTHAL: I think I wrote that because I can't remember now. November 2016 he had a level 4 home care package.

45

MS HILL: How did you manage in that 11 months between the level 2 and the level 4 package?

5 MS ROSENTHAL: Well, there was no break, so there were, so it was 11 months
with the level 2 care package. I think that – okay, the other thing was that I had
people come and stay overnight because Ian sleeps very poorly and he would tend to
need me. He would wake up at various times during the night and need me, and that
would interrupt my sleep, and that – I don't react very well to that and so privately
10 we arranged to have a carer come and the initial – initially it was two nights a week
who would be with Ian overnight. And does that answer the question?

MS HILL: Yes.

15 MS ROSENTHAL: Good.

MS HILL: Can I ask you presently what arrangements you have in place, Joan, to
support Ian at home?

20 MS ROSENTHAL: Okay. Within the level 4 package we have the carers – the
carers that come for one hour every day to shower and dress him and we have a carer
that comes for the rest of the morning, including lunch hour, twice a week. That's
one on a Monday and one on a Wednesday. That's all within the level 4 package.
Then as well, we have carers that come four nights a week to be with Ian overnight
and that's – we pay for that privately and so those are things we paid for. And then
25 we also have – I guess it is visits from some friends who will spend time with Ian
and – particularly this one friend who's there today who is willing to come and spend
time with Ian. We have tried having other people stay while – while I went away
and that didn't work out very well.

30 MS HILL: What's it like for you caring for Ian?

35 MS ROSENTHAL: What's it like for me? Well, it – it really – it defines my
existence a lot, but not entirely. It's – I like – in many ways I'm like a parent caring
for a small child in that their needs – their needs are paramount, Ian's needs are
paramount and, well, I'm – I'm defined as the carer. And so – but – but I have been
able to – to still have a lot of support from friends and – and some of them also – also
support Ian in very friendly ways as well.

40 MS HILL: How do you feel about being defined as a carer?

45 MS ROSENTHAL: Well, it's a new role in my life and – well, I think I – now – I
now admire young mothers very much who, you know, understand how complex it is
to be a carer for somebody. I've never had children, so I've never had to do that
before, and it's – it's something that certainly takes over a lot of your life, but you
have to – you know, there's no choice. You have to do it.

MS HILL: You've provided a photograph of yourself and Ian to the Royal Commission, haven't you?

MS ROSENTHAL: Yes.

5

MS HILL: I will ask the operator to display document ID, RCD.9999.0128.0001. Joan, are you able to see that photograph on the monitor before you?

MS ROSENTHAL: No, but I've got it in front of me.

10

MS HILL: Are you able to describe that photo?

MS ROSENTHAL: Okay. Ian and I are in a restaurant, and there it is there, and we're sitting – it looks as if we might have eaten, and this is – this is a typical lunch hour scene. We're in a restaurant in a – in a neighbouring suburb and we – either we are about to enjoy or we have enjoyed a meal that – and we've enjoyed a good time together.

15

MS HILL: And why did you pick that photo, Joan, to share with the Commissioners?

20

MS ROSENTHAL: Well, first I picked it because it had both of us. Recently, because Ian has – has really had to stop photography himself, most of our current photos are of him rather than me. This was one that somebody else took at our request so we've got a picture of both of us, so that was good. And the other thing is I picked it because we seem to be having a good time.

25

MS HILL: How do you feel about the change in circumstances that's occurred for you and Ian over these past few years?

30

MS ROSENTHAL: Well, it has been a challenge. It has been a challenging role for me. I have various feelings. Sometimes I feel I'm on top of it all. Sometimes I feel – I feel depressed. Sometimes I feel angry. Sometimes – sometimes I cry. Yes, I have a whole range of feelings about it, and sometimes I feel resigned to it. This is – this is what I'm doing. This is what I'm meant to be doing this time of my life. Unexpected, but, you know, you don't have choice.

35

MS HILL: Do you have any particular supports to support you in your role caring for Ian?

40

MS ROSENTHAL: Well, the carers that we have, the people that we have come into the house, they're all – they're all very supportive of me. They're men and women and they're all – while their main focus is Ian, they're all also supportive of me. Also I have a number of very – very close friends who are very important to me and have been very helpful to me. And it's just, you know, it has made a tremendous difference to me that I have those friends that have stayed friends with me. None of my friends have stopped being friends but, you know, particularly these, you know –

45

several friends have just really felt the need to give me support, and it has been wonderful.

5 MS HILL: Joan, you first contacted the Aged Care Royal Commission in March of this year, didn't you?

MS ROSENTHAL: Yes.

10 MS HILL: And you made a public submission?

MS ROSENTHAL: Yes.

MS HILL: What was your motivation for making a public submission?

15 MS ROSENTHAL: Well, I read about the opportunity to make a submission, and first I – I thought I wouldn't. And then I was having difficulty – at that time I was having difficulty arranging respite care, because I wanted to – to have respite to have a holiday with one of my good friends. We – we were hoping to have a holiday in – a tour in South Australia in the Eyre Peninsula for 11 days, and so I was trying to
20 arrange respite care for Ian.

And I was having a lot of difficulty. I was becoming really frustrated because every aged care facility that I contacted said, "Well, you know, we may have respite. We don't know. And we'll be able to tell you a week before it's needed or two weeks
25 before it's needed, but we can't tell you before then."

So that was – that was very frustrating, and it – it was very stressful. And so I thought, "Well, look, if I don't write about this to the Aged Care Commission, I will have missed an opportunity." So I wrote about it. And you can see some of my
30 feelings about it.

MS HILL: What did you end up doing in the month earlier this year that you wanted to organise that holiday?

35 MS ROSENTHAL: Well, I – I went online and somehow I came to an organisation called – which I wrote down somewhere – Aged Care Decisions, and I had never heard of that group. And I still don't know who runs them, actually, but it was Aged Care Decisions and they – they provide a service such as – which included giving me a list of aged care facilities reasonably within distance of our home and those
40 facilities would all be contactable.

None of them could give me – still give me a date, but they could all take information that I wanted to provide about Ian and, they could all say whether they thought they might have respite in the time I needed it. And so that – that gave me a
45 lot more scope to – to think about places and to discuss them with Ian and visit where necessary. And that Aged Care Decisions website, nobody had mentioned it to me. I

was really surprised because it was such a good service, and I had never heard anything about it and I just discovered it by accident.

5 MS HILL: And before you used – or before you had that website, how would you organise respite for Ian?

10 MS ROSENTHAL: Well, I organised it by contacting places that I knew about, and so I did find out about some places from the – the aged care service that – that I was – that we were paying, and so they, for instance, suggested one place and Ian went there, and then the next time I wanted – we wanted respite for him, he said, “Well, I don’t want to go back to that place again.” So then I would look around for another one, I would talk to people and find out another place, and then Ian and I would visit. And then I was lucky enough in the other cases that eventually I did get respite for him, but it was always just in the last two weeks before I was – before I went away
15 and after I’d paid all – made all the necessary arrangements and paid the money.

MS HILL: And what did that mean for you, not being able to book in advance?

20 MS ROSENTHAL: Well, I did. I did book in advance, but it meant stress for me and worry, “Am I going to lose my money?” You know, they – places are not necessarily – say, for instance, this last time when my friend and I went on a tour, there was – if – if you had to cancel for any reason, they would – they would reimburse I think a portion of what you’d paid, but they wouldn’t reimburse the whole lot. And then there would – there might be – I can’t think. In other instances,
25 maybe airfares had been paid. So that’s – that’s why – that’s why I was stressed. And also just not knowing if I was going to be able to go away and if Ian was going to be able to be looked after and if we were both going to get a break, because we both felt we needed a break.

30 MS HILL: Why was it important for you and Ian to take a break?

MS ROSENTHAL: Well, to be honest, it was more important for me. I felt I needed to get away from my role as a carer for a bit so that I could come back refreshed and do it better. Ian did not necessarily think it was such a great idea, but
35 he did realise that, you know, everybody said carers need a break, and so he was – he was willing to – to go to an aged care establishment for that reason. And he was looking for – he was interested in places that would suit his interests and have a high standard of care.

40 MS HILL: Has respite always been available for you and Ian when you’ve needed it?

MS ROSENTHAL: Well, fortunately, yes. Yes.

45 MS HILL: And you referred to using that website. Aside from that website, did you receive any assistance in organising that respite?

MS ROSENTHAL: Not that I can remember.

MS HILL: Would you have wanted any assistance with organising respite?

5 MS ROSENTHAL: I think I would have, yes. Yes. I mean, the assistance that I got from Aged Care Decisions was – was just wonderful.

MS HILL: What do you do, Joan, if something last-minute or urgent means that you've got to leave Ian for a period of time?

10

MS ROSENTHAL: Well, what do you mean? Hours or days or weeks or what?

MS HILL: In any of those circumstances, something comes up and you need to leave him.

15

MS ROSENTHAL: Well, sometimes – let me think. If – well, I can't – I've never had to leave him for – all right. Okay. One time. One time, a couple of – a friend – one good friend and a carer agreed that they would stay with Ian while I went on a birding tour for – I think it was about seven days, and so these two very good women lived with him in our house, one – one overnight and one during the day. And that – that did not end up happily. It ended up with me getting a phone call from Ian saying it was all terrible and then me getting a phone call from one of the carers saying it was all terrible. And so that – that – we couldn't – couldn't ever do that again. And then I've lost my train of thought.

20

25

MS HILL: I was asking you about - - -

MS ROSENTHAL: Yes.

30

MS HILL: - - - what you do in a last-minute or an urgent situation.

MS ROSENTHAL: Yes, an urgent situation. Well, sometimes I'll take Ian with me and sometimes – okay. Sometimes I can take him to a club, one of our local clubs where, as long as it's during the daytime, he can – he can sit in the club lounge and – like an RSL club, you know, something like that, and he can have coffee and food there. And then I can come and pick him up. So that – that happens occasionally. And so I go to an exercise class once a week, and he comes along and sits in the lounge and has coffee and reads the paper while I go to my exercise class.

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40

MS HILL: Joan, can I return to the topic of respite. What's Ian's experience of respite been?

MS ROSENTHAL: Well, he – he has never had – he has never been happy with it, and part of that is – I must say is partly him, and part of it is something to do with the respite place. And so, yes, he hasn't enjoyed it.

45

MS HILL: What's - - -

MS ROSENTHAL: He has appreciated some things about – some different things about each one, but he’s – he tends to remember all the bad things, the things that he hasn’t liked.

5 MS HILL: What do you want from Ian’s experience of respite?

MS ROSENTHAL: Well, I would like him to enjoy it. I would like him to – to feel that he has some – that he’s able to make some decisions for himself. And I would like him to feel that he has people – other residents and/or staff that he can chat to
10 because he’s a very communicative person. And I would like him to enjoy the food.

MS HILL: On your experience, has your and Ian’s expectations of respite been met?

15 MS ROSENTHAL: Only partially, yes. None of the places – one of the places would certainly have met my – my expectations, but they didn’t meet Ian’s. One – another one of them turned out to be an unfortunate time when three of their important appliances broke down, like the – the oven and the washing machine, and so on and so on. Yes. Okay. So whatever. All right.

20

MS HILL: Do you consider that respite should be an opportunity for Ian’s reablement?

MS ROSENTHAL: Look, it would be nice. One – one place he went to, he saw a
25 dietitian and – and that was very good. He got – he got some help from a dietitian. It would be nice if he could have physiotherapy when he went to respite, but I don’t think he has ever had that, although it was available in a couple of places, but I don’t think that he had it. Yes. There – yes, and then the other – the other sorts of things he needs for his reablement, as you call it, would be – would be specialist physicians,
30 and I wouldn’t expect that necessarily in someone who’s – who’s just there for respite.

MS HILL: Reflecting on your time as Ian’s carer, as Ian’s spouse, how do you describe experience of being Ian’s carer?

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MS ROSENTHAL: Well, it’s something that takes over your life. It’s something that changes your relationship. It’s something that affects your physical and mental wellbeing. And it’s something that lets you find out some of the really good things that you still have in your life.

40

MS HILL: Joan, I want to conclude by asking you this question. What do you need or what do you want in order to be able to continue to care for Ian at home?

MS ROSENTHAL: Well – well, first of all, it would be good if we had a home that
45 didn’t have 25 steps to – so that – so that Ian would be more able to get out and about with his roller, so that he could – so that he could do that if he wanted to. That’s not – yes, I don’t know.

MS HILL: Are there things that would make your life easier that could support you in your caring role?

5 MS ROSENTHAL: Yes. All the carers that we have, they've definitely made my life easier. I wouldn't have had any chance of coping with it – with the situation if we didn't have the carers. They – almost universally they have been excellent people and very, very efficient and also very caring, you know, that's what – they're called carers, but they really are very caring and very knowledgeable. So they – they've been just very good. And then my friends have also been very caring.

10 MS HILL: Acknowledging those 25 steps in and out of your home, why is it important for you and Ian to stay at home?

15 MS ROSENTHAL: Because we have a home full of stuff. We both – Ian maybe more so than I, we're both accumulators and if we were to move out of our home, first of all we would have to sell it and we would have to buy something else and then we would have to deal with all our belongings and that's something we just haven't wanted to face. And we would – we would lose our garden which we love, we both love. And so as long as Ian can manage those 25 steps, that's not – there's no reason that we would both want to move out.

MS HILL: Have you talked about giving evidence today with Ian?

25 MS ROSENTHAL: Getting – sorry?

MS HILL: Have you talked about the fact that you're coming along and giving evidence today with Ian?

30 MS ROSENTHAL: Yes, yes, definitely. I showed him my statement and he was very – he was very pleased with the statement. He said he thought it was good and he was glad that I'm coming.

MS HILL: Commissioners, that concludes my examination of Joan.

35 COMMISSIONER TRACEY: Mrs Rosenthal, thank you very much for your evidence. It's given us some insights into the difficulties confronted by carers on a day-to-day basis in this country, and we're looking very closely at what we can do to improve the lot of people like you and we can only do that with the sort of insights that you've provided us today. We thank you for that. We will break the connection now to Sydney.

40

<THE WITNESS WITHDREW

[2.52 pm]

45

MS HILL: As the Commission pleases. Ms Bergin will call the next witness.

COMMISSIONER TRACEY: Yes, Ms Bergin.

MS BERGIN: Commissioners, I call Barbara Jean McPhee.

5

<BARBARA JEAN MCPHEE, SWORN

[2.53 pm]

<EXAMINATION-IN-CHIEF BY MS BERGIN

10

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

MS MCPHEE: Barbara Jean McPhee.

15

MS BERGIN: Where do you live?

MS MCPHEE: I live in the Hunter Valley in a little place called [REDACTED] which is about 45 kilometres west, south-west of Newcastle.

20

MS BERGIN: Ms McPhee, is there a copy of a statement in front of you?

MS MCPHEE: Yes, there is.

25

MS BERGIN: Operator, could you please bring up document ID, WIT.0311.0001.0001. Is that your statement in front of you, Ms McPhee?

MS MCPHEE: Yes, it is.

30

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

MS MCPHEE: Not at this time, no.

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

35

MS MCPHEE: As far as I remember, yes.

MS BERGIN: Commissioners, I tender the statement of Barbara Jean McPhee dated 22 July 2019.

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COMMISSIONER TRACEY: Yes, the witness statement of Barbara Jean McPhee dated 22 July 2019 will be exhibit 7-6.

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EXHIBIT #7-6 WITNESS STATEMENT OF BARBARA JEAN MCPHEE DATED 22/07/2019 (WIT.0311.0001.0001) AND ITS IDENTIFIED ANNEXURES

MS BERGIN: Ms McPhee, you supplied a number of photos with your statement and I want to take you to each of them and ask you to describe each of the photos for the Commissioners. Operator, could you please bring up document RCD.9999.0137.0001. Ms McPhee, what is this photograph of?

5

MS McPHEE: This is my mother about 10 years ago.

MS BERGIN: So when was it taken?

10 MS McPHEE: 2007, 2009, I'm a little bit hazy on that one.

MS BERGIN: Thank you, Ms McPhee. Operator, could you please bring up RCD.9999.0137.0002. Ms McPhee, could you describe this photograph, please.

15 MS McPHEE: Yes, this is my father at the air force memorial in Englefield Green in England. He was a trip to – the bomber command – opening of the Bomber Command Memorial in London in 2013.

20 MS BERGIN: Now, operator, could you now please bring up RCD.9999.0137.0003. What does this photograph show, Ms McPhee?

MS McPHEE: This is my parents. I think this was at my father's 90th birthday. My mother was 92, my father was 90. That was the only time they smiled all day because they realised they were old.

25

MS BERGIN: Thank you, Ms McPhee. Operator, could you please leave the photograph on the screen while Ms McPhee gives her evidence. Where was your father born?

30 MS McPHEE: He was born in Pennant Hills in Sydney in 1924.

MS BERGIN: Where was your mother, Norah, born?

MS McPHEE: She was born in Norwich in England in 1922.

35

MS BERGIN: Your mum was in the Women's Auxiliary Air Force in the UK?

MS McPHEE: That's right.

40 MS BERGIN: And your dad was an Australian Air Force pilot.

MS McPHEE: That's right.

MS BERGIN: Your parents met through their respective World War II service?

45

MS McPHEE: That's right.

MS BERGIN: Your mum had several hobbies. Could you tell us about those?

MS McPHEE: Yes. Well, she was a librarian by training; she became a librarian later in life and she became the Clan McPhee's genealogist and also historian, and she loved reading, she loved talking to people. She loved history and she was a great communicator. She talked too much, of course, as we all do, but she was very much a people person and knew a lot of people, travelled a lot and was able to recall, if I might say, if you asked her about anybody in the clan or anybody who had had a history in the clan, she could recall details of properties bought, when they were bought, who bought them, why they bought them, you know, the whole lot. And so she was just a walking – a walking, you know, encyclopaedia of clan and other historical.

MS BERGIN: And was that the McPhee Clan?

15

MS McPHEE: That's the McPhee Clan, yes.

MS BERGIN: Your dad also had several hobbies. Could you tell us about those.

MS McPHEE: Yes, my father was – I think he would have loved to have been thought of as an amateur scientist but he wasn't quite, but anything scientific – anything with any kind of scientific bent he was always a little bit dotty about and he could quote you all sorts of wonderful theorems and other things all the time and got great delight in getting us up when we were children to watch Julius Sumner Miller, Why Is It So? and we all grumbled and griped but we still remember the program. He loved stargazing; he navigated by the stars when he was on car trials. He loved motor sports, and he loved aeroplanes, gliding, all that sort of boy stuff.

25

MS BERGIN: And his love of aeroplanes became a professional interest.

30

MS McPHEE: Well, it was right from the start. He was a little boy with a model aeroplane that was twice as big as him; there's one photo we have of him, and he went into the air force after he left school, and just loved flying. He loved aeroplanes, loved flying all his life.

35

MS BERGIN: Ms McPhee, during your adult years your parents lived near you and your sisters in the Hunter Valley.

MS McPHEE: We moved up there in the last 15 years but we were from Sydney but my sister has lived near them for 30-odd years and they had 25 acres and for a while they had cows and those sorts of things and they loved that as well.

40

MS BERGIN: You and your sister lived around eight or nine kilometres from their house by car?

45

MS McPHEE: There's three communities, and my sister lived in one, my parents lived in the other and we lived in the other.

MS BERGIN: In their 80s and 90s, your dad had access to aged care services provided by the Department of Veterans' Affairs.

MS McPHEE: That's right.

5

MS BERGIN: After your mum had access to services provided by the Department of Social Services.

MS McPHEE: That's right.

10

MS BERGIN: And then after your dad died in 2015 at the age of 91, your mum had access to aged care services from the Department of Veterans' Affairs; is that right?

MS McPHEE: That's right, yes.

15

MS BERGIN: Now, you and your sister continued caring for your mum until she passed away in 2017 at the age of 95.

MS McPHEE: That's right.

20

MS BERGIN: Now, I want to ask you, Ms McPhee, about your – the care needs of your parents. Your parents' care needs increased as they turned 90 - - -

MS McPHEE: Yes.

25

MS BERGIN: - - - which was in around 2012 to 2014. What employment did you have at this time?

MS McPHEE: Well, I have always worked as a consultant here in work health and safety and risk management, and my sister works in the same business. We're a sort of family business. And my husband works in the same business. So we were called away on occasions to – we work in mining, so we go to – I'll often go to quite remote mining towns in Queensland and New South Wales and might be away for three or four days at a time and then come home and have to write reports and those sorts of things. That's how we work. So we were home intermittently but not guaranteed all the time.

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35

MS BERGIN: At this time, what prompted your parents to need assistance from you and your sister as carers?

40

MS McPHEE: Look, it was so gradual. I think this is the one thing that – when dementia isn't an issue, the lack of physical ability and short-term memory issues as well creeps up on you and so there was little things, and I suppose with Dad we were – we were looking at help around about when he was in his late 80s because he had very, very bad skin. He had been in the tropics too long as a pilot. That's where they went and sat in the sun beside the pool – lucky them – and his skin was very bad and he often had wounds and things that required nursing.

45

So through the Veterans' Affairs they would send nurses out to help him with that. And then with my mother, she was reasonably self-sufficient until my father died. She had managed all her little ailments, but her eyesight and hearing were the things that really went in the end, and they are the things that caused us the most trouble.

5

MS BERGIN: Tell us about your Mum's vision impairment and hearing impairment.

MS McPHEE: Well, my Mum had macular degeneration, which I don't think she really understood, even though she was reasonably intelligent. I don't think the doctors really described to her what was going to happen. So she suddenly was railing against the fact that she couldn't see and she couldn't hear us at the dinner table, and our dinner table tends to be a bit noisy and robust, and she would complain because she couldn't hear us. And it was all our fault. It wasn't her fault. We would say, "Mum, wear your hearing aids." Well, no, no, no, no. It's me, it's you."

15

So we then had to start seeking help for those particular problems. But when my Dad died, she really did lose quite a lot of confidence in her physical ability. So she kept on falling out of bed and became a bit forgetful with the stove. She had always been forgetful with the stove, but it became a lot worse. So you had sort of melted metal all over the top of the stove when she'd left a pan on or something. It was - - -

20

MS BERGIN: Ms McPhee, you mentioned that had your mum was a great reader and communicator. What impact did her hearing and vision impairment have on her and her mood?

25

MS McPHEE: I think it was social isolation more than anything. She couldn't read the subtitles on – on the television in the end. So the subtitles was what was – what she relied upon to – you know, to get television meaningful, and when she couldn't see those, she began to get very frustrated and – and impatient.

30

MS BERGIN: And what impact did that have on you, Ms McPhee?

MS McPHEE: I – I think we were required – my sister and I were required to do quite a lot more supervising, helping, you know, kitchen stuff, cleaning, that sort of stuff. And we did it for a while and suddenly realised that there were points in our lives where we just couldn't do it and we needed help. So that's when we started to look for outside help.

35

MS BERGIN: Ms McPhee, I want to ask you about the outside help that you sought. But before I do that, you mentioned that you lived, or your parents lived on a large property. How did you manage the upkeep of the garden as your parents got older?

40

MS McPHEE: Well, with difficulties. They – the problem for us was that we didn't know quite – like all the other people who have spoken today, we didn't quite know where to go for help. And the local – there was a local volunteer service where

45

somebody – sort of, men were paid to come round and do mowing of lawns and things like that. So we sought help there, but that proved to be a little bit of a disaster in more ways than one. And we – my – my father refused to have them back because they – they weren't particularly honest in what they were doing.

5

MS BERGIN: Ms McPhee, you said that there was a – you explained the disaster in part in your statement as relating to destroying a water tank.

MS MCPHEE: Yes, well, my parents were on tank water and they'd had a plastic pipe, which was rather prominent, but it – they should have been able to see it, and they were whizzing around as fast as they could on ride-on mowers and they crashed into it, and we lost at least 10,000 – I think it might have been more like 30,000 litres of household water, and my father was not happy.

MS BERGIN: So, Ms McPhee, after this experience, how did you manage mowing the lawns?

MS MCPHEE: Well, my sister would mow them when she could because she came up and used my father's mower, and then my father's mower sort of died, and so we used to transport our mower up there and ride around and do it. So we used to take it in turns. Sometimes it didn't get done, which was pretty distressing for my dad. But my mum couldn't see by that stage properly, so it was less distressing for her.

MS BERGIN: At this time, Ms McPhee, you're assisting your parents with the lawn mowing, as was your sister. You're also assisting them to attend appointments; is that right?

MS MCPHEE: Doctors – yes, endless doctors' appointments and assessments and, you know, all sorts of arrangements for eyes, ears, skin. My father had a lot of skin cancers, so they had to be removed. So day surgeries, those sorts of things, yes.

MS BERGIN: So as well as people attending in the house to examine and treat your father's skin condition, he attended appointments externally; is that right?

MS MCPHEE: Yes, a lot. Yes.

MS BERGIN: And did you also assist your parents with the shopping, Ms McPhee?

MS MCPHEE: Yes, always. And we tried to take Mum shopping. The problem was again she couldn't see. The noise – when she had her hearing aids on, the noise was always a little bit overwhelming, and you'd lose her. She was a bit like a two-year-old. She'd suddenly scamper off on her walker, and we'd find her down another end looking at chocolates or things she shouldn't be eating at all. But she was totally in – in – you know, control, but she wanted to be in control, if you know what I mean. She wanted to do her thing shopping, rather than what we wanted to do. So she enjoyed it in a way. It was a bit of a challenge.

MS BERGIN: Ms McPhee, how did you and your sister organise suitable care at home for your parents once you realised you needed some additional assistance and support?

5 MS MCPHEE: Well, I think we had the exact same problems that everybody else here has described. Trying to find what was available, who gave it, government department – and I'm now talking much earlier, probably 2010 to 2013. We were trying to find information from Veterans' Affairs, Social Services, local government, local hospitals, anybody who could give us information, and there was nothing –
10 there was nothing – there were lots of brochures but nothing that actually met our particular needs, which were quite minor for most of their lives, most of the later lives.

We really didn't have a major problem until the last few years of their lives. But
15 trying to – to make it out – and then when we tried to get assessments, the ACAT assessments, we started – Mum had one and she was assessed, I think she had another one, it was lost. She had to have a follow-up one because you had to have one every two years, as if things were going to get better at her age, which they didn't, of course. And then we had quite a few people to come to do different types
20 of assessments. The doctors did assessments. It was endless. But there was no – there was – you didn't get the feeling at any time that there was any central point where all of this information was kept and could be accessed by appropriate people.

MS BERGIN: Who assisted your parents to navigate the system, Ms McPhee?
25

MS MCPHEE: We did. We did it all. My mum had done Veterans' Affairs with my dad. But by the time we got to needing help for her, she wasn't really in a position to do anything.

30 MS BERGIN: Did you assist your mum with communications with Department of Veterans' Affairs this time?

MS MCPHEE: Yes. Yes. Well, we did it all. There was no point in putting her on the phone because she couldn't hear.
35

MS BERGIN: And how did you find communicating with that department?

MS MCPHEE: Veterans Affairs was difficult. It was like a little silo all to its own. Social Security – Social Services was a bit better and they were empathetic on the
40 phone, but nothing ever happened, if you know what I mean. And if, in our particular region or area, the services weren't available, they just weren't available. You couldn't access them. So we were often handed from one department to another to another having spent maybe three-quarters of an hour on the phone only to find that nobody could help us anyway.
45

MS BERGIN: You refer in your statement, Ms McPhee, to the assessment of your mum for a home care package. What happened; who sought an assessment for your mum for a home care package?

5 MS McPHEE: I did. I did all those ACAT ones, yes, and - - -

MS BERGIN: What was involved with those assessments, Ms McPhee?

10 MS McPHEE: Well, actually getting them in the first place was actually quite tortuous. It wasn't one - everybody gave you a different number to ring and then when you rang that number they'd say no, you've rung the wrong number, ring this number and, you know, you would be passed on. But I finally got the first of several and they were fine, but it was a sort of a one - a one - a one size fits all. There wasn't really any recognition of the fact that they were moderately independent, they
15 just needed a little bit of help at the beginning. We couldn't get through to the OT on one occasion, when he rang her and she didn't answer, my mum didn't answer I said, "Yes, but she's deaf", but he had already been told that she was deaf. It was really very hard to get the message through that they had to either ring us or they had to write a letter and we had to read it to her.

20

MS BERGIN: So are those services that you're describing now, Ms McPhee, services that were organised by the Department of Veterans Affairs?

25 MS McPHEE: The first couple for my mother - the first couple for Dad were organised by Veterans Affairs, the first couple for my mother were from social - - -

MS BERGIN: From the Department of Social Services. And so in relation to your mum's application for a home care package did you have to wait long for the ACAT assessment to occur?

30

MS McPHEE: Yes, sometimes six to eight weeks, yes.

MS BERGIN: Was that after your father had passed away?

35 MS McPHEE: No, that was before. That was about 2012.

MS BERGIN: What was the outcome of the assessment?

40 MS McPHEE: Well, the outcome was that she needed home help and she did get a cleaner, but the cleaner, I think, took it on herself to become Mum's companion when she was there for an hour and a half a fortnight, and sat and had tea. And we would go in there and nothing had been done and it was a little bit of a tricky situation because we - Mum loved sitting and talking but we had to go in and do the housework anyway. So it was a bit of a failure.

45

MS BERGIN: Ms McPhee, in your statement you mentioned that your mum was granted an ACAT package but you were told that packages were not available from local providers.

5 MS McPHEE: A 3/4, yes.

MS BERGIN: A 3/4.

MS McPHEE: That's a much more - - -

10

MS BERGIN: So the services you were referring to initially, was that a home care package or - - -

15 MS McPHEE: It was a fairly basic home care package of showering a couple of days a week, and cleaning. And I think there were other services but they weren't available in our area.

20 MS BERGIN: Thank you, Ms McPhee. So then in relation to the ACAT assessment for a level 3 to 4 care package, when was that assigned to your mum, Ms McPhee?

25 MS McPHEE: Well, about two years before she died, she was 93 I think. I think just when my dad had died and we were realising that it was a bit – she couldn't sit on her own, stay on her own.

MS BERGIN: Thank you, Ms McPhee. So you were advised by the department that she was – she had been assessed as a level 3 to 4 package. Did the higher level services ever commence for your mum?

30 MS McPHEE: No. No, they rang me 14 months after – well, Social Services rang me 14 months after Mum died and said that the package was available and I said, "But, you know, Mum died 14 months ago. Why didn't Veterans Affairs tell you?" and apparently the two departments don't exchange information. So that was as far as it went.

35

MS BERGIN: Ms McPhee, I just to ask you now about your father. When did your dad enter residential care?

40 MS McPHEE: Well, he was in hospital for eight weeks having had what the doctors describe as a cardiac event, we think it was some kind of heart attack. But he actually had congestive cardiac failure, so he had the two. So he was pretty sick, and he was in hospital for six or eight weeks but then we were suddenly told that he couldn't keep him in and at some stages he nearly died and then we thought, yes, he rallied and we thought we could take him home. But he never quite got to that point
45 but we never quite knew and he – he knew where he was, he was pretty miserable about being in hospital but then we suddenly found we had to find a nursing home, you know, a care facility for him, and, of course, at short notice there's nothing really

available. You just have to take what you can get. So that's when he went into a care facility but he only lived for another two weeks.

5 MS BERGIN: And at this time when your dad went into the care facility, was he receiving palliative care?

10 MS McPHEE: No, no. And thinking back, you know, we were so foggy and sort of disorientated at the time and upset that we should have perhaps asked for palliative care but I'm not even sure that would have been available but as it was, he was sort of just left in a normal nursing home without the care that he – the day-to-day and hour-to-hour care that he really needed. He'd come from an acute care hospital where he was looked after well to somewhere where he didn't see a nurse for hours on end. And he had – by that stage he was beginning to become incontinent and had a few other issues.

15 MS BERGIN: Ms McPhee, after your dad passed away in 2015, to give you and your sister and a break, your mum had three stays in respite care.

20 MS McPHEE: That's right.

MS BERGIN: And in April 2016 she went first into a facility that we will refer to as the older facility. This was 17 kilometres west from your home.

25 MS McPHEE: North-west, yes.

MS BERGIN: North-west from your home. And in April 2017 so a year later, she went into a facility that we will call the newer facility and this was 17 kilometres to the east from your home; is that right?

30 MS McPHEE: Yes, yes. No, directly east actually. Yes, yes.

MS BERGIN: She then went back to the older facility in August 2017. How did you select these two facilities; did you have much choice in the Hunter Valley?

35 MS McPHEE: No choice at all. Nobody does respite. They had – each – each – very large facility had one respite room available and you had to book six months in advance, sometimes a year in advance, sometimes if it's Easter or Christmas, longer I think.

40 MS BERGIN: While Norah was in her first experience of respite in the older facility, how was that for your mum?

45 MS McPHEE: Well, we took her out – we took after six days because we could tell she was very unhappy but being who she was she was controlling it but only just controlling it. I might say that when we arrived – they were very caring and they all arrived outside to greet her outside. Out came the wheelchair, she was trotted inside but as she was getting out of the car she said, "I've been betrayed" and, you know,

that – you know, the guilt that all of us feel in these situations that we can't do enough and we thought oh no, so we went in every day. We had two or three visits every day so respite really wasn't what it was about. It was about just getting her used to being away from us, I suppose. Sorry, now I've forgotten.

5

MS BERGIN: How was that first experience of respite in the older facility - - -

MS McPHEE: Well, they were very caring, very – very competent as far as the system let them be competent. And she was always helped with showering and
10 toileting, but because of the design of the care – the care facility it was a long way to dining rooms and her room was right at the entrance. So it was very noisy and chattery and a lot of people walking past and that sort of thing. The care was good. The facility itself was dated and needed a good old spruce up and rethink.

15 MS BERGIN: Ms McPhee, you mentioned that you or your sister visited every two to three days during that first stay in respite care. How much of a break did you get
- - -

MS McPHEE: We don't – we didn't really, no. In fact, it was harder for me
20 because I used to go round there every couple of days. For my sister it was much more a daily thing. But I would do the visits and the – you know, doctors' visits and that sort of thing and take her out which wasn't an easy thing. She was fairly demanding in many cases but we were quite happy to meet those demands as much as we could.

25

MS BERGIN: Were you also juggling your own workload at this time?

MS McPHEE: Yes, yes. While I wasn't working – while neither of us was working
30 full time we definitely had – we had to plan it. So somebody was around, particularly with my mother, when she was on her own. We couldn't leave her alone.

MS BERGIN: How did it make you feel, seeing your mum in the older facility?

35 MS McPHEE: Guilty. It wasn't easy. We tried our best to make it as sort of cheery as possible. We had people in in to fit her with slippers and shoes and all sorts of other things but she's the sort of person who goes into a shoe shop and tries everything on and then walks out and buys nothing so there were slippers and shoes everywhere but at least it kept her entertained for an hour and a half. It was one of
40 those things we tried to do to make her feel as if we were doing something and not abandoning her.

MS BERGIN: Ms McPhee, your mum secondly went into the newer facility in
45 April 2017 for respite care when your sister went on a holiday. What observations did you make about your mum's care in the newer facility?

MS McPHEE: Well, it was a beautiful, newly built facility; it only been open about nine months, I think – well, you know, probably six months when we booked her in, and it had been opened about a year by the time she was there. So the care – look, to be honest, I didn't see much caring. I didn't see anybody. There was just nobody, I
5 could not find a nurse, I could not find a cleaner. I found the lady who was preparing the meals, but she said she couldn't help me, but not once in the two weeks that I was going backwards and forwards, not every day, did I find a nurse, certainly not a registered nurse. And all I wanted to find out was how Mum was going and were there any issues. Because she's not – she wasn't an easy person, she was quite
10 demanding but she would sit back and she would wait to be asked before she told anybody anything and I don't think that quite penetrated.

MS BERGIN: How did you get information about how your mum was going?

15 MS McPHEE: She was telling me. I said "Now, have you had your shower today?" "No, no, I showered myself." We know that she was having help at home so that wasn't a good situation. She was toileting herself most of the time and at night, at one time – at one stage later in the day – later in the stay, she fell out of bed and was on the floor for several hours before they found her.

20 MS BERGIN: Ms McPhee, how often were you visiting while your mum was in respite care in the newer facility?

MS McPHEE: Well, the thing about that was we were supposed to have a break and the first week I thought I will go in every two or three days and that's what I did.
25 Then I began to twig that things weren't quite the way they were so I started going in a bit more regularly. But there was absolutely nothing I could do because at no – I couldn't even leave a note for anybody; there was nothing, there was nothing there. And the other thing was that her rubbish bins weren't being emptied and she had incontinence pads in these bins and they obviously hadn't been emptied for days, and
30 she was putting bits and pieces, rubbish in drawers and because she couldn't see that washing was getting muddled up with the rubbish, and that disappointed me, I must say, and worried me.

MS BERGIN: So how much of a break did you receive while your mum was in this
35 newer facility?

MS McPHEE: In the end it was not a break at all. You just felt really guilty even if you knew that – there was not much you could do. It was more of a worry than it was a break.
40

MS BERGIN: Thinking about these three experiences in respite, in that your mum went back to the older facility in August 2017 finally, how effective was it for you and your sister?

45 MS McPHEE: The older facility, again, as I said, was very good and they were very caring. It was during that dreadful flu epidemic and at the end of the first week I had – was getting the flu. So I didn't go near my mum. I went in to explain to her what

was the problem. She said, “That’s fine, that’s fine” and she was quite cheerful about it. But we then heard that they were still being wheeled up to the dining room for meals and that they had already had several cases of the flu at the older facility.

5 And my sister and I were pretty alarmed but it seems that my mother contracted the flu, I would imagine – she was complaining of a sore throat for a day or two and then on the Sunday my sister went in in the morning and my husband went in in the afternoon and it was the day before she was due to come home, and she was complaining of a sore throat, she was coughing. And my husband – she said, “I
10 really want to go home” and my husband said “Yes, tomorrow we’re taking you home, tomorrow’s the day”, and she died that night. Sorry. I’m not saying she was young. She wasn’t. And she wasn’t healthy, but she wasn’t about to die as far as we were concerned.

15 MS BERGIN: Were you concerned that your mum died from influenza that she contracted - - -

MS McPHEE: No, I think she started coughing and I think she became breathless. She may have inhaled something, we don’t know, but just the palaver of getting the
20 doctor there from [REDACTED] to the care facility in [REDACTED] was just too difficult so we thought there was no point in taking it any further.

MS BERGIN: Yes. Commissioners, there’s a non-publication order that relates to the reference to [REDACTED] and the older facility.

25 COMMISSIONER TRACEY: Yes.

MS BERGIN: I understand that that reference has been redacted from the feed.

30 COMMISSIONER TRACEY: Well, we don’t know that, but if it has, then it hasn’t been redacted from the running transcript. So something may need to be done about that.

MS BERGIN: Thank you, Commissioner. We will check the redactions in the
35 transcript.

COMMISSIONER TRACEY: Yes.

MS BERGIN: Ms McPhee, you set out in your statement helpfully a number of
40 considerations that would assist in relation to respite facilities. At paragraph 46, you make some suggestions, and I would just like to ask you to read that paragraph out, if that’s all right.

MS McPHEE: Okay. 45 or - - -

45 MS BERGIN: I think paragraph.

MS McPHEE: 46.

MS BERGIN: It's my paragraph 46, Ms McPhee, home care services.

5 MS McPHEE: Yes. Okay.

Home care services that enable carers to take breaks could be an alternative –
and this is one of the things that just was not available.

10

These would provide more timely response for carers who are in need of urgent relief. This is particularly pressing in regional areas where access to facilities is insufficient to meet demand.

15 MS BERGIN: Ms McPhee, what issues arise for carers in regional areas?

MS McPHEE: Well, there's quite long distances between home and the care facility in many cases. I think out here it would be much worse than it is for us, but also the care facilities, the good care facilities don't take respite care patients or clients at all.
20 And the ones that do, do so I think under duress almost because they see it as a social requirement. But they're certainly not enough. And in my – in my opinion, I think respite probably needs to be separated from long-term care because the respite care is quite different and so varied and there's so much paperwork involved that dedicated places for respite might be a much better way of dealing with the situation.

25

MS BERGIN: Ms McPhee, would cottage or day respite have been of assistance to you?

MS McPHEE: It would have been marvellous, yes, it would have been wonderful.

30

MS BERGIN: Why is that?

MS McPHEE: Well, just because, you know, it's short term. It just gives you freedom during a particular period to do something knowing that you're not going to get a call to say that, you know – because she had a little telephone button thing that she would ring, either my sister or me if she was in trouble, but you weren't going to get a telephone call to say that she was on the floor and needed to get up.

35

MS BERGIN: Ms McPhee, is there anything else you wanted to say about your experience as a carer to the Commissioners which we haven't covered in your examination?

40

MS McPHEE: No, I think other people have actually covered a lot of what our experiences were. I think it was just the paucity of respite care for us and when it was there, it was almost seen as somebody who was separate to the rest of the community and they weren't given the same care as I think they do need. They need a different type of care.

45

MS BERGIN: Thank you, Ms McPhee, and thank you for travelling all the way from the Hunter Valley to be with us today. Commissioners, I just wanted to clarify that I would like the three photographs that I took Ms McPhee to to be included in exhibit 7-6 because they're not currently referenced in her statement.

5

COMMISSIONER TRACEY: Yes. Very well. They will be included as part of exhibit 7-6.

10 COMMISSIONER BRIGGS: Ms McPhee, could I ask you, in addition to the emergency respite or the dedicated respite services that you talked about, you said earlier on that certain services that she was entitled to within the package simply weren't available from the provider. Was that different from respite care or was it other services?

15 MS McPHEE: Well, I think that – I was under the impression and I may be wrong but I was under the impression that level – the levels of care provided were something that the care facility would be reimbursed for.

20 COMMISSIONER BRIGGS: Right.

MS McPHEE: So if they were level 3/4 they would get level 3/4 care, which means daily help with showering, toileting help and others things like vision and those sorts of things and for that they would be paid more. I didn't get any evidence of any sort of care at all, other than meals. There was some showering in the new facility but I just don't think that it was – but I don't think it was – I don't think it was the facility's fault, I think they were just overloaded and the distances were huge. People just couldn't get around in time.

30 COMMISSIONER BRIGGS: Thank you.

MS BERGIN: Commissioners, I seek to clarify that the location of the newer facility was cut from the web-stream and I will do that with your leave?

35 COMMISSIONER TRACEY: Yes. Certainly.

MS BERGIN: If Ms McPhee may be excused, I understand that we need a short break in order to set up the video link for the next witness.

40 COMMISSIONER TRACEY: That's right. So you will attend to it during the break?

MS BERGIN: I will need to ask for the assistance of Law In Order for that confirmation.

45 COMMISSIONER TRACEY: All right. Well, I will leave it with you and you can tell us after the break what the position is.

MS BERGIN: Thank you, Commissioner.

COMMISSIONER TRACEY: Yes. Ms McPhee, thank you for adding your
account of your experiences as a carer to those that we've already heard. You've had
5 a different number of experiences that are equally relevant to the work that we've got
to do, and we will certainly be taking your evidence into account when we come to
make our recommendations with a view to improving the system.

MS MCPHEE: Thank you.
10

COMMISSIONER TRACEY: Thank you also, as Ms Bergin has already said, we
add our thanks to you for being willing to travel this distance to be here and give the
evidence in person. Thank you.

MS MCPHEE: Thank you. Thank you for the opportunity. This is the first time in
15 my life that I've been given this opportunity to – to actually follow-up verbally with
a written report. So that's wonderful. Thank you.

20 <THE WITNESS WITHDREW [3.32 pm]

MS BERGIN: Commissioner, before we adjourn for the short break, could I ask
you to please clarify for the people in the room that the location of the newer facility
25 which was heard by people in the room today should not be published.

COMMISSIONER TRACEY: We will give an oral direction that there be no
publication of the name of the location of the new facility and foreshadow that there
will be a formal written direction in that regard as soon as that can be arranged.
30

MS BERGIN: May it please the Commission.

COMMISSIONER TRACEY: Very well. The Commission will temporarily
adjourn.
35

ADJOURNED [3.33 pm]

40 **RESUMED** [3.47 pm]

COMMISSIONER TRACEY: Yes, Ms Hill.

45 MS HILL: If the Commission pleases, I call Shontia Saluja-Honeysett, who I can
indicate is present in the hearing room, and Lynette Bishop, who I indicate is present
on the telephone. I might clarify, Lynette, are you able to hear us okay?

MS BISHOP: Yes, I can.

MS HILL: Thank you, Lynette.

5

<SHONTIA MICHELLE SALUJA-HONEYSETT, AFFIRMED [3.48 pm]

10 MS HILL: Ms Bishop, we're – the associate is just about to administer your affirmation, and she's just walking to the microphone now to do that.

<LYNETTE JOYCE BISHOP, AFFIRMED [3.49 pm]

15

MS HILL: Lynette, I will just check that you can hear Shontia okay. Shontia, could I ask you to say hello to Lynette.

MS SALUJA-HONEYSETT: Hi, Lynette.

20

MS HILL: Hi, Shontia.

MS HILL: And could I clarify with both of you that you've asked me to refer to you by your first names today.

25

MS SALUJA-HONEYSETT: Yes.

MS BISHOP: Yes.

30 MS HILL: Thank you. Now, Lynette, I might start by asking you a few questions. Lynette, could I ask you to state your full name.

MS BISHOP: Lynette Joyce Bishop.

35 MS HILL: And how old are you?

MS BISHOP: 56 this year.

MS HILL: Lynette, where do you live?

40

MS BISHOP: At Stratford in Victoria. [REDACTED]

MS HILL: And is that where you're calling in from this afternoon?

45 MS BISHOP: Yes, from the landline.

MS HILL: And what do you do for work, Lynette?

MS BISHOP: My title is – sorry, Aboriginal Access and Support. My role provides basic support to people living at home, keeping our elders and disability stay living longer in their homes, keeping them safe while they’re living there and partly keeping them as independent as possible. Registering them to My Aged Care and any other referral pathways that they may need, and reporting back on any issues they have struggled with in obtaining any services.

MS HILL: And, Lynette, do you also hold a position with the Victorian Committee for Aboriginal Aged Care and Disability? Lynette, can you hear me there? I can see that the operators are trying to identify the issue, Commissioners.

COMMISSIONER TRACEY: Yes. We will wait.

MS HILL: It may be that the witness needs to dial back in. I suggest it’s probably appropriate that we sit tight while that occurs, Commissioners.

COMMISSIONER TRACEY: Yes. That’s perfectly all right. I was going to suggest that if it’s not inconvenient, it might be suitable for you to continue with the witness who’s here.

MS HILL: Shontia, if I can ask you some questions. Could I ask you to state your full name.

MS SALUJA-HONEYSETT: Shontia Saluja-Honeysett.

MS HILL: And what’s your age, Shontia?

MS SALUJA-HONEYSETT: I’m 38.

MS HILL: And where do you live?

MS SALUJA-HONEYSETT: I live in Craigieburn in Melbourne.

MS HILL: And where are you from?

MS SALUJA-HONEYSETT: I’m a Wiradjuri woman from Leeton, New South Wales, but I’ve been in Victoria for 16 years.

MS HILL: And what do you do for work?

MS SALUJA-HONEYSETT: I’m also an Aboriginal Access and Support worker, so very similar to what Lynette does but in a city kind of setting.

MS HILL: And you hold a position with the Victorian Committee for Aboriginal Aged Care and Disability, don’t you?

MS SALUJA-HONEYSETT: Yes, I’m the vice-chair.

MS HILL: And are you able to tell the Commissioners what sort of work that committee does.

5 MS SALUJA-HONEYSETT: So, basically, it's a platform for us to share and network about issues that are arising around aged care and disability. We also have representatives from local State and government who also come to provide information around aged and disability. So it's a good opportunity, especially for us Aboriginal workers, to sit down and talk around issues that our elders are having in each of our communities as we're very different in each of our roles. So, yes, that's
10 basically it. Yes.

MS HILL: And you've prepared a statement, haven't you, for this Commission?

15 MS SALUJA-HONEYSETT: Yes.

MS HILL: And that statement is dated 26 July 2019.

MS SALUJA-HONEYSETT: Yes.

20 MS HILL: And do you have a copy of that statement there - - -

MS SALUJA-HONEYSETT: Yes.

25 MS HILL: - - - in front of you? Are there any changes you'd seek to make to that statement?

MS SALUJA-HONEYSETT: No.

30 MS HILL: Commissioners, I refer to the statement of Shontia Saluja dated 26 July 2019, document ID, WIT.0317.0001.0001, and I tender that.

COMMISSIONER TRACEY: Yes, the witness statement of Shontia Michelle Saluja-Honeysett dated 26 July - - -

35 MS HILL: 26 July, Commissioners, yes.

COMMISSIONER TRACEY: 26 July 2019 will be exhibit 7-7.

40 **EXHIBIT #7-7 WITNESS STATEMENT OF SHONTIA MICHELLE SALUJA-HONEYSETT DATED 26/07/2019 (WIT.0317.0001.0001)**

45 MS HILL: And could I clarify, Shontia, that the contents of that statement are true and correct.

MS SALUJA-HONEYSETT: Yes.

MS HILL: I want to ask you, Shontia, some questions about the relationships of Aboriginal elders and their carers. Are the relationships of Aboriginal elders and their carers the same as for non-Aboriginals?

5 MS SALUJA-HONEYSETT: In most aspects, yes. But in other aspects we're a little bit different because we've got more complex health issues, as we have the Closing the Gap. So there's – our elders are dying a lot younger than the majority of the other Australian people. Also the fact that a lot of our elders, you know, have passed down or experienced intergenerational trauma through being Stolen Gen,
10 through racism, isolation. They're probably the biggest ones that - - -

MS HILL: And could I ask you to describe what you mean about the experience of international – pardon me, intergenerational trauma and the Stolen Generation.

15 MS SALUJA-HONEYSETT: So I will use an example which is not in my statement but – and in a previous role that I was in prior to, I was working at a hospital as an Aboriginal liaison at the time. I had an Aboriginal elder who was a fail-to-attend quite a few times for a heart specialist to have surgery, so I kind of went out of my way and made a time to meet with her just to kind of get a gist of
20 why that was happening, and her story was – is that when she was a lot younger and was from a remote town, her young son became very unwell and she had to wait outside of the health service at that point until the rest of the non-Aboriginal people were serviced. And her child was taken in and she wasn't allowed in and – and then was informed the next day that her child had died.

25 So for her accessing a hospital setting at that point was very traumatising. She hadn't really sought any kind of medical kind of interventions – seen her local GP and that was about it. So then I kind of worked with her to kind of get her to start attending those appointments by supporting her. So that's one example of, you know
30 – that was passed down from her mother but her experience of being excluded and having that trauma happen to her and the reason why she wasn't actually accessing and using the hospital at that point.

35 MS HILL: Shontia, what sorts of things do you do to support someone who's in that situation?

MS SALUJA-HONEYSETT: In my current capacity, I have a little bit more lee work –leeway because I'm more outreach, whereas in – when I was working as the
40 liaison I was bound to the hospital. So in my role, it's basically going out promoting my position in aged care services predominantly. As you know, NDIS has come in, so where I work we've kind of transitioned out of that space, but I still work with disability families. But it's about providing that information to the elders because they're not always aware of the services and support that's out there. And there may be circumstances where trauma has happened in the past that actually is a barrier for
45 them accessing services.

So I'm basically there to kind of give them the information they need and support them through navigating through that system. And I also promote, you know, all the services and provide options for packages and CHSP services. Also there as a support person during assessments as well. Just being there throughout the whole
5 kind of process as a support, because some of our elders actually don't have carers or there may be multiple carers, so they don't – in our culture we kind of put family before we put ourselves, so they will be the last one on the backburner to be looking after themselves, but they could be having – a friend that they're caring for, four grannies in their care and they're looking after their children and maybe aunty.

10 So there are really complex clients that we work with within our community, and that kind of can be a little bit of a barrier sometimes too. But it doesn't always mean that they can get a reliable carer, so there's no one really looking out for them. So that's where my role is kind of really vital, because I'm able to help them and navigate
15 through that and kind of be the record-keeper to say in regards to that with their aged care numbers and codes and referrals, so yes.

MS HILL: And so what happens if people don't have a Shontia in their life?

20 MS SALUJA-HONEYSETT: They pretty much fall through the gaps. I have another example of an aunty that I work with who I happened to meet at a NAIDOC event and, you know, we were just sitting down yarning and she had been for an assessment back in 2014 and she said, "I had someone come out and do an assessment, but I never heard anything, never knew what happened."

25 So I started prompting in and asked her if I could start to look into who that was, and so I contacted ACAT to find out if they actually had a record of her and they did have a very limited record that she actually was accepted for a level 2 package, but the client had no idea. And, like, I said to Aunt, "Did you get anything in the mail back then?" And she said, "Not that I know of." And some of our elders don't know
30 how to read. Some of them see a government letter and think, "In the bin."

So I don't know what her circumstances is. I just go by what has been told to me. But then it was just a lot of work around, you know, ringing the RAS, the Regional
35 Assessment Service, to get her back into the aged care system. So it was about me supporting with that initial phone call to My Aged Care and then following her through the process of the RAS assessment and then through to the ACAS assessment, which is a lot of work, and it's a lot of information for our elders too. And she kind of got dropped through the gap, so they – on the RAS's side and the
40 ACAS, they didn't really have much notes, so – but the good, positive thing that came out of that, I've made a good partnership with the assessors at ACAS and I said, "This is her situation."

45 She has had no services since 2014, no contact with anybody and she's struggling, really struggling. I mean, she's a carer of four kids, she looks after her son, she looks after her friend. You know, she never goes to the doctors because if the kids have got to go to doctors or she has got to go to court because of the kids being in her care,

she's flat out. So I got up a really good rapport. They were quick. Within two weeks, they came out to assess her. I was there with her to support her, prompt Aunt with her – you know, get her ready for the questions, because they can be very invasive around toileting and things.

5

So I supported her through there and they were quite quick. They got her on a level 2 package within a month, and now, I just got an email a couple of days ago that she was actually approved for a level 3, which is what I really thought she was in need of. But without me there, she could have gone for who knows how long without that. So, you know, sometimes our elders kind of get – she's in the city area, but she was so isolated because she has got so much going on in her life and her health was the last priority. You know, so sometimes talking to them and saying, you know, "You can't help anyone if you can't help yourself", but it's easier said than done in our community. So - - -

10

15

MS HILL: Shontia, do you consider that the different needs of elders, Aboriginal elders and their carers are recognised in the My Aged Care system?

20

MS SALUJA-HONEYSETT: I think there could be a lot more support for, like the aunty was talking about. Like, she's got four kids under the age of 16, you know, the youngest being 11. You know, she could probably use a bit more support. And I know that's not aged care directly, but she has aged and she's dealing that, because she doesn't want the kids to go into the system because we see a lot – a lot of our kids are removed and put in the system. They end up running away, and then that's more stress to us, you know, that they're not in the family. So I think a lot more support for carers who are looking after young people would be good.

25

30

I don't think she gets any respite at all still to the day because she's always – even when they put them in temporary respite, they're still ringing her and telling her that they hate it, they don't like the place where they are and all that, so she doesn't really get any kind of respite. So I guess looking at the carers and respite with younger people as well. And also, like, for older people too. Like, I've been told by friends and other elders that are looking after their parents that the respite that they get, I think they get six weeks per year. You know, that doesn't seem like enough because they could be caring for someone else as well, so they don't – they get a break from one person, but they're still caring for someone else. Yes, I think that's all I can comment at the moment that I can think of.

35

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MS HILL: What do you say the role for respite for Aboriginal elders and their carers should be?

MS SALUJA-HONEYSETT: Can you repeat that again?

45

MS HILL: Certainly. What do you say the role of respite is or should be for Aboriginal elders and their carers?

MS SALUJA-HONEYSETT: Look, in Melbourne, we only have two Aboriginal-specific respite and aged care facilities. I think it would be more beneficial if we could get more options. Like, you know, if I live in Craigieburn, you know, even if there was a nursing home that's closer, because, like I said, like, we care about our family. We want to be able to be close to our family as well. We don't want to be travelling half the country because we've got no other option. So looking into mainstream nursing home and respite centres offering two or three beds with a cultural link or support person with that, and to make sure that that facility is also culturally appropriate and safe for them as well.

10 MS HILL: And how can facilities be culturally appropriate, culturally safe?

MS SALUJA-HONEYSETT: I think definitely having more involvement with the Aboriginal community. Having more of a presence. You know, you can do the tokenistic stuff like putting up artwork and putting a plaque up, but it's always more sincere when mainstream services – sorry, I refer to non-Aboriginal service as mainstream. Services have a presence at our good and bad events. You know, we celebrate NAIDOC, which is our celebration, but then we also celebrate Sorry Day. So it's having a presence there and promoting and consulting with our community around new programs, new services. Actions speak louder than words is the way that I look at it, so it means it's more genuine if you've got a person who's there and who's really wanting to work with us.

MS HILL: Shontia, I understand that Lynette can now hear us in the hearing room. I might just check whether that is, in fact, the case.

MS BISHOP: Yes, I can hear you.

MS HILL: Thank you, Lynette. Lynette, I was just asking Shontia some questions around cultural awareness and cultural safety.

MS BISHOP: Yes.

MS HILL: In your role as an Aboriginal Access and Support officer, do you come across an absence of cultural awareness or cultural safety in My Aged Care?

MS BISHOP: Yes, I do.

MS HILL: What - - -

MS BISHOP: I heard the question about the respite stuff. With our elders, they have a way that they need to be cared for, and by putting them into respite and into residential unit, sometimes it's very stressful for them because they've gone back to the times of they feel like they are locked up, being told when to come out and eat, and it's just inappropriate.

Their families are multiple large families, aren't able to flow in and out and that's what they have in their own homes and their residential units do need to use culturally appropriate mannerism with our elders, so they need to be respectful to all elders. And sometimes this is hard for them when they actually, you know, only
5 have a certain period of time to work with each of their elders in there, whether they're Aboriginal or non-Aboriginal. So respite in a residential, I find a lot of our elders are coming out complaining and absolutely not thinking that they're ever going to go back in there.

10 Medical staff in there don't believe in, you know, sorcerers or Aboriginal spiritual beliefs and believe more in scientific methods so they often dismiss our elders' beliefs as superstitious or uneducated. So they find that they're not listened to, they find that they are, you know – have a dreadful time when they're in there. I think with residential care like Shontia is saying, we don't have residential culturally
15 appropriate places outside of Melbourne.

Respite for our elders would be going somewhere else where their families are and having respite, whether it's in a motel close to families. Respite's not about taking everything away from them and just making sure they have the rest. It's about
20 catering for the whole family, the children they care for, everybody around them as well.

We talk about respite all the time and it's hard for me, in my role, to actually push respite onto our elders because they haven't had a very good experience about it
25 when they have went into care. What I find is the best respite is getting another family member or getting them down close to other family members that they haven't seen for a while whether it's in a motel or whatever, but that respite is not ready and available. They aren't offered that respite very often.

30 MS HILL: Lynette, you're, in fact, involved in work on a respite wing at a residential care facility at the moment, aren't you?

MS BISHOP: Very, very early stages and it's come about when I visit ACES, the committee that I'm on down in Melbourne, we had our meeting at ACES and I
35 thought well, why can't we all have this. I spoke to a lot of elders while I was there, because you had time in the break to do that, and what they were talking about is even our meeting was there and they could interact with us so they were finding out what was happening in Gippsland from us by having our meetings there. That's culturally appropriate, you know, they're not locked away, they're still having an
40 input in finding out what's going on around the country. But some of them were from far away, but Melbourne's not their place where they want to be but they have to be there if they want to be in the culturally appropriate one.

So I came back and I – because I work for Bairnsdale Regional Health, I had a talk
45 and haven't stopped the talk, so I will continue to look at, even if it's a wing on a residential unit, but make it culturally appropriate. And by doing that we can even look at Aboriginal people working there as the PCAs, you know, the personal carers,

having a cultural space where they can just all come. And then having – having the girl, you know, anybody who visits there, they visit the whole mob, not just coming in to visit one aunty. They're not isolated and being able to come and go and not signing in as if they're in prison again and signing out.

5

Yes, we have to have them protocols but let's do it, you know, less red tape in that, give back to them so they can have this quality of life and allowing them to know they can come and go. And the most important is keeping families included and keeping them included in community. Because once they go into residential care they don't attend the groups, you know, back at their own community because money don't allow it. So they are isolated again straightaway, so there's lots of work to be done and I am working and hopefully we will be able to look at an eight bed ward that's already there, just making it culturally appropriate.

15 MS HILL: And what - - -

MS BISHOP: And hopefully – sorry, and hopefully we have elders, I don't know if you know about the Lake Tyers Aboriginal Trust but we've got many elders out there, right up to the New South Wales border. Bairnsdale is nowhere near as far as Melbourne so it would make a difference.

20

MS HILL: And what's - - -

MS BISHOP: And the aim from that is further down the track, sorry, I will just make this last point and I'll stop. The aim is if we get one right, let's then put a wing or a ward or a bed in every one of them. It won't cost a million dollars to be putting in – because we're not asking for a brand new service, we're asking for the same service but making it culturally appropriate.

25

30 MS HILL: What sorts of things are you doing, Lynette, to make sure that that wing will be culturally appropriate?

MS BISHOP: By having the spaces open, by having two rooms, so say for instance couples could come in, so you will have a room and then they will have another room off that, so it's like two bedrooms, but one will be a lounge room. So the first room would be their bedroom where they sleep together. The other one would be a lounge room and as they age and get older they – we could, you know, split them if they need to be in separate beds so then we will have two rooms in that, but having that connected to a communal area outside. So you will have your kitchenette and you'll have your lounge room and all that as well and outside and having us have our meetings there, so when we're going in there we're feeding them information that we are doing out in the community so they're always switched on about what's happening to their own communities. Hang on a minute, I'm just going to have to – sorry.

45

MS HILL: That's okay. I might turn to Shontia, Lynette.

MS BISHOP: Yes.

MS HILL: Shontia, in your experience are Aboriginal elders and their carers asking for support?

5

MS SALUJA-HONEYSETT: No. But working with them, you can see they need it. We're proud people. We take it on because it's part of the way we grew up and it's part of family, you know, like I've said in my statement we don't – even anyone with a disability in our community we've always had a place for them within
10 community so they didn't feel like they're isolated or they're different from us, you know. Some of them will. They're very switched on. But some of them who are really drowning in their complexities, some of them are used to hearing no as well. So they just don't ask.

15 MS HILL: Would you like to respond to that, Lynette?

MS BISHOP: Just adding that we're sort of expected to take time out to care for loved ones, whether they're old or hurting or whatever, and sometimes we actually –
20 the families are actually thinking they're doing the right thing by taking, you know, the children out of school to look after their nan or pop or whatever, so we can actually see what Shontia is saying, is that when we're talking with them, we can see the dilemma of our elders not wanting to ask because the families already are thinking they're looking after them but it can come down to they are not getting the best care even from the families.

25

MS SALUJA-HONEYSETT: And another thing that I would add to that, sometimes with our elders too, like the example I gave before, you know, she's looking after her children who have substance abuse and she's looking after their children, so sometimes they're too scared to even take another payment or cut off
30 their kids' payment so that they can get, you know, the payment for the kids because they don't want to – they don't want any more people coming into their house. They don't want their kids to be going into care. So they're doing it on their own which is a bit of a barrier as well. You know, and yes, there are families that kind of hinder as well because they kind of come in and take over as well, like, with caring for them.

35

So they say no, no, no, don't go down the shops, you might break a hip or something like that, so it's a fine line sometimes in our community, you know, because you don't want to take control of it, but you still want them to be independent. And some
40 elders don't have good carers to be able to distinguish that, between the two, when they're actually hindering or they're actually helping. So there's multiple kind of layers to why they won't ask for help because if they tell Centrelink, then Centrelink will get involved, their kids will go out on the streets and get worse in whatever substance they're in, they stress about even that as well. So they won't ask for it. They will just keep going and keep going without the support.

45

MS HILL: Shontia, you've given a couple of examples there about barriers that Aboriginal elders and their carers face in accessing support. What do you consider can be done to overcome those barriers?

5 MS SALUJA-HONEYSETT: Having Aboriginal workers, you know, where me and
Lyn have – we provide support around providing information on services, you know,
linking them and supporting them through that, when they may not have the
confidence to do so, or they may, you know. You know, more support for the carers
as well. You know, like I said, they could have multiple people that they're caring
10 for, so not just considering yes, because you're looking after mum we're only going
to give you respite for mum.

So – and just having that respect for the elders, you know, like Lyn was saying, the
mannerisms, you know, that's the first – if you start talking to our elders with
15 disrespect, you're going to lose them at that first point. So I guess that's probably
that's probably the most important thing, having that basic respect and listening to
what they've got to say as well, you know, just saying don't try and take over and
assume what you think they need, you know, listen to what they actually need.

20 MS HILL: Shontia, is there that respect in the aged care system at the moment for
Aboriginal elders and their carers?

MS SALUJA-HONEYSETT: Sometimes. I think it really depends on the
individuals that we're dealing with. You know, I've come across case workers with
25 elders on packages and they don't return calls. Our elders like face to face, you
know, if you've got a case manager, you know, they don't want to have to be chasing
you by phone. Or they may ring and the case worker doesn't ring back for two
weeks, you know. So we like face to face as much as we can, you know, and in my
job role, when they do get a package, like, when we're – they've been approved for a
30 package, I sit with them and I actually prepare them for some of the questions when
we go for the package provider, because I do like a shop around because you've got
choices now in the packages, so, you know, I will say all right, pick your top three
and we will meet each one and see what they've got to offer.

35 If you think they're good, you know, and I even put in there, when the case manager
is there, how many clients do you have because I know that if they've got 60 clients
they're only going to see my client once a year, you know, so our elders like contact
and the case manager is the person who is basically arranging every service for them.
So that one on one, having that more support – and it goes the same with the
40 mainstream too with the really complex cases, you know, but we've always been a
face to face, you know, people. So I find that works a lot easier because it makes the
decision when they're picking a provider, to know that they're going to be seen more
once than once a year, you know.

45 That person is going to become pretty much the person in their life that's going to
make everything happen. So and the carers, you know, having a carer there is
definitely a must. Like that's one thing that I'm really working on in my role is

trying to get the elders a carer who, if I'm not here, because my role finishes next year, if I'm not here, at least they've got a carer to keep following up and keep in contact with that case manager and make sure they're still getting those services, holistically and culturally and spiritually, you know.

5

MS HILL: Lynette, would you like to respond to what Shontia has said?

MS BISHOP: Yes. Just by working with the elders, the service provider staff don't seem to reflect back enough on what they've been told or our clients, our elders aren't given enough time to gather their thoughts and answer the question. So you can tell they're just reading off a script and then just answering as it goes. So what – and backing up what Shontia is saying, yes, our elders ain't being heard or enough time for yarning. It has to be face-to-face or you can – they just won't take on the service. They will find that it's too difficult. You know, there's no phones and there's no, you know, care in the way spoken to on the phone.

So it has to be face-to-face. I push for all assessments to be done as a home visit, and sometimes it's very difficult but there's questions that they ask and roll off that the carers or the elders and carers in the room too ain't able to answer it to the way it might score them higher. Not because they, you know – not because they – what am I trying to say? Not because they don't need it. It's because they're not understanding the question that's being asked of them.

So, for instance, if someone asks you, "Oh, so do you need help in going down the street?" And they straightaway, "Oh, no, I've got, you know, my granddaughter who drops in", but that granddaughter is not dropping in on a regular basis. She might have dropped in yesterday and that's still in that elder's mind. So, of course, they might have been looked after that one day in that month, but the other days. So they're not reflecting back enough by asking, you know, "So how often does your granddaughter drop in?" So it's being seen as if they're not needing the services, if that makes sense.

MS HILL: Thank you, Lynette. Lynette, are the carers of Aboriginal elders asking for support?

35

MS BISHOP: Some are. Some are. And I find the ones that are working are screaming out for help for support for the elders because they want to continue to work, and it's – you know, it's stopping them from working. So, yes, there are some. There's others who think they're actually doing a great job, but when you actually have a look into it, you could call it elder abuse, and we reflected on that earlier. So, yes, the carers, there is some that are asking, but they are normally the people that can stand on their own two feet, have been able to work through some of the systems and then at the end when Mum and Dad's really frail, find it difficult to actually be with them every day. So those carers are asking, yes. Again, they don't really know where to ask or where to go.

45

MS HILL: Lynette, how can those carers be encouraged to access support for themselves?

5 MS BISHOP: Just education. We need to get more and more of this information
out there for – for our carers, our elders and that. When I actually see an elder, if
I’ve got a phone call, I’ve made an appointment, I say to them, “Bring whoever you
want at the table”, and I’ve showed up out at people’s places and had eight people
around the table, because the more you educate them – I don’t care how old they are
– the more you educate them, further down the track if they need this service, they’re
10 going to at least have, you know, some idea on what we might have done for Aunt or
Uncle or their grandparents.

So it’s about education, getting it out there. A series of little films run in Aboriginal
organisations or on the TV about services, you know, just little tiny films that are not
15 complicated, and places on where they can go, the posters and – yes, just educate as
much as we possibly can through carer support, through our elders and through our
Aboriginal organised, you know, health services.

MS HILL: Shontia, would you like to respond to what Lynette has said?
20

MS SALUJA-HONEYSETT: Yes, I think Lynette is right on the ball, definitely
around education. Like, I’m the same as Lyn. I’ve had, you know, six or eight
people at the home just talking about aged care services, you know, because if you
teach Aunt, then you’re teaching the whole mob. You know, it’s – in our community
25 it’s all word of mouth, you know. So I’ve had – you know, I also kind of oversee our
social support group, an Aboriginal-specific one. And, you know, when we get new
members in they’re like, “Oh, you know, Shontia will help you with the aged care
stuff. Do you think you need a package?” So it’s good to hear that because I’m sure
that’s not the only person they’re talking to.

30 So for the education, you know, the fliers. Like I was saying before, having the aged
care services be a part of community, being a part of community events, you know,
getting themselves out there more. We do access and support. We can’t do
everything. We’re already all-rounders. We’re doing a little bit of case
35 management, we’re doing promotion, we’re doing – you know, supporting our
elders. Our role seems to be getting bigger and bigger because there’s all these kind
of gaps because they’re not – they’re not out there enough for them to find it, you
know. Yes, that’s what I – I will leave it at that. But I agree with what Lynette is
saying as well.

40 MS HILL: Now, Lynette, I asked you this question before and the call cut out, so
I’m optimistic if I ask it again that the call won’t cut out. Lynette, do you also hold a
position, in addition to the work you do as an Aboriginal Access and Support officer,
with the Victorian Committee for Aboriginal Aged Care and Disability?
45

MS BISHOP: Yes, I’ve been on that committee pretty late in my role and then last
year, just late in last year I become the chair of that committee. With that committee,

we feed up – we bring in all access and support workers within the area. We feed up into that committee and then that – then that committee feeds up into, you know, VACCA and the Department of Health and Human Services and the Department of Health. We have them meetings every fortnight – sorry, twice – every second
5 month. So there’s a few of us that do our roles. Not enough of us. There’s eight access and support and four regional development officers on there. So we keep feeding these up.

So, yes, one of the questions I would like is where does that information go?
10 Because we’re feeding that back into the department on a regular basis about all these issue that we’re talking about today. And a lot of them issues, it was from our roles and keeping our Aboriginal elders and people with disabilities and their carers’ services open, and how do we get the services out there and what the issues are of them not accessing services, which we’re talking about today. So, yes, I am on that
15 committee.

MS HILL: And you’re on that committee with Shontia as well; is that right?

MS BISHOP: Yes. Yes.
20

MS HILL: And Lynette, are you also currently studying?

MS BISHOP: Yes, I’ve just finished a study, and I’ve got to knock off a couple of hours in finishing that study, and that’s personal care, individual personal care in
25 aged care.

MS HILL: Lynette, why are you undertaking that course?

MS BISHOP: The same reason I took this role on. It crossed my path and we had
30 major issues. I took this role on because my father and his partner struggled to get anywhere with aged care services. And when he became really ill, it was impossible. Now, even for me, who I think is, you know, quite switched on, I couldn’t navigate the system of My Aged Care or to get them just simple HACC services into the home. So when this job come along, I was like, “Well, everyone is like my dad. I
35 need to do something.” So after the four years I’ve looked at, well, where are our elders going? And I’ve found in our community that there’s a lot of elder abuse from carers thinking they’re caring for them, so how can we help – how can I help in regards to doing that?

40 So part of my role, I want to lessen hours. And I thought, “I can make a different to our elders at the end of their life.” So I’m not really thinking about taking on a full-time work, working in residential care. My aim for doing a lot of this will be making sure our elders are able to stay in their own homes. I live in Stratford, so Stratford, Maffra, Briag. I know of a lead that waited in Stratford for three months for a
45 cleaner to be replaced because no one want to travel here, 45 minutes, to do one hour work for that lady. So for a whole month, she didn’t get any personal care or it didn’t – except for district nursing, but she didn’t get the other stuff that she was

entitled to because there was no one to replace the lady that left. So that's, you know, part of why I'm actually doing this course.

5 MS HILL: Thank you, Lynette. Now, Lynette, you've prepared a statement dated 26 July 2019?

MS BISHOP: Yes.

10 MS HILL: And in that statement, you've set out your experience in your role as an Aboriginal Access and Support officer.

MS BISHOP: Yes.

15 MS HILL: And you've also given evidence to the Commission in that statement about your experience of caring for your father when he was in need of care.

MS BISHOP: Yes.

20 MS HILL: And you've indicated to the solicitor that there were some changes that you wanted to make to those – to that statement?

MS BISHOP: Yes. Yes.

25 MS HILL: And with those changes, are the contents of that statement true and correct?

MS BISHOP: Yes, it is.

30 MS HILL: Commissioners, I refer to the statement of Lynette Bishop dated 26 July 2019. The document ID is WIT.0316.0001.0001. And I tender that statement, Commissioners.

35 COMMISSIONER TRACEY: Yes, the amended statement of Lynette Joyce Bishop dated 26 July 2019 will be exhibit 7-8.

**EXHIBIT #7-8 AMENDED STATEMENT OF LYNETTE JOYCE BISHOP
DATED 26/07/2019 (WIT.0316.0001.0001)**

40 MS HILL: As the Commission pleases. Before I conclude, Shontia, you wanted to give evidence with Ms Bishop today, didn't you?

45 MS SALUJA-HONEYSETT: Yes.

MS HILL: And why was it for you to give your evidence together with Lynette?

MS SALUJA-HONEYSETT: First of all, it's a very formal setting. And it's always good to have a bit of a back-up. The second reason is, is that our communities are very different; remote is very different from the city, and rural is very different from remote and the city. So I just felt that I didn't want to come and talk on behalf of all
5 Aboriginal people in Victoria, and it would be nice to hear from the remote sides and the rural sides as well because the issues are not the same. Some of them will be but like in Lynette's case, respite is a bigger issue. We have two. Yes, it's not enough, but, you know, some – we have different needs, different way of doing business, different approaches when we're dealing with barriers and bringing in new services.
10 So it's just good to hear the two different comparisons that we are different in some aspects.

MS HILL: Lynette, what are your thoughts on that?

15 MS BISHOP: Very similar to Shontia's. And what's really good is sometimes when you're banging your head all the time in regards to what issues we have out here in the country, by going to these meetings, by putting our issues and concerns, we do find that a lot of our issues are the same, and so it's around, you know, working together and hopefully we can make some change. And being in the
20 courtroom with Shontia today, there's times – because it's very official, there's times where, you know, I might get off the phone and go, "Oh, I should have said this", where Shontia has backed it up or Shontia has said it. So it's just less stress with dealing with that as well, so yes.

25 MS HILL: Thank you, Lynette. Now, I've come to the end of my questions. Lynette, did you have anything that you wanted to say further this afternoon?

MS BISHOP: Yes, the main thing I want to absolutely say – and I'm hoping this is the place to say it – is where are all the other recommendations? In my role, we do a
30 monthly report. Every six months, we do a six-monthly report to the Department of Human Services, DHHS. In those reports are all the barriers that our elders and our carers face and the challenges for me in my access and support role, which are barriers again. I've been here for four years. I've reported up. In the Victorian Aboriginal Community Control, the committee that both Shontia and I are on, we've
35 been feeding issues and concerns up through there. Where do they go? And, you know, how do we get – you know, how do we get things changed so we're not talking about the same issues in another four years?

40 MS HILL: Thank you, Lynette. Shontia, was there anything that you would like to say further?

MS SALUJA-HONEYSETT: Just around two things. One is palliative care. I don't think it's – we've got it right. I heard one of the other ladies who was a
45 witness here earlier talk about it briefly. In our community, most of the time it comes through when they've already paused. Because our elders come right at the critical stage where they're so unwell that the packages are not even keeping up. They're not getting the levels that they need. Like, sometimes some elders we get in

and we've got to go straight to the level 4. The palliative care, like, we had some work around, you know, the statement around palliative care, but we don't really see it much out there and it's coming in too late. It's coming in too late.

5 So that's an area. And I haven't really had to deal with that as of yet because most of the majority of elders I've worked with are still alive. But I know from working with other workers that that is also a real issue that there – there's about – a girl that I worked alongside with, she has left currently but she had three clients who had passed that just because of the assessment, they've got to come out and assess and it
10 just took two or three weeks for them to get out there and the person already passed, like, before they even got out there. So that's a big thing that we find.

The second thing too is that when we ring My Aged Care and we work alongside with assessors and other services, sometimes it feels like me, as an Aboriginal
15 worker, that I'm not valued enough by them. They just don't want to hear what I've got to say. Like, I talk to case managers because my clients are too intimidated by their caseworkers to tell them that they need a shower more than once a week. You know, that's not right, you know. And then I ring on their behalf and they don't want – “Oh, you've got to get the client to ring me.” You know, “And I'm ringing
20 you because I deal – I meet these people all the time. You see them once a year.”

You know, so I don't feel valued from assessors as well. And in My Aged Care, some of them are so rude, but I've just got to deal with them. You know, even that first question, asking are you Aboriginal, if they don't ask that question on MAC and
25 they're under 65, they tell them that they're not eligible. They get cut off at the first point, you know, because they don't nose that they're supposed to ask them are they Aboriginal, because in My Aged Care any Aboriginal person who's over 50 can access. But if they're not asking that question and they're under 65, “Sorry, you're not eligible.” I've had clients come to me. I've had to work with clients who have
30 had that said to them. That's not right.

You know, power to them that they actually called them, you know, that they actually noticed that they needed the service. And to be cut down there, it just makes my work so much harder to get them back again because, like I said, a lot of our
35 elders are so used to hearing the word “no” that they just don't even bother because it's too hard. They're just scared they're going to be told “no” again. So just – even just asking the question, “Are you Aboriginal Australian?” And why I say “Aboriginal Australian” is because there's also another complexity. We get referrals for other Aboriginals from other countries because they identify as being Aboriginal
40 to their country.

So that makes us a little bit of time consuming to get that rectified and get them off to where they need in their services. But they're the two, like, main things that, you know, that first point of contact. And if we're not there, us workers, they miss out
45 completely, you know.

MS HILL: Commissioners, that concludes my examination of Shontia and Lynette.

COMMISSIONER TRACEY: I hope you both did not find your experience this afternoon too daunting. We've listened carefully to what you've said and we are alert to the sorts of problems that are culturally significant, and we will do our best to see what can be done to ensure that in the revised system that we will propose that
5 there are proper checks and balances to ensure that those sorts of problems don't recur. But thank you both for your assistance. We're very grateful to you for taking the trouble to make statements and come and give your evidence this afternoon.

MS BISHOP: Thank you.
10

COMMISSIONER TRACEY: The Commission will adjourn until 9.30 am tomorrow morning.

15 <THE WITNESSES WITHDREW [4.45 pm]

MATTER ADJOURNED at 4.45 pm UNTIL TUESDAY, 30 JULY 2019

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