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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**

SYDNEY

10.00 AM, FRIDAY, 17 MAY 2019

Continued from 16.5.19

DAY 22

**MR P. GRAY QC, Counsel Assisting, appears with MR P. BOLSTER and MS B.
HUTCHINS
MS K. RICHARDSON SC appears for the Commonwealth**

COMMISSIONER TRACEY: Please open the Commission. During this and earlier hearings the Royal Commission has been greatly assisted by evidence from people with direct experience of the aged care system. Hearing this evidence is very important if we are to fully understand the issues and concerns of the community about aged care. We continue to encourage members of the public to come forward and share their stories. In our engagement with various members of the public a number have expressed concerns about not being identified and the potential impact talking with the Royal Commission may have on their families.

10 It, therefore, appears that it may be necessary to repeat some remarks I made at the Commission's preliminary hearing on 18 January 2019. Those remarks were as follows: under section 6M of the Royal Commissions Act it is a criminal offence for a person to injure another who has appeared as a witness or produced a document or given information or a statement pursuant to a summons requirement or notice issued
15 by the Royal Commission. Were an employer to seek to deter a person from assisting us, this may give rise to an offence. If, for example, an institution or individual sought any form of legal redress against a member of the public or of their staff acting as a whistleblower seeking to volunteer information to us, that would result in very close attention being given to the lawfulness of that conduct and the
20 motives behind it.

I would add that section 6M of the Royal Commissions Act is not limited to employers. It is a criminal offence for any person who uses, causes or inflicts any violence, punishment, damage, loss or disadvantage to any person for or on account
25 of reasons, including the person having appeared as a witness before the Royal Commission, or any evidence given by him or her before the Royal Commission. The Royal Commission will also view seriously any situation where a person providing information to the Commission through written submissions or as part of our community engagement program, such as public forums, suffers prejudice as a
30 consequence of doing so.

Let there be no doubt, the Royal Commission will not hesitate to take steps within its powers to ensure that witnesses and those otherwise engaging with us are protected in accordance with the Royal Commissions Act or the common law. Yes, Mr Gray.

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MR GRAY: Thank you, Commissioner. Our next witness is Professor Henry Brodaty AO.

40 <HENRY BRODATY, AFFIRMED

[10.08 am]

<EXAMINATION BY MR GRAY

45

MR GRAY: What is your full name?

PROF BRODATY: Henry Brodaty.

MR GRAY: Operator, please bring up WIT.0116.0001.0001. Professor Brodaty, have you made a statement for the Royal Commission?

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PROF BRODATY: I have.

MR GRAY: If you would kindly look at the screen - - -

10 PROF BRODATY: Yes.

MR GRAY: - - - is that a reproduction of the front page of your statement bearing your signature at the bottom?

15 PROF BRODATY: It is.

MR GRAY: Do you wish to make any amendments to your statement?

PROF BRODATY: I do not.

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MR GRAY: To the best of your knowledge and belief are the contents of your statement true and correct and the views expressed in it views which you hold?

PROF BRODATY: They are correct.

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MR GRAY: I tender the statement.

COMMISSIONER TRACEY: Yes. The statement of Professor Henry Brodaty dated 16 May 2019 will be exhibit 3-80.

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EXHIBIT #3-80 STATEMENT OF PROFESSOR HENRY BRODATY DATED 16/05/2019 (WIT.0116.0001.0001)

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MR GRAY: Professor, before I ask you some questions about the specific contents of your statement, can I ask you an initial question: starting from the need for awareness of dementia and early and accurate diagnosis, is there a service pathway in our country catering for the need to provide post-diagnosis support for a person diagnosed with dementia?

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PROF BRODATY: No, there is not a clear pathway for that, and, in fact, it's an area we just have received a European Union grant to work with four other countries to develop exactly that. It varies across different countries and Australia does not have a clear pathway, and most countries don't.

45

MR GRAY: In terms of progress towards the planning and budgeting necessary for a pathway, how far along that route are we?

5 PROF BRODATY: I don't think we've started on that route. So we have a pathway for diagnosis, although that's not a systematic pathway, but people generally go to their GP and most will be referred to a specialist for assessment the GP recognises them as having dementia which will occur in about 50 per cent of cases in the early stages. And often diagnosis is made and there's no post-diagnostic pathway subsequent to that.

10 MR GRAY: Thank you. I will ask that the operator bring up page 2 of your statement. And I will direct some questions to you under the heading Quality of Care and Person-Centred Care. In paragraph 8 you refer to five facets of person-centred care as defined by the National Institute for Clinical Excellence in the UK.

15 PROF BRODATY: Correct.

20 MR GRAY: In a nutshell, as those present in Court can see, there's human value, individuality, the perspective of the person in question, the relationships and their potential for the promotion of wellbeing, and the needs and input of carers. With respect to the interests of an organisation in achieving productivity and efficiency in executing tasks, how is the balance that's necessary between these facets of person-centred care to be achieved by a particular organisation providing care.

25 PROF BRODATY: It varies considerably across organisations. Some people embrace these principles and do it as well as they can. Others pay lip-service to them, but there is a lot of variability and many organisations do not really do person-centred care in the spirit of what's listed here.

30 MR GRAY: You give some examples of the contrast between an organisational focus on the execution of tasks, compared with person-centred care.

PROF BRODATY: Yes.

35 MR GRAY: Could you elaborate on some of the examples that you have in mind there.

40 PROF BRODATY: Sure. I visit nursing homes as a doctor every Monday afternoon, and so I see what happens. I see everyone works very hard and the nurses are very busy and they're feeding and they're changing and they're cleaning. They're not talking to the people. We see that residents are very lonely in nursing homes. I had a PhD student who, her thesis was on social relationships in nursing home. The median number of relationships that a person in a nursing home had was one. That means 50 per cent had zero, and most of the relationships are with the staff. So staff are busy doing their tasks and they have their tasks, there are a lot of tasks to do. And people do need help with feeding, they do need help with cleaning, and often incontinent, need to be cleaned up and so on, but they don't focus on the

45

person. No one actually sits down and talks to the person and spends some time with them.

5 So the examples I gave were some nursing homes are now saying, well, it's not like everybody has to have breakfast at 7 am, and it's all over by 7.30 am, which is the traditional institutional pathway. They're saying, well, you can have a sort of continental breakfast, as it were, between 6 and 10 am. If you want to have your hot breakfast that's available between 7 and 8.30am, for example. And so giving some flexibility, giving some choice to the person. Another example is bathing. Tradition
10 has been to bathe everyone, shower everyone first thing in the morning. Some people don't like to be showered in the morning. They don't want to be showered at all; they want to be bathed. And so giving them the flexibility. Some people don't wash every day; they wash every second or third day. It doesn't matter that much unless there's hygienic reasons for doing that. So it's choice and autonomy, which
15 is what people fear loss of most in the community.

MR GRAY: You've referred to research in your paper, including research of your colleague, Professor Lynn Chenoweth.

20 PROF BRODATY: Yes.

MR GRAY: And you've referred towards the end of your paper to a list of publications including the report of a study in 2009 on agitation reduction, that is, agitation reduction when person-centred care is adopted as - - -

25 PROF BRODATY: Yes.

MR GRAY: - - - in effect the operating culture of a workplace.

30 PROF BRODATY: Yes.

MR GRAY: Could you elaborate on how you interpret those studies.

35 PROF BRODATY: Yes. So it was a randomised control trial. I can't remember the number of nursing homes; it might have been about 30. And we randomised people to get person-centred care or another technique called dementia care mapping, which is not relevant for this discussion, or usual care, and we measured agitation as the outcome, the primary outcome, and we did the intervention for about four months. What the intervention was, it was a one day training workshop for nurses, by a senior
40 professor of nursing, Jane Stein-Parbury, and then some follow-up telephone calls to the nurses. And over the four months the agitation levels fell in the person-centred care arm, and they rose in the usual case arm.

45 And then we did a further four months follow-up where we hadn't done any intervention, and we found that the divergence of those increased and so they fell more in the person-centred care arm of the study. And I did send these results to the department and, you know, I think this is something that could be embraced

nationally, that we could have proper training for nurses on person-centred care with continual reinforcement, and if we reduce agitation, in fact the workload becomes lighter. The need for medication becomes less. So it's a recurring theme, I think, through this Commission of the need for education and training for nurses – well, it's not just nurses, which I can come to later, but that was exemplified in that study. And in the second study we did led by Lynn Chenoweth, we found the same results, that person-centred care was effective in reducing agitation.

MR GRAY: In that second study, which was reported in a paper in 2014, I believe - - -

PROF BRODATY: Yes.

MR GRAY: - - - The PerCEN paper.

PROF BRODATY: Yes.

MR GRAY: Was it the case that the investigators also looked at whether there's a similar effect from having a person-centred environment?

PROF BRODATY: We did, and we didn't find an effect for that, but we underestimated the difficulties of local councils. It might sound strange, but what we had, for the person-centred environment part of this study was we had up to \$10,000 to give to a nursing home to do modifications to make it more person-centred. So access to the garden, changing lighting on colours, furnishings, perhaps changing walls, internal walls, something like that, but these often needed approval from councils and within the timeframe of our study we found we had huge delays. So the person-centred environment arm of the study didn't prove effective, but the person-centred care one did.

MR GRAY: And you were looking at whether there was an additional or a marginal effect of adding a person-centred environment over the top of the person-centred - - -

PROF BRODATY: Yes. We had four arms: we had person-centred care alone, person-centred environment alone, the combination, or neither. And person-centred care alone was the one that worked best.

MR GRAY: Thank you. You referred to a summary of a number of studies on – is interventions is the correct word?

PROF BRODATY: Yes.

MR GRAY: Interventions in relation to behaviours that are of interest and this has been published recently, I think in 2017, in The Lancet, The Lancet Commission's article.

PROF BRODATY: Yes, it was in The Lancet which is probably the most prestigious medical journal in the world. Yes.

5 MR GRAY: I'll ask the operator to bring up the general tender bundle, tab 18, and there's a handy diagrammatic representation.

10 PROF BRODATY: There's what's called a meta-analysis which is – comes along much further in the study but it shows the effects of person-centred care, and then there's a summary diamond which shows the combined effect when you combine all the studies, showing that they are beneficial, yes.

MR GRAY: Yes.

15 PROF BRODATY: It's a 30 or 40 page document so it will take a while to find it on here.

20 MR GRAY: Yes. I will ask the operator to take that down now. Thank you. Now, at paragraph 14 and 15 you refer to remarks made by a UK expert to the effect that there's a bit of lip-service involved.

25 PROF BRODATY: That's right. That was Dawn Brooker who's one of the leading researchers in this area, and she said that it's now PC, politically correct, to say that we do pc, person-centred care in lower case, but, in fact, it doesn't happen and I think that's – that article was written more than 10 years ago and in my experience, when I go around nursing homes, I see that as well, yes.

30 MR GRAY: So is it the case that you're encountering that reasonably often or what's your estimate of how we're doing in terms of conversion of culture to actually integrating real person-centred care as opposed to paying lip-service.

PROF BRODATY: I think things are getting a little bit better but it's a long way to go in the majority of nursing homes I go to, yes.

35 MR GRAY: Now, a minute ago, professor, you mentioned, with respect to the reduction in agitation, when appropriate person-centred care is actually adopted, to a positive effect on workload.

PROF BRODATY: Yes.

40 MR GRAY: And it's for this reason, is it, that you refer at paragraph 16 to the cost efficiency of the PCC approach.

45 PROF BRODATY: Yes, well, in the first study from Chenoweth that we discussed we estimated that the cost per point reduction in the Cohen-Mansfield Agitation Inventory, which is a scale that is most commonly used in measuring agitation, was only \$6 a point which is very cheap. The argument a lot about using psychological

or social approaches to trying to reduce agitation is it's too costly and, of course, a pill is a lot cheaper. But this wasn't costly. Yes.

5 MR GRAY: Now, in paragraph 17 you refer to some of the things that you say are needed for person-centred care to become business as usual.

PROF BRODATY: Yes.

10 MR GRAY: There's obviously a number of prongs to achieving that.

PROF BRODATY: Yes.

15 MR GRAY: From the – from the perspective or with respect to the internal arrangements of the organisation providing care, what's needed?

20 PROF BRODATY: Well, it needs both top down and bottom-up approaches, so the top-down is that management needs to embrace this as a philosophy for their nursing home or most commonly now chains of nursing homes, and so that needs to come from the top management, but also the director of nursing needs to also say this is our philosophy, that really the person is our first priority. It's not about profit. I'm not saying that all nursing homes work just on profit. But it's trying to make their life as good as possible, the people living there, and for most people going to nursing homes this is their home and this is their final home.

25 MR GRAY: Later on you refer to carrots and sticks as well.

PROF BRODATY: Yes, yes.

30 MR GRAY: I will ask you about that in a minute but do you also see a role for the regulator here?

35 PROF BRODATY: I do. I do. So there are changes to the regulators and the people who do the assessment, which I'm very strongly in favour of. But up until recently it has been more about sort of mechanics of running nursing homes and making sure things are clean and that people are well looked after and looking at critical incidents, but we don't actually get the quality of the interaction between the residents and staff. And in my reading of the current assessments now they're now talking to families and talking to staff and talking to residents, and are getting some more qualitative information from them. But if, looking at the application of person-

40 centred care in a more systematic way, then it will certainly drive, that would be the stick as it were. That would be a way of driving improvement in that aspect of care.

45 MR GRAY: Right. I'm going to ask you a little bit more about that in a minute with respect to the suggestion you've made for some sort of performance rating to be made public - - -

PROF BRODATY: Yes.

MR GRAY: - - - in respect of the metrics of care.

PROF BRODATY: Yes.

5 MR GRAY: And I'm going to ask you about your ideas on that topic.

PROF BRODATY: Okay.

10 MR GRAY: But sticking for the time being with the order in which you've addressed matters in your statement, in paragraph 18 under the heading Medical Reviews and Multi-disciplinary Approach, you open up a point that you elaborate on later about the need for effective, perhaps preventative, interdisciplinary care. Could you elaborate on that, please?

15 PROF BRODATY: Yes. I think the average age – it's in one of your background papers – of admission to nursing homes is about 82, 83, something like that.

MR GRAY: It's different for the different sexes and it's between 82 and 85.

20 PROF BRODATY: Yes. And then people live there for a while so that's why I said 85 might be the average age of people living in nursing homes. So people 85, wherever they are, are likely to have complex medical issues, particularly those in nursing homes. People do have a general practitioner who attends to them and the Aged Care Act says they can have the general practitioner of their choice. But that's
25 not always possible because the nursing home may not be in the geographical area of that general practitioner or the GP may not want to go nursing homes because of the financial impost on the GPs; it's not very rewarding to them compared to office practice. And GPs do come and they come usually for a short period of time.

30 Some nursing homes have clinics and sort of particular GPs who come and see a large number of the patients and that may be a better model as well. So there's no sort of systematic review. It's reactive; if there's a problem occurs then a health practitioner is called in to try and help with that problem. But if there were some sort of review process, so if we're in hospital, for example, people will be reviewed daily
35 or at least two or three times a week and have ward rounds and discussions and it's much more acute and the tempo is much faster. But in nursing homes where we have a lot of acute illness happening we don't have that sort of review process.

40 So one model I proposed in the past was to have a interdisciplinary team which visits nursing homes say on a monthly basis, and if they visited for, say, two hours or three hours once a month they could handle 40 nursing homes in a 20 day period, in a month. So we could have a hub and spoke model and they would be able to do that, so that's one model. Another model that I think I refer to later is the assertive follow-up from people who have been discharge from hospital and so my colleague
45 Nicholas Cordato from St George Hospital did this study which was published which showed that by doing this assertive follow-up with a clinical nurse consultant and himself – and they did about three or four visits over six months – they cut the

readmission rate to hospital in half. They cut the costs by half, and they cut presentations to emergency department from the nursing home; I'm not sure if it was by half but a lot.

5 So assertive follow-up with a fairly small investment of time and the cost was certainly repaid, well repaid by doing that. So the other area is mental health problems and behavioural problems. Some nursing homes have specialists who might help with that. But usually it's reaction to behaviours that have become difficult to manage rather than trying to work on things early in the piece and
10 reducing the behaviours before they become a crisis. And so that doesn't need to be with doctors, in fact, it may better be done by psychologists or other health – or in one nursing home an occupational therapist I know who has got dementia expertise advises on that, or it may be nurses with expertise in this. So there are different models available, but it's recognising that the people in nursing homes are not just
15 there to be – it's not just hotel accommodation. It's more than that.

MR GRAY: A recurring theme in your statement appears to be the desirability, particularly for an interdisciplinary approach perhaps supervised by a geriatrician is adopted in de-prescribing.

20

PROF BRODATY: Yes.

MR GRAY: There seems to have been – perhaps it's a tendency adverted to a minute ago that a pill seems to be the solution at least in the short term. There seems
25 to be a tendency for polypharmacy or over-prescription.

PROF BRODATY: Yes.

MR GRAY: And is that a particularly acute issue with older Australians?

30

PROF BRODATY: Very much so. So I know you had testimony from Juanita Westbury a couple of days ago, and I've worked with Juanita and I think her figures pretty much accord with what we've found that, you know, over half the people in nursing homes are on some psychiatric drug – psychotropic, and 20 to 25 per cent are
35 on an antipsychotic drug which we know have serious side effects. I was just saying in one nursing home I go to where I chair the clinical advisory committee, we find 90 per cent of people are on at least 10 medications but that includes eye drops and creams and vitamins. So I haven't been able to get the breakdown from the pharmacy on how many of these are, sort of, oral, regular pharmaceutical
40 medications, but it's very common for older people to be taking increasing number of medications. We sort of accumulate them as we get older, and they stay with you, or you stay on them, and even more so with people in nursing homes.

MR GRAY: The review that you recommend, do you have in mind that those social
45 – those psychosocial interventions will very often be more efficacious in accordance with the – consistently with that person-centred care - - -

PROF BRODATY: Yes. Yes.

MR GRAY: - - - intervention, agitation reduction - - -

5 PROF BRODATY: Yes. Yeah.

MR GRAY: - - - research as you mentioned before.

10 PROF BRODATY: I mean all the guidelines say the first step is to look for
reversible causes. There – there is a pathway, as it were, that – that we recommend
that people follow before prescribing medication, and medication needs to come,
like, third or fourth along that pathway and trying other things first. And so, yes, we
can show and we have shown in other studies as well that if we do institute
15 psychosocial interventions, we can reduce – we can reduce the amount of
psychotropic medication.

MR GRAY: And there are specialists who can advise on those interventions,
diversional therapists. Are they available in that respect?

20 PROF BRODATY: They – they are available and – sometimes, they appoint nurses
to be activity officers. They may not have exactly the same training, but it's also
requires some diversional therapist to have a bit more latitude, more creativity in
their thinking. So not all diversional therapists have the same quality.

25 MR GRAY: And there's no reason why a person providing those sort of
interventions needs to have a particular label. I suppose - - -

PROF BRODATY: No. No.

30 MR GRAY: - - - registered nurses might be very adept at - - -

PROF BRODATY: Yes.

35 MR GRAY: - - - providing those supports.

PROF BRODATY: Yes. Yes, indeed. And a lot of nursing staff have talents and
creative skills that are not being utilised, and one of my colleagues suggested we
should actually be working with the nurses to find out what they like doing and so
that we can employ their talents more usefully.

40 MR GRAY: Professor, on the following page under the heading safety,
Psychotropic Medications, with respect to this tendency for over prescription of
psychotropics, you raise a number of particular issues. One of them is around
informed consent in paragraph 23, and you refer to a survey you've been involved
45 with concerning the rarity of documented informed consent in the residential aged
care context where you have a person who has impaired cognition and, perhaps,
incapacity to provide that consent. Can you elaborate?

PROF BRODATY: Yes, Dr Nicolas Rodina – Nicola Rodina did this study for his thesis with me. He was trained to be a psychogeriatrician, finished his psychiatry training, and he went into nursing – I think it was three nursing homes and we identified people who were started on a psychotropic medication in the nursing home in people who lacked the ability to give informed consent and found – and then went through – did an audit file – sorry, audited the files and found that only in 6.5 per cent, had there been actual written consent provided, even though in New South Wales, the Guardianship Act requires written consent for psychotropic medication on a regular basis. It’s seen – seen as a major medical treatment, and in another 6.5 per cent, there was verbal consent documented in the file. So in 87 per cent, there was no consent at all provided.

MR GRAY: Professor, do you know how those sorts of results would be – would compare with results in an acute setting, say, in a public hospital?

PROF BRODATY: Well, my geriatric colleagues say it’s even lower in – in that setting because he wanted to repeat the study in the geriatric ward, and the head doctor there said, no, that’s not necessary because it’s probably closer to zero per cent. Yeah.

MR GRAY: It might be a very far-reaching problem.

PROF BRODATY: Yes. Yes.

MR GRAY: In paragraph 23, with respect to the point you identified in residential aged care, you go on to say:

This may be a failure of the facility, the prescribing doctor or the family to realise that this is their responsibility.

PROF BRODATY: Yes.

MR GRAY: And this touches on a point that you’ve recently had involvement in, in your capacity as member – as a member of the Minister’s Aged Care Clinical Advisory Committee in February and March of this year.

PROF BRODATY: Correct.

MR GRAY: Where does the responsibility lie, firstly, for obtaining consent - - -

PROF BRODATY: Yes.

MR GRAY: - - - or proxy consent on - - -

PROF BRODATY: Yes. Yes.

MR GRAY: - - - behalf of a person who lacks capacity for the prescription of psychotropic medication?

5 PROF BRODATY: So if the doctor is prescribing, the doctor needs to be certain that consent has been provided for that, and as I said, the Act does require that be in writing. I'm not aware of anyone ever being prosecuted for not going through that. It's often difficult for the doctor, particularly in a nursing home where the proxy is not available and so the doctor may and often does delegate that to the nursing staff, saying, "Next time, this person's spouse or child comes in, could you ask them to
10 sign the consent for that." So the initial responsibility is with the doctor. The person who's actually giving out the medication, it would be advisable if there was some easy way for them to see that this documentation had been provided.

15 So the nursing home itself, I think, bears some responsibility as well, and I think the family bears a responsibility. Often, families just leave it to the doctors or nurses to say, well, so-and-so needs this, rather than questioning why, and the first time they may know about it is when they get the account at the end of the month, and they find the person has been put on these medications. So I think it's a bit simplistic to put it all on the doctor, although, I think the doctor is the primary person in this
20 chain, but I think the – the facility and the family need to be involved, and I give the example if you had a child who was in hospital, you would be want to – you would want to be very involved in what's happening with the care of that child and with the medications and treatments being given and, often, families abrogate that responsibility, rather than taking it on.

25 MR GRAY: With respect to the facility, the Royal Commission has heard some evidence that there seems to have been some views that, occasionally, facility staff will – and I might not be using the exact words, but put pressure on prescribing clinicians - - -

30 PROF BRODATY: Yes. Yes.

MR GRAY: - - - to prescribe something in order to manage what are seen as challenging behaviours - - -

35 PROF BRODATY: Yes. Yes.

MR GRAY: - - - because of perceived workload issues and such like. Is this something that you know of through your - - -

40 PROF BRODATY: Oh, yes. Yes.

MR GRAY: - - - professional activities?

45 PROF BRODATY: I mean, it's quite common, you know, the – a nurse will ring up the local doctor and say, "Mrs X is becoming agitated. Can you write her up for something?" And the doctor may even fax over the script without even coming to

see the – the patient to do that. Or I saw a patient just a couple of weeks ago where the doctor had written up some extra medication for this patient, and I was speaking to the patient’s husband, and I said did Dr X come and see – came and saw your wife. He said, “I never saw – I never” – he – he lived in the next room, and he’d
5 come there, talked to the nurses and written up the script, but hadn’t seen the patient, but took the report from the nurses. So ,yes, that happens very commonly. We did a study of de-prescribing antipsychotics in nursing homes - - -

MR GRAY: Yes.
10

PROF BRODATY: - - - and we – I think we may be going into this later. If we – would you like me to go into it now or - - -

MR GRAY: Please.
15

PROF BRODATY: Yeah.

MR GRAY: I will just find the paragraph reference in a minute, but please.

20 PROF BRODATY: Yes. Okay. So this was – so perhaps I could just do a bit of history on this, is that in 2003, we published a study showing that risperidone, which is a type of antipsychotic, was more effective than placebo in reducing aggression, and the – the paper got a lot of publicity, not so much for the finding, but because six
25 people in the placebo group – in – in – sorry, six people in the risperidone group had a stroke and zero people in the placebo group. There was about 150 people in each group, and that led the drug companies, then, to look through their records, and they found there was an increased rate of death as well.

30 There followed warnings by UK, by France, by United States against use of antipsychotics in nursing homes, and there has been a lot of publicity about that, and people have been calculating the excess number of deaths that have been caused by antipsychotics. As a percentage, it’s quite small, but because the – the number we calculated the percentage on is high, the numbers of people affected are – are
35 significant. And there was a – a program on ABC with the then Minister for ageing, Mark Butler, questioning him about the use of antipsychotics, and that led to some interest, then, in trying to reduce that ,and we were successful in getting a grant to do a trial of person-centred care as a way of getting people off antipsychotics. This was halting antipsychotic in long-term care, or the acronym was the HALT study.

40 MR GRAY: Paragraph 47, please, Operator.

PROF BRODATY: Yep, and we found that we could get 75 per cent. So what – what it was is we trained a nurse in each of the homes that we were in – there was 24
45 homes, one dropped out, 23 homes – to be the nurse champion and they did a three-week – three-day training program – three-day training program with Professor Lynn Chenoweth, and then they became the champion at that home and it was a train the trainer model. They did mini tutorials at handover times, so it didn’t disrupt the

normal working of the nursing home, and so the nurses understood there were other techniques to managing behaviours, rather than medications. We wanted to do this so that if we were taking people off medications, the nurses wouldn't feel apprehensive that they would be facing a re-emergence of the behaviours for which the medication was prescribed.

We also had a GP – Dr Alan Shell who worked with us – visit the GPs who did the prescribing to talk to them about the study. Usually, it was about a half hour session and that was sufficient, and we also had a pharmacist talk to the – the pharmacies. Usually, most nursing homes have a single pharmacy to do all their dispensing, and we reduced the medication in 85 per cent. We stopped it in 85 per cent of residents within the first three months, and that was the end of our intervention, and then we followed people up for another 12 months, and we found that over 12 months, 75 per cent were still off the antipsychotics. We didn't find any re-emergence of behaviours. The behaviours were the same before, as after, and we didn't find the use of substitute medications such as benzodiazepines on a regular basis.

We did allow the GPs to write up for PRN, small dose of oxazepam, but it wasn't – was hardly used, but it was just for security. Everyone felt safe in doing this. So it – it's quite clear that we can reduce people's antipsychotics without any untoward psych effects, but some families were very trepidations about this. Some nursing – some nursing homes didn't want to participate in the study because they were frightened about this as well. We did a second part of the study where we went back and interviewed the nurses, the doctors, the families and the residents where possible of those residents who couldn't get off the antipsychotic or wouldn't – wouldn't go off the antipsychotics or who were re-prescribed within that 12-month period and – I've got my notes here. That – I – I haven't given you this document because the paper is under review with a journal and it's – so I – but – and the reasons – the most common drivers of re-prescribing were nurses, 63 per cent; family members, 40 per cent; GPs, 24 per cent; specialists, 13 per cent; and hospital staff, 11 per cent. The numbers add up to more than 100 because, often, there were multiple drivers for the antipsychotic use. Yep.

MR GRAY: And this was the – for example, the 25 per cent of the 85 per cent - - -

PROF BRODATY: That's right.

MR GRAY: - - - who were re-prescribed - - -

PROF BRODATY: Yes. Yes.

MR GRAY: - - - and those people who weren't able to get off the antipsychotics in the first place.

PROF BRODATY: It's – it's 25 per cent of the whole 100 per cent, sorry. Yeah. Yeah. Exactly.

MR GRAY: Oh, it was 25 per cent of the whole - - -

PROF BRODATY: Yep. Yeah.

5 MR GRAY: Thank you.

PROF BRODATY: Because 75 per cent were still off the antipsychotics at the end, yep.

10 MR GRAY: Thank you. Now, I was asking you questions about, in effect, the responsibilities concerning - - -

PROF BRODATY: Yep.

15 MR GRAY: - - - obtaining informed consent, and as a separate matter, I wanted to ask you about your views on good practice with regard to the recording of the fact that obtained consent - - -

PROF BRODATY: Yes.

20

MR GRAY: - - - has been – I beg your pardon, that informed consent has been obtained.

PROF BRODATY: Yes.

25

MR GRAY: That was a focus of the study you referred to in paragraph 23.

PROF BRODATY: Yes.

30 MR GRAY: Could I have, put up on the screen, please, tab 107 which – if we go past the ministerial briefing to the attachments to - - -

PROF BRODATY: Oh, yes. Yep.

35 MR GRAY: - - - that briefing at page 0378, you may recognise. Is that the options paper of the committee - - -

PROF BRODATY: It is.

40 MR GRAY: - - - that you participated in in February/March.

PROF BRODATY: It is – it is the paper, yes.

45 MR GRAY: Yes. And if we go, please, to page 0387. I won't ask the operator to go back, but I will just read the heading and the introductory words on the preceding page. They are:

Next Steps: subject to the Minister's views, the committee proposes the following initiatives be further explored by the department and/or the Aged Care Quality and Safety Commission including developing costing proposals for the consideration of government as required.

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And then there's a set of – if we could please go to page 0387, and then there's a set of points. There are five points. The second of those points is at the top of the page the operator has brought up:

10

Development of the following specific measures: (a) requirement for documentation of the specific indication for prescribing, the behaviours to be addressed, and documentation that informed consent has been provided, and weekly documentation of the impact on any behaviours and the documentation of a formal 12-week review or other agreed time point.

15

Now, that documentation and, in particular, documentation that informed consent has been provided and weekly documentation of impact of behaviours, whose – in your opinion, whose responsibility is it to maintain that documentation?

20

PROF BRODATY: I – I think it's the facility. It would be simple to have a little tick box on the top of the prescription. You know, column in – in – in there that's saying the documentation had been provided, and that would only need to be done once. If I'm prescribing for blood pressure, I would need regular measurements of blood pressure to see if my medication was working, and so it's not unreasonable to ask for some documentation of that. And then the 12-week review is – pretty well, all guidelines say that should definitely be reviewed within 12 weeks, and if the medication has been successful, then, perhaps, slowly weaning off, or if it hasn't been successful, then why continue it, and it may be the medication dose is too little, that's possible as well, but it may be the wrong medication, or medication may not be the answer, as is the case for many behaviours such as intrusiveness and wandering and screaming.

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MR GRAY: So, Professor, with respect to the documentation in all the categories in that paragraph, documentation of the specific indication for prescribing the behaviours to be addressed, including the two matters I specifically asked you about and then the review documentation, do you – in your opinion, would good practice dictate that the facility maintain all of that documentation?

35

40

PROF BRODATY: Yes. Yes.

MR GRAY: Yep, and there's a reference here to prescribing, in respect of behaviours. The context of the paper, as I understand it, is largely directed to psychotropics, particularly in the nature of – beg your pardon, antipsychotics and anxiolytics; is that right?

45

PROF BRODATY: Yes. Yes.

MR GRAY: Yep. Does it extend to antidepressants, or is that more difficult - - -

PROF BRODATY: No, it – it – I think antidepressants are much more difficult because, 20 or 30 years ago, we used to decry the fact that depression wasn't being
5 treated in nursing homes, and in those days, the antidepressants were, like, six tablets a day with the old tricyclic antidepressants. Now, people can have one tablet a day of the new SSRIs, the selective serotonin reuptake inhibitors, or dual action ones like mirtazapine or venlafaxine. So I think that they're being given too much now. Things have changed and, also, they're not that very – not effective. So the two
10 largest randomised control trials, one from the US and a bigger one from the UK, showed no difference to placebo. This is in group data.

I still prescribe antidepressants for people who I think warrant it, but the effects are not brilliant in people without dementia, and they're far less effective in people with
15 dementia. And, often, they're not reviewed, so people may be on antidepressants for – indefinitely, rather than trialling them off the antidepressants. General agreement is that people, for a first episode of depression, shouldn't take the antidepressants – should take the antidepressants say for about six to 12 months, average about nine months, and then try reducing them, but I see that antidepressants are given for other
20 behaviours apart from depression, too, which is not indicated.

MR GRAY: So tell me if I've got the wrong – if I'm drawing the wrong conclusion, but accepting that the focus of the options paper is on antipsychotics and anxiolytics
25 - - -

PROF BRODATY: And benzodiazepines mainly, yes.

MR GRAY: - - - in the nature of benzodiazepines.

30 PROF BRODATY: Yes.

MR GRAY: But your own personal opinion extends further, does it, Professor, and you would include antidepressants in a regime of the kind referred to in - - -

35 PROF BRODATY: Antidepressants and anticonvulsants. Anticonvulsants are often used, not just for epilepsy, but as a way of behavioural control, and they have been very disappointing in efficacy in all the trials, yes.

MR GRAY: Epilim and so forth.

40 PROF BRODATY: Yes, Epilim – particularly Epilim, is the one that's most used or sodium valproate is the other name for it. Or Tegretol, a carbamazepine is the other one that's sometimes used. But valproate – when I reviewed literature, there were seven studies on valproate; five found no difference to placebo. One found a
45 benefit, and one found placebo was better than the valproate. Yes.

MR GRAY: All of those four families of pharmaceuticals - - -

PROF BRODATY: Yes.

MR GRAY: - - - would be included in a regime of the kind that's outlined in 2(a)
- - -

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PROF BRODATY: Yes.

MR GRAY: - - - of the paper in your view.

10 PROF BRODATY: Yes. If drugs are being used to control behaviour. The other
way people try to slip through it is prescribe antihistamines which have a sedating
effect. I don't know that's so popular but it does happen. And I am excluding
people with primary psychiatric problems, so if a person has schizophrenia or bipolar
15 affective disorder then it's perfectly correct for them to be continuing on that
medication. Anecdotally, what I've heard in the United States where there has been
a strong move to reduce antipsychotic by publishing rates of antipsychotic use in
nursing homes state by state – and I get a report every quarter from them – and it's
20 dropped to under 20 per cent now, is they exclude people with schizophrenia from
these statistics, so people are being re-diagnosed as having a primary psychotic
illness to escape this reporting regimen.

MR GRAY: Just getting then to the carrot and stick - - -

PROF BRODATY: Yes.

25

MR GRAY: - - - and in particular, I suppose, the stick, is your own personal
opinion around reporting, that rates of prescription of those for families and possibly
even the antihistamines should be reported to the safety commission?

30 PROF BRODATY: Yes, I do. I have a caveat, and if that means that nursing homes
will then refuse to take patients that might need these medications or could need
these medications, I should say, it may be more difficult for those people to get
placed. And it's like publishing surgical complication rates or hospital complication
35 rates. It then distorts the admission policies or – of those people or those institutions.
So it needs to be done carefully in such a way, whether these should be made public
or not I think is a contentious issue, and there are points for and points against
because people may not drill down into the details.

40 MR GRAY: I want to ask you about what should be made public in perhaps five
minutes.

PROF BRODATY: Sure.

45 MR GRAY: But could I just ask you about some of your other particular concerns
and the need to balance different aspects of care and duty of care.

PROF BRODATY: Yes.

MR GRAY: You mention in your statement at paragraphs 24 and 25 what has been called by at least one other witness to the Royal Commission the concept of the dignity of risk.

5 PROF BRODATY: Yes.

MR GRAY: I don't think you've used that expression - - -

PROF BRODATY: No.

10

MR GRAY: - - - yourself, Professor, but you've talked about the tension between safety and autonomy.

PROF BRODATY: Exactly.

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MR GRAY: And you give an example; would you elaborate, please

PROF BRODATY: Yes. A patient of mine springs to mind. He was a man with quite severe Parkinson's disease and moderate dementia, and he was in a nursing home. He was quite an active man; he loved working with his hands. His room was decorated with model cars, that was his passion. He loved walking, and he would often go walkabout around the grounds of the nursing home but sometimes he would outside the grounds – they had quite nice grounds – and onto the road. And because of his Parkinson's disease he would sometimes freeze, and if he's in the middle of the road that's obviously dangerous. So the nursing home said, no, he's not allowed to go out. And he became quite agitated at that stage, and so the treatment was to give him some medication to stop the agitation.

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Antipsychotics are difficult in people with Parkinson's disease because one of the side effects is to worsen the Parkinson's disease and so that wasn't an option. And eventually he was moved into a locked ward where he couldn't go wandering and he became quite agitated. He was sent to hospital for admission and he did settle down in the hospital, then moved back, but stayed in the locked ward. Early on in the piece his wife said, "I'm very happy for him to walk and to take that risk because his quality of life is more important than his safety". And this is a tension. The nursing home said, "We respect that but it's our reputation. If he gets hit by a car, we bear the responsibility. It will be all over the, you know, media and it's very bad for the nursing home", and they refused to allow that.

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And so I understand from both points of view. The nursing home does have what they call a duty of care and responsibility, but there's this – always this tension between cotton wool, safety and autonomy and independence. I don't know if advanced care directives can be used to try and work through this, whether there are some legal framework that can be provided for nursing homes or some safety for them, but if they have these things written down and confirmed by families that they can take those risks, but it's one of these wicked problems that we have in looking after people in nursing homes.

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MR GRAY: In paragraph 26 you do suggest there might be a role for regulatory leadership.

PROF BRODATY: Yes.

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MR GRAY: On this point.

PROF BRODATY: So if the people who regulate nursing homes could give some guiding to nursing homes on how they should deal with this, that would be a help to them.

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MR GRAY: Another point of concern you raise in the very next paragraph is what you refer to as, in confronting terms, involuntary detention.

PROF BRODATY: Yes. So I can think of several patients I've seen who are very depressed. I go and talk to them, and I usually spend about an hour with a person I'm seeing for the first time in a nursing home. And the primary thing that's depressing them is being in a nursing home. They don't want to be there, they want to be home, they want to leave. This may not be a locked nursing home. I say, "Well, why don't you leave?" Well, they can't, or they have nowhere to go to, there's no family who can look after them. So they feel they're prisoners, and they use that word. They say, "I'm a prisoner here". Now, I was head of a psychiatric ward for a decade and as medical superintendent, we can't keep somebody in a psychiatric ward without a legal framework to approve that. There is no legal framework for most of these people who don't want to be there.

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Now, it opens up a can of worms to say should everybody go through some sort of guardianship hearing to override the objections of the person keeping them in. I think strictly by the law that should occur, but the guardianship would drown in applications if that happened here – tribunal now. So I don't know what the answer is. So there was a patient of mine who had had strokes. He had a dense hemiparesis, in other words he couldn't move one side of his body at all. He had no insight. He had a house which was – squatters were in the house and he didn't mind that, but he wanted to go home. He couldn't stand up without falling over, but he lacked the insight to know that he shouldn't stand up. So there was a lot of difficulty with him. His daughter said there's no way that she could provide the care for him. He needed two people 24/7. That's probably \$2000 a day. It's not sustainable for most people, and so there was no option for him but to stay in the nursing home. He swore at me, he swore at the nurses, he was angry and he was depressed. Antidepressants weren't going to fix him.

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MR GRAY: Professor, we got to the topic of the use of the antipsychotics and the anxiolytics, and even antidepressants and possibly even antihistamines for purposes of addressing behaviour for other than clinically indicated reasons - - -

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PROF BRODATY: Yes.

MR GRAY: - - - but we in effect skipped the clinical analysis that you provide in your statement about what is it that might prompt a nursing home to ask a clinician - - -

5 PROF BRODATY: Yes. Yes.

MR GRAY: - - - to prescribe these things. If we could take a few minutes, please, to - - -

10 PROF BRODATY: Sure.

MR GRAY: - - - address the Brodaty triangle on page 0006. Would you please explain, in summary terms, the research - - -

15 PROF BRODATY: Yes. Yes.

MR GRAY: - - - the analysis that led you - - -

20 PROF BRODATY: Yes.

MR GRAY: - - - to this concept for, in effect, categorisation of behaviour and service delivery.

25 PROF BRODATY: Right. Yes. I was very concerned about the fragmentation of service delivery for people with behaviours. Mental health problems being a State responsibility, aged care being a Commonwealth responsibility. It's not uncommon we get people who fall through those cracks between State and Commonwealth, and so I tried to conceptualise with my colleagues, Brian Draper and Lee Fay Low, a model about how we could actually provide services in a more systematic way. And
30 so the triangle has seven tiers, and the first tier being people without dementia and, you know, obviously, if we could prevent dementia, we could prevent all the behavioural issues associated with it. The second tier is people with dementia who don't have behaviours, and that's about 40 per cent from epidemiological studies that had been performed at the time.

35 This was published in 2002 or '03, I can't remember, and then we go up the – the hierarchy with moderate, severe, very severe and extreme. So we estimated, from the literature that we could find, the relative – the approximate prevalence of these different behaviours. We haven't updated this since then. There haven't been a lot
40 of epidemiological studies to help us with that, and we estimated from clinical what we thought might be the behaviour – the prevalence in some cases because there was no data, and we outlined what we thought would be the management strategies in each of those behaviours. So taking to tier 3, mild behaviours, these might be people who are wandering, mildly depressed, apathetic or asking questions over and over.
45 It's mainly being managed by primary care workers or by families with advice on how to do that.

As it goes up, we might need specialist consultation or management in dementia specific homes or by specialist teams. This was before the dementia behaviour management advisory services were established or the severe behaviour response teams. So, now, we would be including DBMAS in tier 5 and the – the severe
5 behaviour response teams in tiers 5 and 6. Tier 6, we thought there should be special neurobehavioral units or special dementia care units, and that recommendation has been around for some time, and it's just being taken up now by the Commonwealth with one unit to be established within each primary health care network around Australia which will be approximately 240 beds for the whole of Australia.

10 Now, if it's – it's about 180,000 people in nursing homes in Australia. If it's one per cent who have got tier 6, very severe behaviours, then – and, sorry, of the 180,000 people in nursing homes, let's say about 100,000 have dementia, then there might be up to 1000 people who are eligible for this tier 6 level of care and there'll be about
15 240 beds. And it – it might be enough because we now have severe behaviour response teams and not everyone wants to go into a special care unit. It may not be geographically available. I should point out that people can move up and down this triangle. So, in my example, a person with a urinary tract infection who has dementia with mild behaviours, they can become very agitated, even aggressive
20 because they have, say, a urinary tract infection or in pain which – very common cause of being untreated, and when that's treated, they get better and their behaviours deescalate, and they go back to tier 3 or even lower, yes.

MR GRAY: Thank you.

25 PROF BRODATY: So it's a – it's – it's a – it's a conceptual system for organising services. It's being used as a classification of people saying, "I'm looking after a 6 or a 4," you know, it's certainly not what we intended when we developed this triangle, yeah.

30 MR GRAY: But in terms of addressing the correct level of service delivery to a person with particular needs - - -

PROF BRODATY: Yes.

35 MR GRAY: - - - it's, without any doubt, a very useful construct.

PROF BRODATY: It's – it's been adopted by state and federal governments in trying to organise services. So that was our purpose, and I think it's certainly the
40 purpose.

MR GRAY: And that tailored level of interventions, not only very important for the person concerned to alleviate their distress – you refer to this at paragraph 36 – but also carers.

45 PROF BRODATY: That's right, yes.

MR GRAY: That might be family.

PROF BRODATY: Yes.

5 MR GRAY: They might be volunteer carers.

PROF BRODATY: Yes. Yes.

MR GRAY: And, of course, workers in the sector.

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PROF BRODATY: Yes, and – and – I mean, I haven't – because we were mainly concentrating on residential care, but a lot of these behaviours occur in the home with people living at home with – with – with carers, and we know that if we train carers on how to prevent behaviours or how to manage them, that it's very effective. It's as effective as drugs. In fact, that's another study that we published which was a meta-analysis where we looked at all the – the training programs for carers and showed it had an effect at least equal to that of antipsychotics without side effects.

15

MR GRAY: Are you satisfied with the level of training programs that are made available including for carers to access?

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PROF BRODATY: Of course not. There's never enough, and it's not only that there weren't enough. They weren't actually subscribed to. There was – Alzheimer's Australia, as it was then, did provide Living With Memory Loss, I think was the name of the program, but the numbers of people who were referred to them, people who wanted to go into the – into the programs was very few.

25

MR GRAY: Do they not have the time because they don't have respite from 24/7 care?

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PROF BRODATY: Maybe. It – it may be that. It may be they weren't referred, they didn't know about it, or they didn't realise what a great help it could be. If it was a seven-week course, it was like seven mornings a week if they did that, yep.

MR GRAY: Now, if we go to page 0008, having identified – I won't take you to it, but you actually - - -

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PROF BRODATY: Yes.

MR GRAY: - - - broke down the sort of behaviours that are – that can be involved, depending on the individual and depending on the particular form of dementia - - -

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PROF BRODATY: Yes.

MR GRAY: - - - and the individual's own unique condition, various kinds of behaviours might be involved, but I won't ask you to go through them. In the

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residential aged care context in paragraph 38, you, in effect, have that methodology

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PROF BRODATY: Yes. Yes.

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MR GRAY: - - - that you adverted to earlier in your evidence about the way to rule out possible other – possible alternative causes, etcetera.

PROF BRODATY: Yes.

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MR GRAY: Could you please elaborate?

PROF BRODATY: Yes. The – the behaviour, in a medical term, is a symptom, but in a nonmedical term, it's a communication. So understanding what the behaviour is about, what – what – who the person is behind the behaviour. So, first of all, excluding some biological causes, like I mentioned urinary tract infection and pain. In our – in our de-prescribing study, we found untreated pain was probably the most common cause of – of behavioural disturbances, and there has been a study just putting someone on two Panadol three times a day was effective for a number of people – a large percentage of people in reducing their agitation. So that's the first step.

And then understanding the meaning of the behaviour. So the example I give was one was told to me was about the milkman who became very agitated when he was being put to bed in his pyjama and became quite aggressive, and the nurses said to the doctor, "Well, can you give him something so that he will sleep?" This was in the days when milk was delivered, and he – and the wife said "Well, you know, what – what he used to do when he was home, he would have a bath in the evening, he would get changed into his tracksuit, go to bed early, so at 4 am when he woke up, he was dressed ready to go on his milk run." So they changed their routine and, suddenly, this night-time disturbance disappeared. So understanding what the communication is, understanding the person and what the behaviour is all about.

And then, as I mentioned with blood pressure, you don't treat something without knowing what you're treating, so we need some quantitative measure of the behaviour. Is it occurring once a month; is it occurring every hour? How severe is it? So frequency and severity and then having established a base line, then start looking at the intervention, and so it may be things like playing music, hand massage. People have tried lavender oil or lemon balm with mixed results. There are different strategies. We did a study with a humour therapy where we had someone who would come in and engage the resident with their most interesting things. So it might be an English teacher where the therapist actually read poetry and then asked the resident to rate how – she was an English teacher. You know, "How – how good was my reading," and so got the person engaged, or got them – people doing singing or dancing.

We – we did a – a pilot work where we – we got a woman who was an Australian ballet dancer, retired. About 10 people were just sitting around the room, really, mouth open, apathetic, out to it, not engaged with anything. Got them in a circle listening to the music, then holding hands, then swaying, then moving their hands, then standing up, and by the end of two weeks, they were dancing with each other. You know, we've got – so you can do things that are creative in a nursing home that make the quality of life so much better. So that would be the psychological, social, environmental.

10 Then the medications. There are some people, none of this will work, and their behaviour is a danger to themselves; it's a danger to others. It's an unbearable situation for other residents too. It can be a source of danger for them as well and for visitors and, for them, we do try medications, but with all the caveats about consent, about explaining possible side effects, getting approval and – and monitoring it and then making sure that, within 12 weeks, we're making a decision whether they should continue with that. So that's the pathway as it were, yeah.

MR GRAY: Thank you. I want to ask you about an aspect of your evidence on page 0009. You've already addressed overprescribing; you've referred to Dr Westbury's work. But what I do want to ask you – not so much about the side effects of the pharmaceuticals involved, but, in fact, what the alternative is that you propound, the intervention of non-pharmacological psychosocial supports and, in particular, person-centred care - - -

25 PROF BRODATY: Yes.

MR GRAY: - - - driven interventions. And you say in 40, that there's – there are tools to measure - - -

30 PROF BRODATY: Yes.

MR GRAY: - - - the – what the extent, the quality of the person-centred care that's provided in a particular setting.

35 PROF BRODATY: Yes. Yes.

MR GRAY: Can we bring up, please, RCD.9999.0064.0001. This is the person-centred care assessment tool, the PCAT, at Latrobe University source, and if we go over the page, we see, in effect, a rating of 1 to 5 from disagree completely to agree completely in a familiar form. A series of metrics concerning what aspects of the quality of the care that's provided against a benchmark of good person-centred care practice. Is that so, Professor?

45 PROF BRODATY: Yes, that's correct.

MR GRAY: So is this tool accepted as providing consistent and systemic data that's measurable?

PROF BRODATY: It – it – it’s useful for that. It’s mainly been used in research studies. It’s not used, I think, as a routine in any home that I go to, yes.

5 MR GRAY: Would – could this be the beginnings of a structured approach to rating how different approved providers and different residential aged care services are faring in - - -

PROF BRODATY: Yes.

10 MR GRAY: - - - implementing person-centred care?

PROF BRODATY: Yes, it – it could be the basis. It would need to be tested and made sure it was acceptable and maybe able to reduce the number of items. So, yes, and there may also be a version that’s required for the families to rate as well, not just for the – and for the person, if they can, who’s – who’s a resident, yeah.

MR GRAY: I want to ask you, just on the carrot and stick point that you’ve mentioned already and you refer to in paragraph 63 of your statement. You say in paragraph 63:

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Carrots incentives and sticks regulations, inspections and higher standards should be used in regard to approved providers. Incentives would be making the facility more attractive and competitive in the marketplace. A transparent internet accessible system of rating quality care would drive customers to highly ranked facilities.

25

This is on – thank you, Operator. Do you have any ideas for the indicators that might be covered by a rating system of this kind and - - -

30 PROF BRODATY: Yes.

MR GRAY: - - - would they include person – the degree of implementation of person-centred care?

35 PROF BRODATY: It could be that. There could be – I mean, there’s a whole lot of things that could be provided such as critical incidents, complications of nursing homes, the use of antipsychotics, and the degree of person-centred cared-ness or satisfaction with care. You know, we – we’re used to this sort of system now on the internet with trip adviser when we look up the hotels we’re going to stay and we read the reviews, we look at the ratings, we look at restaurants. There are people calling for this sort of rating system to be available on the net for nursing homes as well, but, again, it can be distorted, as I’ve mentioned earlier, by admission policies, and that would need to be factored in. Yeah.

45 MR GRAY: Thank you. You refer to improving training and leadership in the care environment of organisations towards the end of your statement. You take an

interdisciplinary approach to it. You refer to what I take you to be characterising as a – a bit of an omission in the medicine degree itself; is that so?

PROF BRODATY: Yes. Just remind me what - - -

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MR GRAY: Well, you – at paragraph 67, you say:

Changes should definitely be made to the curricula for doctors, nurses - - -

10 PROF BRODATY: Oh, yes. Yes. Yeah, definitely. Yes. Yes.

MR GRAY: You don't spare anybody.

PROF BRODATY: Yes.

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MR GRAY: Professor, are you able to – I won't ask you to go into - - -

PROF BRODATY: Yes.

20 MR GRAY: - - - too much detail, but are you able to summarise for the Commissioners your views about where we're at in training for dementia care and what should be done from here?

25 PROF BRODATY: Well, it's pretty rudimentary. I mean, I teach medical students in their fifth year, and they get a one-hour lecture on dementia from me. They may get some tutorials as well. In geriatrics, they may go and see nursing homes. It's always been the poor cousin in medicine. Not the most attractive area to – to attract people who are the, you know, career minded. In nursing, again, aged care nurses get paid less than hospital nurses with the same qualifications. So it has certainly
30 been not accorded the same status as other branches of – of health care and medicine in general. Even in hospitals, I see that people who are – I remember my own mother in hospital, the nurses really had – and she was about 90 at that time, and the nurse really had no idea about how to look after older people.

35 She was actually stuck in a toilet because she wasn't strong enough to open the door to the toilet. You know, she was a small – very small lady. So just – and I've seen people in – in hospitals who unable to – people with dementia, it's quite a dangerous place for them. They're unable to order their food because they can't fill in the menu each day. I've seen people with a fractured arm, and they get the cornflakes in a
40 packet and their arm is in a plaster, and they can't physically open the packet of cornflakes and then the food is then swept away. So it's – it's – it's in every arm of – of health care, social work, occupational therapy, nurses and doctors. So there need – need – need to be more emphasis on dementia in curricula. Curricula are very crowded places. There's competition between the different branches within each
45 discipline, and so it's not always possible to get the time that you think your branch deserves in – in that space.

MR GRAY: Professor, that exhausts the questions that I have for you, but if there's anything you have in mind that you wish to tell the Commissioners on the topic of dementia care in particular and the context of residential care, anything I've omitted to ask you, please feel free to inform the Commissioners about that.

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PROF BRODATY: Wow. That's a very kind invitation, Mr Gray. Yeah. So I – I feel strongly that education and training really needs to be at the forefront of changing the culture within nursing homes, and this needs to be on a continuous basis. We've demonstrated that it can work, and we've also demonstrated that nurses can be receptive to this if they're given the support from management as well, and it can make their – their jobs more enjoyable and more fulfilling. So it – it's a win for everybody, and what we're trying to establish now is it's also cost beneficial for nursing homes, I think that's a harder task to – to sell, but we're actually looking at that right now to try and make that case, and we – we have some evidence that that is the case.

So – and that's important. I – I think having the – the regulatory authorities making person-centred care part of their assessment procedures, which I think is happening, is a very positive move and should be advanced even further. And transparency with nursing homes about what they provide is important, too, and I think it will be driven by the market to some extent because there are now more vacancies in nursing homes. I'm really surprised by this but some nursing homes are having, particularly the higher end of the market, are having vacancies now, maybe reflecting the economy, but if there's vacancies then there's competition for residents, then people will have to offer better services to provide that.

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MR GRAY: Thank you, Professor.

PROF BRODATY: Thank you.

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COMMISSIONER TRACEY: Professor, you've mentioned that you regularly visit a nursing home as a clinician. The impression that we've got from the evidence we've heard thus far is that that is a practice that is a rarity and that geriatricians are rarely to be seen in nursing homes.

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PROF BRODATY: Yes.

COMMISSIONER TRACEY: Is that a correct impression?

PROF BRODATY: Well, let me say, I'm a psychiatrist for older people, so a psychogeriatrician, not a geriatrician. In our area we have a geriatric flying squad which does go to nursing homes, and in the Sutherland area I know there has been a geriatric flying squad which has reduced admissions to hospital by half. So I think that's increasing as the hospitals realise it's cheaper for them to have a geriatric – a mobile geriatric group going to a home rather than having people coming in and taking up bed days which are much more expensive. So I don't have figures for geriatrics – geriatricians going into homes, but I can certainly see within the South

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Eastern Sydney Local Health District where I work that that is happening to some extent.

5 COMMISSIONER TRACEY: So the initiative comes from the government-sponsored health authority rather than the nursing home?

PROF BRODATY: That's correct.

10 COMMISSIONER TRACEY: Are you able to say whether in your experience the nursing homes are cooperative at receiving - - -

PROF BRODATY: They're very appreciative of that, yes.

15 COMMISSIONER TRACEY: Yes.

PROF BRODATY: Of course, they are. The other model – there's a model in the Netherlands where they have physicians who when they finish their training and become doctors, do a two year training – it's like a diploma of geriatrics, and they become nursing home physicians, and so you have somebody who is within the
20 nursing home and you can actually do planning and providing medical care on that basis. The Aged Care Act, as you know, says people have the ability to choose the practitioner if they have the choice of their practitioner, but in practice that doesn't happen. And if you've got a 100 bed nursing home and theoretically, you would
25 have 100 different GPs coming, it's very hard to have any coordinated approach to providing medical care. So – this has been a real gap in how services are provided. The people who are actually interested in providing primary health care or specialist geriatric or psychogeriatric care, it's haphazard, it's not organised.

30 COMMISSIONER TRACEY: We've heard that it's often very hard to get general practitioners to attend nursing homes and provide one-to-one care, and part of that has been the unwillingness of nursing homes to provide proper facilities for practitioners to examine and deal with patients, and oversee their general care. In your observation, are nursing homes becoming more amenable to providing facilities that will assist doctors in doing their work?

35 PROF BRODATY: No. There are some nursing homes which have a clinic and have GPs coming on a regular day and who see a lot of the patients, and a couple of them even have dental clinics and a dental chair for the oral health which is another big issue. But typically what happens, I go into a nursing home, I have to find the
40 patient, I have to find a nurse, I have to find the notes, have to get the medication charts; all of that takes time. Sometimes there's no nurses at the nurses' station, because they're busy doing other things. And you get a domestic to try and find the nurse who can help, then the notes and get the medication charts. Then the person you want to see may be in a group or may be in another part of the nursing home, so
45 it can take about 10 minutes, or more, just to get all the bits and pieces you need.

So the nurse who knows the person, the notes, the medication charts and the residents. And so my practice is to always find the nurse, talk to the nurse first, read the notes first, then go and see the resident, then come back and talk to the nurse and often then ring the family after that. But for GPs, that's not – I mean, I get paid a
5 salary anyway, I get paid as a specialist, it's quite a different rate to the GP who gets quite a small amount of money. So it's not very attractive for them and it's very inefficient of their time, and every minute is how they support themselves.

10 COMMISSIONER TRACEY: Yes. Thank you.

COMMISSIONER BRIGGS: I, too, was interested in following up the issue of the doctors, and thank you for your evidence this morning, Professor Brodaty. I'm particularly interested in some of your comments in evidence about the extent to
15 which general practitioners will take the suggestions from the nursing staff of residents about the care without having seen the person concerned. That raises for me some ethical issues. It also raises some serious issues about inappropriate prescribing. And I'm wondering if you could talk about both the ethical side, and what really should happen in practice.

20 PROF BRODATY: Yes. Okay. So I'm not saying this happens a lot but I have seen it. And it's not like the doctor has never seen the patient. They know the patient, often they know the patient well, and they take as accurate what the nurses report. And in fairness to the doctor, if the doctor is coming there for 10 or 15
25 minutes, they're not going to know what the behaviours are. The nurses who are there for eight hour shifts are much more likely to give an accurate response. So having said that, for the doctors, then it may be in that case that, you know, they get rung at 6 o'clock at night, they may fax something over and then come and see the person another time. But it's not an analysis about why the behaviour is occurring. It's a response, the first response to the behaviour, rather than trying to understand
30 why the behaviour is – which takes more time.

COMMISSIONER BRIGGS: And we've heard evidence about records in residential care and records in hospital, and we know the challenges with getting a
35 universal health care record. But it seems to me that appropriate record-keeping, whether it's in a hospital, whether it's transferring to a residential care facility, recording not only the background and history of a person when they come into care but what follows from that, and we've seen a lot of evidence that there is record-keeping but not a lot of evidence about electronic record-keeping that might maintain a more digestible and more effective series of records. Have you seen an effective
40 system of electronic record-keeping operating?

PROF BRODATY: I find it quite a challenge. I – because I'm a visiting specialist, I'm not on their system. I have to find a nurse. I can't write in the notes for those
45 who have got electronic records so I have to find a nurse who can log on for me, and show me where I need to write my notes up. And if I want to read what other doctors have written or what the nurses have written, again, I'm reliant on the nurses to help me with that. The other issue you're alluding to is the lack of communication

between different aspects of the health system, for example, between the hospital and the nursing home, and this occurs between hospitals and GPs; it's an issue which is hopefully moving towards better resolution with electronic medical health records with a sort of personally controlled, whatever it's called, electronic health records
5 now being opt out, and we will all have one. But it hasn't taken effect as yet.

COMMISSIONER BRIGGS: The other thing I wanted to ask you about was the experience of caring for people with dementia who are in the community. And I think in witness statements and, indeed, in some evidence we've had there's a view
10 that there's quite a low level of diagnosis of people with dementia, and I'm wondering if you could take us to ways and means that we might increase that diagnosis because we've heard that early diagnosis enables more effective management of the condition as it goes forward.

15 PROF BRODATY: Yes.

COMMISSIONER BRIGGS: Or as people go forward.

PROF BRODATY: This is a particular passion of mine and we've worked very
20 hard in trying to increase diagnosis in primary health care. So when the dementia is moderate or severe, the shopkeeper will recognise dementia. You don't need a doctor to do that. When it's mild, probably about 50 per cent will be diagnosed and it may be the GP suspects it but doesn't want to give the diagnosis because he or she doesn't know what to do next or doesn't want to alarm the person or thinks there's no point
25 in giving the diagnosis because there's nothing that can be done. We designed a rapid tool for doing a cognitive assessment. We've designed training programs; we did that in conjunction with Dementia Australia and La Trobe University and we reached something like 2000 GPs around Australia over the last few years and 5000 people working in primary care and, you know, so it's a continuing education for
30 them as well.

There are also issues that a lot of the diagnosis relies on interviews with the family member. My teaching is that you should always interview the patient but also interview an informant, someone who lives with the person, and preferably
35 separately because the informant is more likely to be open at that time. There's no rebate for seeing a carer or informant about a patient so GPs are reluctant to do that. And I think in one country, I'm not sure if it's the Netherlands or UK, there was a special payment for doing cognitive assessment of patients. I don't think that's necessary because we don't specially pay to do blood pressure but it should be part
40 of the routine care. There is a 70 plus assessment which is a special rebate item for GPs, which does include a cognitive assessment, and so that's one way of trying to improve that.

But it depends on the prevalence of the condition. If 10 per cent of people over 70
45 have dementia, then it would be pretty sensible that everyone should have some cognitive assessment. That has been debated, and I won't go into technical reasons, but certainly over 80, 20 per cent will have dementia so I think everyone should be

having cognitive assessment in the same way you get your blood pressure checked. In – at the Prince of Wales Hospital where I work about 30 per cent of people coming, admitted through ED, are over 70 – sorry, about half of them are over 70. About 30 per cent will have cognitive impairment, either from delirium or dementia
5 or both. And so everyone over 70 should be having a cognitive assessment on admission to hospital.

So it's making people more aware and more comfortable and they're knowing that there are things they can do once they do find that. You know, you can live very
10 positively with dementia as you will see later this afternoon. I've been talking to Kate Swaffer who's going to appear before you and she's a prime exemplar of positive living with dementia, yes.

COMMISSIONER BRIGGS: Thank you.
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MR GRAY: With your permission, Commissioners, I will just ask Professor Brodaty to tie up a couple of loose ends that I left hanging. Professor, I wanted to take you to a chart that you referred to in paragraph 13 of your statement which summarised the - - -
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PROF BRODATY: Yes.

MR GRAY: - - - non-pharmacological interventions and their efficacy in The Lancet Commission's article. If we can bring up tab 18, please, at page 0428.
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PROF BRODATY: Yes.

MR GRAY: Thank you, is that the chart you had in mind, Professor?

PROF BRODATY: Yes.
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MR GRAY: Thank you.

PROF BRODATY: So this is the effects of psychosocial interventions for agitation. And this is called a meta-analysis. And you will see the different interventions, therapeutic touch, training family caregivers, light therapy, dementia care mapping, person-centred care and communication skills, music therapy and activities. And anything to the right of that vertical line is an improvement, so it reduces agitation. Anything to the left, it doesn't; it worsens agitation. And so there were a number of
35 studies with light therapy, for example, which don't show any benefit. And what a meta-analysis can do is it bring together all these different – in a summary score, and if I just take you to the biggest group there which is person-centred care communication, you see everything is to the right of the line, and it's statistically significant if it doesn't touch the line.
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45 So nothing is to the left of the line, and several studies, principally the ones led by Lynn Chenoweth, are the furthest to the right, are to the right of the line and the

summary of all those which is in another graph, shows that is it's significantly – quite significantly positive in reducing agitation. But we can see there are benefits. If we go to, say, where's music – music therapy, there are two studies there showing benefit, and also engaging in activities matched to interest, that was quite
5 significantly effective – or matching to functional level was to the right but crossed the line so it's no longer significant. So there are different – and there's no one way to do it for everybody, and that's the whole point of understanding the person and tailoring the intervention to the person. That's part of the principle of person-centred care.

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MR GRAY: Thank you.

PROF BRODATY: Thank you.

15 MR GRAY: Professor, the next question related to a report of a study by Dr Westbury which you footnoted in your statement and discussed at paragraph 46 on page 0009, statement at page 0009, paragraph 46.

PROF BRODATY: Yes.

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MR GRAY: And if we were to take you to that report, which is available in the general tender bundle at tab 49 – I will ask that the operator now bring that up. Thank you. Page 0136. There's good results in New South Wales in respect of – this is the top left graph – in respect – and particularly of prescribing rates of
25 benzodiazepines by comparison with the other States.

PROF BRODATY: Why?

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MR GRAY: And the ACT, and why is that so?

PROF BRODATY: I don't know. I don't know.

MR GRAY: Thank you.

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PROF BRODATY: Yes. I'm sorry.

MR GRAY: No, not at all. And finally, Commissioners, may I please tender the Person-centred Care Assessment Tool, the PCAT, which Professor Brodaty referred to, at RCD.9999.0064.0001.

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COMMISSIONER TRACEY: Yes. The La Trobe University document entitled The Person-centred Care Assessment Tool will be exhibit 3-81.

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EXHIBIT #3-81 LATROBE UNIVERSITY DOCUMENT ENTITLED THE PERSON-CENTRED CARE ASSESSMENT TOOL (RCD.9999.0064.0001)

MR GRAY: Thank you, Commissioner. Subject to anything further that you might have for the Professor, perhaps he might be excused?

5 COMMISSIONER TRACEY: Yes. Thank you. Professor, we are most grateful to you for - - -

PROF BRODATY: Thank you.

10 COMMISSIONER TRACEY: - - - giving us your time this morning, and the expertise that will assist us in coming to some important decisions about how best to assist those who are elderly and suffering from dementia, and related conditions. Your evidence will be of great assistance in that regard, and we're again very grateful to you for having come and spoken to us this morning. The Commission will adjourn until 12 noon.

15

PROF BRODATY: May I say thank you to the Commission, and just to say how valuable your work is not just for the elderly here now but for us who are going to be elderly one day, so thank you very much.

20 COMMISSIONER TRACEY: Thank you.

<THE WITNESS WITHDREW [11.39 am]

25

ADJOURNED [11.39 am]

30 **RESUMED [12.07 pm]**

COMMISSIONER TRACEY: Yes, Mr Bolster.

35 MR BOLSTER: Thank you, Commissioners. Our next witness is Mr Trevor Douglas Crosby, who is in the witness box.

<TREVOR DOUGLAS CROSBY, SWORN [12.07 pm]

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<EXAMINATION BY MR BOLSTER

45 MR BOLSTER: What's your full name?

MR CROSBY: Trevor Douglas Crosby.

MR BOLSTER: And if the operator could bring up the document, WIT.0142.0001.0002, Mr Crosby, is that your statement?

MR CROSBY: It is.

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MR BOLSTER: And is that statement true and correct?

MR CROSBY: It is.

10 MR BOLSTER: And would you like to read it out for the Commission, commencing at paragraph 4?

MR CROSBY: Yes:

15 *My full name is Trevor Douglas Crosby. I was born in 1950. I am currently 69 years old and I am retired. I live in Sydney, New South Wales, with my wife Jill. We have three children together. Throughout my life, I have always been a fit, active and contributing member of society. For more than three decades, Jill and I ran a farm in rural New South Wales and I was a member of a*
20 *committee that manages water resources in central New South Wales. I was an active member of my local golf club, serving as president for three years. I was also a keen supporter of The Primary Club in rural New South Wales for many years.*

25 *Four years ago when I was 65, I was diagnosed with Lewy body dementia.*

Diagnosis:

Around 10 years ago, Jill and a good family friend of ours, who happened to be my GP, started to sense something was not quite right. They noticed that I wasn't engaging socially like I had been previously. Throughout my life I had always been the leader of the pack. They noticed that I had started dropping off to be at the back of the pack, for want of an expression. Around the same time, Jill and I went on a trip overseas with a group of about 10 people. It was during this trip that I started to feel something wasn't right. Beforehand, I had
30 *been so – so excited about it. When we got there, instead of being the usual leader, I was literally dragging my feet around the group, and behind the group. This was totally out of character for me. At the time I thought it was just old age. Pity it wasn't.*

40 *After the overseas trip, at the suggestion of Jill and my GP, I underwent some medical tests. I was referred to a neurologist in Sydney. The neurologist didn't seem to think there was much wrong with me. I suggested I come back – he suggested I come back in 12 months time. In 2013 we decided to move from the farm to – farm in Mudgee to Sydney. This was always a long-term plan for Jill and I, but unfortunately we had to make the call a bit earlier than we had*
45 *intended. We anticipated the best of services and medical advice to be in Sydney.*

5 In 2014, I changed neurologists and was diagnosed with Lewy Body Dementia. This happened to be six months after we moved to Sydney. When I received my diagnosis, I was dumbfounded. I couldn't believe there was something that would be wrong with indestructible me. The very first moment that I found –
found out, I tried to speak, but I couldn't. I really understood what the definition of speechless was. I choked. I cried. All my defences had been smashed. I felt helpless, pathetic. 'I'm going to die' I said. I haven't even thought about that yet.

10 Although I felt a little stronger when my diagnosis was confirmed, I still took an almighty knock. Having Jill, my wife, beside me helped tremendously in handling this news. It took me some time but with Jill's support I was able to ask the hard questions: how long do I have to live? How many quality years do I have? The answers didn't please me. But I believe a positive and an
15 optimistic attitude can delay the inevitable.

Support programs for people living with dementia:

Living with Dementia Program.

20 The real turning point for me came after Jill and I took a Dementia Australia program called Living with Dementia referred to earlier by Henry. I met up with another dozen people who were floundering around, feeling sorry for themselves, pretty well down in the dumps. The Living with Dementia course included people from all different socio-economic places. I enjoyed the activities that came from participating in the program. The program buddies
25 you up with people and provides you with peer support. The first day I walked into the program, I didn't know anyone. I was in a state of denial. I didn't know how to talk about dementia, let alone to people living with different variations of dementia.

30 Within three weeks, we were all chatting, laughing and carrying on. Within eight weeks there was a total turn around for Jill and I. However, after the course ended, gaps started to appear in my life. The course lasted for eight weeks with an additional few weeks of support to help you phase back into society. Eight weeks just wasn't enough, isn't enough. After I completed the
35 course, I felt cheated. The course was so good, but there was no follow-up. There was no follow-up course. There was no second instalment. I didn't want it to end. I raised this issue with Dementia Australia in a meeting with their customer service manager. I said there was a need for ongoing support, needs to be established for people like me. I said "You've let me down".

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Younger Onset Dementia Key Worker Program:

45 Another program – another support program run by Dementia Australia that I feel I could have benefitted from is the Younger Onset Dementia Key Program Worker Program, commonly known as a Key Worker Program. The Key Worker Program applies to people aged 65 and under who are diagnosed with dementia. It is an assistance program that helps you to do things like writing a

payment at the end of the month or anything that is a bit awkward for a person living with dementia.

5 *In my case, one of the benefits of an early diagnosis would have been the ability to access the Key Worker Program. The killer here is I was 65 years old and two months when I was diagnosed. I had been diagnosed earlier – had I been diagnosed earlier, I would not have missed out. I question why there was such a rigid cut-off at 65 years. Why not – why not 80? Why not another number? I wrote to the decision-makers and there was no movement, no response, even though – even though I was that close to 65. It was not – I was not able to participate in the program. I stopped writing to the decision-makers last year when I – when I didn't feel I was being heard. The underlying program is that the Dementia Australia hasn't received enough government funding to support and fund a second stage of the program.*

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15 *This brings me to another point about early diagnosis and age limits like this one. I have observed that some people can be in denial about their early onset dementia. I am so frustrated by this attitude. The category cannot be set on the education trail. I'm sorry, I'm going to read that again. I am so frustrated that people in this category cannot be set on the education trail that would fit their quality of life – that would lift their quality of life from low to something meaningful. Further, frustration exists in that even if we could reach these people, would they be sufficiently – would there be sufficient programs to cater for them? I fear the answer is no and I think I agree with Henry on his similar assessment.*

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25 *University of Sydney peer support program:
I am currently part of a peer support program funded by the University of Sydney, the Faculty of Science and Medicine. It's in the – the faculty is in the throes of, early stages of developing a coaching and peer support program. The aim of the program is to build up a network of support. The program identifies itself, and it identifies individuals who have been diagnosed as living with dementia. In particular, it finds people who have recently received a diagnosis, pairs them up with someone like myself who has had several years of experience of living with dementia.*

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40 *At present, I am one of three individuals that support – do a support role. I think that the peer support is really valuable. For example, I have an old university friend. He was further down the track than me after his diagnosis of dementia. He was worse off than me. I was – told his wife that I could try to help. We would read the newspapers of about 40 years ago when we were playing football together, and recall the memories we created back then. Just spending time together helped. It was all about the peer support.*

45 *Strategies for living with dementia:
I have a new neurologist now. Up until recently, I had been seeing him for six months. After the last visit, he suggested I come back within four months.*

That's an indicator that I'm not too happy about, and I guess I – he doesn't think I'm doing as well as he thought, but I'm out to prove him wrong because he is, and to – to achieve that objective, I will need to employ my own strategies to fill the gaps. Although I still have my moments, I focus on staying positive.
5 Dementia support programs leave gaps, as I said, and they are not 24/7. So I have to develop my own exercises and strategies that will fill my life with all the things that are good for me and others, hopefully.

For example, I do yoga three times a week. I use yoga to put me into another zone. It keeps my mind off negative things. I feel it is doing me good, I feel elevated when I finish the hour-long session. Yoga gives me an all-encompassing feeling of goodness. I do have good days and bad days. However, the good days are my own doing; they outnumber the bad quite significantly. I have managed to fill the gaps with things like golfing, sailing and doing other work for – and doing work for Dementia Australia. On my bad days, sometimes I don't even want to get out of bed in the morning. I get very bad tremors usually in my left hand and up to my elbow. If it's a really bad day, it might creep to the right hand. This does – this doesn't happen as often now that I am taking some medication.
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For about three years, I have been taking Aricept. Aricept works great for me. It's a breakthrough – breakthrough drug for times when – for the three years, anyway, of my usage. There are a few side effects. It is a – we have – there are a few side effects, but it's – I'm able to stall the symptoms by using Aricept, the symptoms of Lewy Body Dementia. It has put me in a better place and a better place than where I was previously. I experience clearer thinking, better memory retention, better social ability and more. With my medication, I am able to play a full round of golf. This is pretty important to me because I love my golf. It's something I look forward to every week. I'm not sure how long the drug will last. That is the million-dollar question at the moment.
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I also work as an advocate for Dementia Australia. As part of my advocacy work, I speak – I speak at – I speak at advocacy and engagement events. I also write about my life experiences as a person living with dementia and about how dementia changes you. I try to record my life and its – and its changes. In my case, Aricept has the ability – Aricept has the ability to fill my life with good things and has helped me delay the onset of dementia. I attach examples of personal pieces that I have written, and the details are here.
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Respite for support people:
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Jill has taken much – taken on much of the caring role since my diagnosis. Jill would say she has – she has enough support, but I would say she needs more. She is a real Trojan when it comes to that – that sort of – that sort of thing. She needs days off. She needs things like the Key Worker Program. We would say – she would say that she can't – she can handle everything, but she doesn't – she doesn't stop. Having a peer support program would make it easier for Jill. I'm sure there are lots of well-qualified nurses that would be able to help.
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There should be a squad of flying – a – a flying squad of nurses to go from person to person at home, doing the things that Jill does. Basically knocking on the door, giving the car keys to Jill, telling her to get out and enjoy the day, and give her some respite.

5

Research and policy:

I think that the future of dementia comes down to one key issue, research. I can't believe that – almost word for word on what Henry said, and yet we – so I gather he – it must be pretty close to the mark. Everyone knows someone with dementia. Everyone knows some person going through this hideous trial of waiting to see what's going to produce next. We know it's going to be ugly. I try and be as dramatic as I can when discussing dementia because it is dramatic. I want a cure. I want to be – to continue to live.

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In April 2019, I addressed a meeting with Aged Care Quality and Safety Commission. It was part of a group that updated the standards of – for aged care. The meeting included doctors, scientists, clinicians, nurses and hospital representatives. Early in my presentation, I said we must remember that this is all about me. There were 20 or so people in the room. I was the sole person there living with dementia. I hammered the point home as part of – as hard as I could. At the end of my speech, the chair said to me “Thank you for that. So we – so we don't forget – we so often forget about why we are in this room and what for and who benefits from it.” I felt my speech was quite a revelation for some of these people.

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Final comments here.

Being diagnosed with Lewy dementia – Lewy Body Dementia has impact on me in many ways. I miss the ability to read books. I concentrate – my concentration levels have worsened. There is no getting away from dementia. It is a cruel, ugly killer, lurking in the shadows of my life. It destroys the very fabric of humanity, the brain. Astoundingly, there is still a lack of understanding in the community of what dementia really is. This is frustrating to me, yet there are good things that have come from – or come into my life as a result of the diagnosis. Having dementia gave me new opportunities to do things, to meet – meet people – meet different people. I would have – I wouldn't have – I wouldn't have met these people if it hadn't been for the – if I didn't have a problem.

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The fact that I – that I have dementia has increased my quality of life, would you believe. It was helped by me – it has helped me face the evil monster and seek out the true priorities of life. I make time for my true friends and doing this – doing things that make me happy, spending time with my family and caring dear friends, golf, yoga, those I mentioned earlier, eating well, speaking out about dementia. I speak out about dementia and let people know there is no shame in having this diagnosis. I have – I have learnt the importance of family and happiness that comes from that. I'm a better person because of that. Life is an emotional roller coaster. It has required certain levels of bravery

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and committed management to ensure the appropriate direction is maintained. I want to get the most out of life by focusing on making tomorrow the best day of my life. Thank you.

5 MR BOLSTER: Thank you, Mr Crosby. There were a couple of questions I would like to ask you, if you don't mind. You mentioned in your evidence people in denial. What would you say to those people today?

10 MR CROSBY: The – pretty well quote from this document. There are bits and pieces in there that would answer that question pretty well. I know that's not the full thing. Just repeat it, please.

MR BOLSTER: No. That's - - -

15 MR CROSBY: That's adequate?

MR BOLSTER: That's good enough for me.

20 MR CROSBY: Okay.

MR BOLSTER: I've got another couple of questions though. For people who have a diagnosis and haven't had the sort of supports that you had around them, that perhaps don't know where to turn, don't know who to talk to, don't know who to call, where do you say they should reach out to?

25 MR CROSBY: Well, the system is set up and ready to – I mean, it has been running for ages, and that's the help line, Dementia Australia Help Line, 24/7. Very successful program, and that would be first port of call, and they will re-direct people as they – they see fit. Don't go and see your GP first, and probably – I don't think
30 anyone would go directly to a specialist, but I think that they should come – come in after the specialist – specialised people.

35 MR BOLSTER: Is there anything else that you would like to tell the Royal Commission?

40 MR CROSBY: Heaps. I could – I think there are research funding, relevant research funding because a lot of the – I sit on a couple of review panels. Would you believe they call them a customer review panels. I'm a person living with dementia, and they've called me a customer. So there are some things like that too that annoy the hell out of me.

MR BOLSTER: How should people refer to you?

45 MR CROSBY: Someone living with dementia. So other things there.

MR BOLSTER: What's the most important thing for the Commission to know?

MR CROSBY: I think the most important thing at this stage is to – well, two things. The cure. I won't see the benefit of a cure. That's out the window. What do I – what's next? Prevention. Each way, bearing in mind there's 100 plus variations of dementia, how are you going to solve all those in one hit? And to me, not enough
5 relevant research going into the cure which should be the prime objective of Dementia Australia, and it doesn't appear there in the mission statement, nor in their actions. So this Commission goes to another city; is that right?

MR BOLSTER: Yes.
10

MR CROSBY: Is there an - - -

MR BOLSTER: To all – effectively all the capitals and other cities as well, eventually.
15

MR CROSBY: Yeah. Is there an opportunity to submit mark 2 of – to add a few things as well?

MR BOLSTER: There certainly is.
20

MR CROSBY: Yeah. Okay.

MR BOLSTER: But is there anything else you want to say now?

MR CROSBY: I think that the job the Commission has, they might see it differently, but is to sort out the relevant – the relevant – I don't know if you had any suggestions yet how to fix – fix the – sorry. I'm not – sorry. How to – no, look, I might sit on that.
25

MR BOLSTER: All right. Commissioners, I formally tender Mr Crosby's statement. That's WIT.0142.0001.0001 dated 8 May 2019.
30

COMMISSIONER TRACEY: Yes. The statement of Trevor Douglas Crosby dated 8 May 2019 will be exhibit 3-82.
35

EXHIBIT #3-82 STATEMENT OF TREVOR DOUGLAS CROSBY DATED 08/05/2019 (WIT.0142.0001.0001)

MR BOLSTER: Those are my questions, thank you, Commissioner.
40

COMMISSIONER TRACEY: Mr Crosby, you may be aware of this, but purely coincidental, last night I was at a fundraising occasion for Neuroscience Australia in which hundreds of thousands of dollars were raised on the night for dementia
45 research. There is a lot going on out there, and hopefully it will be productive.

MR CROSBY: I do appreciate that and we, about 30 or 40 people more – or events like that to get some meaningful big number amounts into the system. Not – yes.

5 COMMISSIONER BRIGGS: Mr Crosby, you mentioned you come from Mudgee, which was where I was brought up. So I'm interested in hearing what you think about the range of services available in country areas for people with dementia, given that your evidence today says that you felt there was a need to move to the city.

10 MR CROSBY: Well, the gaps I referred to in the different education processes; they're all in the country. Give you an idea. Well, they're more than all in the – but that's where it is.

COMMISSIONER BRIGGS: Thank you.

15 MR BOLSTER: Thank you, Commissioners, might Mr Crosby be excused.

COMMISSIONER TRACEY: Yes. Certainly. Mr Crosby, thank you for sharing your journey with us and we're most grateful for the insight you've provided to us. And may I also extend our thanks to Mrs Crosby, who has obviously been a tower of strength for you and has supported you through your presence at this hearing. Thank you very much.

MR CROSBY: Thank you.

25

<THE WITNESS WITHDREW

[12.43 pm]

30 MR BOLSTER: Commissioners, there was a housekeeping matter that I needed to attend to. Earlier this week, Mr Farmilo – it's actually last week, Mr Farmilo made a second supplementary statement which has not yet found its way into evidence. Could document RCD.0011.0025.0001 be brought up, please. I tender that further statement dated 10 May 2019.

35 COMMISSIONER TRACEY: Yes. The statement of Mr Farmilo dated 10 May 2019 will be exhibit 3-83.

40 **EXHIBIT #3-83 STATEMENT OF MR FARMILO DATED 10/05/2019
(RCD.0011.0025.0001)**

MR BOLSTER: Commissioners, if it's convenient, it might be the time to take the luncheon adjournment, and we come back at quarter to 2.

45

COMMISSIONER TRACEY: Yes. Very well. The Commission will adjourn until 1.45.

ADJOURNED

[12.44 pm]

RESUMED

[1.50 pm]

5

COMMISSIONER TRACEY: Yes, Ms Hutchins.

10 MS HUTCHINS: Commissioners, I call our final witness for the Sydney hearings.
It's Ms Kate Swaffer.

<KATE SWAFFER, AFFIRMED

[1.50 pm]

15

<EXAMINATION BY MS HUTCHINS

20 MS HUTCHINS: Ms Swaffer, have you made a statement for the Royal
Commission?

MS SWAFFER: Yes, I have.

25 MS HUTCHINS: Operator, please bring up WIT.0127.0001.0001. Ms Swaffer, is
this your statement dated 16 May 2019?

MS SWAFFER: It does look correct.

30 MS HUTCHINS: And do you wish to make any amendments to the statement?

MS SWAFFER: Not at this point.

35 MS HUTCHINS: To the best of your knowledge and belief, are the contents of the
statement true and correct?

MS SWAFFER: Yes, they are.

MS HUTCHINS: Thank you. I tender that document.

40 COMMISSIONER TRACEY: Yes. The statement of Kate Swaffer dated 16 May
2019 will be exhibit 3-84.

45 **EXHIBIT #3-84 STATEMENT OF KATE SWAFFER DATED 16/05/2019
(WIT.0127.0001.0001)**

MS HUTCHINS: Ms Swaffer, you were diagnosed with a rare form of younger onset dementia at the age of 49. Before we turn to explore your personal experience in this regard I would like to touch on your professional experience in humanitarian work. What qualifications do you hold?

5

MS SWAFFER: I have a Master's of Science in Dementia Care which I received in 2014, I have a Bachelor of Psychology, a Bachelor of Arts, I am a retired trained nurse, not that it's particularly relevant, but a retired chef, and I'm currently doing research in universities.

10

MS HUTCHINS: And you are also currently the chair and chief executive officer of Dementia Alliance International.

MS SWAFFER: That's correct.

15

MS HUTCHINS: What is Dementia Alliance International, and what does your role there involve?

MS SWAFFER: Dementia Alliance International is an organisation that was set up five years ago in January by eight people with dementia – with medically confirmed diagnosis of dementia – from three different countries. We provide peer-to-peer support on an almost daily basis for members around the world. We've grown from eight members in three countries to members in the thousands representing currently 49 countries. We provide monthly educational webinars for people with dementia, their families and the wider community, including the dementia sector. We have online cafes and a whole range of other online and free services for people with dementia. So we set it up because the eight of us that set up Dementia Alliance International felt that we weren't receiving enough services or enough support, and we felt also that we often weren't given a voice at conferences, meetings and in places like, for example, today.

20

25

30

MS HUTCHINS: And in your statement, you set out a range of humanitarian work that you've been involved in. You've been the recipient of numerous national and international awards for your work in dementia. What global work are you involved in?

35

MS SWAFFER: The global work, it's really that started, apart from attending conferences, that began – I was an invited keynote speaker at the World Health Organisation First Ministerial Conference on Dementia in 2015, and from there I have been invited to speak at many organisations around the world. I am on a number of international expert or international working groups with the UN and the World Health Organisation amongst others.

40

MS HUTCHINS: I mentioned earlier that you were diagnosed with early onset dementia at the age of 49. What was that experience like?

45

MS SWAFFER: Being diagnosed with dementia at that age was number one, a shock because even though I had worked in dementia for a short period, I didn't realise that younger people were diagnosed with dementia. Certainly in my nurses' training I doubt that I had 30 minutes education on dementia, and in the seventies it was only known as senile dementia or pre-senile dementia, so very limited knowledge of dementia. I was not – I didn't have the usual experience of younger people of having to convince my GP to send me to a specialist. I was already seeing a specialist because of a brain malformation, so I had some changes in my cognitive capacity which I thought were a direct result of the brain surgery. That turned out to be this rarer young onset dementia. But it still took a couple of years for the diagnosis.

I wasn't referred to anybody for support back then. I probably, like Trevor Crosby mentioned earlier, I fell into a bit of a state of thinking there was no life ahead of me. I was advised to give up work, to give up study; I was a mature age student. To get my end of life affairs in order, and to get acquainted with aged care by going to day respite once a month to get used to it. So that was the advice, not of my neurologist. My neurologist did the diagnosing and most doctors generally just do the diagnosing, in my experience. But everyone around me, basically told me to give up my life and go home and prepare to die. And I think for the first 12 months I was probably spinning, thinking that that seemed an unreasonable group of – an unreasonable amount of advice, and I was lucky that I was a university student and I was talking to a lecturer one day and I said to her, everyone is telling me I have to give up study, it's too stressful for someone with dementia. And she said well, we have a full disability suite of services to support you. Go over and see them, we will need a letter from your doctor, we need some outline of the types of symptoms that you've got. We're going to treat them as disabilities because that's what they are, and I'm still being supported by the University of South Australia to continue studying.

MS HUTCHINS: Thank you. And just in relation to your study with the University of South Australia, operator, could you please turn to paragraph 118 on page 15 of Ms Swaffer's statement. So in this paragraph at subparagraphs (a) through to (i), you set out a number of services that have been provided to you. Can you explain to the Commission how important access to these types of services are to enable you to engage with university.

MS SWAFFER: Well, these types of services are not just imperative to engage with university. They're actually imperative to engage with living, so I termed what happened to me being only a pathway of deficits towards death, as opposed to being given disability assessment and advice towards continuing living. We're all going to die, whether we've got dementia or cancer or no illness. And to have a pathway that supported me to keep living Kate Swaffer's life was absolutely imperative and the health sector then did not do that, and I believe today still does not do that.

MS HUTCHINS: Operator, if you could please turn to paragraph 196 which is on page 23 of the statement, here you set out what you describe as the usual advice or

pathway that people receive. Could you explain what your observations are in relation to the usual experience of people when they are diagnosed with dementia?

5 MS SWAFFER: Well, this is what happened to me 10 or 11 years ago, and I feel I was lucky to get a diagnosis in the very early stages of the disease. Back then I wasn't referred to Dementia Australia. In fact, I was only referred to somebody about 12 months into my diagnosis because I had a friend who worked in aged care. I did attend a living with – it was called living with memory loss course back then which my husband also attended. However, we both feel that the course then caused
10 us to – it set us up to fail. It told me that I wasn't changing. It told him that I was changing, and it mostly talked about behaviours to expect and advised me to get my end of life affairs in order and to get acquainted with aged care.

15 When I eventually accessed services the only assessments I had really were to assess my activities of daily living and I had a shower rail put in, and a ramp for the front door for when I would need it. I still don't need either of them. I did need to have a driving assessment because I have an acquired dyslexia so I was going down one-way streets the wrong way and seeing red and green back to front which is not especially helpful at traffic lights. But not being supported to keep living is still
20 happening to members of Dementia Alliance International today. I have new members join DAI every week from all around the world and nearly all of the members report that that is still happening to them. They're supported to go home and die, not to live with dementia.

25 MS HUTCHINS: What do you think can be done better to support people at the point of diagnosis?

30 MS SWAFFER: Well, if I had had a stroke or a brain injury after a car accident, I'm almost certain, unless I was unlikely to recover at all, I would have been provided with intensive brain injury rehabilitation, and I would have – at my age, I would have been supported to stay at work with reasonable accommodations for any disabilities that I may have been left with. And that's what we need to do for people with dementia at the time of diagnosis.

35 MS HUTCHINS: In your statement, you refer to a term "prescribed disengagement", can you please explain to the Commission what you mean by that term?

40 MS SWAFFER: Well, I came up with that term sometime after my diagnosis because being told only to give up work, only to give up uni, only to get my end of life affairs in order and get acquainted with aged care was like a prescription for giving up life. Hence, I called it prescribed disengagement, and trademarked it. And I guess for most people with dementia, if you're lucky enough to be prescribed with something like Aricept which may slow the symptoms down but is not a disease-modifying drug, there is no cure, currently, for dementia and probably not one on the
45 horizon in my lifetime. I feel quite lucky that there is no medication for me because I think I would have sat back and done very little to improve my health, to change

my lifestyle and to get back to living. I think I would have sat back and hoped that the magic pill might work. So prescribed disengagement happened to me, and it is still happening for most people with dementia today, in my experience.

5 MS HUTCHINS: Do you think there is a stigma present in the care of people living with dementia.

MS SWAFFER: Stigma and dementia; that is such a hot topic. Definitely I experienced many forms of stigma. People with dementia even experience what's called self-stigma. There seems to be an obsession with cognitive capacity and when your cognitive capacity changes, I felt shame and embarrassment and humiliation for a couple of years, so that sense of self-stigma, not having the same functional cognitive capacity that I used to have, but stigma from others is still very, very prevalent in the community. The research data supports that. The anthropological evidence from members of DAI definitely support that. I see many examples of lots of different types of stigma, including economic stigma. I think being denied access to rehabilitation is stigma within the health care system.

20 Three or four years ago I recommended rehabilitation as one of the points to put into Australia's national dementia clinical guidelines, and they were left out. I was told that even though I had plenty of data to prove that rehabilitation for dementia was positive, it may not be a cure, but it definitely improves wellbeing and quality of life. Now those very same experts are lecturing and talking about rehabilitation for dementia. So I think that was stigma. I think that our attitudes to dementia are stuck in the last century. When I was first nursing we didn't see people with dementia until they were quite late in the disease process. So possibly things like rehabilitation and speech pathology and other forms of positive lifestyle, it may have been too late for people.

30 I'm pretty sure if I hadn't had speech pathology early on in the disease, that maybe coming to a speech pathologist later in the disease process may have been too late for it to be effective for me. So I think it's important that we develop a 21st century view of dementia particularly as the sector is aiming to diagnose people at a much earlier stage. So stigma for older people, dementia in Australia has taken over as the most feared disease for the over 65 Australians. In the UK, dementia is now the most feared disease for people over 40, and I think that has to be related to stigma and the fear of being – your family, a lot of family and friends don't engage with you as often as they used to before dementia. I've been treated – it's the only time in my life where I've felt what Dr Martin Luther King talked about, that sense of otherness, that sense of being a nobody, and having dementia has taught me deeply what that means.

45 MS HUTCHINS: In your statement, you touch on the notion that a person's goals for living are important in providing good dementia care. Where in the process should this be feeding in?

MS SWAFFER: Would you repeat the question, please.

MS HUTCHINS: Certainly. The question, I can rephrase it, is what role do a person's goals for living play in providing good dementia care?

MS SWAFFER: I think they're imperative but they're mostly being ignored.
5 Generally when a person with dementia is first diagnosed, often their doctor stops talking to them, stops looking at them – this is reported to me by Dementia Alliance International members regularly. The doctor or the providers only want to talk to another family member. I have many experiences of being at events where people will go up to my husband and ask him how am I doing, and when he says why don't
10 you go and ask Kate herself, they disappear. So I think there's a real stigma about not wanting to talk to people with dementia about what they want right on from the time of diagnosis and it's imperative. If you don't talk to people when they're first diagnosed, by the time they get to late stage dementia it's probably too late. And to expect children, for example, of an older parent to know what their parents really
15 like, they probably haven't lived at home for 40 or 50 years.

My – my needs and my likes and desires have changed fairly regularly over my life and I'm pretty sure my parents have, but I don't live with them and haven't since I was 16 and a half. So how can I rely on knowing what would be best for my parents,
20 and therefore how can somebody else know what's best for me. It's absolutely imperative that we engage with people diagnosed with dementia at a very early stage. In post-diagnostic support for people with cancer, often a palliative team moves in really quickly to support the person and their family. They are provided with counselling and, in my experience, they are also provided with a biography service.
25 That would be a really useful additional service for people newly diagnosed with dementia.

MS HUTCHINS: And in relation to the needs of families, or loved ones involved in the care of people living with dementia, what type of needs or supports do they –
30 should be addressed for them?

MS SWAFFER: I – Dementia Australia provides some services for family care partners or families, some education and, as Trevor Crosby said, for a period of time he got a lot of good support but then that fell off because Dementia Australia – or it
35 used to be called Alzheimer's Australia – they're having to deal with people being newly diagnosed regularly. So they can't look after the 440,000 plus in Australia. We need more people to do that, more providers. Could you repeat that question because I've lost my train of thought.

40 MS HUTCHINS: No, that's okay. I think you've answered it sufficiently and it leads me to my next question which is - - -

MS SWAFFER: I wanted to add what's missing.

45 MS HUTCHINS: Certainly.

MS SWAFFER: For – I think that families are left without adequate education, one, on dementia and, two, on how to support a person with dementia as the disease progresses in the ways that Professor Brodaty talked about, in all of those non-pharmacological, psychosocial and disability interventions that could help a person remain independent for much longer, and I suspect a lot of the anxiety and apathy and perhaps anger that people may express are just a basic human response to being, one, having a diagnosis of dementia, and, two, people around them not knowing how to either communicate with them or adequately support their needs. So families need a lot more support.

10 MS HUTCHINS: And what do you think could be done to assist and support people with younger onset dementia to continue to live in the community?

MS SWAFFER: Well, depending on the progression of the dementia, when one – a person is diagnosed, and for younger people often we're diagnosed earlier in the disease process, we should immediately be given some disability assessments and reasonable accommodations to stay at work if we so wished. It's quite clear now – it wasn't at the beginning to me, I thought I was going to progress really quickly, that's what everyone told me. But it is clear now that with adequate disability assessment and support, which because dementia is a terminal progressive chronic illness, does need to be re-assessed quite regularly, that would be much more proactive and productive for people to live meaningful lives to them, and remain independent for longer, instead of being told to just get their end of life affairs in order and go and play golf or take up painting.

25 MS HUTCHINS: Thank you. I would like to turn now to the topic of dementia care in residential aged care facilities. What do you think are the key quality and safety issues for people living with dementia in residential aged care?

MS SWAFFER: I'm not sure I feel equipped to talk about the key quality and safety issues. What I feel needs to be said is that we have people living in aged care facilities who generally don't want to be there. It's not – they're not treated like it's their home. They're locked in. They can't get out into the community. They're rarely taken out into the community. And a bus trip every two or three months around the block or around the golf course, where you don't even get out to the coffee shop, is not access to the community. Risk assessments, of course, aged care providers have all these compliance issues that they have to deal with, and that is clearly important but a person's freedom to take risks shouldn't be negated once they live in a – in an aged care facility.

40 I have as much right to take a risk now that I have dementia as I had before I had dementia and there's very few examples in my experience of going into aged care facilities of where I would want to live. I would rather die being hit by a bus on the highway than go and be locked in a dementia facility.

45 MS HUTCHINS: Operator, please go to paragraph 201 which is at page 24 of the statement. Here, Ms Swaffer, you include a list of what you think people living in

residential aged care facilities want. Which of these matters do you think are the most important?

MS SWAFFER: Am I allowed to say all of them.

5

MS HUTCHINS: Certainly.

MS SWAFFER: I think I – I've done a number of focus groups and interviews over 12 to 18 month period with Associate Professor Lee-Fay Low for a book that we wrote called Diagnosed with Alzheimer's or Another Dementia, and it was really the book that I wanted when I was first diagnosed, instead of lots of loose help sheets that I no longer have the ability to file. I wanted one book that could tell me about dementia, that could tell me what to expect, that could direct me to services and that could also tell me about end of life issues. So we did these interviews and the people coming into aged care now are going to be baby boomers, and unlike the older generation like my parents who are unlikely to make a complaint to their doctor or to an aged care provider, people my age and probably most people in this room, if they were admitted into an aged care facility and didn't like it, they're probably going to complain or a family member will. So my father-in-law lived in two different aged care facilities and, my witness statement, I dedicated to my father-in-law who had Lewy body dementia and a young friend with vascular dementia, both who received quite devastating care in royal aged – in aged care facilities. They were denied exercise; they were denied decent food; they were denied access to outside spaces. They both lost 15 to 18 kilos within a few months of entering aged care. They were denied access to go outside into parks or listen to birds. They were denied all of these things on this list.

MS HUTCHINS: And how important is consideration of the features of the built environment for people living with dementia in residential aged care?

30

MS SWAFFER: Well, I think that the built environments, what we've been used to, nursing homes, were – generally, the design of them is based on hospital care. It was a very medicalised view of supporting people in aged care and/or with dementia, and – and then when I first started working in the city in Adelaide, I worked in an aged care facility and, quite ironically, worked in the first dedicated dementia unit in South Australia. So at the time, I thought that was a quite positive step from people being shackled to beds and chairs, but, really, we went from that to people being incarcerated, in my opinion.

40 And as Professor Brodaty said, we can't just lock people with mental illness away in secure units or institutions now without going through a whole range of legal sanctions and, yet, for the last 30 or 40 years, we've been locking people who need assisted living support, either with or without dementia in actual fact because, in the first facility that my father-in-law lived in, even though it was a low care, he couldn't get out the front door. So we've taken to thinking it's okay to incarcerate people for getting old or for having dementia. I'm not sure if I – I answered your question - - -

45

MS HUTCHINS: No, you certainly have.

MS SWAFFER: - - - because I forgot the question.

5 MS HUTCHINS: You have. Thank you. What approach do you think needs to be implemented by residential aged care?

MS SWAFFER: I think we need to move away from institutions and we need to move away from segregation. They are a breach of human rights in every sense of those words. The CRPD clearly talks about – many of the articles of the CRPD support that. We need – Group Homes Australia is a very good example. Alzheimer’s Western Australia have a dementia enabling household model of care which I know is not residential facility, but a really, really positive way of supporting people with dementia. One of the unique things that they do when they employ staff is that they actually also look for people with high emotional intelligence, and that’s, for them, has been one of the unique, but important parts of achieving what they’ve achieved in Western Australia.

There’s another facility, I think it’s an Anglicare facility, where they’ve stopped having any locked doors and they’ve done that very successfully. The Commission should look to those places. Gallipoli Home in Australia – in Sydney, rather – I think it’s at Auburn. They now don’t have a secure dementia unit. They’re actually – their food is so good there it was featured on Food Safari by – as a restaurant in Auburn and, by the way, the restaurant is in an aged care facility. So we need those types of things. We need – the built environment is really important and, you know, in later stage dementia when, perhaps, someone can’t recognise a toilet only because the whole bathroom is white. So it’s not – they’re not going to the toilet in inappropriate places because they want to. They can’t actually see the toilet. So there’s some really, really simple design principles that we need to put into any aged care facility that currently are freely available, but to my knowledge, less than 50 per cent of new aged care builds use those guidelines.

MS HUTCHINS: And what are some other features of good group home models?

35 MS SWAFFER: Well, I have visited Group Homes Australia in Sydney. I’ve been to a number of their sites. What I really like about those facilities is they look like home, they smell like home. They have double beds. They almost all have ensuite bathrooms. Now, a double bed is really important. I haven’t slept in a single bed since I left home at the age of 16 and a half. Why would I want to go and sleep in a single bed now? I definitely don’t want to. I believe that if I needed to go into assisted living, if I – I’m not 100 per cent sure, but I believe that if I needed to go, I would choose Group Homes Australia probably, and my husband, I think, could live there with me until I died.

45 Now, that really is relationship, person-centred care. They do have their front door locked, just the same as I do at home because I don’t want strangers coming in, but people have access to the outdoors all of the time. The times that I’ve been there,

many – and they have a limit of how many residents live there. Something between six and 10, I think, is their maximum. Many of the residents are out doing activities in the community. So the first time I went to visit them, there were family members there waiting for the residents to come back from community activities. That’s what I would want if I was living in a nursing home.

MS HUTCHINS: And in relation to institutional-style models, what are some features of those models that are a cause of concern?

MS SWAFFER: Well, I think, historically, if we look back to orphanages, we shut down orphanages in Australia and in other developed countries decades ago, and one of the reasons we did that was because we started to understand that institutions encourage poor care. Institutions for people with dementia and people who are older and need care have – as this Royal Commission has highlighted, well and truly, the examples of poor care around Australia. We should be ashamed that we’ve let this happen and institutions are part of the problem because it’s easy to understaff institutions.

If you’ve got a small group home with a half a dozen people living in it and you only – it’s very easy to have adequate staff for people to be enabled to have a good quality of life. Where my father-in-law was, often, overnight, they had one or two staff for the whole facility overnight. So if they were busy helping somebody else, there was nobody else for the other 150 residents there, and there’s funding issues with – I know that aged care providers have all sorts of compliance and funding issues, but the understaffing, the under-education is – I absolutely believe the under-education is human rights issue.

MS HUTCHINS: I would like to turn now to the advocacy work you have done and to the work of Dementia Alliance International. I understand that DAI was – you cofounded it in 2014. What were the primary reasons for its establishment?

MS SWAFFER: Well, the primary reasons were for us to have an authentic voice, and to be included, and even, most often, being included still means self-funding inclusion, particularly around the world, and to provide services for each other and, specifically, peer-to-peer support and advocacy. So we felt that – and I still believe that people with dementia don’t get enough services. I could direct you to a number of websites around the world in rich developed countries where you will see a peer-to-peer support group or a support group for family carers, but you won’t see any support groups for people with dementia.

So DAI provides them, almost seven days a week around the world, for free, and that’s a really, really important service that we provide that we have minimal funding to do that. We are often told by people who attend and – yes, they’re only online, but we don’t have funding for an office, let alone to have face-to-face, peer-to-peer support, but we have people who have been diagnosed for one year, two years, 10 years who say it’s the first time they’ve smiled or laughed since their diagnosis. So I see that as the most valuable thing I could do with the rest of my life.

MS HUTCHINS: Do you think the voice of people living with dementia is adequately heard and addressed in current government policy?

MS SWAFFER: Absolutely not.

5

MS HUTCHINS: Why is that?

MS SWAFFER: Well, I am here today and Trevor Crosby was here today, but DAI, for example, is almost never consulted by government for the – to be included or for the voice of the broader group of people with dementia in Australia. Of course, Dementia Australia represent us and our families, but their brief is not specific and exclusive to people with dementia. Dementia Alliance International is not influenced by anybody else's agenda. We're not influenced by what funding or getting funding because we don't have very much funding. We really are an authentic voice, and we're not out to make friends. We're out to try and change the world.

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MS HUTCHINS: And how do you think input from advocacy groups such as DAI can improve dementia care experiences and standards?

MS SWAFFER: I think that we have to highlight what's missing, and what's missing is universal health coverage for people with dementia. What's missing is appropriate post-diagnostic support which includes rehabilitation, which includes disability assessment and supports, which includes – should include rehabilitation. There's no funding for people to have speech pathology at the time of diagnosis. The only time that there is funding for a speech pathologist for people with dementia is when they're closer to death and can't swallow.

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Frankly, from my position, that's far too late. So for all of the rehabilitation services that I've self-prescribed and have a neuro-physiotherapist and others that now support me with that, if I didn't have the funds to support that, I possibly would be dead as was predicted when I was first diagnosed. So we have a healthcare system that is setting people with dementia up to become dependent on their families and, therefore, dependent on the health care sector and government. We are setting people up to have a low quality of life, to become independent and to fail, basically. To go home and die. That's what we're telling them to do, and we need to change that.

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MS HUTCHINS: I would like to turn next to the topic of human rights which you set out in some detail in your statement, and I would like to take you to some matters now. What human rights risk do you think Australians living with dementia face?

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MS SWAFFER: Have we got a week? I think that the fact that lots of doctors don't want to even tell a patient they've got dementia. That's a breach of human rights. Imagine if we didn't tell a patient they had cancer. The fact that we don't immediately get referred to disability assessment and support for acquired cognitive disabilities. That's a breach of human rights. The World Health Organisation clearly states on their website that dementia is a – one of the major causes of disability and

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dependence globally for older persons, and yet no sector that I know of is helping managing people with dementia as people with acquired cognitive disabilities. We have a human right to disability support and that is not being provided.

5 MS HUTCHINS: Yes. In your statement, you refer to the World Health Organisation's global action plan on the public health response to dementia 2017 to 2025, dementia action plan. In broad terms, what is this document and what does it seek to achieve?

10 MS SWAFFER: In broad terms, I – I think the document is really – it's meant for guiding policy at government level and at organisational level. There are seven action plans within that document. I don't agree with all of them, but I do agree with most of them. I would have to go to my notes to be able to remember them. Sorry. I – shall I do that perhaps?

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MS HUTCHINS: Certainly. That would be helpful.

MS SWAFFER: Thank you. So the – I haven't spelled it out in my statement, but this global dementia action plan was put together in, actually, record time for a
20 national – international agency, and it does aim to improve the lives of people living with dementia and our families, and also to decrease the impact of dementia on communities and on countries. It was unanimously adopted at the World Health Assembly, coming up for two years next week. The World Health Assembly is in Geneva next week, and it provides a set of actions towards dementia risk reduction,
25 and that people with dementia and their families receive the care and support they need to live with a high quality of life. So - - -

MS HUTCHINS: What are the key action areas in the document that you would like to see implemented in Australia?

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MS SWAFFER: All of them. I'm sorry. I haven't got them listed here, so I can't be specific. I would like them all to be – in fact, from my knowledge of the document, from my memory of it, the only countable parts of this global action plan on the public health response dementia are the cost cutting principles that relate to
35 human rights. The rest of it is a bit of a feel good document. It's aspirational, but probably not able to be – make governments accountable, but we really do need governments and dementia organisations to embed human rights into policy and programs. It's imperative.

40 MS HUTCHINS: Thank you. Commissioners, that document is already in evidence at exhibit 3.41. The next document I would like to go to is the World Health Organisation document which is titled Guidelines on Risk Reduction of Cognitive Decline in Dementia. Operator, this is document RCD.9999.0063.0001. So, again, in broad terms, what is this document and what does it seek to achieve?

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MS SWAFFER: I've read it very briefly because it has only just come out, but I've been a member of the World Dementia Council for some years now, and when the

World Dementia Council first was developed, their only brief was to increase funding for research for a cure. They now have five domains that they focus on, and one of the World Dementia Council's briefs is risk reduction for dementia, as is the World Health Organisation now and, from my perspective, that's completely in line with risk reduction for other chronic diseases. So a lot of the risk reduction evidence is – would be similar to risk reduction for heart disease or risk reduction for diabetes or risk reduction for other serious chronic illnesses.

Similarly, if we can create communities who are focused on – and governments who are focussed on risk reduction in the same way that we did – and Australia did it really well in reducing rates of smoking to reduce rates of things like lung cancer and other diseases that are attributed to smoking, we have a much better chance of reducing the incidents of dementia, and some countries and organisations talk about it as prevention. I think that's completely idealistic. We haven't prevented cancer yet, but if we can reduce the risk of dementia, we not only reduce the risk of dementia.

Most of the same lifestyle changes that risk reduction of cognitive decline and dementia go hand in hand with reducing the risk of all of the other diseases, non-communicable diseases that we talk about. So it also is quite well aligned to some of the emerging research into reversing dementia and early stage dementia and mild cognitive impairment which is coming out of the United States, and there's two or three different researchers there who have had some quite good small cohorts of reversing MCI and early Alzheimer's. It's very similar to the risk reduction evidence that's coming out now.

MS HUTCHINS: Are these guidelines something that you would support or encourage government to have consideration to in the development of policy?

MS SWAFFER: I very strongly support a risk reduction policy for cognitive decline and dementia. Healthy heart, healthy brain, it's – I mean, we're all interconnected. Of course we need to support this, and there's 50 million people estimated to be living in the world currently with dementia. There's a new diagnosis somewhere in the world every three seconds. There's apparently a new diagnosis in Australia about every – well, 1800 a week so I'm not sure how many that is, one every six minutes, that's a lot of people predicted to have dementia. Currently there's no disease-modifying drugs and no cure. We want afford not to do that, not only from a human cost perspective but from a government economic perspective, we must reduce the risk.

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MS HUTCHINS: Commissioners, I tender that document.

COMMISSIONER TRACEY: Yes. The World Health Organisation guidelines entitled Risk Reduction of Cognitive Decline and Dementia will be exhibit 3-85.

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**EXHIBIT #3-85 WORLD HEALTH ORGANISATION GUIDELINES
ENTITLED RISK REDUCTION OF COGNITIVE DECLINE AND
DEMENTIA (RCD.9999.0063.0001)**

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MS HUTCHINS: Your statement refers also to the United Nations Convention on the Rights of Persons with Disability and Optional Protocol. Operator, please bring that document up which is RCD.9999.0061.0325. Again, Ms Swaffer, in broad terms could you explain for the Commission what this convention is and how it's relevant for people living with dementia in Australia.

MS SWAFFER: This document is relevant for people living with dementia all around the world. The fact that the WHO states clearly on their website that dementia is the leading cause of disability and dependence means that as human beings with acquired disabilities we have exactly the same rights as every other person with a disability, whether they're born with a disability or whether they acquire a disability through a disease or through ageing or through a road accident. So we have the same right to equal recognition before the law, for example, to non-discrimination, to full and adequate universal health care which we don't currently get.

We have the right to living independently and being included in the community and, yes, I absolutely acknowledge that there is a time as dementia progresses, people do need to be assisted to live, either in a facility or at home, but I do believe as a society we need to find better ways to support people to live independently in their own homes because almost everybody I've ever talked to says they want to die at home. And the one gift that I was able to give, or we were able to give my mother-in-law with cancer who, by the way, you know if you get diagnosed with cancer, everyone races to help you. If you get diagnosed with dementia, almost everyone runs away, but my mother-in-law with cancer was provided so many in-home services and supports that we were able to support her to die at home. That is the greatest gift we can give any member of society. And to be able to do that with other people with other terminal illnesses means we must start to find ways to do that for people with dementia.

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MS HUTCHINS: And do you think that staff of government and providers and medical professionals have a good understanding of documents like this and the ones that I've taken to you previously?

MS SWAFFER: To be honest I – I'm still questioned about whether people with dementia are people with acquired disabilities, a lot of people have never heard that. I regularly hear from government officials, aged care providers, medical professionals, dementia experts who've never heard of the World Health Organisation global dementia action plan. They have never associated the fact that people with acquired disabilities have the same rights as anybody else, from the CRPD. There's a real disconnect about dementia as a disability and the rest of society.

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MS HUTCHINS: Commissioners, I tender that document.

5 COMMISSIONER TRACEY: Yes. The United Nations publication entitled
Convention on the Rights of Persons with Disabilities and Optional Protocol will be
exhibit 3-86.

10 **EXHIBIT #3-86 UNITED NATIONS PUBLICATION ENTITLED
CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND
OPTIONAL PROTOCOL (RCD.9999.0061.0325)**

15 MS HUTCHINS: Thank you. Ms Swaffer, what observations could you make
about changes that would be necessary, or required to the current system in order to
facilitate a greater human rights emphasis?

20 MS SWAFFER: Well, I think if we think about some of the media and some of the
other witness statements that – I haven't heard them all, but you probably have – it's
very clear from witnesses that people living in residential aged care facilities around
Australia have not been free from torture or inhumane degrading treatment. They are
not free from being locked up. This is happening around Australia on a regular basis,
even during this Royal Commission. And, you know, frankly, I feel that one day my
grandchildren or my great grandchildren are going to demand a Prime Minister or if
25 we change to a republic, a president to say sorry for the way we've treated people
with dementia and our frail elderly who need to have assisted living.

MS HUTCHINS: Ms Swaffer, do you have any other matters that you would like to
bring to the attention of the Commission that you could address for them today?

30 MS SWAFFER: I – I think there's a couple of things that I would like to add. I
guess I – there's a lovely quote that I think fits well with the Commission – the Royal
Commission. Safety is what we want for those we love, autonomy is what we want
for ourselves. So we need to work more towards autonomy for everybody, including
those living in residential aged care. Unlike others, I am a lot less worried about
35 finding a cure. We haven't found a cure yet for most cancers or most other diseases.
We may have got rid of polio and one or two, but we haven't really found a cure for
too many things in the world yet. I would really like a balance of research that, yes,
we must keep researching for a cure, of course, but we must do more research for
improving care.

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45 This Royal Commission is making it very clear that the care of people living in
residential aged care facilities is predominantly very poor care, and especially for
people with dementia. I think that the sector and that governments have been taking
really, really expensive bandaid approaches to fixing the problem, instead of fixing
the root cause of the problem. If we don't fix the root cause which is increased
diagnosis rates and then change what happens at the time of diagnosis to enable

people to live more independently for longer, then everything we do after that is a very expensive bandaid.

5 MS HUTCHINS: Thank you. I have no further questions for this witness.
Commissioners.

COMMISSIONER TRACEY: Ms Swaffer, thank you again for your contribution to the work of the Commission. Your insights are deep and we greatly appreciate them.

10 MS SWAFFER: Thank you.

COMMISSIONER TRACEY: You're excused from further attendance at this hearing.

15 MS SWAFFER: Thank you.

<THE WITNESS WITHDREW [2.44 pm]

20 MS HUTCHINS: Commissioners, that concludes the evidence for the Sydney hearings. Mr Peter Gray QC has prepared a closing address, and if it should be convenient for the Commissioners, may I suggest a short 15 minute adjournment before that occurs?

25 COMMISSIONER TRACEY: Yes, very well. We will adjourn for a short time but if you would arrange for our associate to be told as soon as Mr Gray is ready to commence.

30 MS HUTCHINS: Thank you.

COMMISSIONER TRACEY: Very well.

35 **ADJOURNED [2.45 pm]**

RESUMED [3.00 pm]

40 COMMISSIONER TRACEY: Yes, Mr Gray.

45 MR GRAY: Thank you, Commissioner. By way of a brief closing address, I intend to outline how this hearing proceeded, and in doing so to mention a selection of the themes that have emerged from the past eight hearing days of the Royal Commission. As I mentioned in my opening remarks, the subject matter of this hearing has been residential aged care, with a focus on the care of people living with

dementia. This hearing has built upon the evidence in previous hearings relating to these themes. In particular, the Commission heard in Adelaide hearing 1 from the CEO of Dementia Australia, Ms Maree McCabe. The body of evidence received during this hearing has been vast and complex. Over the coming weeks the staff of the Royal Commission will be analysing this material closely.

I will not attempt to do so in any great depth now. However, this much is clear: the constant theme that emerged from the witnesses in this hearing was the need to respect the enduring humanity of the people in care, no matter how far their cognitive function might have declined and no matter how challenging it might seem to be to care for them. Older Australians who move into residential care do not leave their rights at the door of the facility and a resident living with dementia is entitled to respect and dignity and the freedom to live their life as they choose to the greatest practicable extent, as much as any other human being.

The progression of the disease can leave the person without the power of communication and in a position of extreme vulnerability; all the more reason for care and respect to be accorded them. In this hearing, witnesses have told the Royal Commission of the extent to which those rights are honoured and needs provided for in residential aged care in some ways, and in some cases, or neglected in others, and their evidence has furnished insights into the reasons why this is happening.

The structure of the hearing which has just concluded was as follows. The Royal Commission heard the accounts of residents in two different aged care facilities, Ms Darryl Melchhart and Ms Merle Mitchell AM about their experiences and impressions in residential aged care. The Commission heard from Mr George Akl and Ms Dilum Dassanayake. Mr Akl gave evidence about his father who comes from an Egyptian background and is living with Lewy body dementia. Mr Akl's father became more connected to his culture as his dementia progressed, including through language. Mr Akl found it difficult to find a facility that adequately catered for his father's needs.

Ms Dassanayake gave evidence about her mother who comes from a Sri Lankan background of Sinhalese heritage and who is living with Alzheimer's disease. Ms Dassanayake told the Royal Commission about a range of matters relevant to the quality of her mother's care across three facilities as well as the importance of culture and care that is sensitive to culture. These accounts all provided rich insights into experiences of those in the residential aged care system. The accounts of Mr Akl and Ms Dassanayake provided an entry point for the hearing into complexities and challenges and the sheer humanity of the journeys of people when they are living with dementia.

Evidence was then heard in a series of four case studies involving claims of substandard residential care made by close relatives of four residents. The first of these case studies related to the experiences of Mr Terance Reeves during a period of residential respite care at Garden View Aged Care. The second related to the experiences of a woman given the pseudonym CO at Brian King Gardens, a facility

operated by Anglicare. The third related to the experiences of a woman given the pseudonym CA at Oberon Village, facility operated by Columbia Nursing Homes. The fourth related to the experiences of a woman given the pseudonym DE at a facility at Willoughby operated by Bupa Aged Care Australia, and the experience of her daughters in connection with DEs end of life care.

As I foreshadowed at the commencement of this hearing, we will not make closing remarks about the findings sought in those case studies at this time. The findings we seek in those case studies will be set out in four sets of written submissions to the Commissioners, one for each case study. We expect to have completed those written submissions by Wednesday, 29 May and we will shortly be seeking directions from you to that effect. At the same time as we provide those submissions to you, Commissioners, we propose to provide them to affected parties who have obtained a grant of leave to appear. We propose that those parties should have one week to lodge their own submissions in relation to the case studies, and then any of those parties wishing to reply to those submissions and counsel assisting will have a further three business days to do so. The submissions in question will relate to each particular case study respectively.

The evidence on which those case studies will fall to be determined will be the tendered documents in each case study and the oral evidence that was heard in that case study and will not extend to any other observations that might have been made by witnesses later in this hearing. We propose that parties with leave to appear have one week, as I said, to provide submissions in response to our submissions, and I will return to those directions in a few minutes when I conclude these remarks. The role of care staff in residential care is all important.

Separately from the case studies, last week the Commission heard the harrowing account of Ms Kathryn Nobes, who as a staff member of a residential aged care facility, was present at the facility at the time of a grave incident of resident on resident violence leading to a death. Over much of the rest of this week the focus of the hearing turned to experts in the field and to the government perspective on dementia and residential care. Mr Glenn Rees, chairman of Alzheimer's Disease International provided the perspective of the peak global advocacy body supplementing the evidence which was received by the Royal Commission in February from the CEO of Dementia Australia. Mr Rees outlined key areas requiring urgent attention and was critical of the Australian Government's progress on national action on dementia on a number of fronts.

An informative panel session on innovative models of care for people living with dementia in various residential settings then followed. The panel consisted of Tamar Krebs and Jonathan Gavshon of Group Homes Australia, Jennifer Lawrence of Brightwater Care Group, and Lucy O'Flaherty of Glenview Community Services, Tasmania. This panel painted a picture and set a benchmark for what can be achieved by way of good care for people living with dementia. Amongst many insightful points that were made, we note the evidence that the built environment should be enabling and engaging and safe and familiar.

Building design should readily permit access to outdoor spaces and those spaces should include purposeful routes for walking; it should reduce where possible barriers to free movement. A person's room might promote positive reminiscence through, for example, family photographs, books or other items. Those items might
5 also help the person to identify the room as their own. Disturbing stimuli for people living with dementia, whether noise, light or smell, should be reduced. Colours and textures on wall and floor coverings and points of reference should promote wayfinding for them. A home-like environment with familiar furnishings, together with smaller scale and lower density living arrangements is preferable.

10 Lighting can also be used to give people with dementia a sense of time of day. Staff employed to work in facilities catering for residents with dementia need to be empathetic, and must be appropriately trained to provide person-centred care. This evidence was supported by the other expert evidence during the second week of this
15 hearing. The next panel comprised four eminent clinicians, all experienced in critical aspects of caring for ageing Australians with dementia. Professor Dimity Pond is an educator of general medical practitioners in good dementia care, Professor Elizabeth Beattie is an educator of nurses in dementia care as well as having a broad and varied research background into multiple areas of dementia care.

20 Dr Peter Foltyn is an experienced dentist and hospital visiting dental officer with particular expertise in dental and oral health care for older Australians, and Associate Professor Lynette Goldberg is a speech pathologist and educator in the care of people living with dementia at the Wicking Dementia Research and Education Centre,
25 University of Tasmania. The panel as a whole provided many insights into the complexity of providing clinical nursing, personal and allied health care for people living with dementia. For the purposes of raising issues for expert comment, we, the counsel assisting team, prepared four scenarios comprising assumptions reflecting the issues which we saw as arising from each of the case studies that had been heard.
30 Those scenarios did not name the approved providers.

They were provided to the experts who gave evidence this week. None of the opinions expressed by the witnesses on those scenarios will be relied upon in any way to invite findings to be made in the case studies themselves. The scenarios were
35 put to the witnesses to prompt observations about issues which appear to arise in relation to dementia and residential care. Commissioners, I refer again to the four case studies you heard. To be clear, we do not propose to rely on any of the opinions expressed by experts in relation to the scenarios for the purposes of your findings in the case studies. We ask you, Commissioners, not to take any such observations into
40 account when you come to make your findings in the case studies in due course.

The third expert panel comprised staff and former staff of residential aged care facilities: a registered nurse, Elizabeth, two assistants in nursing Suzanne Wilson and Susan Walton and Margaret, or Maggie Bain, a retired diversional therapist. The
45 panel provided a range of views drawn from years of experience in the system, some of it confronting. The Royal Commission heard from three of the foremost experts in Australia in research into dementia and into measures taken in residential care in

response to behaviours seen as challenging. Dr Juanita Westbury gave detailed evidence as to the overuse of psychotropic pharmaceuticals in residential aged care, available measures for de-prescribing, and the persistence of restrictive practices based on the use of psychotropics in the aged care system.

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Professor Joseph Ibrahim gave passionate, thought-provoking and wide-ranging testimony as well as providing a very detailed statement relating to risk factors for residents in care, with a particular emphasis on the challenging nature of providing proper care to people living with dementia while affording them choices as to how to live the remainder of their lives including the important principle of dignity of risk. Scientia Professor Henry Brodaty AO is the elder statesman of dementia research in Australia and a scholar of international renown. His evidence rounded off the expert clinical evidence with emphasis on the imperatives of person-centred care and non-pharmacological interventions in caring for people expressing behaviour considered to be challenging, the so-called behavioural and psychological symptoms of dementia.

Associate Professor Stephen Macfarlane of HammondCare explained that the services provided by Dementia Support Australia, that is DBMAS, Dementia Behaviour Management Advisory Service, and SBRT, the Severe Behaviour Response Teams. Both of these services have been positively evaluated and are important resources available to residential aged care providers. Commonwealth officers also gave evidence, relating to policy on dementia care and related topics, including recent amendments to the Quality of Care Principles 2014 that will explicitly regulate the use of restrictive practices in aged care. The Chief Medical Officer, Professor Brendan Murphy, discussed the clinical consultation that occurred in the lead-up to the making of those amendments as did assistant secretary, Amy Laffan, of the Department of Health. Christina Bolger, executive director of the Aged Care Quality and Safety Commission gave evidence about the Commission's perspective on the content of the amendments during their development and on the approach the Commission is likely to take in relation to compliance by approved providers with standards relating to care for people with dementia. Assistant secretary Josephine Mond spoke of dementia policy development within the Department of Health.

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The hearing concluded today with the accounts of two people living with dementia, Mr Trevor Crosby and Ms Kate Swaffer. Ms Swaffer also spoke as an advocate for the rights of people with dementia and as CEO of Dementia Alliance International. Mr Crosby's account was brave and inspiring. He has hope for a cure and emphasised the need for research. He urged people not to live in denial, to seek a diagnosis and obtain access to support. He told the Royal Commission that while his diagnosis has been challenging, there were good things that had come into his life as a result.

45 Both Mr Rees and Ms Swaffer reminded us of the importance of the human rights perspective on the ways the aged care system has treated and is treating people who are living with dementia. The disparities between levels of subsidy and support

available to those who are diagnosed with dementia after turning 65 or after turning 50 for Aboriginal and Torres Strait Islander people on the one hand, and those who can access the NDIS if they become disabled with dementia prior to that age are stark and seem discriminatory. Without attempting to be exhaustive, I will now mention
5 five lasting impressions from the evidence.

Firstly, attitudes encountered in residential care and the need for respect and de-stigmatisation. We were privileged to hear directly from two older Australians who are living in residential aged care, Ms Melchhart and Ms Mitchell explained the
10 impacts of the residential aged care environment on their dignity, choice and independence. Ms Mitchell referred to the shock of loss, loss of your way of life, finding herself suddenly in an institution without choice of activities, including when to get up or when to eat. She did not regard residential aged care as her home and said:

15 *That there's just that feeling that this isn't a proper life. And so there is that feeling that the quicker it's all over, the better it is for everybody.*

Ms Mitchell added that even though the aged care facility was where she lived, it's
20 not home. Ms Melchhart's evidence was to similar effect. She described her experiences in residential care as a never-ending battle to be seen as a fully competent adult and stated that her wishes for autonomy and privacy were often disregarded by staff. This is deeply disturbing. The clear implication of this evidence is that irrespective of whether one has dementia or is functioning at the
25 highest levels of cognition and articulation, ageing itself attracts poor attitudes and threats of denial of personhood in the residential aged care system. One can only begin to imagine the stigmatisation and deprivation of dignity inflicted on those in the system diagnosed with dementia.

30 We heard indirect evidence from close family members of a number of residents. Ms Dilum Dassanayake gave evidence about her mother, she said that at one aged care facility in which her mother had previously lived, the manager had said that they weren't set up to deal with dementia. That same person had said to Ms Dassanayake in front of her mother that, "She's demented. She doesn't understand what we're
35 saying." It's integral to the work of this Royal Commission to call this out for what it is: a denial of the humanity of our fellow human beings.

Next, in terms of impressions from the evidence, the clinical consensus supports person-centred and relationship-based care. The professional nursing staff of
40 residential care facilities are leaders in the standards of care provided and have the weighty responsibility of creating, sustaining and monitoring what Professor Beattie called the milieu of care. And, in this regard, person-centred, interdisciplinary, evidence-based professional nursing practice is essential. Professor Beattie said:

45 *I think this is really about enriching the environment within which a person is looked after and person-centred care was really first talked about by Kitwood*

in the mid-1990s, and it really points us all to the essential person who is within all of us.

5 And what is it that is unique about each one of us? And to understand people, you
have to understand communication, and you have to understand that nursing care,
especially high quality nursing care, is built on the development of relationship and a
relationship that is reciprocal and in which you're able to do the things that help that
person flourish, and that's really the essence of person-centred care. People living
with dementia are no different from us. All the clinical evidence points to the need
10 for individualised care that respects the choices and preference – preferences,
perspectives of the care recipient. The Commission has heard evidence of the
positive outcomes of this approach to dementia care in terms of reduction in
agitation. It is evidently the approach that best enhances the quality of life of the
person concerned.

15 There is a clear connection between the attitudinal matters I first addressed and the
philosophy of putting the residents at the centre of the provision of care. There is
also a clear connection with organisational culture and leadership, a matter I will
come to last. In the words of Ms O'Flaherty, her organisation Glenview aims to
20 recruit for kindness and train for excellence. One member of the panel of nurses and
care staff, diversional therapist Maggie Bain stated that, in her experience, a good
manager will try to ensure that staff bring compassion and empathy to their work.
Associate Professor Macfarlane was of the opinion that to work in aged care and be
effective, a person needed to have a passion for caring for older people and an
25 empathy for their needs.

Professor Brodaty gave powerful evidence this morning covering the key facets of
person-centred care from both the human and clinical perspectives, identifying areas
of concern such as psychotropic prescription and emphasising the empirical support
30 for the benefits of psychosocial interventions over pharmacological ones. His view
is that in the long run, the person-centred care is more cost effective for the
organisation providing care and ways need to be found to reward those who achieve
and maintain it. Next, the third impression, the expert consensus that dementia care
is not meeting the standards expected. The prevalence of people living with
35 dementia in residential care is significant. Associate Professor Macfarlane estimated
that it might be as high as 70 per cent.

The expert evidence suggests that a lack of understanding of dementia is common in
the health and aged care sector and is likely to lead to substandard care. Regular
40 training about the nature and effects of dementia and what can be done to best care
for people living with it is critical. The evidence on the importance of a
comprehensive care needs assessment, care plan and ongoing review in residential
care is clear. This axiom of care is underscored in the context of residents living
with dementia, particularly those who may have lost the power to communicate
45 verbally, and so will not be able to identify their needs in words. The issue of risk of
miscommunication during transitions between home and residential respite care or
residential care and hospital loomed large during this hearing. So too did concerns

about the inconsistent practices and platforms for communication of critical assessment and planning information, medication records and the like.

5 These issues will continue to receive scrutiny during the months ahead. The Royal
Commission heard evidence about the difficult adjustments experienced by people
moving into residential aged care. Those adjustments may well confound and upset
people living with dementia. A person may become agitated because the person has
recently left the comfort and familiarity of his or her home and may miss living with
10 a spouse or other family member or informal carer. That might lead to ambulatory
behaviour or intrusive behaviour because the person is disorientated and cannot
recall where his or her room is or wishes to return home or to a spouse or informal
carer. Similarly, a person with dementia might resist certain personal care assistants
from care workers such as toileting or become agitated when the person is upset or in
15 pain or discomfort and cannot readily communicate what is wrong.

Associate Professor Macfarlane gave evidence that a focus on the underlying cause
of behaviour was the approach recommended by DBMAS to approved providers
seeking its assistance. If staff at an aged care facility are unable to understand the
underlying cause of a resident's behaviour, the behaviour cannot be addressed in a
20 meaningful way and may recur and get worse. That course of events will lead to
distress for the person with dementia as well as for family and staff. It may also have
multiple indirect consequences for the resident's health. For example, staff may not
have time, training or inclination to attend properly to the oral health and dental care
of a resident who resists tooth brushing or removal of dentures. That might, in turn,
25 adversely affected the resident's dental health and cause, for instance, swollen gums
or decayed teeth or even aspirational pneumonia.

The pain associate with poor dental health might cause the resident to refrain from
eating or resist being fed. That could then have further adverse consequences to
30 nutrition health and wellbeing. It will also often affect behaviour. There is a nexus
between these sorts of outcomes and the underlying attitudinal problems I addressed
earlier. As Mr Rees stated, key systemic contributors to substandard care include a
lack of respect for the person with dementia and for their choices and ability to
express them and a lack of willingness to partner with the person's family or
35 informal carers.

Fourth, I turn to restrictive practices. Toward the more serious end of the range of
potential failings in provision of appropriate care, an approved provider might resort
to restrictive practices against a resident in response to real or perceived workload
40 issues, or on the mistaken footing that this is justified by the need to manage
behaviours that the provider regards as challenging. The expert consensus is that
pressure may be placed on medical practitioners to prescribe psychotropic medicines
in such circumstances. Similarly, there is evidence of a misapprehension on the part
of some practitioners that these medications are an appropriate response to these
45 symptoms. These medications come with significant side effects.

As Dr Westbury, in particular, emphasised, they can be associated with increased risks of falls and strokes and are being overprescribed in residential aged care settings. The expert clinical advisory panel convened by the chief medical officer earlier this year to advise on the issue estimated that psychotropic medication is only
5 clearly justified in about 10 per cent of cases in which they are prescribed in residential aged care. The formal prescribing decision rests with the medical practitioner, but the approved provider often furnishes information to the practitioner and has a continuing relationship with the resident and their family and authorised representative.

10 Professor Brodaty expressed the view in his evidence this morning that approved providers should obtain and retain documentary records that informed consent has been obtained, along with assessment and review documentation. He said that provided care is taken in its design, a regime for reporting of such matters to the
15 Aged Care Quality and Safety Commission could also be appropriate. Seen against the benchmark for good quality and effective dementia care of the kind described by the expert witnesses, restrictive practices are the antithesis of person-centred relational care.

20 The Commission heard evidence from carers, health and medical practitioners and experts that there are only limited circumstances in which the use of chemical or physical restraints might be justified. Both types of restraint are inherently dangerous and have the ability to end or at least contribute to the end of life of the resident. Any use of restraints is problematic, and if they are ever used, this must
25 only be in an emergency as a last resort and to the minimum extent necessary. Associate Professor Macfarlane told the Royal Commission that, as a general rule, physical restraint should only be used in an emergency.

30 An example might be where a resident poses an imminent risk of serious or significant harm to other residents. Associate Professor Macfarlane was of the opinion that where there is no clinical indication for the prescription of medication which acts as a chemical restraint its use is inappropriate. He made his opinion clear that restraints are not appropriate measures to deal with behaviours associated with dementia that are not harmful to the person with dementia or to others.

35 While data on the use of all restraints is limited, the evidence indicates that despite the dangers associated with restraint both forms are far more prevalent than is clinically safe. In the case of chemical restraint there are serious challenges in identifying whether prescribing of the agent in question is for the subjective purpose
40 of restricting the resident's freedom of movement or decision, or is in response to a clinical condition or is a mixture of both. This leads some experts such as Dr Westbury to prefer the approach of regulating the prescribing of psychotropics by reference to whether the decision to prescribe is clinically appropriate or not, having regard to the various practice guidelines that apply.

45 Dr Westbury's work suggests that these drugs are grossly overprescribed. For example, as recently as 2016 looking at 11,368 residents from 150 facilities across

the country 61 per cent of residents were taking psychotropic agents regularly with over 41 per cent prescribed antidepressants, 22 per cent antipsychotics, and 22 per cent of residents taking benzodiazepines. Over 30 per cent and 11 per cent of benzodiazepines and antipsychotics respectively were charted on a PRN or as
5 required basis, and more than 16 per cent were taking sedating antidepressants such as mirtazapine.

The assistants in nursing on the panel of carers and nurses, Ms Wilson and Ms Walton, gave evidence that in their experience use of clinical restraints in aged care
10 facilities was also common. The nurse on that panel, Elizabeth, described chemical restraint, unlike physical restraint, as:

...anonymous, so that everyone looks fine, they're all clean and tidy and they're not crying out.

15 She observed that one consequence of the use of chemical restraints was that residents were not actually getting the care they need and being treated as a person with needs. In the case of physical restraint it takes many forms, ranging from restrictions on access to and departure from areas within a facility to the use of
20 equipment in contact with the body such as lap belts. Government has not hitherto mandated any reporting of these practices. The Commission has been told by witnesses representing the Commonwealth that this is set to change as soon as 1 July 2019 when the existing voluntary National Quality Indicator Program should or will become mandatory but it remains to be seen whether this will result in the capture of
25 data of consistent quality. Concerns have been raised that approved providers may not have a uniform understanding of the concept and breadth of physical restraint.

Associate Professor Macfarlane observed that facilities have discretion about what they report and some facilities might have adopted a narrow definition of what
30 constitutes a physical restraint, even if they are already choosing to report under the currently discretionary National Quality Indicator Program. On the basis of his knowledge and experience, Associate Professor Macfarlane assumed that physical restraint is massively underreported. He said that it was a common weekly occurrence for his consultants to report back to him that they have witnessed physical
35 restraint.

The diversional therapist on the panel of nurses and carers, Ms Bain, said that in one facility in which she had worked she had seen it used on a regular daily basis. The lack of mandatory reporting data from providers means that it is not possible to
40 quantify the prevalence of the practice in any of its forms. However, the situation was considered serious enough by the Minister in January this year following reportage of this practice to announce moves to tighten regulation of the practice. This announcement has led to recent amendment of the Quality Principles 2014 by the addition of provisions regulating the actions of approved providers in connection
45 with both forms of restraint.

Whether those amendments will prove effective remains to be seen, and will be the subject of further scrutiny as this Royal Commission continues. Some of the witnesses in this hearing noted limitations in the principles and queried whether their provisions would be effective in certain respects. Fifthly, and finally in terms of
5 impressions from the evidence, the solution must lie with organisational leadership and in particular supporting the workforce. Good care obviously requires the right staff with the right skills. The recruitment process of an approved provider is therefore important. Staff should be well trained, compassionate and supported. Good care for people with dementia seems likely to be more time-consuming and
10 intensive than a task-oriented approach although Professor Brodaty has expressed the view that in the longer run it might, in fact, be more efficient. As Professor Beattie said, a paradigm shift is occurring for care providers in this regard.

Staff continuity contributes to fostering positive relationships between residents and
15 staff. Social connection is all important, and the potential for this to be supplied or enhanced by staff is significant. A person with dementia may be less likely to experience agitation if they're routinely cared for by the same staff. Familiar staff can reduce insecurity on the person's part, increase the staff's knowledge of how best to care for the person, including the use of appropriate diversions, and better enable
20 staff to discern any changes over time in the person's condition or circumstances.

Ms Lawrence stated that training for those caring for people living with dementia should at least address manual handling, maintaining dignity, identifying triggers and symptoms for behaviours and de-escalation techniques. Ms O'Flaherty described
25 one part of the dementia training conducted by Glenview that involved a simulated exercise of what it might be like to experience dementia. Some witnesses such as Associate Professor Macfarlane called for mandatory minimum training on dementia care for those working in aged care. Professor Murphy observed that any
30 implementation of mandatory training could be affected by, perhaps, registration of carers or by restrictions imposed on approved providers as to who they are permitted to employ.

This is a subject the Royal Commission will need to consider carefully in the course of its inquiry. There is clearly a need for better training of aged care management
35 and staff in the proper assessment of the clinical and other circumstances of residents exhibiting behavioural and psychological symptoms of dementia, and the use of non-restrictive interventions. In the words of Associate Professor Macfarlane:

40 *Better training of staff would give the most bang for your buck in terms of appropriate behaviour management and decreasing inappropriate psychotropic polypharmacy.*

I will now conclude. While many different concerns have been raised about
45 perceived causes of substandard residential care for people with dementia, and these lines of inquiry will all be given close attention by the Royal Commission in the weeks and months to come, what is immediately clear is the need to foster the

adoption of organisational leadership and a culture of care which places the interests and dignity of the resident first. As Associate Professor Macfarlane said:

5 *Their needs mirror those of everyone: respect, dignity, understanding, compassion, decent food, an enabling environment, access to outdoor space, respect for cultural background and sexual orientation. When unwell for any reason, residents need an appropriate level of care commensurate with their individual needs.*

10 The next public hearing of the Royal Commission will be from 17 to 19 June in Broome and then from 24 to 28 June in Perth. The focus of this next hearing will be on aged care for Indigenous Australians, person-centred care and the delivery of aged care in remote locations. Commissioners, I will now seek the directions set out in the minute previously provided.

15 COMMISSIONER TRACEY: Yes. Those directions have been made. Given their length I won't recite them now, but they will appear on the Commission's website this afternoon.

20 MR GRAY: Thank you, Commissioner.

 COMMISSIONER TRACEY: If there are no other matters, the Commission will adjourn until Monday, 17 June 2019 in Broome at a time to be fixed. Please adjourn the Commission.

25

MATTER ADJOURNED at 3.40 pm UNTIL MONDAY, 17 JUNE 2019

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