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O/N H-1013579

**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**

**10.05 AM, WEDNESDAY, 15 MAY 2019**

**Continued from 14.5.19**

**DAY 20**

**MR P. GRAY QC, Counsel Assisting, appears with MR P. BOLSTER and MS B. HUTCHINS**

**MS K. RICHARDSON SC appears for the Commonwealth**

**MR N. DAWSON appears for the Ms Walton and Ms Wilson**

**MS N. SHARP SC appears for Associate Professor Macfarlane**

COMMISSIONER TRACEY: Please open the Commission. Yes, Mr Bolster.

MR BOLSTER: Commissioners, following on from the panel evidence that you've already heard in these hearings we have today a panel of face-to-face assistants in nursing, a diversional therapist, and a very experienced registered nurse. I call, 5 firstly, a person who we will refer to as Elizabeth but her name is known to the Commission. I call Elizabeth who is sitting at the end furthest from the Commissioners. I will call Maggie Bain who is sitting next to her. Ms Bain is a retired diversional therapist. I will call Suzanne Wendy Wilson who is the next in line, and Ms Wilson is an assistant in nursing, currently practicing in New South 10 Wales. And finally, I will call Susan Marie Walton who is also an assistant in nursing practicing in New South Wales. And if they could be sworn, please.

15 <ELIZABETH, AFFIRMED [10.07 am]

<MARGARET ELLEN BAIN, AFFIRMED [10.07 am]

20 <SUZANNE WENDY WILSON, AFFIRMED [10.08 am]

25 <SUSAN MARIE WALTON, AFFIRMED [10.08 am]

MR BOLSTER: Commissioners, can I begin with you, Elizabeth; you've prepared a statement for the assistance of the Commission.

30 ELIZABETH: Yes.

MR BOLSTER: And do you have a copy of it with you?

35 ELIZABETH: I do.

MR BOLSTER: Is the statement correct to the best of your knowledge, information and belief?

40 ELIZABETH: Yes.

MR BOLSTER: I tender that statement, Commissioners. It is WIT.0152.0001.0001.

45 COMMISSIONER TRACEY: Yes. The statement of Elizabeth dated 14 May 2019 will be exhibit 3-57.

**EXHIBIT #3-57 STATEMENT OF ELIZABETH DATED 14/05/2019  
(WIT.0152.0001.0001)**

5 MR BOLSTER: I note for the record, Commissioners, that Elizabeth's surname is not to be disclosed. I would seek a direction that her surname, in the event that it is inadvertently indicated in the evidence not be published.

COMMISSIONER TRACEY: Yes, there will be a direction to that effect.

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MR BOLSTER: I will begin with you, Elizabeth, if I may. You have extensive experience as a registered nurse over how many years?

ELIZABETH: 17 – 17.

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MR BOLSTER: And you currently devote your time to providing nursing care at home to your mother-in-law.

ELIZABETH: That's correct.

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MR BOLSTER: Who is in the Commission hearing room today.

ELIZABETH: That's correct.

25 MR BOLSTER: In your statement you refer to being both an assistant in nursing and a registered nurse. I wanted to focus, if I may, on the role of the registered nurse in delivering care to residents living with dementia. Could you begin by outlining the sort of leadership that is required of a resident nurse in that context?

30 ELIZABETH: The leadership, what - - -

MR BOLSTER: If you perhaps have a look at paragraph 14 and 17 of your statement, 14 to 17, that may assist you.

35 ELIZABETH: The – the registered nurse basically provides the subject and the professional knowledge for that shift, and you're responsible for handing the shift over to the incoming staff, doing all the wound care, the documentation for ACFI, supervision of staff and tending to the needs of dying patients. It can be quite complex in aged care, the duties that are involved because you've not only got to deal with dementia but you've also got to deal with all the physical frailties and conditions that the people have as well. So you have to have knowledge across that board. It can be very, very difficult to do this because to actually provide any sort of effective supervision or care to the patients, the residents, especially when you've got workloads of one RN to 30, up to, I've heard people say 170. In my experience the biggest load I've had is about one to 60, and you essentially have to triage your care because of that. And you have to do all the supervision. Can you – is that sufficient?

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45

MR BOLSTER: That's sufficient. Let me just pause there and say, let's take as an example where you have to be responsible for 60 residents, mixed cohort, half with dementia, half without, on a night shift and you're by yourself, and you've got a couple of assistants in nursing to help you. How do you – is that enough in the  
5 typical experience that you have to adequately care for those residents?

ELIZABETH: No, it isn't. You have to make sure if you have people that are bedridden that they have to be turned every two hours or they're at risk of having bed sores. Depending on the conditions of residents, you are having to deal with medical  
10 issues with the people with dementia. You're then having to deal with the difficult behaviours that they can sometimes experience such as becoming agitated overnight, wandering, and if somebody falls, you've got to be able to assess them for a fractured neck of femur. Other fractures are important but with a fractured neck of femur, there's an extremely high death rate with that and if it's not assessed properly then  
15 that just aggravates that and increases the complications.

MR BOLSTER: All right. I might turn now to you, Ms Bain. You've prepared a witness statement, WIT.0151.0001.0001. You've got a copy of that with you?

20 MS BAIN: I have in front of me.

MR BOLSTER: And is that statement true and correct to the best of your knowledge, information and belief?

25 MS BAIN: It certainly is true.

MR BOLSTER: I tender that statement, Commissioners.

30 COMMISSIONER TRACEY: Yes, the statement of Margaret Ellen Bain dated 14 May 2019 will be exhibit 3-58.

**EXHIBIT #3-58 STATEMENT OF MARGARET ELLEN BAIN DATED  
14/05/2019 (WIT.0151.0001.0001)**

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MR BOLSTER: Ms Bain, you're a recently retired diversional therapist and you hold a Diploma in Leisure and Health and Diversional Therapy, a Certificate III in Aged Care and a Certificate IV in Leisure and Health for Aged Care. We haven't  
40 heard from the diversional therapist at all during the course of the Royal Commission. What's the best way to describe what diversional therapists do for people living with dementia in residential aged care?

45 MS BAIN: The main purpose is to provide and to help a person with dementia to participate and to – just to thrive, really, as best we can enable them through activities. The activities could be anything from a hand massage to walking. It – it skills people up. Even though a person has dementia, they still have personality and

they're still a person. They – they may love to walk and we work to their story. We get to know the individual person as a person. We get to know their families and their friends and we get to know their story. So we work very much to that person as an individual, whether it's in a group or one to one.

5

MR BOLSTER: And how commonly, in your experience, are diversional therapists employed in residential aged care facilities in this country?

10 MS BAIN: Well, a lot of people don't know about diversional therapy. I'm quite surprised about that. We always work in small teams, only around about three or four people and it's very important because diversional therapy enables people. A lot of staff really don't understand the way that we work, mainly because there's a lot of pressure put on other staff members. They may be clinically trained or they may not have enough training to understand about diversional therapy. We really just  
15 work for the best outcome for the residents or for the person.

MR BOLSTER: Can I open that up to the other members of the panel. How commonly do you see diversional therapists in your experience? How about we start with you, Ms Walton, in your workplace.

20

MS WALTON: I don't see them at all. I work night shift. During the day, when I used to go in on certain days, we used to have a staff of two or three that made activities, helped the residents out, got them out of their rooms, joined in, actually did something meaningful. In my new facility that I've been moved to, I know of  
25 only one. I don't see that part of it now. I'm not quite sure what that lady does, but as far as I know there is only one.

MR BOLSTER: What about you, Ms Wilson? Do you have them at your facility?

30 MS WILSON: Yes, we do. We have a recreational activity officer that comes in and does probably seven hours. She's there by herself interacting with the residents and trying to have group activities. Maybe sometimes individual, that type of thing.

MR BOLSTER: Is her focus on people with dementia or the entire population?  
35

MS WILSON: With dementia.

MR BOLSTER: With dementia.

40 MS WILSON: Yes.

MR BOLSTER: And typically, what do you see that therapist doing with your - - -

45 MS WILSON: She does morning teas, she does group activities. She will play maybe bingo, she will get the residents colouring in. If one particular resident needs individual care she will get maybe washing and she will have them fold washing, that type of thing.

MR BOLSTER: What about late in the day when sundowning occurs?

MS WILSON: No, they leave at 4 o'clock.

5 MR BOLSTER: Is that a fault in the system?

MS WILSON: Yes. Yes.

10 MR BOLSTER: What's the most important time, can I ask the panel for a  
diversional therapist to be engaged?

MS BAIN: Between 4.30 and 7.30.

15 MR BOLSTER: Why is that?

MS BAIN: People with dementia actually – in aged care it's called sundowning, but  
really it refers to people that really want to go home, may have been busy people,  
they may want to go and cook a meal for their husband etcetera. May have been a  
20 busy husband that can't – is looking for his home and his meal, and so people do  
walk. They just want to find where they belong.

MR BOLSTER: When you were in practice, what were your typical hours of work?

25 MS BAIN: I work – I actually worked in one facility where it was 8.30 to 4.30 and  
then at my last facility, which was really great, I worked for the afternoon right  
through to 6.30.

30 MR BOLSTER: And what has been the reaction when you've sought to change  
hours to meet the needs of the people with dementia?

MS BAIN: To be perfectly honest, management don't want to know about it. They  
don't seem to understand the need for people with dementia requiring the space to  
walk, yes, just to be themselves, really.

35 MR BOLSTER: Ms Walton, Ms Wilson, would you care to comment on that  
experience?

40 MS WILSON: We have had trials of afternoon activity officers and that worked  
really well, but that just faded out and went back to normal 8.30 to 4.

COMMISSIONER TRACEY: Ms Walton?

45 MS WALTON: We don't get any help at all on, usually, night shift with problem  
behaviours. Sundowners can happen, as they said, any time but mostly from about 4  
o'clock because they're frightened, they want to look for their family, nothing looks  
the same, they're not feeling the same. They're not eating the same, nothing is  
familiar. It can happen any time.

MR BOLSTER: Now, I might turn to you now, Ms Walton. You've made a statement in relation to this matter. It's WIT.0153.0001.0001.

MS WALTON: Yes.

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MR BOLSTER: Is that statement true and correct to the best of your knowledge?

MS WALTON: Yes, it is.

10 MR BOLSTER: Thank you. So you're an assistant in nursing in a large facility in the Illawarra.

MS WALTON: Yes.

15 MR BOLSTER: And there are 120 residents in that building.

MS WALTON: There's 100 residents in the new building. Next door to us is a dementia specific unit with 20 residents.

20 MR BOLSTER: And you work on the night shift.

MS WALTON: I work in the night shift in the 100 residents building.

MR BOLSTER: How many people do you take care of in your night shift?

25

MS WALTON: It depends where I'm allocated. I usually work the top floor and the second floor in the new facility. On the top floor there are 40 residents, 20 in each wing. There's a locked door between both houses. Next floor down is the same, 20 in each, so that's 40, and on the lower floor there's 20 in a locked house.

30

MR BOLSTER: And when you're there, what time do you start work?

MS WALTON: I'm not supposed to start till 11 but I go in early, usually about quarter past 10, 10.30. You're supposed to finish at 7.30 if you can.

35

MR BOLSTER: And why do you go early?

MS WALTON: It's handover, we have a problem with handover between shifts. We don't actually get to see the registered nurse for a handover when we start our shift.

40

MR BOLSTER: Why is that?

MS WALTON: They're busy getting a handover from the registered nurse before for 100 residents. If I'm on a floor with 40 residents, I go to one floor for 20 and speak to the staff previously that have worked the last eight hours. Then I have to go to the other side to get the handover for the staff for the other residents.

45

MR BOLSTER: All right.

MS WALTON: I can't do that at 11, they leave at half past 11 but they're answering buzzers, doing notes

5

MR BOLSTER: During the night from 11 until 7.30 - - -

MS WALTON: Yes.

10 MR BOLSTER: - - - how many nurses are on duty in the facility typically?

MS WALTON: You have one registered nurse that does all floors. On the top floor you have one AIN or community service employee.

15 MR BOLSTER: That's you.

MS WALTON: That's me for 40. Next floor down is one, bottom floor is 20. You only get one. That's if all three nurses turn up.

20 MR BOLSTER: Now, you say that there's a new household model of care.

MS WALTON: Yes.

MR BOLSTER: In this new facility. Just how old is the facility?

25

MS WALTON: We moved in in November last year into the new multistorey building.

MR BOLSTER: So it's - I take it it looks good, it's modern.

30

MS WALTON: It looksgreat.

MR BOLSTER: What do you mean, then, by the household model of care?

35 MS WALTON: They consider each 20 residents one house. That's the household model of care. So they have a household manager that works daytime, care staff and then one of us of a night-time. The household model of care is, they're all by themselves. So they get their own meals there. They do their own laundry there, they intermingle with one another.

40

MR BOLSTER: Of the 40 you look after, how many have dementia?

MS WALTON: 90 per cent of them.

45 MR BOLSTER: Right. And are we talking about serious, or high cognitive impairment?

MS WALTON: Probably fifty-fifty.

MR BOLSTER: Right. So there would be quite severely compromised people there.

5

MS WALTON: Yes, there is.

MR BOLSTER: And what sort of care do they need from you on a typical night shift?

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MS WALTON: The high level care people should need you quite often. Some of them are one-to-one care on a bad night.

MR BOLSTER: All right. We will turn now to you, Ms Wilson. You have prepared a statement, that's WIT.0149.0001.0001.

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MS WILSON: Yes.

MR BOLSTER: And is that statement true and correct to the best of your knowledge, information and belief. Commissioners, I tender that statement and I also tender the Walton one, if I neglected to do so earlier.

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COMMISSIONER TRACEY: Yes. The statement of Susan Marie Walton – what was the date of that?

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MR BOLSTER: 11 May 2019.

COMMISSIONER TRACEY: Dated 11 May 2019 will be exhibit 3-59.

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**EXHIBIT #3-59 STATEMENT OF SUSAN MARIE WALTON DATED 11/05/2019**

COMMISSIONER TRACEY: And the statement of Suzanne Wendy Wilson dated 10 May 2019 will be exhibit 3-60.

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**EXHIBIT #3-60 STATEMENT OF SUZANNE WENDY WILSON DATED 10/05/2019**

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MR BOLSTER: Ms Wilson, you've been an assistant in nursing for seven years now. You're on the north coast of New South Wales and five of which – five of those years have been in a dementia specific facility.

45

MS WILSON: I have, yes.

MR BOLSTER: All the people you deal with are dementia patients.

MS WILSON: Yes.

5 MR BOLSTER: How do you find the fact of having a facility that only has dementia patients?

MS WILSON: We have a 150 bed facility, but the bottom floor is basically for dementia.

10

MR BOLSTER: Yes.

MS WILSON: But we're a locked in facility.

15 MR BOLSTER: Is the lack of interaction between the dementia patients and the non-dementia patients a problem?

MS WILSON: No, no, because they don't mix.

20 MR BOLSTER: Can you explain that?

MS WILSON: Well, as I say, we've got three floors and on the bottom floor it is all a locked, dementia specific area and only our residents that have dementia are in that facility, yes, and they're kept apart.

25

MR BOLSTER: All right. Now, you have a certificate III and a certificate IV in aged care, but you have subsequently completed the online dementia course offered by the University of Tasmania.

30 MS WILSON: Yes, I have.

MR BOLSTER: The Wicking Centre; correct?

MS WILSON: Yes.

35

MR BOLSTER: How useful have you found that course in being able to give care to people with dementia?

MS WILSON: Really good, very informing. It has helped me understand the factors of dementia and how the residents are and what their needs are.

40

MR BOLSTER: We will come back to that later. You didn't stop there. You have also just completed a degree.

45 MS WILSON: Yes.

MR BOLSTER: In dementia care from the University of Tasmania by correspondence.

5 MS WILSON: Yes, I have, yes. Yes, online.

MR BOLSTER: And is that a level above the online course?

MS WILSON: It's an associate degree, yes.

10 MR BOLSTER: Can I ask you this: whose idea was it for you to do that course?

MS WILSON: That was mine.

MR BOLSTER: Did your employer facilitate your study?

15

MS WILSON: No. No.

MR BOLSTER: Did your employer support you with your study?

20 MS WILSON: No.

MR BOLSTER: How much did it cost?

MS WILSON: I was lucky, it was subsidised by the government. So at that stage –  
25 I think in 2015, the government was supporting staff that were willing to increase their knowledge in dementia.

MR BOLSTER: Does your employer embrace the skills that you have obtained in the further study you've done?

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MS WILSON: No. No. I haven't been asked to give my opinion or any assistance.

MR BOLSTER: You don't get an extra say? You're not asked to contribute in clinical discussions as a result of your course.

35

MS WILSON: No.

MR BOLSTER: Were you given time off to complete assessments and study for the course?

40

MS WILSON: We were giving – not really, but we do have a study day which we can take which is either paid or nonpaid.

MR BOLSTER: Can I ask you another question: online – training that's provided  
45 by your employer in the ordinary course - - -

MS WILSON: Yes.

MR BOLSTER: Do you get time off for that or do you do that on your own time?

MS WILSON: We do it, we're supposed to do it at work and we're supposed to find the time to actually do it at work.

5

MR BOLSTER: Are you able to do it at work?

MS WILSON: No.

10 MR BOLSTER: Why?

MS WILSON: Because we don't have the time.

MR BOLSTER: What about you, Ms Walton?

15

MS WALTON: My training where I'm employed is on a computer. Once a year they give you a learning development thing to do which is usually the same as the year before. They tell you if you come in half an hour early to do the course you will get paid for it, or – you can't do it during work. You just don't physically have the

20

MR BOLSTER: So do you get on-the-job training from the nurses and the other caregivers at your facility?

25 MS WALTON: I used to. We used to have face-to-face training. Now, ours is mostly on the computer. They do hold a toolbox talk, where you get a piece of paper and some instructions on it and you sign when you've read it.

MR BOLSTER: Right.

30

MS WALTON: Very rarely that you have somebody come in and you have a face-to-face talk.

35 MR BOLSTER: Just picking up on the issue of mainstreaming dementia and non-dementia patients, you mention in your statement the different types of people that you care for. You deal with both dementia and non-dementia patients.

MS WALTON: Yes.

40 MR BOLSTER: And you say it's very difficult when both types are mixed together.

MS WALTON: Yes.

MR BOLSTER: Can you expand on that, please.

45

MS WALTON: For example, everybody in care is there for a reason, whether it be physical or mental. Most people in our facility have a lot of mental and physical

problems. For example, ours are all mixed together, so the people with problem behaviours that get frightened, wander, or are violent are with other people that aren't as bad. So, for example, you might have someone wandering all night that's frightened, or you've got a person that's bedbound or you've got someone that needs  
5 help to go to the toilet, they're not actually separated. Sometimes they're put next door to people that aggravate their dementia and get them more upset.

MR BOLSTER: Thank you. Now, could I get the perspective of you, Elizabeth, and you Ms Bain, about the mix between the dementia and the non-dementia  
10 residents? From your experience is it a good thing or a bad thing that there's a mixture between the two groups?

ELIZABETH: It depends on the level of dementia. So if somebody – and it depends – so if you've – if you've got somebody who has still got some of their  
15 cognition intact, it's probably better that they're actually with other people who are cognitively intact so they get more stimulating interaction, but once you've got people who are completely unable to interact with other people, it's better to have them just together so that you can manage them there because they have difficult behaviours, and they also, because they're unable to express themselves, are actually  
20 exposed to some – they can be exposed to some quite unpleasant behaviours. They can be quite at risk. Do you want me to go further?

MR BOLSTER: What's the dividing line, from your experience? Is it about verbal – the ability to verbally communicate?  
25

ELIZABETH: In dementia patients, yes; not in stroke patients because somebody can still be cognitively intact, even though they can't speak. So yes, I think when – when they are unable to verbally communicate, that is probably the line and they are actually very vulnerable to – can I give you an example?  
30

MR BOLSTER: Yes, please.

ELIZABETH: Okay. We had a woman who was wandering and she was completely – had complete dementia and she was wandering into a person's room  
35 who wasn't – didn't have dementia who was then sexually assaulting her, and it was only because there was a person there who was – didn't have dementia and who was completely intact who was able to say look, this is – and to alert us to what was going on. So you get that sort of vulnerability and they can't tell you that that's happened.  
40

MR BOLSTER: Right. Who makes these decisions ordinarily in the facilities that you work at?

ELIZABETH: The manager – the management decide where the person is going to be allocated.  
45

MR BOLSTER: Just, we will come back to you in a minute, Ms Bain. Who makes the decisions in your facility about who goes where?

5 MS BAIN: We have a staffer, an administration person that does the enrolment and I think then it's the general manager that makes the decision.

MR BOLSTER: Are you ever consulted about that, about how someone is declining and whether or not they need to be placed in the dementia unit?

10 MS WILSON: It depends on, I would say, the RN or the EEN. Most times they will consult with us but on the whole it's basically their decision, not the AIN.

MR BOLSTER: Ms Walton, are you - - -

15 MS WALTON: The same, I find that the same with ours; any problem behaviour, anything that happens, all of us document. If it's a serious – something that has happened that's serious, that's a higher documentation that goes direct to management, and after a period of time they decide.

20 MR BOLSTER: Ms Bain, I'm very interested in your views about mixing the two types.

MS BAIN: I've worked in a locked dementia unit, and I've worked on the floor with mixed dementia and ordinary everyday residents that come into aged care. And  
25 it works well. It works exceptionally well because it helps the people with dementia to – to be social, to actually be around people, to experience the things that other people experience, like a walk in the garden, like a music concert. And in one facility I managed to engage the management to bring other groups into that facility, like school children and cubs and scout groups and small groups like that to mix with  
30 the people with dementia, and a standard resident, and it worked well.

MR BOLSTER: What effect does that sort of community engagement have for people with dementia?

35 MS BAIN: It was absolutely wonderful. They loved it. We had children coming in getting the – getting the opportunity to read a story to a person with dementia, and their face would light up. And vice versa.

MR BOLSTER: We've heard about pets.  
40

MS BAIN: Yes, that's right.

MR BOLSTER: As therapy.

45 MS BAIN: Yes.

MR BOLSTER: Is that commonly used?

MS BAIN: I don't know about other facilities but it was used in two facilities where I worked.

MR BOLSTER: What effect does that have on them?

5

MS BAIN: The pet therapy is really calming. It brings back memories to people with dementia about their own pets. It brings back memories about what it used to be like at home.

10 MR BOLSTER: All right. Let's go back to you, Ms Wilson. We haven't heard about your facility in any great detail yet. You refer to a fairly similar facility to Ms Walton.

MS WILSON: Yes.

15

MR BOLSTER: A similar structure by the sound of it. You have 22 residents in each ward.

MS WILSON: Yes.

20

MR BOLSTER: They're called wards?

MS WILSON: They're called communities.

25 MR BOLSTER: Communities. Okay. And what shift do you typically work?

MS WILSON: I do morning shifts and afternoon shifts.

MR BOLSTER: And how long are those shifts?

30

MS WILSON: Morning shift can be a four hour shift, a six hour or seven and a half hour shift of a morning. Afternoon shift, we have a 3 till 9 and a 3 till 10, and they've just brought in a 2 till 8 shift.

35 MR BOLSTER: On a typical shift do you deal with two wards at the same time or do you deal with one?

MS WILSON: No, just one.

40 MR BOLSTER: Just one. So that's – it's a different rostering structure during the day, isn't it?

MS WILSON: Yes, yes.

45 MR BOLSTER: Just out of interest, at night, what would be the staffing situation for those two wards?

MS WILSON: We have three staff for 22 residents on one side, and two staff for 22 residents on the other, because that's more a low care area on the other side.

5 MR BOLSTER: Right. All right. And as you've said, the residents are separated in those facilities.

MS WILSON: Yes.

10 MR BOLSTER: I want to ask each of Ms Wilson and Ms Walton about the culture in the facilities in which you work. How do you describe the culture of working in a residential aged care facility for people with dementia? Does it differ from facility to facility?

15 MS WALTON: I think so.

MS WILSON: Well, my facility – our, in dementia our team is very close, the staff that work there. Any new staff that come in, we try and teach them – teach them about dementia and how to interact with the resident. Some staff when they first come in there they find it very overwhelming and they don't come back. They will work on the other floors.

MR BOLSTER: How experienced are the people when they come to work in your dementia unit?

25 MS WILSON: They don't have a lot of experience. They might have experience in actual aged care but when it comes into the dementia area, not much.

30 MR BOLSTER: All right. We will come back to what makes dementia care special a bit later. But you, Ms Walton, what about culture, how do you develop culture in the workplace?

35 MS WALTON: Well, certain night shifts – I work eight night shifts a fortnight. Five of those night shifts I'm on with a great crew, very experienced registered nurse you have a lot of faith in, and care workers that you have faith in. Other nights when you're there, you might have a casual, a workforce person come in because you're short, or a casual registered nurse that has been called in, or another registered nurse that normally doesn't do that particular hours and knows those people. So it's extremely difficult because you can't leave where you are to go and help whoever.

40 MR BOLSTER: Yes.

MS WALTON: So you need a team of a night shift that knows what they're doing, needs experience and needs to be able to trust one another for those people's sake.

45 MR BOLSTER: How often is it – both Ms Walton and Ms Wilson, how often is it that you're able to do all the things that you need to do in your ordinary shift at work? Does it happen often?

MS WILSON: Yes, most times, most nights I don't leave at a 9 o'clock finish, I will stay back. If there's a resident we're halfway looking after you just don't leave; you stay there and you finish caring for them.

5 MS WALTON: Mine is never, unfortunately. Our new model of care, if I'm on a floor with 40 people I don't have a cleaner, a laundry person, a kitchen staff. I have to do all that, plus answer call buzzers, attend to people that are on the floor, pain; you can just imagine, you can never get it done.

10 MR BOLSTER: What are the things that people miss out on because of that?

MS WALTON: If you're there by yourself with 40 people and you have four call buzzers going, and this lady needs to go to the toilet, you're there with this lady by yourself. The other three people unfortunately you can't get to when they need to be  
15 – they need help. If you've got a person on the floor, you're completely taken off the floor with that person and the registered nurse when they come, so your other 39, I'm sorry. So you don't know if they're wandering, there's people at risk you're supposed to check. You can't get to them physically.

20 MR BOLSTER: Elizabeth, would you like to comment on that, from your experience? Is that consistent with your history in aged care?

ELIZABETH: Unfortunately, it is. One – it's – and it's got worse. I was working in an aged care facility where we did half an hour – half an hour unpaid overtime  
25 every day and that was so we could have the handover. And there were – we would be doing up to four hours overtime a day, just trying to manage the care for people. This is when you're doing one to 60 and you've got people with high acuity needs, so people that are dying, for example. The problem with that is when you're staffed with – with that sort of unreasonable workload and you can only actually give any  
30 sort of reasonable care to, say, four or five people, that means everybody else who, you know, may be developing pressure areas, all sorts of other things that can be deteriorating, you have no way of even getting a grip on them so that you can do something about it.

35 And when I left that particular facility, the director of nursing was really great but the management above her were just saying no more staff, no more staff, and after I left they replaced me with two people because the workload was just so unreasonable. And there's other places where you don't even – if somebody doesn't turn up, then you actually have to do your work, their work and that's just bad luck.

40

MR BOLSTER: You mentioned palliative care. Can I ask Ms Walton and Ms Wilson, when there is a – and I take it must happen fairly frequently – when there's a palliative care issue, what extra staffing is provided to you, Ms Walton?

45 MS WALTON: None whatsoever.

MR BOLSTER: To deal with someone's palliative care needs.

MS WALTON: None whatsoever. At end stage of life, when the person is usually comfortable, or before they get comfortable, you don't have any extra staff, you're there with that person and your one registered nurse unless the family members are there that can communicate with you and have a call buzzer. I don't get any extra staff.

MR BOLSTER: Does the nurse who's on duty deal with that issue? Do they spend more time with that person?

MS WALTON: If they can, they do, but it's very rare that they can, because if you need a co-worker or a partner on the floor to turn someone over every two hours, come and help you pick them up off the floor. You've got a gentleman or a lady that has got problem behaviour, they've got to come and help you, or they're with somebody else on a different floor. So you're there by yourself.

MR BOLSTER: Did you read the case we provided to you of the lady who was dying in a facility and there was a palliative care issue? Do you remember reading that?

MS WALTON: I read a few.

MR BOLSTER: Number 4.

MS WALTON: Number 4, yes. I will just get it up. Sorry.

MR BOLSTER: Did that resonate with you when you read it?

MS WALTON: Yes.

MR BOLSTER: What's your comment, just – and I'm not asking you to comment on that facility, but I'm asking you to comment on your experience in similar situations. Is that a common thing that you have to deal with when you're working at night alone?

MS WALTON: Yes.

MR BOLSTER: What do you do?

MS WALTON: The best you can. The best you can. When you read these sort of things, and it does happen quite regularly, especially with family members, decisions are made – a lot of the time you don't have a loving family or you have a fractured family. So to actually get a hold of someone to get their permission is very difficult. It's up to the registered nurse or whoever to get the doctor to do. But it does happen quite often and it shouldn't really.

MR BOLSTER: Ms Wilson, when there's a palliative care event that requires extra, how does that – how is that dealt with at your facility?

MS WILSON: We don't get extra staff to – we just get a - - -

MR BOLSTER: Is the palliative care staff, or are the staff that you work with able to deliver adequate palliative care?

5

MS WILSON: We do the best we can.

MR BOLSTER: Is it good enough?

10 MS WILSON: No. No. No, it's not.

MR BOLSTER: What does it need?

15 MS WILSON: More training to teach staff how to deal with palliative care, what the needs are. It's just – yes, it's just not good enough.

MR BOLSTER: Ms Elizabeth, would you like to comment on that?

20 ELIZABETH: Yes. Palliative care is a very time intensive and very person centred and relative centred nursing event, basically. And you need people who are able to negotiate with the relatives who are dealing with the dying and the mechanisms and the processes of dying, and if I refer to the scenario four, there was several things that just leapt out at me. One was that this person was supposed to be turned every four hours. That's just not good enough. They need to be turned at a minimum of every two. And given that they were being turned at every four, if that, it's – it's not surprising that they ended up with a pressure area. And a pressure area tells you there is not enough staff. The care wasn't good enough. And nobody was reviewing that, and this is not the sort of thing that people should be having to deal with as an end of life issue.

30

MR BOLSTER: Ms Wilson, I see you nodding when Elizabeth was saying that. Do you agree with that analysis?

MS WALTON: Definitely.

35

MS WILSON: Yes.

MS WALTON: Happens all the time.

40 MR BOLSTER: How do you deal with pressure ulcers late stage of dementia who simply can't move?

MS WALTON: Well, as Elizabeth stated, they're supposed to be – you request an Airwave mattress to start with. That doesn't sometimes help.

45

MR BOLSTER: How often do you miss out on the air mattress when you need it?

MS WALTON: All the time.

MR BOLSTER: Ms Wilson, do you agree?

5 MS WARNER: I would say at our facility we do our best – majority of the time, if we ask for an air mattress, that air mattress will come in and we will have that. But you still need to do the two hourly turns to ensure that there's no pressure area.

10 MR BOLSTER: All right. I want to change topic, talk about handover, that was something else Elizabeth mentioned a few minutes ago. How important – I think Ms Wilson you've already dealt with handover. Elizabeth, from a clinical perspective, how important is handover for a registered nurse?

15 ELIZABETH: Look, it's your bread and butter. If you don't know what's been going on, you miss care. And back to the palliative care, there was an assistant in nursing who obviously wasn't the quality of the two on my right who just didn't bother telling me that somebody had had a drip pulled up as part of their – their palliative care, and she just thought, "Oh well, I just don't need to tell you, you're supposed to know that magically." There's – you need to know if there's any  
20 changes in people's behaviour. You need to have a heads-up of things to look out for, because if you don't get that, you can't actually then focus your attention, chase something up. If you're getting handed over that someone's getting reddened area, then you need to follow that up and say listen, everybody, you're going to have to turn that person more often. Because you should not be seeing pressure areas. That  
25 is just bad care. And it goes on and on and on. And – or if somebody's getting more agitated, you need to know what is going on for the residents so you can then provide effective care. And if you don't get a proper handover, you're working blind.

30 MR BOLSTER: Ms Bain, how important is handover to the diversional therapist to understand the person?

35 MS BAIN: Extremely important. Unfortunately in diversional therapy, we don't get a lot of time to read a handover. The handover is usually presented to the coordinator of diversional therapy through the clinical care manager, or the RN in the unit. And unfortunately, in our practice, we don't get enough time to read the notes. We should read the notes. But there is not enough time provided to read notes all the time. It's very important because we need to know if a person has different changes to behaviours or different changes to their physical self.

40 MR BOLSTER: What's a typical behaviour that you need to know about to be able to help someone?

45 MS BAIN: Well, we would really need to know if a person was actually not enjoying talking to a family member. We would need to know if a person had a UTI, for instance. A UTI can cause psychosis. We need to know the physical and the mental and any change of a resident in aged care with regard to that.

MR BOLSTER: That leads me to the source of that information, and Elizabeth, assessment, clinical assessment. How often is it required by the nurse for the resident with dementia?

5 ELIZABETH: You actually need, in – in any aged care and dementia care, you actually need to have eyes on the patient – the resident every day, and you – you have to know what that person’s baseline is and how they interact with you so that you can actually see. And what you’re doing when you’re having that interaction is you’re assessing them physically, you’re assessing them cognitively. The problem  
10 with it is, is that there are too many – the ratios aren’t there, so you can’t actually have eyes on – eyes on the resident. So you’re not actually – you’re being prevented, really, from doing your basic care so – and you can have a person change in an absolute heartbeat if, for example, they get a UTI. They can have a delirium. And you need to be able to know yes, this morning they were able to do so much and now  
15 their behaviour has suddenly deviated. But if you don’t have the time to actually spend with that person, know what their baseline is, you’ve got nothing to compare it against. And – and it’s really critical. And can I give you an example of that?

MR BOLSTER: Yes please.

20

ELIZABETH: Okay. There was a person with dementia, he was a man and he was always very, very cooperative, and the nurse – the assistance in nursing came to me and said look, he’s just being awful, he won’t get out of bed, he won’t stand up. And so it’s –okay, he’s got dementia. He’s trying to tell you something, so what is it and  
25 why won’t he weight bear there? So you’re sitting there, you’re ticking through things in your head. If he’s not weight bearing, is he in pain? If he’s in pain, what is that from? Does he have a fracture? So you go and assess him for a fracture and I made them leave him in bed and there was no actual shortening in his legs and turning out which were tell you his neck femur was fractured. But he had actually  
30 suffered a fracture of his femur lower down.

And if you didn’t know that that – that it wasn’t normal for him to be resistive, then, you know, the alternative is pretty unpleasant. You then drag him out of bed, force him to stand on a broken leg and then instead of having a closed fracture you end up  
35 with an open fracture and the complications of that. That’s why the assessment is important. And it’s across the board and it needs to be – you need to be taking everything in account all the time.

And if I can just put an example of a surgeon and he came into the hospital every day  
40 to check and he would just say hello and how are you going. And you would think why is he wasting his time turning up here and all he does is spend, you know, two or three minutes? That two or three minutes means that he can tell whether you’ve got an infection, he can tell whether you’re cognitively deteriorating because of something else. He can look at you to see if you’re pale, all of those things, and it  
45 only takes a few minutes. And it’s very, very quick and it’s all – and you just do it automatically. So the fact that you can’t actually have that time means you can’t do those assessments which then puts you at all of the risks that carry out from there.

MR BOLSTER: Ms Walton, Ms Wilson, is the result of that sort of assessment conveyed to you in your roles?

MS WILSON: We - - -

5

MR BOLSTER: Or are you required to assess the people you're caring for yourselves?

MS WILSON: We're not required to but we do. It's just automatic, you're constantly observing your residents to ensure they're okay. You're checking who's with who and making sure that they're not with a particular person so that a trigger doesn't happen and a behaviour starts. When they go to their rooms it's very difficult to do that. But if they're in the lounge area you've got better observation and you can try and reduce an incident if it happens, type of thing.

15

MR BOLSTER: Ms Walton do you - - -

MS WALTON: It is very difficult to do that. You have a certain amount of people that you've been told that are at high risk that you have to check a certain period of time.

20

MR BOLSTER: Yes.

MS WALTON: You try and go in and just observe or if someone's up, talk, if there's any changes, document. I don't actually do it, I just document changes.

25

MR BOLSTER: Yes.

MS WALTON: It then goes from there up to whoever.

30

MR BOLSTER: On your night shift, does the nurse traditionally come around and view the residents during that shift?

MS WALTON: No. Unfortunately, the one registered nurse does not have time to do that. We only see the registered nurse if the resident is in pain or if there's problems, we ring them straightaway. They try and get there as quick as they can. They've got lots of paperwork and assessments and things to do themselves. So their actual face-to-face time on a night shift is very difficult when they've got so many people to look after and being called out.

40

MR BOLSTER: All right. Now, I wanted to turn to the issue of BPSD. We've already discussed it in a number of context today. But starting with you, Ms Bain, what are the typical examples of BPSD that you confront in your practice as a diversional therapist and can you give us an idea of the sort of techniques you use to deal with those situations?

45

MS BAIN: We deal with those types of situations through calming a person down. We use techniques such as approaching the person quietly, if they're agitated or if they're upset. We go about it in a different way to the clinical – clinical restraint or anything like that. What we do is we would just sit with them. Once we've  
5 approached them we would sit with them. We might hold their hand, we might offer a hand massage. We might just listen to what they have to say. If they can't speak, then we just sit with them and we take into us what they are feeling, really. We use many different techniques to calm any agitated or wandering resident. Any person with dementia can have multiple different types of – how can I explain it –  
10 challenges.

MR BOLSTER: Yes.

MS BAIN: But they are all really, in my opinion, have all been caused by lack of  
15 knowing the person as an individual person. I know that nursing staff and PCAs are run off their feet, absolutely run off their feet. And we were originally supposed to be able to come in and relieve the challenges of various people through our processes, or through our training, but I find now that few people, or few facility managers are actually using diversional techniques, and so I'm really – I – I'm in  
20 consent with these people here because I know they're run off their feet. I know the PCAs work to their best ability but in dementia we really need people with training in dementia. We need someone that understands the individual person and understands their story.

25 MR BOLSTER: Let me ask, you had a look at the scenario involving the woman who had the problem with her teeth, and who had been a wanderer.

MS BAIN: Yes, yes.

30 MR BOLSTER: And was a wanderer before there was an issue about medication.

MS BAIN: Yes.

35 MR BOLSTER: And was a wanderer after the medication was administered. And you read, I take it, how upset she was and the issues that were fuelling her - - -

MS BAIN: Yes.

40 MR BOLSTER: - - - behavioural issues. How would you have approached that particular challenge? It would have been a challenge.

MS BAIN: It would have been a challenge. And I, really, reading that scenario, that lady was lonely. She was looking for her home, and we would have approached her with something that she found familiar to her, something that she should have or the  
45 family should have provided for that – that woman to actually bring some comfort to her.

MR BOLSTER: Can you give an example? Have you come across that before in your practice?

MS BAIN: Yes, all the time.

5

MR BOLSTER: What do you do?

MS BAIN: Well, we have what is called child representation therapy which is actually the size of a baby that may have a heartbeat, and it may utter small  
10 whimpers or a little cry or something like that, and most of the people in aged care really enjoy that interaction because they claim the child as their own and it reminds – it gives them memory of their past. And the memories from the past are important – for a person living with dementia. They're automatic; they don't have to learn that. They're memories from the past that are always with them.

15

MR BOLSTER: Is another way to give them something or place in their room something from their home?

MS BAIN: Definitely, yes, definitely.

20

MR BOLSTER: Can you give us an example of that having worked before?

MS BAIN: Yes. They really should be provided with pictures from home, memories from home, maybe their favourite blanket from home, something  
25 comfortable, even a favourite cushion, something that the family may have made for them when they were young mums, for instance, like a patchwork quilt. All of those things are very, very important to a person with - - -

30

MR BOLSTER: Books?

MS BAIN: Books, definitely. Picture books; we made multiple picture books for our wonderful people in dementia, and they always loved turning the pages – sorry, I'm getting a bit emotional here – and also their stories, their stories were really  
35 important. I managed to get permission from several family members to make a picture book for their mum or their dad, and made a DVD for them that they could have in their room to play on the TV. Sorry, I'm just getting a bit emotional, my apologies.

40

MR BOLSTER: Don't worry.

MS BAIN: Sorry.

45

MR BOLSTER: Don't worry at all. Ms Wilson, do you have perspectives that mirror what Ms Bain has been talking about?

MS WILSON: Yes.

MR BOLSTER: Would you like to tell the Commission about those?

MS WILSON: We have one resident at the moment who has stuffed animals; she has a cat and a stuffed donkey. She carries that round with her all the time. When  
5 she gets upset, if I'm there I usually try and grab the cat and just say, you know, "How's the cat going?", that type of thing and she will cuddle it. And it seems to ease her. It doesn't always work but it eases her a little bit. That makes a difference. And definitely having like a memory box out the front of their room with little ornaments or little things from home so they can distinguish their room. Or even, I  
10 think there's now research has been done where you can put – it's like a laminated door, like an old style door from their home, that can be put on their door so that can show them where their room is. That type of thing; it's all different things - - -

MR BOLSTER: So the door in the facility is made to look like the door at their  
15 home.

MS WILSON: Yes, yes. Because at the moment everything is just one colour. You know, when you walk into the room their bedroom door is white, the bathroom door is white so there's no distinguishing the colours to let them know where their room  
20 is, where the bathroom is.

MR BOLSTER: Ms Walton?

MS WALTON: I see this all the time. I went from a facility where half the  
25 residents that came with us lived in their own little home; they need a little bit of care. So they had their dressing table, they had all the photos on the wall, the personal things. When they all moved into the new facility, it's a room. Same thing, same colour, no, you can't take this, no, you can't take that. Sorry, you can only hang six photos on the wall. So unless they've got a family member that's very  
30 caring, lots of them make blankets with pictures of the family or little knickknacks, it makes such a change. And especially – we used to be able to get a life story about a person, where they were born, brothers and sisters, pets, children, whatever, we don't get that now.

35 It's very difficult for when someone comes in and they're new to get to know them unless you're actually there to talk to the family. So I'm a great believer in you've got to spend time with them. For example, I'm on night duties, I'm lucky I can spend eight hours with that person that's wandering, that's upset and is agitated. We go back, I will bring the computer up, and he will tell me where he was born and he  
40 fished at this river. We will bring the photos up, so much calming – changes.

MR BOLSTER: So you have developed a familiarity with all of the residents that you - - -

45 MS WALTON: Yes.

MR BOLSTER: And Ms Wilson, you're the same?

MS WILSON: Yes.

MR BOLSTER: How important is that?

5 MS WILSON: It's very important.

MS WALTON: It's extremely important. Education is the key as well. For example, lots of staff members aren't educated enough in all facets of the job. Someone that does a six week course can't walk in and look after a person that's in  
10 trouble. I was at work a couple of weeks ago, I went in to get a report. I could hear yelling in a public toilet, a lady that was very upset, didn't know where she was, incontinent, was telling this staff member, "Leave me alone". She's trying to take her incontinence aid off, so she slapped her. So, of course, you know, she writes down this, it's not what happened at all. So let the lady calm down, you will ring the  
15 buzzer. You go in there, she will call you Joan, "Oh Joan, I've missed you". It doesn't happen all the time but you need specialised education in dementia to actually help these poor people.

MR BOLSTER: The next question is a big one for each of you. What are the most, or the more important features of good dementia care? Why don't we start with you, Ms Bain, because you make a statement, paragraph 44 of your statement.

MS BAIN: I have.

25 MR BOLSTER: You say:

*Good dementia care feels like a living breathing, great attitude held by all management and staff.*

30 MS BAIN: Yes. That's exactly right. I've experienced - - -

MR BOLSTER: Tell us what that means.

MS BAIN: There's a huge difference. I've experienced good and really bad. The  
35 good facilities will have a good mix of people. They will have great staff that love their residents. You have to have compassion and you need to work with – with endurance as well as compassion and empathy, and a good facility manager will really try to encompass that in the facility.

40 MR BOLSTER: All right.

MS BAIN: On the opposite side, a bad facility – I had a facility manager, unfortunately, that was a bully, intimidated people, including family members. And they were – felt they – the family members would come to myself and to the team I  
45 was working with for encouragement, really, because they were getting no support whatsoever from that facility. So there's a huge difference from one to 10 in good and bad.

MR BOLSTER: Elizabeth, what's your perspective?

ELIZABETH: Look, the – the big problem with people with dementia is that they're no – when they get severely demented is they can no longer communicate  
5 with you. If they – so you then have to be their eyes and ears. So because you can have a deterioration in somebody's mental state for all sorts of reasons. You can precipitate all sorts of difficult behaviours because somebody is not being cared for physically. If somebody can't tell you, for example, that they've got a pain in their tooth, if they can't tell you that they're constipated, all of these things, or they're  
10 being forced to sit in the chair and they're not being moved, then they just get agitated.

What you need is good, basic nursing care and then layered over the top of that you need the good emotional care on top of it. It's – with people that don't have, or are  
15 still cognitively fairly intact, they can self-direct and they can tell you what they need and what's good for them and what they would like, but with people with fairly advanced dementia, then you have to take over that role and you have to step in and make sure that care is delivered. And you barely have enough time to make sure they're physically – their physical needs are met and then you have the fallout from  
20 that, let alone having diversional therapists come in and help you.

MR BOLSTER: Ms Wilson, what's the answer to that big question?

MS WILSON: Skill training, skills and training. I would recommend definitely,  
25 highly recommend the University of Tasmania's Massive Open Online Course. That is like a six to 12 week course and that gives you the basics of how dementia affects the person, and also you need empathy. You need to be able to deal with what is confronting you, you know, and not get upset and say, "That person has done this to me". It's not the person that's done it to you, it's the disease and you've got to  
30 sidestep the disease and just work with them and care for them.

MR BOLSTER: Ms Walton.

MS WALTON: I wholeheartedly agree on what the ladies said. Education,  
35 education, training, training. Every person is an individual, no two people are the same. You need to understand the problem. You cannot make a person with dementia do what you want them to. You have to understand what's causing it and help them that way.

40 ELIZABETH: May I - - -

MR BOLSTER: Yes, please.

ELIZABETH: Okay. One of the big problems for people dealing with people with  
45 dementia is that they look like you and I. And if somebody starts lashing out at you and if you don't understand the issues around dementia, you then – you start attributing blame. And that person was being nasty to me, they – they were being

mean to me. When they don't – simply don't have the capacity to make those decisions. If you are sitting there expecting them to have the capacity to behave in what you perceive as a normal way, then that just builds resentment and that comes into poor care. With the dementia training, as was just stated, you actually see,  
5 you're looking at how the dementia is affecting the person and then, rather than it being a – you coming from a position of blame, coming from a position of understanding, and then you can step back and deliver the care that's required.

10 MR BOLSTER: All right. Let's talk about one aspect of care. Oral care. What's the practice in dealing with the dentures, the teeth, the oral problems of the people you work with, Ms Wilson?

MS WILSON: We try and give oral care. Sometimes the residents will be resistive. More – but on the whole we usually clean their teeth, well, I do, I don't know about  
15 other staff members, but when I come in to give them their cares, I always clean their – try and help them clean their teeth. At night-time, you take their dentures out, but not a lot of staff know that. And this is where a lot of the problems stem from, too, with that – with oral care, they don't actually know – they don't understand that you need to take the dentures out and, you know, rinse their mouth.

20 MS WALTON: You can't leave them in either.

MS WILSON: Yes.

25 MR BOLSTER: Is that something you learn when you do your cert III and cert IV, is that something that the course covers?

MS WILSON: Basic – basic understanding of it.

30 MR BOLSTER: Ms Walton?

MS WALTON: I find the same thing. Whether the staff don't know – the previous staff don't know or they don't get the time. You quite often go into work and you will have a resident ring at 1 o'clock in the morning, for example, I've got a lady  
35 that's got MS, only got the use of one. She will call me in at 1 o'clock and say, "Sue, can you clean my teeth? Can you take my partial denture out and clean my teeth". I said, "Haven't they done it for you?" "No, no" So unless she actually asks you, nobody is actually getting to that lady.

40 MR BOLSTER: So you read the scenario we gave you of the lady who had the oral health problems.

MS WALTON: I fully understand.

45 MR BOLSTER: Is that unusual or is that something that happens every day?

MS WILSON: I would say it pretty much happens every day.

MS WALTON: I would say, too.

MR BOLSTER: Elizabeth, from your experience?

5 ELIZABETH: From my experience, in the old days, we just – well, there’s a  
problem with it’ it’s changed. Back in the late seventies, early eighties, most of the  
cohort coming through had no teeth, and the routine was to just go and collect  
everybody’s teeth, take them away and clean them. I think now because people are  
retaining their teeth, there’s a big issue. Number one, people find it an icky job  
10 which they tend to want to avoid. And it’s something that you – you’re always  
saying to them, “Make sure you clean their teeth, make sure you clean their teeth”,  
and they do avoid them and it is a real problem. So yes, it is, it’s an ongoing  
problem. And with people with dementia there’s no actual routine dentists come  
through and check people’s teeth, and I’m not a dentist and I can’t check them, but  
15 what I do know is that tooth pain is probably the worst pain you can ever experience,  
and these people have no way of telling you that they’ve now got a hole in their tooth  
that’s causing them an issue so that’s another real problem that needs to be looked at.

MR BOLSTER: Ms Walton, Ms Wilson, does a dentist visit your homes?  
20

MS WILSON: We do have a dentist come in, I think, yes.

MR BOLSTER: How often?

25 MS WILSON: That I’m not sure of.

MR BOLSTER: Is that something the facility organises or that the residents - - -

MS WILSON: Yes, the facility has organised that now, yes.  
30

MR BOLSTER: Right. And the dentist sees all the residents?

MS WILSON: Again, I’m not too sure on that. I don’t know that side of it.

35 MR BOLSTER: Ms Walton?

MS WALTON: In the old facility, the management or the facility actually set up a  
dental room and had a gentleman come in every so often to look at people that  
complained. I’m not sure about the payment or anything. In the new facility, no, it’s  
40 up to family, unfortunately. If you are lucky enough to discover something and  
you’ve got a family member that can do it, then it goes from there outside.

MR BOLSTER: Is there a direction from management in your two facilities that  
you have to take care of the teeth of the residents? Is that something that’s  
45 communicated to you by management?

MS WILSON: That has been put in place at our facility but that's only from the care manager. Our new care manager has basically told staff that this is what you have to do morning and night to clean the residents' teeth – or assist.

5 MR BOLSTER: How recently is that?

MS WILSON: I would say within the last month.

10 MR BOLSTER: And for the past seven years; what was the position?

MS WILSON: Basically up to the staff to do it.

MR BOLSTER: Up to staff.

15 MS WILSON: Yes.

MR BOLSTER: So there was no leadership on that issue at all?

20 MS WILSON: No.

MR BOLSTER: Right. That scenario that we gave you with the lady with the oral, does anyone wish to comment on that any further?

25 ELIZABETH: I think that perhaps they should have – they were aware that she had compromised dentition. The speech pathologist had come in and said she had difficulty swallowing. I think at that point you can actually get a diet so you don't need all your teeth intact and given the issues that she was experiencing, maybe that denture should have been taken out permanently. And also she had a dry mouth when she came in. She was started on mirtazapine, and one of the side effects of mirtazapine is to give you a dry mouth so that's just going to simply add to the issue. And there is an issue with people as they get older and they have dementia that they do have difficulty and they will hold food in their mouths.

30  
35 So I don't think it's a one or the other situation. I think there's a couple of things going on there. And perhaps it would have been prudent to take those dentures out, seeing as they weren't being able – she was being resistive, they were causing a problem and they were causing a deterioration in her dentition.

40 MR BOLSTER: All right. While we're on that case study, why don't we finish that and deal with this issue of the mirtazapine that you mentioned. Put yourself in the position of the care manager, and the suggestion that 45 milligrams of mirtazapine should be charted for this lady. What would – what would your involvement in that discussion have been?

45 ELIZABETH: There's – there's – the reason you need to know lots and lots about elderly physiology is that you know not specifically on all drugs but you know that the elderly process drugs differently than the adult cohort. So 45 milligrams of

mirtazapine is actually the top dose. The recommended starting dose is 15 milligrams. And when I was reading through this, I was looking and going, oh, she's starting to look sedated. I wonder, and I started to look through it and I thought sure as eggs, she has had a dose that's too high for her. And then as you read further,  
5 when the dose was reduced, she actually became more responsive.

So I don't – I think perhaps my response would have been going to the doctor and say, "Listen, have you thought that maybe this dose is a bit too high in this  
10 circumstance and maybe consider going a lower dose".

MR BOLSTER: Have you done that with doctors previously?

ELIZABETH: Yes.

15 MR BOLSTER: Have you questioned their charting?

ELIZABETH: Yes.

MR BOLSTER: What's the usual response?  
20

ELIZABETH: Generally, they're pretty good and – because not – you don't think about every – nobody thinks about everything all the time. And one of – if you're working as a team, one of the things you have to do is to make sure that if you're seeing a problem that you bring it to the person who can do something about it  
25 attention, and then they go, "Oh, maybe I didn't think about that, I will go and have a look and then maybe I will change it". So at least you give them a heads-up so they know that this is a concern and they usually listen to the registered nurses so – and then actually act on that, so I would have expected a positive outcome.

30 MR BOLSTER: Ms Walton, Ms Wilson, mirtazapine, do you come across that in your practice?

MS WILSON: We do have it, yes.

35 MR BOLSTER: Do you know what it is?

MS WILSON: Not specifically.

MR BOLSTER: Ms Walton.  
40

MS WALTON: We do, too, and I'm – I can't be 100 per cent sure.

MR BOLSTER: Right. Okay. Thank you. You're not involved, though, in the decision-making about prescription medicine?  
45

MS WILSON: No.

MS WALTON: No.

MR BOLSTER: You're not consulted about that at all?

5 MS WALTON: No.

MR BOLSTER: All right. We'll come back to you, Elizabeth, the consent issue there; the drug was administered without speaking to the family who were the decision-makers for the purpose of consent. What's your comment about the process that was adopted there?  
10

ELIZABETH: I think unless you – you have to have consent and it wasn't an emergency. If it's an emergency situation, you do what you need to do and then – and then inform the family. However, if it's something like this that can wait, I think you need to have consent first because there may be issues. She may have been on that before and it may have given her side effects. You've no idea what the background is to that, and you have no right to force treatment on someone without consent from somewhere, whether it's them or whether it's their carer.  
15

MR BOLSTER: All right. The issue also raises interventions by the – potentially, by the DBMAS. You're familiar with the DBMAS?  
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ELIZABETH: Yes.

MR BOLSTER: Tell me, Ms Wilson, how often does the DBMAS get a call-out to your facility?  
25

MS WILSON: We've had them in the last two years, I would say twice, two or three times.  
30

MR BOLSTER: For what sort of cases were they called in to advise about?

MS WILSON: To assist with behaviour management for residents with aggression, that type of thing.  
35

MR BOLSTER: Ms Walton?

MS WALTON: Similar experience. They've been to our facility a few times over the last couple of years. The first incident was a gentleman wandering, sexually advancing towards ladies.  
40

MR BOLSTER: Yes.

MS WALTON: Another gentleman, unfortunately, never had any problems, but all of a sudden he can't help going into rooms and picking up everything and taking it back to his room, and another one was aggression.  
45

MR BOLSTER: And do I take it from that it's usually a fairly extreme case before DBMAS is engaged.

MS WALTON: Yes.

5

MR BOLSTER: What about the lady in that case study? If that occurred at your facility would there have been a call-out to DBMAS, from your experience?

10 MS WALTON: Well, she really wasn't there long enough sort of thing. They didn't check everything out first before they started doing what they did, I don't think, so I'm not sure.

MR BOLSTER: Ms Wilson?

15 MS WILSON: Yes, it would have been too early.

MR BOLSTER: Too early. And we've heard what you would do in that situation, Ms Bain.

20 MS BAIN: Yes, I haven't actually come across the other people coming in to sedate an angry or aggressive person.

MR BOLSTER: You're from Victoria?

25 MS BAIN: That's right.

MR BOLSTER: Is there an intervention team in Victoria?

30 MS BAIN: There is a similar intervention team that would be called a CATT team which is a mental health team that would come in and sedate if necessary - - -

MR BOLSTER: What's your experience of them coming into the facilities that you've - - -

35 MS BAIN: I haven't come across them at all actually in any of the facilities that I have worked in, because that would be - well, it would be extreme but I haven't actually come across it personally myself, so I can't make a comment other than the type of team that would be called, yes.

40 MR BOLSTER: That leads us to another one of the big questions, and I will start with you, Elizabeth, why is chemical restraint used in residential care?

45 ELIZABETH: Because there's not enough staffing, and if you - it's really confronting and unsavoury to physically restrain people, and - and actually it's - I can't think of a time where it actually should be happening at all. So then rather than give proper care, you just sedate people so then they're not annoying you. And it's just - it's not - it's not acceptable, and I think there's one of the - one of the

scenarios where they said that they should have had a special on, one to one, and instead they tied him up. You know, they've identified that they needed a special, which means that that person needs to be a special full stop. But because they didn't have the staffing and they didn't have the money or – and that special would have  
5 been then interacting with that person and distracting them from what they were doing, then you go to chemical restraint, which is an anonymous way of doing it because people come in, they – everyone looks fine, everyone looks, you know, they're all clean and tidy and they're not crying out. But they're not actually getting – they're not actually getting the care they need and being treated like a person with  
10 needs.

MR BOLSTER: Ms Wilson, Ms Walton, are you engaged in the decision to prescribe someone because they're a problem, because they're wandering.

15 MS WILSON: No, we refer it to the nurse in charge.

MR BOLSTER: Do you – are you ever involved in asking for someone to be given something to make them easier to work with?

20 MS WILSON: We've spoken to the EN saying that there have been behaviours and that we tried different tactics, but those tactics haven't worked so then the EEN and the RN will make the decision to provide the resident with the medication.

MR BOLSTER: How commonly does that occur?  
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MS WILSON: It does occur often.

MR BOLSTER: Ms Walton?

30 MS WALTON: I agree as well. Very similar. It is common. You don't have the staff to deal with someone with that behaviour. Lots of documentation from us. We don't actually go apart from that, a registered nurse then documents and it goes above, and then it's discovered but we don't get the end result so, yes.

35 MR BOLSTER: When it comes to medication time and the blister packs or the Webster-packs or however it is – are to be distributed and you – do you take part in that process of administering the drugs.

40 MS WALTON: Yes, at our facility we – we've been – we give out the blister packs or they're a sachet – a roll of sachet.

MR BOLSTER: Would you describe yourselves as having a good working knowledge of the drugs that are being prescribed, or do you leave that to the RNs and the medical staff?  
45

MS WILSON: That's left to the RNs and the medical staff.

MR BOLSTER: Yes.

MS WILSON: I have tried to increase my knowledge in what the medications are.

5 MR BOLSTER: Yes.

MS WILSON: But we have to check the charts and check the medication to ensure that the appropriate medication is given.

10 MR BOLSTER: Would you like to know what the drugs are and the effects?

MS WILSON: Yes.

MR BOLSTER: And what's exactly happening with the residents?

15

MS WILSON: Yes, I would like to know what the reactions are to the medications, what the causes can be, you know, health-wise for them.

MR BOLSTER: How would you describe your knowledge of psychotropic,  
20 antipsychotic, benzodiazepine?

MS WILSON: Basic.

MR BOLSTER: Do you know the differences between them?

25

MS WILSON: Not a lot, no.

MR BOLSTER: And your employers don't engage with you in trying to  
communicate that?

30

MS WILSON: No.

MR BOLSTER: All right. Are you happy with that?

35 MS WILSON: No.

MR BOLSTER: Do you think it affects the care you're able to give to these people?

MS WILSON: I personally don't think as an AIN that I should be giving out  
40 medication. I think that should be the role of the EEN and the RN because they've  
had four years of training – 18 months or four years of training to learn exactly what  
the medication is and how it reacts to a person. I think my role should be providing  
the care and interacting with the resident.

45 MR BOLSTER: Ms Walton.

MS WALTON: I stronger agree with that, I've been in the same facility for 15 years. In the last couple of years, that responsibility has been taken from the registered nurse. She is fully qualified to do that and so is the endorsed enrolled nurse. They give it to a carer. You do a two day course. Here you go, here's the  
5 keys. And you've got an iPad and all you do is there's five tablets, there you go. They don't know whether that person – if they don't see that person all the time, has problems swallowing, whether it's crushed, what it has to be taken with. I've been – I've done their particular course two or three times now and it's been changed, so I am not – I'm qualified through my actual certificate IV, but not at the place where  
10 I'm employed. So in a way I'm lucky I don't have to deal with that, but if I was, I would want to know what that drug is for, I would want to know what the effects was, and you're giving it to someone that can't you consent.

MR BOLSTER: Do residents' families ask you what the pills are for?  
15

MS WILSON: Not really, no, and if they do, we refer them back to the enrolled nurse or the RN in charge.

MR BOLSTER: Ms Walton.  
20

MS WALTON: In extreme cases, yes, they do. For example, if mum is sleeping all the time, why is she, I will go and get the registered nurse so you can tell.

MR BOLSTER: Okay. Physical restraint. Elizabeth, you've seen it; what happens?  
25

ELIZABETH: Look, it's – it's appalling and it shouldn't happen and – and the only time it should – and people should be in the least restrictive environment possible. They shouldn't be tied in chairs and if we're referring to that first, where the person  
30 was tied up, that – the – when somebody is being violent with you, if somebody is really violent and trying to punch you, that's a whole different ball game to if they're being agitated. If somebody's being agitated, you can just give them some space; that's not an excuse to tie them up. And that if they – they actually are lashing out you can actually isolate them so that they're not hurting you or themselves or some  
35 of the other residents. There is just no excuse for that. And what happened – and as I was reading it, it was like there was no consent for the restraint. They forced a person who was mobile to sit for the entire time he was there, so he was deconditioning.

40 If you sit for an excessive period of time you lose muscle mass, you lose your condition, you lose the ability to walk. And people who are elderly are already in a compromised condition for that. So there I think – and – and the other thing was that they had identified that that person needed one to one, and that's what they actually needed, if they actually needed that. So – and what they've done to cut costs is tie  
45 him up because they didn't have the – the staff available. And what that did was then physically decompensate him so that when he did stand up he had a fall. Whereas before he didn't and if he had just been left to be wandering, and we had the

diversional therapist in there to help, that would have been much better. And looking at that, he was just – the agitation, you can imagine why that agitation was happening.

5 This is a person who has dementia, has been living at home with his wife in a familiar surrounding, being put in a place where there's nobody that he knows, he doesn't know what the place is. Going into hospital is bad enough if you're cognitively intact. And this is a person that couldn't process that and it's absolutely no wonder that he was agitated. There was no indication that he was being violent.  
10 So from my perspective, why on earth was he doing that? And I don't think that restraint in the elderly is – it carries with it enormous amounts of risk. It's bad enough doing it to an adult but when you start doing it to somebody who may have osteoporosis and all – and frail skin and the rest of it, and then they can slip out and choke. It's just – it shouldn't be happening at all.

15

MR BOLSTER: Ms Bain, you've seen physical restraint applied?

MS BAIN: Yes.

20 MR BOLSTER: What did you – what's your experience of that?

MS BAIN: I've seen several types of physical restraint because physical restraint can mean putting a table in front of an older person.

25 MR BOLSTER: So they can't get up?

MS BAIN: So they can't get up. They haven't got the strength to get up and push the table away.

30 MR BOLSTER: How commonly have you seen that?

MS BAIN: It's common. I've seen it in two facilities I worked at, and it is a regular occurrence.

35 MR BOLSTER: What other restraints have you seen?

MS BAIN: I've seen the actual strapping of a person using webbing around the middle area, and I have also seen a dressing gown used as a restraint by tucking it underneath the resident's buttocks and just around the waist area. And - - -

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MR BOLSTER: How recently has this occurred, to your recollection?

MS BAIN: Well, it was occurring when I was working at my – not at the last facility, it was occurring at the facility before that, so about 18 months ago, you  
45 could say.

MR BOLSTER: And on an intermittent basis or a regular basis?

MS BAIN: Regular basis.

MR BOLSTER: Daily?

5 MS BAIN: Daily. Daily, regular basis. Even with a gentleman that was calling for help, removing him to his room and shutting the door. That's restraint. There was no help for that person. There was absolutely no help and pleas from the team that I was working with were quite often not taken heed of. Sometimes taken heed of. One woman was actually restrained. She had dementia. She was restrained in her  
10 room facing to the wall, white on white. No person with dementia can see white on white. It means nothing to them. So that other people that have been talking about the facilities with white and nothing else around them is very, very significant because a person with dementia cannot see white on white.

15 MR BOLSTER: Ms Wilson, Ms Walton, physical restraint; you each have limited experience of it. Could you tell the Commission about that?

MS WILSON: In my facility we don't have it. It was – it has been removed. I think it was removed – for as long as I've been in dementia we have not restrained  
20 any residents.

MR BOLSTER: Ms Walton.

MS WALTON: Over my 15 years I've seen lots of certain restraints. It has gone  
25 from, people used to wear a vest, used to tie them to a chair so that they could move but they couldn't get up. In the bed, the same thing. Tray chairs, a similar thing, sit a person in a chair that wasn't very comfortable with a tray. That went out a fair few years ago. Cot rails were a restraint. And when we moved to the new facility there are no cot rails now. So I've seen a lot over the years.

30 MR BOLSTER: And for what behaviours were these restraints applied?

MS WALTON: Wanderers, people that didn't know what they were doing, they might take their clothes off, if they just went into other people's rooms, if they were  
35 loud, intrusive, things like that, yes.

MR BOLSTER: Not limited to people who were violent?

MS WALTON: No, not limited to people that were violent at all.  
40

MR BOLSTER: What's the standard response, in your experience, for dealing with people that are violent?

MS WALTON: Well, they call – it's usually medication, yes.  
45

MR BOLSTER: Yes.

MS WALTON: Usually medication; it goes straight to that level.

MR BOLSTER: Let me ask your perspective. One woman, 40 residents, some presumably are capable of damaging you physically.

5

MS WALTON: Which they have, yes.

MR BOLSTER: What support do you get from that from your employer?

10 MS WALTON: None whatsoever.

MR BOLSTER: Do you get counselling, do you get time off?

15 MS WALTON: It's very hard. If you have an incident where you're injured, you report it to your registered nurse, and there's an incident form to fill in, and then you go from there. So through my experience over the years, no, I've had not much help at all dealing with it. And with the after-effects. I'm on an injury at the moment and you have to fight for everything that you're entitled to through no fault of your own.

20 MR BOLSTER: Yes. Elizabeth, you at the moment care for your mother-in-law at home. How does the care that she receives from you differ from the sort of care that she received when you took her out of residential aged care?

25 ELIZABETH: I have eyes on her every day, and I know what's going on with her physically. When she was in aged care she was isolated, she didn't have the phone to ring up her friends all day.

MR BOLSTER: Yes.

30 ELIZABETH: The – they were taking her to the shower and not putting the rails up on the shower chair if that particular shower chair had the rails because they should have them. Because she's hemiplegic – she's paralysed down one side – it means she has no control over that side, and so there should be the rails so she couldn't fall out. There's also lap belts in some of the shower chairs. None of that was done and she fell onto a concrete floor. We weren't notified. There was no medical follow-up, and she had actually sustained a fracture with that. At home she – the shower chair that we use for her has the side rails so that if she leans to the paralysed side she's not going to fall. She's properly supervised.

40 She – they would only give them sandwiches for dinner and she didn't like that. She – the staff were saying that she had dementia or she was dementing because English is her second language, and they couldn't understand what she was saying, and, in fact, she's not dementing at all. There was – one of the big things is they don't give them enough fluids so she had recurrent urinary tract infections. One of the  
45 problems with urinary tract infections is you can get delirium which may or may not resolve and that delirium – a delirium looks very much like dementia except it happens in an instant. So you go – one minute you're cognitively intact and the next

minute you're not. That may remain or not. And that constant – those constant urinary tract infections can be really damaging. She hasn't had – she had one in 2005 and she hasn't had one since and that's because I push fluid all the time.

5 And in nursing homes you say to people, make sure that they can actually reach the water, make sure they have enough, make sure you check what colour their wee is, and it just doesn't happen, and you walk around and the glasses are not within reach. Even if they could, they can't get something to drink. So she has got sufficient fluid all of the time. They don't give them enough fibre in their diet and so they're  
10 constipated, and constipation makes you very, very uncomfortable. And then the appearance you give people – make your tummy hurt as she says, and when she came home I said to her, do you want the tablets or do you want a drink? Do you want to drink this glass of water? I'll have the drink. So she hasn't been on any aperients since she has been home. It's about basic constant care and having eyes on  
15 her. And when she had the – when she had the one and only urinary tract infection, I was looking at her and I thought you're looking very, very strange. And I just said to her, "Where do you live?" And she went Belmore. She's never ever been to Belmore, lived in Belmore, just straight into the hospital. And this is why you need to know someone so you can tell when their behaviour's changing. She's actually  
20 able to access the community even though that means us putting her in a wheelchair and that's lot of effort for us. But she's able to engage normally like a normal human being with the community.

MR BOLSTER: Commissioners, I can finish this examination probably in 10  
25 minutes. Would you like me to continue?

COMMISSIONER TRACEY: Yes. Continue.

MR BOLSTER: Thank you, Commissioners.  
30

Just on that issue of UTIs, Ms Wilson and Ms Walton, do you have a perspective about that and the need for hydration and to check the urine of the people in your care?

35 MS WILSON: Yes, there's a need to – as Elizabeth said, you need to keep the fluids up.

MR BOLSTER: Who does that?

40 MS WILSON: The AINs do. We do our best. We make sure that they've always got a drink there in front of them or we're always giving them a drink if they can't do it themselves.

MR BOLSTER: All right.  
45

MS WILSON: Whenever I put a resident to bed, I always check if – when they go to toilet I always try and check and make sure what the colour of the urine is, because in that way you can tell - - -

5 MS WALTON: You can tell.

MS WILSON: - - - if there's something going on.

10 MR BOLSTER: Let me ask you a care-related question. Where the resident has an English deficit, whether it's caused by the dementia or otherwise, what sort of complications does that add to the care load that you face and how do you deal with that?

15 MS WILSON: It can be hard. Sometimes you sort of try and like role play, type – I wouldn't say role play, but what would the wording be. We use cards and things like that – picture cards, things like that so I can get them to point to it, that type of thing. But I must say, I haven't had a lot of dealing with is that in our facility.

20 MS WALTON: We deal with that. We do a similar thing. It takes a lot of time. You can't rush somebody like that. We only have a picture book, if they can communicate. It's very difficult. We don't have anybody that can come in unless it's a family member.

25 MR BOLSTER: And so there's no second language assistance - - -

MS WALTON: No.

MS WILSON: No.

30 MR BOLSTER: - - - in the form of interpreters to assist at any stage that you've come across.

35 MS WALTON: No. It gets really bad. Unfortunately, you've got to ring a family member.

MS WILSON: Unless you've got other staff.

MS WALTON: That can talk that language, yeah.

40 MS WILSON: Can talk the language.

MR BOLSTER: That's a matter of luck, isn't it?

45 MS WILSON: Yes. Yes.

MR BOLSTER: I wanted to ask you each a question about the future. And what would be the things that you would like to change?

MS WILSON: I would like to see more staff in our facility. I would like to see more study and training, upskilling for staff and a better understanding of dementia.

MR BOLSTER: Ms Walton?

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MS WALTON: I'm very similar. I'm passionate about aged care, I've been in it for a long time. I come from both sides family, looking after family, family going into care and working into care. You cannot treat people like that, they need more support. You need ratios in care, one person to 40 can't do it. They need lots more communication and lots more education.

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MR BOLSTER: Ms Bain.

MS BAIN: I would like to see an increase in the education of anyone that works in a dementia unit and in aged care in general. I would like to see a palliative care organisation come in and offer information and education about the death and dying process. I would like to see a ratio of staff to residents as well. I think it's very important. The nurses and the – most staff in aged care are run off their feet. And I would like to see an additional support unit for people with dementia in regard to their – their sociology, to actually bringing them into society, into the whole realm of aged care, not just being isolated. There has to be change and that's what I'm working for.

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MR BOLSTER: Elizabeth, could I ask for your perspective and can you deal with the other matter that you wish to raise about homeless people with dementia.

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ELIZABETH: Okay. Two – one of the big things with aged care – and then I will go into the mental – the homeless. In aged care, a lot – there's no real new grade program for people going into aged care, so the RNs aren't specifically trained, and that needs to be targeted. And as the others have said, you can't provide the care. There is no way you can do it. It's just unreasonable on the current staffing. The other problem is in the homeless population – people that are homeless have mental health issues and drug and alcohol issues which make up – the people who are homeless, have a 20 per cent – 20 year lower life expectancy than other people. And I have come across people in the community. We've found them. And at 38 this man was demented from alcohol abuse, from – he was from a heavy trauma background, plus the racism on top of that. We were unable to get him into aged care because he was 38, but he was high level care, locked unit suitable.

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35

And there have been – and there are people who are borderline homeless. They're currently in housing. And because of the change, the Partners in Recovery program has been stopped and there's nothing to fill the gap. So what happens is that people who are marginalised with mental health issues and drug and alcohol issues get into housing, they're not managing because of their cognitive states going down. They're not managing, and so they can't look after themselves and the homes turned into squalor. So they get evicted into homelessness because there is now actually no support to come in and help. And when the Partners in Recovery program was there,

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you could actually come in and do a squalor clean and at least the person, even though they're deteriorating, was now not homeless.

5 And there was one particular man who was – he's just unable to help himself and his unit was putrid. And what would happen is that it would get putrid, he would be evicted and then he would be on the streets. And then somebody would find him and they would get him rehoused. There is no support for people like that. They are never going to make the age to actually access the care that they need. So I think the – I think access to dementia care should actually be on a needs base, not an age base.

10 MR BOLSTER: I've come to the end of my questions. Is there anything that you think we've missed that the Commission needs to know about that we haven't covered?

15 MS BAIN: I would like to actually suggest that there is room for a new type of dementia that includes younger people because I've worked with younger onset dementia people, or people with that early onset. There is nowhere for them to go. And there needs to be a more specific type of dementia care for people with the earlier onset which is inherited dementia. So there is nothing for them at the moment.

MR BOLSTER: We will be dealing with that in a future hearing.

25 MS BAIN: Wonderful. Wonderful.

MR BOLSTER: Was there anything else that anyone wished to raise?

30 MS WILSON: I would actually like to see mandated laws like they have in child care for – for aged care. In child care you have four to one in staff, you know, looking after children, but in aged care you don't have that.

MR BOLSTER: And one other question, what about registration of assistants in nursing and carers?

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MS WILSON: Yes, I think that's important. I think that would basically weed out the staff that don't really want to be there but they've just been put there because they've got to work, or they're being – the employment agency has put them there.

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MS WALTON: I think they do it for registered nurses and endorsed enrolled nurses. If you're in a facility that's changing constantly – these residents' health and medical needs change all the time. If you're not keeping up, you can't understand them, you need to be able to understand them. So yes, I think it's a very good idea.

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MR BOLSTER: Elizabeth.

ELIZABETH: I think there should be mandatory reporting for pressure areas, because it's not that the – because if you have a pressure area, it means that your nursing is not good enough, there's something wrong in that nursing home that is failing that produces that. If there's mandatory reporting and that reporting triggers a review of that nursing home, I think that would be good. It's sort of like testing water. You're looking for E.coli. You know everything else is in had there but you're looking for the target organism. And I think the target organism for aged care should be pressure areas. And - - -

10 MR BOLSTER: It's a proxy for good aged care.

ELIZABETH: It is. Well, it's one of the proxies. But I think as soon - - -

15 MR BOLSTER: What are the others?

ELIZABETH: Incidents, the rates of urinary infections, the rates of violence, if anybody is being restrained, it just shouldn't be happening. There are many, many other things, but I think one of the big things is just if there's a pressure area it means your system is failing and what is going on.

20 MR BOLSTER: Thank you. Commissioners, that's the examination.

MS WALTON: May I just say one more thing. I'm a great believer in accountability as well. Whoever is getting this enormous amount of money, whether it be facilities or the government giving it out or wherever it's going should be accountable to where it's being spent because obviously the enormous amount of money that is going into aged care is not going for the aged people in face-to-face care. So I realise it's a huge complex situation but it's not working at the moment. Sorry.

30 MR BOLSTER: Thank you, Commissioners.

MS WALTON: Thank you very much.

35 COMMISSIONER BRIGGS: Thank you all for your presentations. I do have a few questions and I will try to be short and sharp, recognising our timing constraints. Each of you has argued that there are insufficient staff. We've heard arguments from the industry that it's virtually impossible to specify staffing levels and staffing ratios. Do you see a way or a means to increase or think about how staffing levels might be increased in a way that a government or a provider can relate to?

45 ELIZABETH: I think the Nurses' Union has done a lot of – lot of research into what's required for nursing ratios. I think – and I think they should be looked at. I think it was 50 per cent RNs – no, 30 per cent RNs, 20 per cent ENs and 50 per cent AINs. That's not too bad and that will give you reasonable care. The ratios in the hospitals where there's some really high acuity with behaviours, you need one to three. So when you're starting to run into issues of violence, you need that sort of

ratio, plus backup staff to come in over the top of that. And I think – I think the problem is is that you’ve got people trying to manage the money and the people trying to deliver the care, and there is no appreciation across that gap about what – about why these things need to happen. And you talk to the accountants and because  
5 this is not their area of expertise, they think well, that many bodies on the ground will actually do it. When you’re looking – when you’re trying to actually deliver the care, you can’t actually do it that way. And there has got to be some sort of bridge between the people who are managing the money and the people that are delivering the care.

10 And you’re never going to get a perfect either end but it’s got to be better than what it is, because all you’re basically doing at the moment is warehousing people. And all the examples in your scenarios are what happens when you don’t have proper care and then instead of looking at it and going what – you know, the questions that  
15 should be asked in this is why wasn’t this care delivered, how were, you know, was the person available, did they have enough time to do it, what were the things that were building up that allowed this to happen in the first place? And I can guarantee you that the answer to that will, on the majority of cases, be there wasn’t enough staff, the staff was with somebody else, they missed it, they didn’t have – when they  
20 came in – there was one scenario about the person had swallowing difficulties and – and they came in from a hospital. Now, if you’ve got somebody who’s only ever worked in aged care and they haven’t had any experience or new grad program, that may not stick out to them.

25 And to highlight – highlight the deficits in care, I was actually interviewing first year registered nurses to – because they were trying to get out of aged care and I was asking them questions because I was curious, and I said to them, how do you assess – what do you assess if somebody suddenly changes their behaviour? They couldn’t give me a quick answer. I said how do you assess for a fractured neck of femur, they  
30 couldn’t tell me. The big thing in aged care is you have falls. If you don’t have people that understand that this is what you need to do, you can’t move them, you need to assess them – if they don’t even know what – how to do that and then you’ve got a problem.

35 So there has got to be some connection between the bean counters and the caregivers and there’s none at the moment. And the bean counters have got – it’s far too on the side of the bean counter and not enough on the side of care. And you just – it’s – if something isn’t actually done to stop that, then these scenarios that you’ve given us are just going to keep repeating and repeating and repeating. And it’s there for the  
40 grace of God go I that, you know, it wasn’t you on that shift that missed ringing someone or doing something because you just didn’t have the time to see them. So – and it’s not that I don’t care, it’s that you are put in a position when you can’t do anything about it.

45 COMMISSIONER BRIGGS: Okay. What evidence is there in the system that people who are working in it have a quality career path? And I take it from what you’re saying, Elizabeth, more could be done about education and training, but I was

very interested in what Ms Wilson, her career story. And I'm wondering for the extra training that you've done in the area of dementia were you provided with an extra salary which recognised that training?

5 MS WILSON: No.

COMMISSIONER BRIGGS: Right, the next question that I've got – and I will try and make this the final one – is – it's around care plans, the effectiveness of care plans and the absence of them for people who come in, as I understand it, but I could  
10 be wrong, for respite care. And we've heard some bad cases of the care provided for people who are on respite care. Are care plans successful, how often should they be reviewed, how long does it take to review them in practice?

ELIZABETH: You basically don't have enough time to breathe, let alone read a care plan, and what you're really relying on in the handover. I mean, the care plan is  
15 – if you had the time it would be good to have because it gives you the assessment, you know what the risks are you know that that person has a dry mouth, you know that they've got dental issues. Those things are highlighted to you, so that switches you – your thinking processes on and going, right, I need to make sure that's  
20 followed up.

But quite – on a completely practical level, when you don't even have enough time and you have to stay back on unpaid overtime to actually give a handover where  
25 have you got the time to read a care plan? And when you're ratio is one to 60, or you're having to do the double load for somebody who didn't come in, where can you possibly read it? So you're working blind half the time. And – and not being able to assess the person every day, you've got a problem because you can't do it. And one of the really good things that happens when you're giving out medications as a registered nurse – giving out the medications is neither here nor there, you do  
30 that, but one of the absolutely critical things that you do when you see that person is you see what state they're in, you see if they're agitated, you know what their base line is and that gives you the basis on which to actually then treat them or deal with them in the future.

35 And the other thing is if you have that relationship with people, when they are becoming agitated, you can actually use that relationship to calm people down. And I've had people who have been extremely violent and punching somebody else in the head, and because of that relationship, I was able to step in and talk to that person, even though they weren't rational at the time. There was – they were completely  
40 irrational and extremely unwell. I was able to use that relationship to get them down to – stop them being violent and get them down to just being agitated. And that has been taken away from us, that – that really critical daily assessment.

45 And when you've got 60 people, how can you even see them? How can you even see them, when you divide that by a shift? You've got to do handover. If you're lucky you will get a break, maybe. You don't even get to do that. So you're coming down to minutes and then something else will go wrong and you've got nothing and

there are days and days and days and days with those workloads when you don't actually set eyes on a person. And that's just setting the residents up for disaster and you're setting you up to lose your registration because you didn't provide care that you were supposed to. And one of the reasons my mother-in-law is still alive, 14  
5 years after being taken out of aged care, is because I have eyes on her every day. And I know if something is not wrong – if something is not going right and I can step in immediately and go right, this needs to be sorted now. So - - -

10 COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Thank you all very much. We've really heard the voice from the coalface this morning – what it's really like in institutions that care for our elderly and we thank you for that, and for your very constructive suggestions about how aged care in this country can be improved, both as to quality and to safety.  
15 We're very grateful. Thank you for coming.

**<THE WITNESSES WITHDREW [12.07 pm]**

20 COMMISSIONER TRACEY: The Commission will adjourn until 20 past 12.

**ADJOURNED [12.07 pm]**

**RESUMED [12.29 pm]**

30 COMMISSIONER TRACEY: Yes, Mr Bolster.

MR BOLSTER: Commissioners, I call Dr Juanita Westbury, who is in the witness box.

35 **<JUANITA WESTBURY, SWORN [12.29 pm]**

40 **<EXAMINATION-IN-CHIEF BY MR BOLSTER**

MR BOLSTER: Could the witness's statement, WIT.0117.0001.0001 be brought up. Thank you. Dr Westbury, is that a copy of your statement?

45 DR WESTBURY: Yes, it is.

MR BOLSTER: And do you wish to make an amendments to that statement?

DR WESTBURY: No, I don't.

MR BOLSTER: And its contents are true and correct?

5 DR WESTBURY: That's right.

MR BOLSTER: I tender witness statement WIT.0117.0001.0001.

10 COMMISSIONER TRACEY: Yes. The witness statement of Dr Juanita Westbury dated 29 April 2019 will be exhibit 3-61.

**EXHIBIT #3-61 STATEMENT OF DR JUANITA WESTBURY DATED  
29/04/2019 (WIT.0117.0001.0001)**

15

MR BOLSTER: Now, Dr Westbury, you're currently a senior lecturer in dementia care at the Wicking Dementia Research and Education Centre at the University of Tasmania.

20

DR WESTBURY: That's right.

MR BOLSTER: And you carry out, or you're involved in the course of the diploma course in dementia care; correct?

25

DR WESTBURY: It's actually the Bachelor of Dementia Care, that's right.

MR BOLSTER: One of your former students, Ms Wilson, gave evidence earlier today.

30

DR WESTBURY: That's good.

MR BOLSTER: And spoke highly of the course. Just by way of background, how many people do that degree course every year.

35

DR WESTBURY: I think – I don't have the exact numbers, I think there's about one to 200 each year. I think we've had already 90 to 100 graduates all up.

40 MR BOLSTER: What's the professional make-up of the graduates? Are they nurses, carers?

DR WESTBURY: Predominantly carers, people that are really usually very interested in improving dementia care.

45 MR BOLSTER: And from all parts of Australia.

DR WESTBURY: From all parts of Australia, and from overseas as well. We get some from New Zealand and some from other countries.

MR BOLSTER: All right. You are a registered pharmacist yourself.

5

DR WESTBURY: That's right, yes.

MR BOLSTER: And your academic area of expertise is prescribing in aged care.

10 DR WESTBURY: That's right, and old age mental health.

MR BOLSTER: And old age mental health. Right. And in that field, your specialty is psychotropic medication.

15 DR WESTBURY: That's right. I did a PhD on psychotropic use in aged care.

MR BOLSTER: All right. We will come back to your research later but I just wanted you to assist the Commission with some basic information about what psychotropic medication is, the various terms and how the system works on a regulatory level. Let's start with the word "psychotropic", what drugs does it apply to and what does the term mean?

20

DR WESTBURY: Psychotropic, really, is a term to mean drugs that actually work on the brain, the central nervous system and they affect mood and behaviour and emotions.

25

MR BOLSTER: In paragraphs 11 and 12, you refer to the drugs affecting the mind, emotions and behaviours.

30 DR WESTBURY: That's right, yes.

MR BOLSTER: And you refer to three classes, but to two main classes, and those two classes are antipsychotics, one, and benzodiazepines, the second.

35 DR WESTBURY: That's right.

MR BOLSTER: Can you describe the effect of those two classes and identify what the difference is between them.

40 DR WESTBURY: Antipsychotics – I will give you a bit of a lecture here, that's my job – antipsychotics are – they were mainly developed to treat schizophrenia. The first one was developed in about 1950; it's called chlorpromazine. And they are usually licensed and intended for use for serious mental illness. They work mainly to reduce the levels of dopamine in the brain but they also have effects on other, what we call neurotransmitters or other chemicals.

45

MR BOLSTER: Right and - - -

DR WESTBURY: They are designed to reduce psychotic symptoms, and that's disordered thought. And you see those in people with severe mental illnesses like schizophrenia.

5 MR BOLSTER: So I understand that there's two generations.

DR WESTBURY: That's right. The first generation were the original drugs, chlorpromazine. Another one is trifluoperazine but that's not available any more. Haloperidol is another one, and people who have worked in mental health would be  
10 familiar with those names.

MR BOLSTER: What was the problem with the first generation of drugs?

DR WESTBURY: The main problem – they do – they are – they can be very  
15 effective in people with schizophrenia. They can help them to function better, help delusional thought, psychosis, but the problem with them is they can cause side effects like confusion, but the main thing that came – the main thing that was observed with their use were movement disorders, things like bad tremors, muscle  
20 stiffness. And the problem is that if you use them for a prolonged period of time, you can get permanent movement disorders. There's one called tardive dyskinesia which is abnormal movement of the mouth, tongue rolling – and some people might remember maybe seeing people on public transport that would just continually roll their mouth around, and they probably had been taking these medications for a long  
25 period of time.

MR BOLSTER: Are they traditionally used in the aged care context?

DR WESTBURY: You see them every so often, particularly one called haloperidol. The thing about – the thing about haloperidol, it can be quite effective as a sedative  
30 as well. So you do see a little bit of haloperidol, it's quite fast-acting. But you're more likely to see what we call new generation antipsychotics, and they were developed late nineties, early 2000s, the names that people might be familiar with are risperidone, olanzapine, quetiapine. There's a new one called aripiprazole, and they were developed, and they have a lesser incidence of those movement side effects but  
35 if they're used for a longer period of time or at high doses, still you can see those movement side effects as well.

MR BOLSTER: Okay. And in the context of someone with dementia in aged care, what's a legitimate reason to use risperidone, olanzapine or quetiapine?  
40

DR WESTBURY: Well, the only drug that's actually subsidised and licensed for use in people with dementia to – and it's only licensed in certain instances – are the people who are severely distressed for two particular symptoms, and that's agitation, aggression, or for frank psychosis. So sometimes people with dementia especially  
45 with a type of dementia called Lewy body dementia will have – can experience hallucinations. People with Alzheimer's disease can also have quite strong delusions, as well, where they think, say, relatives are stealing their property or that

they've taken money or that their spouse is cheating or something like that. So when it's appropriate to use that – when those sort of symptoms really cause significant distress, or they cause a risk of harm. So there could be a risk of harm to the resident. Sometimes it might exert a risk of harm to other residents or to staff.

5

MR BOLSTER: Right. And the drug that is indicated is risperidone.

DR WESTBURY: That's right. Is the only drug in Australia that is actually licensed for use but only under specific circumstances, as I said, under particular  
10 distress, and when someone is at risk of harm.

MR BOLSTER: We will come back to the indication, PBS, TGA aspects of this in a moment. What are the broad risks of these drugs for the elderly person with  
15 dementia?

DR WESTBURY: Well, you know, there are minor risks. We know that all of those drugs, they will cause confusion and they reduce what we call cognition, so they can reduce the functioning of a person with dementia, they can make them  
20 drowsy, confused, and you're talking about a group of people who have problems with cognition in the first place. So you're sort of reducing their function a little bit more by giving them. They can cause as I said, tremors, movement disorders, they can cause excessive drowsiness, but what is the big concern that we have about it, about them, is that in 2004 there was a large – what we call a meta-analysis so a  
25 group, a special study looking at a number of different research papers and they reported that antipsychotics, when used by people in dementia, increase the risk of stroke.

And that resulted in a large safety warning, and I was in the UK at that particular point in time and we had to check for people taking these medications and really try  
30 to make as much effort as we could to reduce them. But in 2005 in America, there was another safety warning which linked the use of these drugs again in people with dementia to an increase in what we call all-cause mortality. So it means that people with dementia taking these drugs will die at a higher rate. They've got more risk of dying of a number of conditions.

35

MR BOLSTER: Now, later in your statement, you refer to a case that was considered by the Victorian Coroner that's in evidence before the Commission, the case of Barton.

40 DR WESTBURY: That's right.

MR BOLSTER: And olanzapine as the drug that was used and criticised in that case. Just very briefly, the criticism was directed to the falls risk that was – that  
45 faced Mrs Barton, the deceased in that matter. Could you tell the Commission about the falls risk that's apparent for people that have these sorts of drugs and in particular olanzapine.

DR WESTBURY: I don't know whether olanzapine is more highly associated with a risk of falls. We know that all psychotropic medication in older people, particularly in people with dementia or cognitive impairment, we know that all of them increase the risk of falls, so that benzodiazepines as well as antipsychotics, as well as antidepressants, and that's part of the main reason why you should be very judicious and really be thoughtful before prescribing them.

MR BOLSTER: All right. The next main category after antipsychotics, is the anxiolytics, anxiety relieving drugs, is that another way of putting it?

DR WESTBURY: That's right, yes.

MR BOLSTER: What's the difference between them and antipsychotics?

DR WESTBURY: They're a different class of drug; they work on a different neuroreceptor or different parts of the brain. They belong to a group of drugs called benzodiazepines. People might be familiar with names like diazepam, oxazepam, temazepam. And the shorter – in general the shorter acting agents are known as hypnotic agents and they put people to sleep, temazepam – people may have experienced. The ones for anxiety last a bit longer and the one I know that is used most commonly in aged care is oxazepam.

MR BOLSTER: Can we bring up, please, RCD.9999.0057.0019, please. Page 19 of that. We will come back to the document that this is extracted from, but you can see on the screen in front of you, we've got a list of the drugs that we've been talking about and may be of some assistance to the Commission and to you. So the difference between anxiolytics and hypnotics?

DR WESTBURY: Well, they're from – if you give enough of a hypnotic, it would also help with symptoms of anxiety. They're basically from the same drug class called benzodiazepines and it's about the length of time that they stay in the body, or how quick they take to exert their action. Hypnotics like temazepam are very quick acting and they will put people to sleep quite quickly. Oxazepam is known as an anxiolytic, it takes longer to work, to be absorbed but it lasts longer and so it's generally used when someone is agitated or anxious.

MR BOLSTER: Now, the third broad category of psychotropic are the antidepressants.

DR WESTBURY: That's right.

MR BOLSTER: And what's the difference, the broad difference between the antidepressants and the other two categories that we've been discussing?

DR WESTBURY: Again, it works on what we call different neurotransmitters, without giving you an all over type of description, it – when antidepressants, they work mainly to increase the level of serotonin but they work in other ways as well.

And – but you have to remember that the brain is quite complex, and variable effects in different people as well.

5 MR BOLSTER: It depends on the age too, doesn't it?

DR WESTBURY: Well, this is the issue with the use of these drugs in older people. Older people have a different metabolism. Their liver takes longer to clear these drugs. Often the renal system, the kidneys takes longer so they stay in the system for longer. And a thing about older people as well is they have a higher fat composition.  
10 You don't have as much muscle, you have more fat, and these drugs, to get into the brain, they have to be what we call fat soluble, and so in older people who have a higher level of fat and not as much muscle they tend to stay in their system for a lot longer.

15 MR BOLSTER: Right. The risks for people with dementia of antidepressants?

DR WESTBURY: There's quite a bit of debate about whether they're even effective at all, and the risks with this particular class is that some of them can cause sedation, but also we do know that nearly – out of all the psychotropics, they tend to  
20 have one of the highest falls risks.

MR BOLSTER: So you're familiar with one of the summaries of facts that have been compiled by the Commission staff concerning a lady who was prescribed mirtazapine.  
25

DR WESTBURY: That's right.

MR BOLSTER: Would you like to comment on the dose of mirtazapine for a woman of that age?  
30

DR WESTBURY: She was prescribed 45 milligrams as a starting dose. You wouldn't give that dose to a young 25-year-old who had never been exposed to it. The normal starting dose would be – probably the maximum would be 15 milligrams. I - - -  
35

MR BOLSTER: Is there a rule of thumb for older people and a starting dose?

DR WESTBURY: With all the psychotropics in general it's recommended that because they are more sensitive to them and they stay in their systems longer that  
40 you generally start them at a lower dose than you would in a healthy young adult. The rule of thumb is about half the dose, but you really should be monitoring the effect. If they're excessively sleepy you really should be, you know, changing that dose quite quickly.

45 MR BOLSTER: Okay. All right. So if you were the pharmacist who was given the script for that particular drug, even if the doctor did not consult with you, what would your reaction have been?

DR WESTBURY: Well, with – as a pharmacist in a community pharmacy, you have prescribing software and really, with these sort of drugs, you should check whether they've been given out before. And if they haven't, it's important to ring up and check, you know, is this the first dose. If I found out that this was for an 84-  
5 year-old person who was a resident in a nursing home first off, I would be ringing up the doctor and just saying that the recommended dose is 15 milligrams and that I'm just informing her of this. Usually the doctor would go whoops and change it.

10 MR BOLSTER: In practice, have you had to do that?

DR WESTBURY: I have done. I've practiced as a community pharmacist and as an accredited pharmacist working in aged care, and we do draw attention to high doses.

15 MR BOLSTER: Can you give us an example of the sort of situation where you do intervene for an elderly person.

DR WESTBURY: I think it's not only about high doses, it's about interactions. If someone is taking – you know, if someone is taking a particular drug that may, for  
20 example, some antidepressants interact with statins, which are cholesterol drugs, I have encountered that and I've contacted the prescriber. And generally, you know, 99 per cent of cases, they're really, you know, happy to have this drawn to their attention, you know, because it protects them but, you know, usually they're trying to do the right thing for their patient.

25 MR BOLSTER: Now, how are these drugs classified under the Therapeutic Goods Act?

DR WESTBURY: The psychotropic drugs?  
30

MR BOLSTER: All the psychotropics we've been talking about, yes.

DR WESTBURY: Under the Therapeutic Goods Act, the vast majority of what we call schedule 4 which means that they have to – they can only be supplied if a  
35 prescriber writes a prescription for them. In most cases, it's a medical practitioner, but increasingly we have nurse practitioners who have prescribing rights and they can prescribe them as well.

MR BOLSTER: When a drug is registered under the TGA, they're registered in  
40 respect of certain indications.

DR WESTBURY: That's right. An indication is basically a reason why something is prescribed and you've got approved indications, that's right.

45 MR BOLSTER: And so what is an indication?

DR WESTBURY: I just said that, I think.

MR BOLSTER: Sorry.

DR WESTBURY: It's a reason why something is, why a drug is prescribed.

5 MR BOLSTER: All right. Are drugs ever prescribed when there's no indication?

DR WESTBURY: Very commonly.

10 MR BOLSTER: Is that what we call off label use?

DR WESTBURY: It's called off label or off licence use and I think off licence use is a term that's more commonly used in the US.

15 MR BOLSTER: And so, for example, if we go back to the antipsychotics.

DR WESTBURY: That's right.

MR BOLSTER: There's only one of those drugs that's indicated.

20 DR WESTBURY: That's risperidone, that's right.

MR BOLSTER: When the other antipsychotics are used for someone with dementia is that what we call off label use of the drug.

25 DR WESTBURY: Yes, you would call it that but it is the prescriber's discretion whether or not to use that or prescribe that.

MR BOLSTER: The Pharmaceutical Benefits Scheme as a role to play.

30 DR WESTBURY: That's right, yes.

MR BOLSTER: To gain a subsidy for a particular drug does the use have to be indicated?

35 DR WESTBURY: I think there's a complex now. I'm not an expert in how to get a drug on the PBS, but there is a process where the drug company has to apply. It goes to a committee. And usually to be able to be subsidised or to meet the criteria for subsidisation, there has to be evidence that it's effective, there has to be considerable safety evidence as well.

40

MR BOLSTER: So what are the risks, then, that are associated with off label use of medicines, in a general sense?

45 DR WESTBURY: In a general sense, really there may not be – there's likely not to be a lot of evidence supporting its use. There may be safety concerns that have been highlighted that prohibited its listing on the PBS as well. It's generally, I suppose, less regulated use.

MR BOLSTER: Are there greater risks of side effects in the off label use?

DR WESTBURY: There can be, that's right.

5 MR BOLSTER: All right. We've heard about risperidone being indicated. What about the other crosses of psychotropics? Are any drugs in those classes indicated for other treatments for people with dementia.

10 DR WESTBURY: I think you've really got to treat each resident or person with dementia as an individual. You have to realise that some of these people, before they actually developed dementia, had mental illnesses that may still require treating. So you can't just say as blanket use that you can't use them. Every person has to be individually assessed, you know, as with – in mind of their medical history as well.

15 MR BOLSTER: All right. I want to ask you a very hard question now. It goes to paragraph 20 of your statement. Why are these drugs used in aged care? Let's leave aside the obvious mental health issues, the schizophrenia, the pre-existing mental health problems where we can assume that there's a safe indication in use for the drugs. But why are they otherwise used in residential aged care?

20

DR WESTBURY: I'm going back – I did a PhD in this. I actually received the PhD in 2011 but I started it in 2007. And there were three key components of it. Firstly, I wanted to see what was being used in aged care homes, but the second sort of addresses your question where I wanted to find out why they're used as much as they are. I did quite a bit of literature review, which wasn't very conclusive, so part of my research I went out and I interviewed people in aged care homes. And I interviewed 40 of them as part of this study. After my PhD, I conducted a series of focus groups. And we also had follow-up focus groups from the intervention project that I did as well.

30

So I've interviewed over 50 nursing staff, I've interviewed GPs, pharmacists and relatives to really try to get to the bottom of this, or try to sort of increase the understanding behind why they're prescribed. And I think, you know, I had – I had a couple of questions, research questions at the time. I wanted to know why they were prescribed, and secondly, I wanted to know who was the key influencer or who was the people for the professional group that was really responsible – not responsible so much, but the key influencer might be the better way to describe that.

40 So I had a case study that I went – that I used, as well, as part of my work. And I went through the case study and that was just to tease out people's attitudes. So I think – I think in general – firstly, I think that in terms of the nursing staff, when I spoke to them about why they – why these medications were prescribed or were needed, they – in general, most of the staff were very supportive of their use and they felt that they were necessary to provide comfort and to calm residents. And I think, 45 you know, one of – a quote was surely it's better to have someone calm and cosy than to have them agitated and upset. So I think underlying this is a belief that

they're doing the right thing, that they're medically treating a behaviour in a lot of cases with people with dementia.

5 I think doctors in general had a strong belief that they were probably more effective than the evidence suggests, as well. And most of the doctors that I spoke to kept on emphasising that they were only using them at very small doses and that really at that minimal dose, surely they wouldn't have a high risk of side effects. Some of the doctors told me that they felt a lot of the risks were overblown, overpublicised, and again they justified use by saying that they only used a small amount. Relatives that  
10 I spoke to often weren't consulted before the medications were started. A lot of them said the first time they found out that their – their relative or their mum or their dad was taking these medications was when they received their pharmacy bill. And pharmacists, as well, who worked in the sector often said that they encountered real resistance to actually reduce the overall use, because a lot of the staff were quite  
15 concerned that behaviours would return or be escalated if the use was reduced.

MR BOLSTER: Your research has been paralleled by other academics around the world.

20 DR WESTBURY: Yes, there was a very good, what we call a systematic review, which, again, is a collection of studies. It was done by Kieran Walsh and published in 2017.

MR BOLSTER: Would you go to paragraph 21.  
25

DR WESTBURY: Yes. And I think he looked at 18 studies in whole. And I've listed the reasons that he concluded. Would you like me to - - -

MR BOLSTER: Yes, please.  
30

DR WESTBURY: Firstly – and this is specific to prescribing antipsychotics. My research that I did as part of the PhD wasn't only antipsychotics, so this was for some particular group. He said the reasons are that there was understaffing and insufficient to time to engage with the residents and staff. There was – and that  
35 resulted in less assessment and an inability to perform other strategies apart from using medication. There was staff inability to deal with the severity of the behaviour of some of the residents. There was a lack of training on other ways to manage changed behaviours, and that often led to pressure on prescribers from staff to initiate antipsychotics.  
40

There was poor knowledge of prescribers and the staff itself on the risks and benefits of this medication. There was poor communication between health care teams and with families. I think one thing that he stressed and I found as well, there was uncertainty regarding whose responsibility it was and whose role it was to review  
45 and to, I suppose, monitor the use of antipsychotics. And, again, as I've found, a fear of recurrence of the behaviour if the medication was changed.

MR BOLSTER: Right. Could we then turn to the question of how appropriate they are in aged care in Australia, and if we could go perhaps to paragraph 14 through 17 of your statement. If you could - - -

5 DR WESTBURY: Right.

MR BOLSTER: - - - summarise the key criticisms that you've been able to identify from your research about use.

10 DR WESTBURY: This isn't only – I would love to say it's all my research. I have had credit, there has been quite a body of research that has been conducted. One – as I said at the beginning of my PhD, what I tried to do was to investigate the pattern and appropriateness of use, guidelines say that antipsychotics, in any case, need to be reviewed every three months. The PBS stipulation for risperidone is that it is only  
15 used for a maximum of three months. But what I found in my research when I went, when I compared one year's worth of prescribing to the next years' worth of prescribing, there was very little change. Over two-thirds of residents were taking exactly the same medication at exactly the same dose. And other studies have found a similar pattern.

20 There was – there's a study called HOLT, which you will probably hear about later as well. That was conducted in New South Wales homes. He found that the duration of use of antipsychotics was 2.1 years, and that's quite different from the recommended three months. With benzodiazepines, again, I compared year to year  
25 use. I found there was very little variation. In fact, benzodiazepines were less likely to be altered than antipsychotics. Dosages – the dosages, as the doctors were alluding to, were on the low side apart from benzodiazepines, and in that case they were often used at higher doses than recommended. So we're talking about too long use, too high doses in some cases, but I think another thing that I did find, you can  
30 see that graph that's up there.

MR BOLSTER: Big graph.

35 DR WESTBURY: My pink graph. Basically, what I wanted to say every line on that graph represents an aged care home in a subsequent study I did. And it represents 150 homes in six States in Australia and in the ACT. There was six homes in the ACT. And what I tried to illustrate there was the marked variation in use. You had – this is antipsychotic medication rates. So in some homes you had 45 per cent of residents taking an antipsychotic every single day, but on the other end of  
40 the scale you had some with six per cent of residents. I have to say with that sample, none of them were dedicated what we call psychogeriatric homes. They didn't have a higher than average number of residents with severe behavioural problems. So I think the question that I had – and these studies have been shown around the world as well – how can some homes operate on six per cent and other homes operate with  
45 45 per cent of their residents. And it really speaks to what I call a prescribing culture in the home where some homes are very quick to rush to the medication for management, whereas other homes are much more prudent.

MR BOLSTER: Commissioners, I note the time, I will be some considerable time. Perhaps now is the time for the break.

COMMISSIONER TRACEY: If you wish to complete a topic, please feel free.

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MR BOLSTER: I think that is a convenient point.

COMMISSIONER TRACEY: It is a convenient time.

10 MR BOLSTER: To stop.

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

15

**ADJOURNED** [1.02 pm]

20

**RESUMED** [2.06 pm]

COMMISSIONER TRACEY: Yes, Mr Bolster.

25 MR BOLSTER: Thank you, Commissioners. Could tab 33 be brought up onto the screen, please. Dr Westbury, this is a paper that came out in May of last year, which records certain aspects of your research over a very long period of time. The research began when, in 2010?

30 DR WESTBURY: This project was funded in 2013 but we started the project in 2014.

35 MR BOLSTER: Right. Now, the description of the project is a multi-strategic program comprising psychotropic medication, audit and feedback, staff education, and interdisciplinary case review at baseline and three months final audit at six months.

DR WESTBURY: Right.

40 MR BOLSTER: Correct me if I'm wrong, this is an engagement with the staff.

DR WESTBURY: It involved – we targeted the project at the key people involved with prescribing in aged care facilities.

45 MR BOLSTER: These are the 150 nursing homes that you referred to before lunch in the pink graph that you took us to.

DR WESTBURY: That's right, yes.

MR BOLSTER: Okay. If you can go forward, please, to table 3 on page 6386, if we can just call out that table.

5 DR WESTBURY: Right, that's – what that shows are the baseline measurements of psychotropic use and the effect of the audit, education and review at three months and at six months. And the little P mark at the end is, for those people who aren't researchers, it indicates statistical significance.

10 MR BOLSTER: Right. And that the lower the number, the greater the statistical significance; is that correct?

DR WESTBURY: That's right. They're all quite low and all of those are statistically significant.

15 MR BOLSTER: It was a very large study.

DR WESTBURY: That's right.

20 MR BOLSTER: 1200 residents.

DR WESTBURY: That's right, 12,157.

25 MR BOLSTER: 12,000, sorry. And can you talk us through the education side of this, the program that enabled you to achieve a reduction in a very short period, that is, six months.

30 DR WESTBURY: In a six month period. I was lucky enough as part of the project to have an educational consultant who helped with the design of the education. It was two components really. First, to be able to enact behaviour change you have to really challenge beliefs underlying that behaviour, a bit of behavioural science here. So we identified that one of the key beliefs of the nursing staff in particular was that these medications were effective, more effective than the evidence suggests. And so we tried to challenge that belief. So we tried to – by giving a case study, what we tried to do was to actually ask the staff what was quality of life in an aged care home, and we did that as part of the training. It was very interactive.

MR BOLSTER: So there's presumably some course work, some material, some information sheets.

40 DR WESTBURY: It was – it was a very short – you don't get access to staff in an aged care home for very long periods. It was two one-hour sessions of the staff. We also educated pharmacists who were delivering the training and we also educated a champion nurse. That was a key component of the project and that nurse was either an RN, sometimes an EN and that person was our point of contact with the home. And I think I alluded to, there was GP education and we call that academic detailing. That was offered to GPs.

MR BOLSTER: So if we see there, this table deals with antipsychotic and benzodiazepine prescribing.

DR WESTBURY: That's right.

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MR BOLSTER: You were able to achieve significant reductions over just a six month period.

DR WESTBURY: When we grouped all the homes together, in terms of antipsychotic use we achieved a 13 per cent reduction in overall use and our reduction in benzodiazepines use as actually higher, and that was 21 per cent all up.

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MR BOLSTER: If we can go over the page, please, to a table dealing with antidepressant prescribing, that's table 5, you were able to achieve a similar reduction.

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DR WESTBURY: We didn't have a significant reduction in antidepressants. We didn't target antidepressants as part of this project. And there are a number of reasons for that. But we did show a slight reduction but it was not statistically significant.

20

MR BOLSTER: All right. What about PRN prescribing. What do your results demonstrate about that - - -

DR WESTBURY: Just to explain, PRN stands for pro re nata, it's a Latin term and it means "when required". In an aged care home you have two prescribing charts: one is regular so that's given every single day. The other one is PRN medication and, really, when it's on that list it's given as required. So when it's on that list the staff decide, mostly and hopefully nurses decide when it's to be given.

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MR BOLSTER: If we can just go to the conclusion on the same page there, to the last five lines on the right side of the page. You made the claim that:

*It led to statistically significant reductions in the prescribing of antipsychotic agents and benzodiazepines for residents and the program should be made available to all residential aged care facilities to reduce the inappropriate prescribing of psychotropic medications.*

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DR WESTBURY: That's right.

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MR BOLSTER: And you maintain that position to this day?

DR WESTBURY: You know, we could improve on it but it certainly did make a difference. It was well received by staff and I still have demand – I still get requests from staff, from homes, from pharmacists, can we please do the reduced program, and that's three years after it has finished.

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MR BOLSTER: Now, that process was funded by the Commonwealth.

DR WESTBURY: That's right, yes.

5 MR BOLSTER: And did you apply for further funding?

DR WESTBURY: I did. I – I applied as part of what we call a community pharmacy trial, that's right.

10 MR BOLSTER: And were you successful?

DR WESTBURY: No, I wasn't.

15 MR BOLSTER: All right. The final report in relation to your research, was that provided to the Commonwealth?

DR WESTBURY: Yes, it was provided and I received a letter saying it had been accepted in full and that was in 2017.

20 MR BOLSTER: Has the Commonwealth taken any action to implement the contents of your report to it?

25 DR WESTBURY: The project has been – I suppose it was spruiked by the Aged Care Minister, Wyatt, and that was at the AAG conference in 2016. It has been mentioned in no fewer than three fresh reports but, no, it has not been implemented or no funding has been received to continue the project.

30 MR BOLSTER: All right. We will come back to that in a minute but can we bring up, please, tab 49. This is a paper that you put out this year.

DR WESTBURY: That's right, yes.

35 MR BOLSTER: Which is slightly different from the earlier paper we were looking at.

DR WESTBURY: Yes.

MR BOLSTER: It looks at a longer time period.

40 DR WESTBURY: It – what we did, with this paper, I realised that there are no national studies of psychotropic use in aged care. There is no nationally available data. There has been smaller studies, but they've been confined to just one State on the whole. So this is the first national audit of psychotropic use to my knowledge that's been published in Australia and it gives a snapshot of use, that was in 2014 and  
45 2015.

MR BOLSTER: All right. If we could go, please, to the first table, or figure 2 on page 0132, that shows the location of the facilities that you covered in your study; correct?

5 DR WESTBURY: That's right, yes.

MR BOLSTER: And how many facilities are we talking about?

10 DR WESTBURY: There were 150 facilities that were involved in the project, but I only was able to obtain complete prescribing data for 139, so it's 139 out of 150 of my sample.

15 MR BOLSTER: So do I take it there's a correlation between the original 150 in reduce and this 150?

DR WESTBURY: For 11 homes, because of – we – we actually designed a computer program. Because staff and pharmacists going to aged care homes are really time poor, we developed a data mining tool that collected information. It didn't work completely in 11 homes, and that's why.

20 MR BOLSTER: If we could go, please, to figure 3 on page 0136, just a couple of pages after that – that one – and figure 3n which is the graph at the top of the page.

25 DR WESTBURY: Yes.

MR BOLSTER: If we could just look at that for a moment. On the left we have benzodiazepine use by State.

30 DR WESTBURY: That's right.

MR BOLSTER: And on the right we have antipsychotic use by State.

35 DR WESTBURY: That's right, yes. We used Queensland, sorry, we used Queensland as a comparator State. And the reason we did that is that we have a higher number of participant homes in Queensland than any other State. No reason, it's just the way it fell.

MR BOLSTER: So compared to the original study, this is a prevalence study.

40 DR WESTBURY: That's right. It's a baseline information of what we found before the project started.

MR BOLSTER: So it wasn't an education campaign like the original study.

45 DR WESTBURY: No, no, this was just what we found as our very first measure.

MR BOLSTER: Can I just observe a couple of things about the study. In South Australia, it seems to be an outlier when it comes to benzodiazepine use.

5 DR WESTBURY: A much higher – significantly higher rate of use.

MR BOLSTER: What do you attribute that to?

10 DR WESTBURY: That has been shown in other government information. There is, I think, Australian Institute of Health and Welfare study, alcohol and drug rate study as well, lower socio-economic profile of the population. I think another reason is, for some reason, prescribing benzodiazepines is more endorsed there. And you can see, if you have a look at the antipsychotic use of South Australia, it's one of the lowest, so it's like they almost use – pick your poison.

15 MR BOLSTER: From what I can understand from your report, you seem to think that the two rates for South Australia in combination suggest that one is being used at the expense of the other.

20 DR WESTBURY: That's right. There is use of alternate agents, that's right.

MR BOLSTER: Wouldn't that suggest very much that these drugs are being used for sedating purposes rather than the clinical purposes for which they were originally intended?

25 DR WESTBURY: I think you could perhaps make that conclusion, that's right.

MR BOLSTER: The other thing that jumps out, you rightfully point out, is the position in New South Wales where benzodiazepine use is markedly different from the rest of the country.

30 DR WESTBURY: It's much lower and in the ACT as well, actually, that is the lowest.

35 MR BOLSTER: And you have an explanation for that, don't you?

40 DR WESTBURY: Yes. There was a lot of media attention on this issue. This issue isn't new. Overuse of psychotropic medications has been reported. First of all, it was highlighted by the Sydney Morning Herald, I think, in 1995. And what happened – there was a New South Wales task force, and because of that task force there was enhanced attention on this issue. New South Wales Health, I know, have a division that specialises in educating people about overuse of benzodiazepines and other medications.

45 MR BOLSTER: How do they do that? What's the secret with that program?

DR WESTBURY: They have released a number of guidelines. I think they have psychogeriatricians who are very active. I know New South Wales – the University

of New South Wales has quite a few psychiatrists, old age psychiatrists who are very active in this field and have influenced prescribing.

MR BOLSTER: We will be hearing from Professor Brodaty on Friday.

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DR WESTBURY: He's one of them, yes.

MR BOLSTER: Are you aware whether the curriculum is different in New South Wales for medical training?

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DR WESTBURY: I'm not. Sorry.

MR BOLSTER: I just wanted to ask you, then, about something that Mr Murphy – Professor Murphy said yesterday. If we can bring up transcript reference 1659 at line 41, and he had this to say – do we have that? Page 1659, the foot of the page and this was – he was speaking yesterday in relation to reducing psychotropic prescription, and he said:

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*The broader strategy is, again, to identify all of the doctors who work in aged care and target them with educational material. Now, that's very hard to get educational material to GPs, and we're looking with the college and other people at how we do that. We're thinking of even targeting them with short, sharp video messages from me that point out to them that, you know, if they are continuing to prescribe in a manner which is not based by the evidence and if they're not getting proper informed consent they're exposing themselves significantly to allegations of inappropriate and unprofessional practice. So we want to push that method out there.*

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He then adds that he wanted to do this in the context of cultural change. You've had a chance to review what he had to say. What would you say to Professor Murphy about your report of your reduce program that was provided to the Commonwealth some years ago?

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DR WESTBURY: I – I'm going to be very honest here. I don't think he's got a complete understanding of the issue. I don't think the answer is educating GPs. If you talk to – it might be part of the answer, but if you talk to all the GPs that I spoke to, they said that they are asked for these medications by the nursing staff. So I think that it isn't a quick fix of just educating or providing guidelines, because there are plenty of guidelines in this space, to GPs. I think it speaks to also educating aged care staff, but also providing support for them, for appropriate assessment. Support, also, in terms of staffing to be able to apply nonpharmacological strategies.

45

But I would also say that in terms of the reduce project, we produced very short, succinct guidelines for GPs. We asked each home to identify their top 10 prescribers, and those prescribers were sent – we had a brief guideline that I produced here, that was part of the project validated by the National Prescribing Service. It was edited, also, by the aged care industry. So they were sent this. Each

GP that was identified as well was offered what we call academic detailing, and that was part of the project. And academic detailing is like when you get a drug rep, they go out to the doctor, and the drug rep will tell them about their particular product. With academic detailing, it's a trained professional and this person either came from  
5 ..... or they came from the National Prescribing Service, medicine-wise. They are trained to talk to GPs about appropriate prescribing. And that was actually delivered as part of the reduce project.

10 MR BOLSTER: Thank you. Could we obtain a copy of the chart that you were - - -

DR WESTBURY: Yes, it's just a simple two page – it's just a brief summary of the guidelines and suggestions to reduce use.

15 MR BOLSTER: If we could get a copy of that, we will tender it in due course. I wanted to change tack slightly. You're familiar with the fact that from 1 July of this year there will be a new set of eight quality standards.

DR WESTBURY: Yes.

20 MR BOLSTER: For residential care. And they will replace the current four standards and 44 expected outcomes.

DR WESTBURY: The accreditation standards at present, that's right.

25 MR BOLSTER: Have the current accreditation standards been have any use, in your opinion, in tackling, reducing physical and chemical restraint?

30 DR WESTBURY: I was quite concerned when I looked at them because there are no specific directions or, I suppose, guidelines or instructions regarding what even is restraint, or what's defined as restraint. There's a brief mention of what we call restrictive practices. That was in the original draft.

MR BOLSTER: Are you talking about the new - - -

35 DR WESTBURY: The new standard, that's right.

MR BOLSTER: I'm just talking about the current ones at the moment. Do the current ones achieve anything in terms of restraint, chemical restraint?

40 DR WESTBURY: They do give some guidance but not much, no.

MR BOLSTER: All right. When the currently planned guidelines or standards were being drafted, were you engaged in that process?

45 DR WESTBURY: Yes. I was asked to be a subject expert for framing guidance on restrictive practices, or the practice of restraint, for the new guidelines that are coming into effect on 1 July.

MR BOLSTER: And if we could bring up RCD.9999.057.001. That was a submission that you made as part of that process?

5 DR WESTBURY: That's right. I – I had to – I saw a call for subject experts and I applied and I produced materials for the Department of Health, the area that relates to the standard production.

10 MR BOLSTER: And the focus of your submission – I won't take to you it in any detail – was to give advice about the way in which the standards could be drafted to do something about chemical restraint; correct?

15 DR WESTBURY: That's right. There are various sections of the standards. There are the – the main ones that are produced, but there's also guidance material for aged care providers and clinicians within the aged care industry. And I was asked to advise on that and also to provide suggestions for what could be done in the new standards.

20 MR BOLSTER: Do I take it you were given drafts of the standards and asked to comment and - - -

DR WESTBURY: I didn't get an awful lot of direction. I was just sent an example of the first draft. I think it's the first standard. And I was told to model it on that.

25 MR BOLSTER: And did any of your advice about chemical restraint end up being reflected in the final - - -

DR WESTBURY: Not a single word.

30 MR BOLSTER: I tender RCD.9999.0057.0001.

COMMISSIONER TRACEY: The submission made by Dr Westbury relating to aged care quality standards will be exhibit 3-62.

35 **EXHIBIT #3-62 SUBMISSION MADE BY DR WESTBURY RELATING TO AGED CARE QUALITY STANDARDS**

40 MR BOLSTER: The next issue I wanted to discuss were – are the changes to the principles that were announced this year. And you've had a close examination of them, I take it?

DR WESTBURY: That's right, yes.

45 MR BOLSTER: Will they work? Will they achieve anything when it comes to chemical restraint, in your opinion?

DR WESTBURY: I don't think they will make much difference. I think they're very soft and there's lots of caveats on them. As in they say there is no informed consent required to use these medications or stipulated. It just says that it's advisable to inform the resident or their legal proxy that they've been used, if possible, yes.

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MR BOLSTER: The – they seem to be completely silent on the question of consent.

DR WESTBURY: Not for physical restraint. Physical restraint, I think they're framed very well and there are protections and safeguards and informed consent is required. There's proper assessment required. There's monitoring required. And there's also a stipulation that they have to be used for a maximum period of time, or that has to be set down. For chemical restraint, it's the opposite. It's – there doesn't seem to be monitoring stipulated, there is no maximum period stipulated. Assessment is not – it is mentioned, but it's not stipulated. And it seems like, in a way, it endorses the use of chemical restraint as opposed to physical restraint, and it's quite concerning.

MR BOLSTER: Did you happen to read Professor Murphy's comments about the intention behind this – the framework or the definition of chemical restraint when he gave evidence yesterday?

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DR WESTBURY: I could do with a refresher if you don't mind. I did read it but  
- - -

MR BOLSTER: If you could go, please, to – I will just see – let me see if I can summarise it for you. Assume that his position is this: that the chemical restraint that's defined in the regulation, or in the principle is in relation to the manifestation of a physical behaviour by the resident, the typical behaviour you might associate with someone who had schizophrenia, actual physical behaviours, actual violence, as opposed to more passive behaviours, such as wandering or perhaps anxiety or irritation or that sort of thing. So in a sense he seeks to narrow the meaning of medical treatment to what might be called a traditional mental health issue or manifestation of a mental health condition. Do you gain any comfort from that sort of approach to the interpretation of the principle?

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DR WESTBURY: I think it just shows that there are varying interpretations of what chemical restraint is. And I just – when – when I conducted my research project, I was trying to recruit aged care homes and I was interviewing staff as part of the research that I've done. I tried to avoid using the word "chemical restraint" because I felt that it imposed blame. But I have to say that directors of care, and more than a few would tell me categorically that they did not have any chemical restraint and nor was chemical restraint ever used in their home. And the thing is I knew that some of the homes were using 70 – 75 per cent psychotropics, that the majority of their residents were taking these medications. And I tried to ask them why, you know, why don't you use chemical restraint and they said, well, because the people that they're prescribed for have dementia and so therefore, in their understanding and their interpretation, dementia is a medical disorder. Dementia is deterioration of, you

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know, the nerve cells in the brain. And in that case it was perfectly justified by the definition of “chemical restraint” to use them.

5 MR BOLSTER: What would be your approach, what would be the philosophy that you would adopt to regulate this field?

10 DR WESTBURY: Well, I think it’s really about whether psychotropic medication is used appropriately or not, and I think it can’t be – you can’t say all psychotropic medication is chemical restraint or psychotropic medication used in someone with dementia is chemical restraint because there are times when someone is severely agitated or, you know, has a psychosis or a delusion that really distresses them or causes a risk of harm that it’s inappropriate to not use a psychotropic medication. But it’s following the guidelines, it’s whether the use is appropriate or not, and there are a number of guidelines that stipulate when it’s appropriate or not, and there has been proper assessment, other things have been tried, monitoring is done  
15 appropriately.

Monitoring for effect and monitoring for adverse effects and continual review, and when someone has settled down because people with dementia do progress and sometimes a behaviour that they might show at one period of time will get – will reduce in intensity or disappear completely in a couple of months. So you need to review whether that medication is necessary at that time and then, you know, reduce the medication with the hope for eventually cessation.

25 MR BOLSTER: That’s all the questions that I have. Was there anything that you wanted to let the Commission know about that you think is important in this area?

30 DR WESTBURY: There is one – one area. The research project that I did, the implementation project, when we put out a call, we – we engaged heavily with the aged care advocacy bodies, that’s LASA and ACSA. They put out a call for participation. We had 50 homes already who had committed before their call and we needed 100 homes. We had over 320 homes contact us in two weeks to want to be involved, because I think there is a willingness and an awareness that this is an issue, it has been an ongoing issue and there is a demand for quality education and for a program and support to do something about this. So it isn’t completely hopeless and you don’t have to accept this situation. There are things we can do and we showed that this sort of approach, interdisciplinary with a number of strategies really can work quite effectively.

40 MR BOLSTER: Those are my questions. Thank you, Commissioners.

45 COMMISSIONER TRACEY: Doctor, we’ve heard evidence of instances where educative material from medical bodies and from the Department of Health have been sent to aged care centres, and have simply languished in the in-trays of administrators and haven’t come down to the staff. We’ve heard some evidence as recently as today of staff members who say they haven’t even got the time to examine individual care programs to inform themselves as to how best to look after

an individual patient. And one infers that if such material had come down through the system, they simply wouldn't have had the time to examine it and be assisted by it. I'm interested to know whether the willingness to engage that you found when you asked for homes to participate carried over to when you produced the final  
5 report, the educative parts of it, and whether you found a willingness to engage with the findings and whether that led to, in part at least, the reduction in the overprescribing that you had found?

10 DR WESTBURY: Are you saying engagement once I got in the home?

COMMISSIONER TRACEY: Yes.

DR WESTBURY: And the participation of the staff?

15 COMMISSIONER TRACEY: Yes.

DR WESTBURY: It was very good. There's a couple of reasons for this. I think first of all it's an issue that people are interested in, that the staff are particularly interested in. I think there was a real willingness for – and there's a hunger for  
20 education. I had staff saying look, I'm too busy dishing out the medications to know actually what they are. And so this – we often – we also – the educational session that we provided was also provided by a pharmacist, and that pharmacist was often known to the staff so it was someone who they were familiar with. It was face to face, it wasn't just e-education or a piece of paper. We tried to make it also  
25 interactive as possible. So we questioned staff and we wanted to encourage debate and we usually had – it really did involve spirited debate because you had some staff saying these drugs are necessary, and then you had other staff saying well, maybe there's a better way, and even that discussion made people think and hopefully impacted the behaviour.

30 COMMISSIONER TRACEY: On a related but separate matter, does your university advertise the availability of your bachelor's course widely within the aged care industry?

35 DR WESTBURY: Is that the offering from Wicking or the offerings of my particular project?

COMMISSIONER TRACEY: No. I'm thinking about the – we heard from a lady  
40 this morning who had done an online course for a bachelor's degree.

DR WESTBURY: I'm a lecturer on that course and we do advertise widely. And it is readily available, and we try to subsidise it for – for people as well.

COMMISSIONER TRACEY: Well, it just links into the comment you had made  
45 earlier about there being a hunger for proper education by people engaged in providing aged care services, and I would like to think that your course was well known within the industry and people were encouraged to participate in it. One last

question, and it's totally unrelated to the earlier ones, it's this: what of the side effects of psychotropic drugs makes people more prone to falling injuries?

5 DR WESTBURY: They say it's to do with – see, when you take psychotropic  
drugs, I'm going to group them all together which I probably shouldn't but I will,  
you – it impairs the way that the brain works. And it's not only in thinking, it's also  
in the way muscles work as well and interact. So it's about movement as well. So  
you're slowed in movement. Your perception is different as well. And also it – what  
10 we find is that if an older person is on these medications, and often they're on more  
than one as well, it sort of groups together as effect and if they get up quickly, they –  
you just get a rush of blood and you just lose your balance. And it just affects the  
central nervous system that way.

15 COMMISSIONER TRACEY: Anything arising out of that?

MR BOLSTER: I just wanted to indicate Commissioners that the University of  
Tasmania has put in a submission which is in the general tender bundle which deals  
with the issues I think you were raising.

20 COMMISSIONER TRACEY: Thank you for that. Dr Westbury, thank you so  
much for your evidence. We've learnt an enormous amount about the chemistry that  
affects so many of the older residents in the last hour or so, and we're enormously  
grateful to you for sharing your expertise with us. Thank you.

25 DR WESTBURY: Thank you. I just wanted to also thank the Commission also for  
their focused attention on this issue because it is really important. Thank you.

COMMISSIONER TRACEY: You're excused from further attendance.

30 <THE WITNESS WITHDREW [2.42 pm]

35 MR BOLSTER: That concludes my evidence for the day. I understand Ms  
Hutchins has one more witness.

COMMISSIONER TRACEY: Yes.

40 MS N. SHARP SC: At this point, Commissioners, may I announce my appearance.  
My name is Sharp, and I appear on behalf of Associate Professor Stephen  
Macfarlane and HammondCare both of which have been granted leave.

COMMISSIONER TRACEY: Thank you, Ms Sharp. Yes, Ms Hutchins.

45 MS HUTCHINS: Thank you, Commissioners. Before we call the next witness  
there's a couple of administrative matters that I would like to attend to, the first of  
those being a correction which we would like to make to the evidence of Dilum

Dassanayake who has provided a witness statement to the Commission and given evidence. There's just an error in the evidence insofar that there's references made to support that was provided by an entity called Dementia Australia. This entity is actually Dementia Support Australia so we would like to have that formally fixed on the record. We have got an email from Ms Dassanayake which is document RCD.4444.0054.0001 and this sets out confirmation as to what those issues are with the specific transcript reference and the paragraphs in the statement. So I would seek to tender that as a formal record of the correction.

10 COMMISSIONER TRACEY: Yes. The emails dated 12 May 2019 and 13 May 2019 passing between Dilum Dassanayake and Izabela Bozym will be exhibit 3-63.

15 **EXHIBIT #3-63 EMAILS DATED 12/05/2019 AND 13/05/2019 PASSING BETWEEN DILUM DASSANAYAKE AND IZABELA BOZYM (RCD.4444.0054.0001)**

20 MS HUTCHINS: Thank you, Commissioner. And the next matter I would like to attend to is the tendering of the scenario summaries, which have been given to a number of the witnesses in the course of yesterday and today. These documents in turn, RCD.9999.0059.0001. This is case study one – sorry, scenario document one.

25 COMMISSIONER TRACEY: Do you propose to tender them in bulk or by case study?

MS HUTCHINS: In bulk might be appropriate.

30 COMMISSIONER TRACEY: Well, whatever is easiest. How many scenarios are being covered?

MS HUTCHINS: There will be four.

35 COMMISSIONER TRACEY: Yes.

MS HUTCHINS: Perhaps, Commissioner, if it is a reference, it might be best - - -

40 COMMISSIONER TRACEY: It might be better to do them separately, since they've got different identifiers, I think.

MS HUTCHINS: Yes, Commissioner.

45 COMMISSIONER TRACEY: All right. Well, the case study summary scenario 1 will be exhibit 3-64.

**EXHIBIT #3-64 CASE STUDY SUMMARY SCENARIO 1**

MS HUTCHINS: Thank you. And the next case study 2 is RCD.9999.0056.0007. I tender that document.

5

COMMISSIONER TRACEY: Yes. Scenario summary 2 will be exhibit 3-65.

**EXHIBIT #3-65 CASE STUDY SUMMARY SCENARIO 2  
(RCD.9999.0056.0007)**

10

MS HUTCHINS: Scenario document 3 is RCD.9999.0056.0012.

COMMISSIONER TRACEY: Scenario summary 3 will be exhibit 3-66.

15

**EXHIBIT #3-66 CASE STUDY SUMMARY SCENARIO 3  
(RCD.9999.0056.0012) AND ITS IDENTIFIED ANNEXURES**

20 MS HUTCHINS: There is an attachment to exhibit – the exhibit that you’ve just marked, Commissioner, if you could please mark the case – the scenario document 3 is with exhibit.

25 COMMISSIONER TRACEY: Yes. Very well. Exhibit 3-66 will include, in addition to the scenario, the attachment that appears at 0017.

MS HUTCHINS: Thank you, and finally we have scenario document 4 which is RCD.9999.0056.0018. I tender that also.

30 COMMISSIONER TRACEY: Yes. Scenario summary 4 will be exhibit 3-67.

**EXHIBIT #3-67 CASE STUDY SUMMARY SCENARIO 4  
(RCD.9999.0056.0018)**

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MS HUTCHINS: Thank you, Commissioners. The next witness that we call is Associate Professor Stephen Macfarlane.

40

<STEPHEN MACFARLANE, SWORN [2.47 pm]

45

<EXAMINATION-IN-CHIEF BY MS HUTCHINS

MS HUTCHINS: Have you made a statement for the Royal Commission?

ASSOC PROF MACFARLANE: I have.

5 MS HUTCHINS: Operator, please bring up the statement of Associate Professor Macfarlane, document WIT.0125.0001.0001. Is this your statement dated 24 April 2019?

ASSOC PROF MACFARLANE: It is.

10 MS HUTCHINS: I understand you wish to make some amendments to the statement.

ASSOC PROF MACFARLANE: I do, I have three amendments please. Firstly, to paragraph 30 add the sentence:

15 *These 7291 have over 101,000 points of contact via phone, email or on the ground support with DBMAS. Each DBMAS client case stayed open for an average of 45.43 days.*

20 MS HUTCHINS: Thank you.

ASSOC PROF MACFARLANE: Second amendment to paragraph 48, amend the first words from in March 2015 to in late 2014, and third amendment to paragraph 52, add the sentence:

25 *These 811 clients had over 21,000 points of contact via phone, email or on the ground support with SBRT. Each SBRT client case stayed open for an average of 54.45 days.*

30 Thank you.

MS HUTCHINS: And to the best of your knowledge and belief, are the contents of your statement true and correct and any opinions stated within it opinions which you hold?

35 ASSOC PROF MACFARLANE: They are.

MS HUTCHINS: Thank you. I tender that statement with amendments, Commissioner.

40 COMMISSIONER TRACEY: Yes, the statement of Stephen Robert Macfarlane dated 24 April 2019 subject to the amendments that have just been read onto transcript will be exhibit 3-68.

45 **EXHIBIT #3-68 STATEMENT OF STEPHEN ROBERT MACFARLANE  
DATED 24/04/2019**

MS HUTCHINS: So, Associate Professor, you are the head of clinical services for the dementia centre at HammondCare; is that correct?

ASSOC PROF MACFARLANE: That's correct.

5

MS HUTCHINS: What professional qualifications do you hold that are relevant to this position?

ASSOC PROF MACFARLANE: I hold an MB BS I obtained in 1992, a fellowship of the Royal Australian New Zealand College of Psychiatrists in 2003 and a certificate of advanced training in old age psychiatry.

10

MS HUTCHINS: What was your professional experience prior to you commencing that role in 2016?

15

ASSOC PROF MACFARLANE: Up until 2008, I was serving as head of aged psychiatry at Peninsula Health, a position I held for about three years. Subsequent to 2008 and leading up to 2016 I was director of aged psychiatry at Alfred Health in Melbourne.

20

MS HUTCHINS: And in your role with the dementia centre, you oversee clinical services for dementia services support.

ASSOC PROF MACFARLANE: Dementia Support Australia.

25

MS HUTCHINS: Sorry. Dementia Support Australia. Of course. And it's also commonly known as DSA.

ASSOC PROF MACFARLANE: That's correct.

30

MS HUTCHINS: And what is Dementia Support Australia?

ASSOC PROF MACFARLANE: Dementia Support Australia is a partnership led by HammondCare that came into being in 2016 when the national tender for the DBMAS program was joined with the existing severe behavioural response team service. HammondCare was involved, at that point, with the provision of both services. So rather than separate them both, they were brought together under the single umbrella of DSA, although they're both run separately as Commonwealth programs.

35

MS HUTCHINS: Certainly. And stepping that out, you referred to the DBMAS program, which is the Dementia Behaviour Management Advisory Service. What does that program do?

40

ASSOC PROF MACFARLANE: DBMAS has been funded by the Australian Government since about 2007 in different States and Territories with the intent that a broadly similar service model would be followed. In practice, that didn't happen,

and we had eight different service models in the different States and Territories. They were brought together under a single national provider in 2016 to provide that nationally consistent service with KPIs to ensure that it was done in a specific way according to departmental guidelines and that those widely differing models of  
5 service were brought together, so that if a referrer from Tasmania they would get the same service as they would in remote Northern Territory, for example. So a nationally consistent service, not - - -

10 MS HUTCHINS: And is the DSA Commonwealth funded?

ASSOC PROF MACFARLANE: It is.

15 MS HUTCHINS: And in your witness statement you note that the current arrangements are due to expire in July this year. What's the intention after that time?

ASSOC PROF MACFARLANE: I believe the intention is to roll the contract over. I believe the papers for that are in the final stages of preparation and that the extension period will be for at least 12 months, so the finer details are not known to  
20 me.

MS HUTCHINS: And the other service that you mentioned, then, was the SBRT, which is the Severe Behaviour Response Team. What is it that that team does and how does it differ from the DBMAS?

25 ASSOC PROF MACFARLANE: The Severe Behaviour Response Team was an idea that came out of a ministerial conference on dementia in late 2014. The idea at that time was to initiate what were described at the time as dementia flying squads, so teams of highly trained multidisciplinary staff with expertise in dementia  
30 behaviour management that would be able to go out and provide a rapid response to clients living within Commonwealth funded residential aged care facilities who were displaying severe to very severe to extreme behaviours on the Brodaty Triangle. The difference in the service to that which DBMAS provides is DBMAS is also funded to provide services to clients in the community, so living at home being cared for by a family carer. And DBMAS also targets the lower tiers of behaviour disturbance on  
35 the Brodaty triangle, whereas SBRT targets the more severe behaviours.

MS HUTCHINS: Certainly. Operator, could you please bring up the Brodaty triangle, which is at tab 1 of the Sydney hearing general tender bundle, and go to page 0016. So on the screen here, we can see the seven tiered model of service  
40 delivery which is commonly referred to as the Brodaty Triangle. Does your service have reference to this model when it's performing its functions?

ASSOC PROF MACFARLANE: It does, yes, we use it as the basis for our triage, for example.

45 MS HUTCHINS: Yes. And so what does the triage process involve?

ASSOC PROF MACFARLANE: We have a national 1800 call in number for all referrals. There's also an online web portal and a fax referral. When a referral comes in, the worker who answers the phone asks a number of questions of the referrer to determine that the client meets our referral service criteria, specifically  
5 that the person involved has a diagnosis of dementia, that the behaviours that the client is being referred for are best explained by that diagnosis of dementia, rather than by another comorbidity, and also to determine the acuity and level of risk that the behaviours pose to the individual, their environment and other people within it. So if there's a high degree of risk associated with it, and a high likelihood that the behaviours could lead to an adverse outcome in the short to immediate term, the  
10 behaviour, the case would likely be triaged to an SBRT level of service response. And our KPI there is we provide on the ground face to face response within 48 hours of the referral being accepted. Or if the case is of lower acuity and the behaviours are of lower risk, it would be triaged to a DBMAS level of service response, which is  
15 a response within seven days.

MS HUTCHINS: Yes. And appreciating that needs can move up and down the triangle at any given time, do you have a general approach in terms of which tiers would be allocated to which service?

ASSOC PROF MACFARLANE: In general, SBRT would deal with the severe to very severe and extreme behaviours, there's some overlap in tier 5. Some of the behaviours that are severe would be dealt with by DBMAS, but generally 5, 4 and 3 would be DBMAS, and 5, 6 and 7 would be SBRT. There is the flexibility for  
25 people to move between their service allocation. Occasionally triage gets it wrong. If our staff go out and find that the behaviours are of higher acuity, for example, than we had determined over triage, we simply reallocate the case internally.

MS HUTCHINS: Yes. And do the operators working on those phone lines have  
30 any particular qualifications?

ASSOC PROF MACFARLANE: They're all accredited DSA consultants and comprise a number of health related backgrounds. About half of our workforce is nursing, whether aged care nursing, general nursing or psychiatric nursing. And we  
35 have virtually all of the allied health disciplines represented as well, I think, with the exception of social work.

MS HUTCHINS: And with reference to the triangle, what levels would you expect the providers should have the capability of addressing, without the need to refer to  
40 your services?

ASSOC PROF MACFARLANE: I would expect that a provider for whom dementia is core business would have the capacity to manage internally for lower tier behaviours, tiers 3 and possibly 4. Anything beyond that and certainly the very high  
45 levels, I wouldn't expect a provider to be able to manage without specialist support.

MS HUTCHINS: Yes. And in your experience, do you have providers referring to you people that would be categorised on the tiers 3 or 4?

ASSOC PROF MACFARLANE: We do, yes.

5

MS HUTCHINS: How often would that be happening?

ASSOC PROF MACFARLANE: Very frequently. If you look at the Brodaty Triangle, the numbers correlate to the breadth of the – of each level. So most of the behaviours that affect people living with dementia are the lower tier behaviours and the more severe ones are less common. So by that basis alone, the majority of referrals to DBMAS would be those lower tier behaviours.

10

MS HUTCHINS: Does your service collect data that could provide insight to the commission in relation to the care needs of the residents accessing your services?

15

ASSOC PROF MACFARLANE: In as much as our triage between SBRT to the higher levels of the triangle and to DBMAS at the lower levels provides some sort of cut-off between approximately levels five and six, those ratios are useful, but we don't have data on the exact number of clients within each group in Australia because we haven't been into every residential aged care facility. I think our penetration is about 60 per cent of all aged care homes at this point.

20

MS HUTCHINS: And in relation to the various tiers of behaviours, do you think it's appropriate for people of all levels to be housed together or do you think that there's a need for specialist dementia units for people with the more extreme end of the scale?

25

ASSOC PROF MACFARLANE: I take the latter view, that there is a need for specialist units. The Commonwealth, in fact, has responded to this by announcing funding for specialist dementia care programs which will be rolling out from later this year. The intent is that those units will cater for individuals with severe to very severe behaviours, but even those specialist units with a specialist model of care and staffing we would not expect would be able to cater for the needs of people whose behaviours lie at the extreme tier 7.

30

35

On your broader points, certainly, not all dementia is created equal. The way residential care tends to operate is there is a dementia specific unit for people living with dementia and general living areas for those without. But if you simply count up the population on that basis you could have physically robust relatively young 100 kilogram males housed with physically frail 95-year-old ladies who are non-ambulant with no behavioural disturbance. So there's a need to set the resident mix within the rubric of dementia to cater for specific types of individuals showing specific types of behaviours.

40

45

MS HUTCHINS: As a matter of practicality, if you receive a call to DSA what are the steps that will go – what's the steps in the process that you will go through with the provider, say, if they call in relation to an existing resident?

5 ASSOC PROF MACFARLANE: Our general flow chart for the model of care firstly involves a triage process and the decision whether (a) the client is appropriate for DSA services at all. If so, whether they go to DBMAS or SBRT. A consultant gets assigned the case at that point and they will attend the facility or make contact with the facility within a KPI timeframe. During the assessment part of the process  
10 the consultant would generally consult with staff within the facility, as many staff as possible who know the patient well, the patient themselves, of course, their family members or authorised decision-maker and the general practitioner as well. And we go to great lengths to consult widely because our management strategies are really predicated on that information that we obtain during the detailed assessment process.  
15 It's a very individualised and personally tailored set of strategies that we would suggest to the facility.

Once we have made the assessments, our management strategies are provided back to the facility in written form and our consultant, whilst the case remains open, then  
20 makes efforts to support the facility in their implementation of those recommendations. If they're implemented but unsuccessful, we have a feedback loop to go back to reassessment, to reiterate our approach, rinse, wash and repeat, monitoring of implementation, support of the facility, some mentoring or capacity building if required. Once behaviours have been settled for a reasonable period of  
25 time we would then go through a process of disengagement. We do have the capacity to readily accept re-referrals, however, because we have a single national computer database, and there's an acceptance that behaviours can fluctuate over time and can reoccur, so it's an easy in, easy out type process with several steps to it.

30 MS HUTCHINS: Who is able to make referrals to your service?

ASSOC PROF MACFARLANE: Really anybody – anybody can make a referral. General practitioners can refer, family members can refer, facilities can refer, family carers at home can refer. There are a number of sine qua nons though without which  
35 we can't proceed. We need to have consent from the facility for us to go in and provide an assessment and management plan. If the facility doesn't consent to us visiting we can't go in. And also we require that consent be obtained from the next of kin or authorised family caregiver or substitute decision-maker before we conduct an assessment.

40 MS HUTCHINS: Do you have circumstances where a family member might call up concerned about what's happening to a relative in a residential aged care facility, and then that facility won't consent to you attending?

45 ASSOC PROF MACFARLANE: That has happened, yes. But we do require consent from the facility before we can lawfully enter their premises. And in practical terms if they don't consent to us visiting there's not a lot of point us

providing detailed recommendations which they wouldn't implement because they haven't consented.

5 MS HUTCHINS: Yes. You have been provided with a number of scenarios, factual scenarios. One of these scenarios relates to a lady that didn't have a diagnosis of dementia but she did have a cognitive condition. In a situation like that, would she be able to access your services?

10 ASSOC PROF MACFARLANE: We define dementia in the traditional way, a progressive neurodegenerative condition. There has been modifications to the technical definition of dementia in recent years, and technically if you have a head injury, for example, and an enduring cognitive impairment as a result of that, that technically meets the definition of dementia but not the traditional understanding of what dementia involves. We're fairly strict around our service criteria for a number  
15 of reasons. We make no claim to expertise in behaviours arising from severe psychiatric illness, stroke, epilepsy, head injury, intellectual disability, so our skill set in managing behaviours related to those conditions is quite different from the skill set our consultants have in relation to dementia behaviour management as that term is traditionally understood.

20 So we don't feel that we would be well positioned necessarily to provide advice for people suffering with head injury or the sequelae of brain tumours or neurosurgery and so forth, and would make all attempts to try and encourage the referrer to access a more appropriate service provider for the needs of that client whether it's a  
25 specialised acquired brain injury service or a disability service, for example.

MS HUTCHINS: And are there services that do run a similar type of service to what you do in relation to dementia or these other types of injuries?

30 ASSOC PROF MACFARLANE: In relation to other types of injuries, yes, I mean, it varies a bit from State to State and some conditions do miss out. I believe each State has an acquired brain injury specialist service, for example. There are disability services in each State. There are psychiatric services in each State and Territory where behaviours relate to psychiatric problems, but it does tend to still be  
35 a grey area though and people fall between the gaps and often those are people who have cognitive impairment with no clear cause or cognitive impairment in relation to previous substance abuse. Younger people also tend to fall through the gaps because certain services have age cut-off criteria as regards eligibility so they're an underserved group.

40 MS HUTCHINS: Earlier we touched on the importance of the admission process, or the steps that you would go through when your team is first doing an assessment. When someone first enters a residential aged care facility, particularly one that's experiencing BPSD, how important is a holistic approach to care and, say the  
45 emphasis that's put on the initial admission process?

ASSOC PROF MACFARLANE: I think it's a vital part of the care planning process. Unfortunately many facilities seem to use that initial ACFI assessment within the first 30 days as simply being an administrative requirement to try and, I suppose, maximise the funding returns that they might receive in relation to a  
5 particular resident. It's been our experience that when we visit facilities a lot of the carers – this is more common than not – will not really have a holistic sense of who the person with dementia they're caring for is. It's not that the information isn't there, it's in the original ACFI document but that document tends to be filed and never looked at again beyond the initial period of assessment.

10 So although it should be used as a vital tool for care planning, in our experience it often isn't and the people caring for those with dementia have really a very poor knowledge of the people that they're looking after, which is a centre point of person-centred care when you think about it.

15 MS HUTCHINS: And have you made any observations about the updating of care plans once someone has been in a facility for a while?

ASSOC PROF MACFARLANE: I've seen a number of care plans that are updated  
20 and they're often updated by institutional requirement once there has been a behavioural incident. They're often – again in my experience, the update of the plan simply involves cutting and pasting the same stock phrases out of the original stock phrase bank within the ACFI behaviour dictionary, and that they're utilised without any real sense of commitment or any thought about how the individual might be  
25 impacted by their environment, their social milieu and the way in which those things can produce behaviours. The responses and the recommendations are often generic and not tailored.

MS HUTCHINS: Do you think that the current ACFI system is incentivising better  
30 care approaches for people?

ASSOC PROF MACFARLANE: I think the current ACFI system is a funding instrument by definition and facilities will attract more funding for residents if those residents have greater degrees of need and disability. So there's a disincentive, a  
35 perverse disincentive perhaps in any facility providing activities that could be viewed as reabling or maximising the function of a resident. They have to put in resources to get that outcome and the perverse result is they get lesser degrees of funding having done so, so why would you.

40 MS HUTCHINS: In your experience, how important is family involvement in the care of people that are in residential aged care facilities?

ASSOC PROF MACFARLANE: Vital. Families are often the main advocates for residents and it's usually families, almost invariably, who have the detailed  
45 knowledge of the person's past personality, likes and dislikes, hobbies, occupational interests and so forth, that knowledge being vital to us in formulating an

individualised management plan that flows on from the assessment. So families are a great resource to us and they're invaluable.

5 MS HUTCHINS: I would like to turn to the issue of physical restraints. What do you understand constitutes a physical restraint?

ASSOC PROF MACFARLANE: Any physical means whose intent is to restrict the freedom of movement or mobility of an individual.

10 MS HUTCHINS: And do you think there's circumstances where the use of physical restraints is appropriate?

15 ASSOC PROF MACFARLANE: Really only in emergency situations. If a young robust person with dementia is acutely unwell and behaviourally disturbed and clearly at risk of causing acute and imminent serious injury to third parties I think there's little alternative to physical restraint in that emergency circumstance. But the extent to which physical restraint is used in the broader sector, I think is not justified by either the nature of the behaviours that the restraint is intended to address or the duration of time for which the restraint can be applied.

20 MS HUTCHINS: And could you provide an example for the Commission of, say, an instance where you've seen a physical restraint applied where, really, other measures should have been taken that could have corrected the need or the perceived need for that restraint to be used?

25 ASSOC PROF MACFARLANE: In terms of me having observed those I can't in recent memory because my job doesn't involve me physically going out and assessing the clients. Certainly I hear anecdotally on a weekly basis from our consultants stories where restraint has been inappropriately applied. Unfortunately, 30 in the circumstances I can't bring any to mind for you.

MS HUTCHINS: Certainly. Well, perhaps I can point you to an example. Scenario 1 which you've been provided with deals with a male resident who has been diagnosed with Alzheimer's disease. He was wandering during the night and was 35 then drowsy during the day. The restraint chart showed that there were numerous instances where physical restraint was used on that particular gentleman. Do you think that the restraint was appropriate in that case?

40 ASSOC PROF MACFARLANE: On the basis of the information available, no, the description of the behaviours is limited to the fact that the resident was unsettled, whatever that means to the person who made the report, and wandering. Simply wandering or walking around the facility is not in itself an indication to physically restrain a person, and simply being unsettled, similarly, without greater clarity on what's meant by "unsettled", it's impossible to be sure. Certainly from that case 45 scenario, there were periods of time where the person was restrained whilst being asleep, and you can hardly reasonably argue that restraint is necessary at that time when no behaviours are being displayed so that would be more obviously clearly

inappropriate in my book, but simply to restrain somebody because they're wandering makes no sense on the face of it.

5 MS HUTCHINS: And if you or your services were providing advice in relation to better care strategies in this circumstance what type of recommendations would be made?

10 ASSOC PROF MACFARLANE: Well, we tend to focus our strategies not on the symptom but on the underlying cause. Wandering, if you want to call it that, is not a problem in itself, but it's indicative, it's the expression of an underlying problem, so we would be wanting to try and find out why that person is wandering, to use the term. It may well be, in the case of this gentleman, that he's a new resident at the facility, there on respite, he has a room presumably but he's unlikely to know where it is because his short-term recall and new learning is affected so he might simply be wandering the facility looking for his room, or looking for a way out or looking for his wife. So trying to determine the cause for it, and if the problem is in wayfinding, he doesn't know his way back to his room, then putting appropriate signage on the door of the room would be a relative simple and potentially effective behavioural intervention; it's not rocket science.

20 MS HUTCHINS: Yes. And for facilities that – you know, say, it is a large facility that has been around for some time and doesn't have a lot of money to be able to implement a lot of structural changes for wayfinding, say, what are some other practical cost effective solutions that these facilities could be implementing?

25 ASSOC PROF MACFARLANE: Facilities don't have to spend a lot of money to ensure adequate wayfinding. A common problem is residents having difficulty finding their way back to their room. Simply putting a sign with the resident's name or a picture of the resident or a picture of something that is familiar to the resident on the door is a very low cost intervention. It doesn't cost anything, really.

30 MS HUTCHINS: Did DBMAS ever make recommendations around those types of practical solutions to providers?

35 ASSOC PROF MACFARLANE: We do, and occasionally our recommendations include things that may not necessarily be in the ordinary remit of an aged care provider, so we do have access to a limited pool of brokerage funding with which we can purchase items that the aged care provider normally wouldn't provide, and that may include aids to wayfinding or other activity based aids that cater to a person's particular interests to modify their specific behaviours.

40 MS HUTCHINS: And back in – back to the scenario 1 which we were just discussing which involved wandering at night, but then also, you know, numerous instances where physical restraint was used. If Dementia Support Australia had been called around the time when the man had now been physically restrained for a period of time, what would the likely triage be in that situation?

ASSOC PROF MACFARLANE: Depending on how long he had been physically restrained and the reason for it, certainly if he had been called – if we had been called later in his stay and there was evidence that he had been restrained on a daily basis for three weeks, we would see that as a pressing need to get out there with some  
5 urgency. If the restraint had been applied on one day and they called us on that day because of wandering we probably wouldn't assign that necessarily high priority. We would simply advise the facility not to use restraint for that purpose. When we do see restraint, we see it as our responsibility to advise the facility manager of what we see. There is a tension between what we maybe should do, and you could argue  
10 that we might have a role in notifying aged care commission or quality agencies. But the tension there is that if we're seen to be the so-called restraint police, facilities then won't ask us then to provide behaviour management because they fear the scrutiny. We've taken the view that our responsibility is to inform the facility manager of what is going on within the facility and in the hope that the facility itself  
15 will take appropriate action.

MS HUTCHINS: Another scenario, number 3, it involves a resident who was described as displaying intrusive wandering. It also involved the issue of resident aggression. What observations could you make about measures that could have been  
20 put into place in relation to that scenario?

ASSOC PROF MACFARLANE: Okay. I would certainly start by having a look at what's in the scenario in relation to the care plan. If you look at the behavioural problem, which is described as restless, angry and agitated, the suggested  
25 management strategy is diversional activities such as doll therapy. Doll therapy is not a therapy that you can universally implement for somebody who is restless. It's implementation has specific circumstances where it may be of use, and in the majority of cases of behavioural disturbance it's of no use at all because it's not tailored. So to have doll therapy down there as part of a generic care plan for  
30 managing a particular behaviour is a bit of a nonsense, so the care plan merits review.

There was a graphic put up earlier in relation to the layout of the dementia specific unit within which this lady was housed. Looking at the graphic it would appear that  
35 both this lady's room and the rooms of two other residents who had showed aggressive behaviours were located down the back end of the unit out of direct line of sight of the nurses' station. Again, if you have residents who are known to have displayed difficulties with aggression it might make sense to relocate them to a room that has direct line of sight to a staff outpost. I see from the scenario that it's a 14  
40 bed unit within which 12 of the beds were occupied. My assumption is that the two beds shown within the two twin bed units were not fully occupied. So, essentially, everybody had a single room. So, certainly, with beds up your sleeve there is scope to relocate people within the unit.

45 All that depends, of course – and the scenario focuses on the behavioural histories of the two other residents in particular, but a lot depends on what the behavioural profile of the other residents may have been as well. That much is unstated. But if

those were the two with aggression risk on the unit, there are environmental moves or strategies that don't cost anything to implement which would have been prudent risk management measures in that circumstance.

5 MS HUTCHINS: Are you aware of any reliable data which shows how prevalent the use of physical restraints are in residential aged care?

ASSOC PROF MACFARLANE: I'm not aware of any reliable data. I'm assuming the aged care standards bodies have records of the incidents of restraint that are provided to that body through mandatory reporting. But as I understand it, facilities have a large degree of discretion as to what they do report. And there's a large degree of lack of clarity about what the facility might consider to be restraint. For example, if a lap band is applied with the intent to stop a person from having falls, the facility might argue that that is part of a treatment package rather than a measure of physical restraint where, in fact, the result is a restriction in somebody's mobility. Similarly, the putting of tables in front of residents, the use of deep chairs from which it's difficult to arise without assistance, the facilities may well argue that those don't constitute physical restraint. But if the end result of what they have put in place is a restriction in mobility, I think the threshold for restraint is met, thus my assumption is that restraint is massively underreported.

MS HUTCHINS: And do you have a sense of how common the use of physical restraints might be?

25 ASSOC PROF MACFARLANE: I don't. We see a biased sample within Dementia Support Australia, of course. We see people who have significant behavioural disturbances who it could reasonably be argued are therefore more likely to be restrained. We don't know what's happening with the residents. We don't have the opportunity to visit and assess. But certainly, it's a common weekly occurrence for our consultants to report back to me that they have witnessed physical restraint.

MS HUTCHINS: And do your consultants make recommendations to providers to stop restrictive practices?

35 ASSOC PROF MACFARLANE: We do indeed. We highlight their indication as a last resort. We bring that to the attention of the facility manager. And in cases that have been referred to us where restraint is being used, we will try and make suggestions that are reasonable alternatives to restraint. Unfortunately, a lot of the cases that our consultants witness are in residents who haven't been referred to us but who arguably would benefit from such a referral in order to minimise the ongoing use of restraint. The facility may feel that the behaviour is effectively managed with the use of a restraint. It may be effective, but it's not necessarily appropriate or safe or empowering in any way for the person living with dementia.

45 MS HUTCHINS: Yes. And are you aware or do you have a sense of whether recommendations made in relation to removing restraints are followed – are then followed by the providers?

ASSOC PROF MACFARLANE: In those cases where we see restraint occurring in clients for whole we have a referral, we can get that data, certainly, because we have ongoing contact with the client. Where we have witnessed it in our consultant's passage through a facility whilst assessing another case because we're not  
5 necessarily going back to that facility and because we're not involved with those particular clients, we have no way of determining what impact our feedback has on the facilities or the practices.

10 MS HUTCHINS: And for the referred people, are they being followed?

ASSOC PROF MACFARLANE: Yes, anyone who is taken on as a case is followed until the point of their discharge. I don't have the figures to hand, I'm afraid.

15 MS HUTCHINS: Do you find though generally in relation to the recommendations that your services might make that they are followed by the providers?

ASSOC PROF MACFARLANE: Yes and no, to varying degrees. We audit these things occasionally, and our computer dataset captures reasons for discharge or reasons for case closure. And a recent snapshot of a six month period of activity  
20 showed that 87 per cent of our cases were closed because the facilities had followed the advice that was provided, either to a complete or a partial extent. So there was a high degree of compliance, at least partially, with behavioural interventions. We have a slightly different picture with medication based recommendations.

25 MS HUTCHINS: I will turn to those shortly. In relation to behavioural based or physical recommendations, in instances where they're not being followed, why do you think that might be occurring?

ASSOC PROF MACFARLANE: I think a lot of times when facilities refer to us,  
30 their hope is that we will come along and provide the magic pill to address the behaviours. A lot of them are expressing disappointment when we don't come in and prescribe. In fact, our philosophy involves de-prescription rather than prescribing psychotropic medications. So if our service doesn't meet the expectations of the referral, there's an expectation performance mismatch there and they're not  
35 necessarily motivated in that circumstance to implement a suite of behavioural recommendations.

Human nature is such that if there's an apparently simple solution to a problem versus a more complex one that requires that I actually do some work, the easy  
40 option will be selected. I also think that at times, the skill set of the majority of the aged care workforce is not necessarily sophisticated enough to enable faithful implementation of these behavioural interventions. And that's one of the reasons why we have a capacity building service within Dementia Support Australia as well, so that we can actually get into facilities and provide some quite intensive and  
45 protracted case based mentoring around the behaviours of a particular client over and above what our individual consultant might be able to do, to try and upskill the providers and their staff in order to do that.

MS HUTCHINS: Certainly. And in relation to medication, do you think that it can be effective to treat BPSD?

ASSOC PROF MACFARLANE: Depends how you define “effective”.

5 Effectiveness, I suppose, relates to whether something works or not and whether it works in relation to BPSD. You could argue if it stops the behaviour, it works. There’s plenty of things that are effective in that necessities can stop the behaviour but then not necessarily, by extension, either safe or appropriate or indicative of quality care. For example, the use of medications for behaviours such as wandering, 10 so-called, or inappropriate disrobing or inappropriate voiding. I don’t have an anti-wandering pill. You can effectively manage that behaviour with a psychotropic medication, but you can effectively manage it by – only by sedating the person to the point where they can no longer engage in that behaviour. So it’s effective, but it’s by no means appropriate, and it’s frankly dangerous.

15

MS HUTCHINS: Yes.

ASSOC PROF MACFARLANE: Having said that, there’s clearly a role for psychotropic medications, as we heard from Dr Westbury. If somebody has 20 psychotic symptoms, psychosis is tailor-made for a responses to an antipsychotic. There’s limited efficacy for agitation and aggression, but not really for the other behaviours. And overall, I think they’re massively overused.

MS HUTCHINS: Yes. And I will turn to scenario 2, which involved the 25 prescription of an antidepressant to a resident living with dementia who was known to wander and was experienced an increase in emotional – in emotion and crying. Do you think that the prescription of an antidepressant was appropriate course in this scenario?

30 ASSOC PROF MACFARLANE: The scenario doesn’t outline what I would consider to be an appropriate attempt at assessment to determine the cause for the lady’s tearfulness. That would have justified the prescription of an antidepressant. Not all tearfulness means you are depressed. You can be tearful for a variety of reasons. Only one, the existence of a depressive disorder, would be an indication for 35 an antidepressant to be prescribed. So from my knowledge of this scenario, a very limited assessment as to the appropriateness of an antidepressant was conducted in this case.

40 Having said that, again, it’s very difficult to make a diagnosis of depression in somebody with a significant degree of dementia. I know we’ve heard repeated reference in these hearings to the use of the Cornell scale for depression in dementia. It’s referred to frequently, but the reality is, when you look at the research that validated that Cornell – to my knowledge there has been 17 validation studies of the Cornell, only four of which were done in a residential care environment and none of 45 which involved validating it in residents with an MMSE score of less than 15. So to apply a scale that has not been validated in a particular population to that population in itself is fraught and tends to overestimate the prevalence of depression when you

apply it to that group, particularly if that group have behavioural disturbances associated with dementia because the symptoms overlap.

MS HUTCHINS: Yes.

5

ASSOC PROF MACFARLANE: So the diagnostic criteria nor depression that doctors are taught in medical school don't apply to people with significant degrees of dementia because they're reliant on the patient being able to report symptoms to you. If you can't report a symptom, you can't make the diagnosis. My own practice,  
10 when diagnosing depression in the setting of severe dementia would be to look at biological indicators, such as a recent change in loss of appetite, change in sleep patterns, loss of interest in usual activities and, of course, any attempts at self-harm or self-injury. But it's a difficult diagnosis to make.

15 MS HUTCHINS: Yes. And do you think there are any other measures that could have been put into place before the prescribing of the antidepressant in this situation?

ASSOC PROF MACFARLANE: Absolutely. I mean, if you look at dementia  
20 behaviour management guidelines regardless of from whom those guidelines originate, they're all unanimous in recommending non-pharmacological approaches towards behavioural disturbance prior to the prescription of any psychotropic, and the use of any psychotropic should be seen as a last resort. So I'm not clear from the scenario that non-pharma measures were attempted at all in this case.

25 MS HUTCHINS: What are some practical examples of non-pharma measures that could have been tried?

ASSOC PROF MACFARLANE: For example, if this lady is crying because of  
30 negative thoughts from her childhood or perhaps she's, you know – well, if she's crying because she has negative thoughts from her childhood she could be supported in dealing with those thoughts better, either through supportive counselling, one-on-one contact, frequent reassurance and reorientation to the present so that her attention is diverted away from the unpleasant past which may constitute a large part of what she's able to remember at the moment, all of those require staff time, staff  
35 commitment and a degree of staff training as well as empathy and compassion. An antidepressant is quicker and easier.

MS HUTCHINS: You mentioned earlier that those instances where DBMAS might  
40 recommend to a provider de-prescribing of medications and you find those recommendations aren't being followed: how common is that and why do you think that's occurring?

ASSOC PROF MACFARLANE: Okay. We did a limited audit of prescribing  
45 practices in our SBRT clients. This was about 18 months ago now. It was a small sample size but we had access to the medication charts of residents at the point of referral to our service and at the point of discharge from our service and we audited those medication chart changes against the recommendations that had been provided

to general practitioners by our clinical associates, our medical specialists. And at that stage we found that the de-prescribing advice was only fully implemented by GPs in about 10 per cent of cases, partly implemented in another 40, and not implemented at all in another 50. That finding concerned us obviously so we tried to put measures in place to try to improve those compliance outcomes on the part of GPs, and I've just seen some data over lunchtime which suggests that one approach that we've taken is actually improving compliance by about 40 per cent for full implementation.

10 To turn to the question why our recommendations aren't necessarily accepted by GPs, there's a number of possible explanations. It's all conjecture but those which occur to me, given that most of our referrals aren't actually coming to us from the GP but from the care providers, maybe when a GP receives an unsolicited letter from a medical specialist whose only contact with the patient has been via electronic or  
15 phone communication with our consultant, the GP might be inclined to discount that as something that he didn't solicit. We've heard from Dr Westbury, that GPs experience pressure to prescribe from residential aged care staff. If that's the case, they might be reluctant to decrease a medication because they feel that pressure. But at the end of the day GPs have to be held accountable for their own prescribing.

20 You wouldn't expect a doctor to hand over a prescription for morphine to anybody who entered their surgery just because their carer demanded it. I don't see why doctors are in any way let off the hook by saying the residential aged care staff told me to do this. That doesn't sit well with good medical practice.

25 MS HUTCHINS: And do you think that providers have a clear understanding of what constitutes a chemical restraint?

ASSOC PROF MACFARLANE: I don't. I don't believe that that's the case. I think that the current standards around behaviour management muddy the waters. I think that the proposed new standards around both behaviour management and the principles that relate to chemical restraint are deeply flawed. For example, with the new proposed standards it's my understanding that any drug that's prescribed for any reason other than the treatment of a diagnosed disorder is to be considered chemical  
35 restraint. To me that's a nonsense because it demonises completely innocuous medications. I see plenty of residents who are prescribed vitamin C on a daily basis, and fish oil; I'm sure they're not fish oil deficient so arguably they're being prescribed it for no diagnosed condition. But it's ludicrous to consider fish oil as a chemical restraint.

40 Also – and I think Dr Westbury alluded to this point – it provides a lot of looseness around the continuing approval for the use of antipsychotics because behavioural and the psychological symptoms of dementia by definition are symptoms of a diagnosed condition, that condition being the dementia, so an antipsychotic can be prescribed  
45 for those symptoms according to the principles so they're not helpful on a number of levels.

MS HUTCHINS: Do you have a view as to what a more appropriate definition should address?

5 ASSOC PROF MACFARLANE: I think any definition of chemical restraint needs to take into account the intent for which the medication is prescribed. If the intent, similar to physical restraint, is to restrict a person's freedom of movement or mobility or indeed to sedate a person, then the intent there is to chemically restrain. A lot of psychotropic medications, as we've heard, are prescribed for behaviours that could not reasonably be expected to be medication responsive. We've mentioned  
10 wandering a number of times. I don't know whether the intent necessarily in those cases is to sedate, or whether the medication is prescribed in ignorance of what could reasonably be expected from a medication in that setting, but I fear the former.

15 MS HUTCHINS: Certainly. Turning now to some systemic matters, there appears to be some debate about the actual number of people that are living with dementia in residential aged care facilities. Are you able to make any observations based on information that you receive in your role as to how many people there might actually be in residential aged care facilities living with dementia?

20 ASSOC PROF MACFARLANE: I think the official prevalence data is based on ACFI entries, so the number that I'm aware of is 52 per cent of aged care residents have a diagnosed dementia. I suspect the number of those who actually have dementia is considerably higher, possibly as high as 70 per cent. Authorities such as Dementia Australia will tell you that about a third of people who have dementia  
25 haven't actually been diagnosed yet, and I'm sure the same is true of a number of people in residential care who clearly have cognitive impairment that would most likely be best explained by dementia but they don't have the formal diagnosis.

30 MS HUTCHINS: And so DSA commenced in 2006?

ASSOC PROF MACFARLANE: 2016.

MS HUTCHINS: Sorry, 2016.

35 ASSOC PROF MACFARLANE: SBRT was 2015, DBMAS 2016, and that's the point at which DSA was formed.

40 MS HUTCHINS: Yes. And has there been an increase in demand for DSA services since it commenced?

ASSOC PROF MACFARLANE: Significantly. I think in the last 12 months the demand for both arms of the service – SBRT and DBMAS – has gone up by about 40 per cent in 12 months.

45 MS HUTCHINS: Why do you think that is?

ASSOC PROF MACFARLANE: There's a number of possible reasons, none of which I can swear to but again it's speculation. Certainly I think that there has been an increased awareness of scrutiny of inappropriate medication practices arising from the Royal Commission. That's one possible reason. I think it's taken some time for  
5 DSA to penetrate. I mentioned earlier that DBMAS services were operated under different providers as far back as 2007. And services that may have had negative experiences with the previous providers may still associate us with the old provider and not have been referring. That's potentially changing as people become more familiar with our service. People may be referring more because they have referred  
10 once and had a positive outcome and therefore are inclined to refer again.

We know anecdotally that some providers are referring because they've been told to by the aged care accreditations bodies when they visit, so some of it might be compliance driven. Some of it unfortunately might be slavish adherence to a tick  
15 box formula or tick box approach on the part of the providers. I've seen some policy documents from providers which state that any behavioural disturbance should trigger a referral to DBMAS, for example. To me, that's unnecessary because it covers the whole spectrum, some of which behaviours are quite trivial and to me that also abrogates the provider from upskilling their own staff in the ability to manage  
20 those lower tiers of behavioural disturbance which I think should be within their reasonable capacity. There are other possible contributors which I think I've outlined in my statement.

MS HUTCHINS: And I would like to touch on, I guess, what you perceive to be the  
25 causes of some of these instances of substandard care that we're seeing. Why do you think that these – why do you think these instances of substandard care are happening?

ASSOC PROF MACFARLANE: I accept that many providers feel that they're  
30 under-staffed and the staff feel under incredible pressure. I'm also very conscious of the fact that the training that many aged care staff receive, both in general medical issues and specifically in relation to dementia and dementia behaviour management in particular, is really inadequate. If the majority of your workforce are personal care attendants and the requirement is for them to complete a six week course in aged  
35 care, it doesn't really give you much opportunity to gain any understanding about what dementia is, let alone to understand the complexities of how to assess somebody with problem behaviours to determine their cause.

So if we're not equipping our aged care staff out of their training institutions with the  
40 necessary skills to at least have an understanding of dementia, you're almost setting providers up to fail. I don't think necessarily that increased staff numbers on that basis is the answer because whether you have five people who have little idea what they're doing or 10 people who have little idea what they're doing on the floor, the end result is still that regardless of number of staff the behaviours are going to be  
45 poorly managed.

MS HUTCHINS: Yes.

ASSOC PROF MACFARLANE: So I would like to see an increased emphasis on basic training for all levels of aged care staff and a commitment from providers where they're finding that the graduates from those training courses are ill-equipped to do the job to actually provide that training, commit to doing that themselves, to upskill their own workforce.

MS HUTCHINS: Do you think it's necessary that there be a mandated minimum training requirement for staff in carer roles?

10 ASSOC PROF MACFARLANE: I do, yes.

MS HUTCHINS: In – for both personal care workers and further training for nurses?

15 ASSOC PROF MACFARLANE: I think further training for nurses is highly desirable and should be mandatory as well. I know there's a lot of talk about mandated nursing staffing ratios in particular, but knowing about the training curriculum of nurses, I'm not convinced that having completed a nursing degree, necessarily gives you any particular expertise in dementia, simply by virtue of being  
20 a nurse. I suppose in defence of that population, I would draw your attention to perhaps the one environment where problem behaviours in dementia are managed less well than in residential aged care and that's in the acute hospital setting which is full of nurses and doctors.

25 Now simply having the qualification doesn't mean that you have the necessary skills to manage behaviours in dementia. I think if you're going to work in that environment you need to be specifically trained to look after the cohort of people with their particular problems that you're going to find in residential care and a generic nursing background doesn't give you that.

30 MS HUTCHINS: And training aside, do you think that there's a general issue with attracting appropriate staff into the aged care system?

ASSOC PROF MACFARLANE: I do. I was reading last week that the vacancy  
35 rate for registered nurse positions in aged care is currently 41 per cent. You know, if you mandate higher nursing ratios, you're going to have a higher vacancy rate on that basis. I think to work in aged care and be effective in that role you need to have a passion for it. You need to have a love and a passion for older people and an empathy for their needs. There are disincentives to becoming a nurse in aged care.  
40 It's not as well paid as some of the roles in acute hospital settings, so accordingly you tend to get two groups of people who might end up doing the jobs. They're the people who have a real passion for it and who should be doing it, and there's the people who perhaps can't get employment in a higher paid position, which again comes back to quality and safety.

45 With people with passion, you get both quality and safety. With people who are just taking the job because it's all they can get, you're not getting either, really, despite

5 them both having the same qualification, and to me the providers who do best in this space, particularly in relation to managing the needs of people with complex behaviours are those who recruit on the basis of passion rather than qualifications. They actively seek those people out and spend the time and effort to train them up to perform the role, rather than assuming that simply having a qualification or having completed a six week course means that you're an appropriate person to work in that milieu.

10 MS HUTCHINS: When DBMAS or SBRT team members attend the facilities, what are some common problems that you see that would just be attributable to staffing issues?

15 ASSOC PROF MACFARLANE: To staffing issues; the consultants that we employ maintain a database of what they feel are the contributing factors to behaviour. And chief amongst those by a long shot is under-recognised or undertreated pain in between 60 and 70 per cent of all our referrals. Close behind are carer approach to the person living with dementia, a lack of recognition of the person's particular needs in view of their background, likes, dislikes, personal history and so forth, and deficits in the both built and the social environment, under or  
20 overstimulation, and an inappropriate built environment that doesn't facilitate wayfinding, for example, or doesn't maximise or enable the person with dementia to an appropriate degree. In fact, we find that many environments compound and amplify the deficits of people living with dementia rather than enable them to do the best they can within a particular setting.

25 MS HUTCHINS: And you mentioned earlier issues that you see in relation to the admission process; why do you think that that is not being done as fulsomely as it could be in some instances?

30 ASSOC PROF MACFARLANE: The admission process, I think, is done reasonably well because the provider's funding depends on accurate and comprehensive completion of the ACFI documentation. So I don't see the problem as being a deficit in the admission process from a facility's point of view, but in  
35 continued reference to the ACFI document as a living document that should inform care beyond the initial month of admission. I think there are deficits around medical admission processes, to take a different angle on the question, and in particular newly admitted residents who are transferred from the acute or subacute hospital setting, the discharge summary is not providing sufficient information in particular on why certain medications are being prescribed, how long they've been prescribed for,  
40 advice or guidance about when they should be reviewed or ceased.

45 And when GPs receive the discharge summary if, in fact, they're lucky enough to receive one, they might be inclined to continue a medication simply because of fear out of what might happen if they stop it because they don't know why it was commenced in the first place.

MS HUTCHINS: And you mentioned earlier the importance of a holistic approach to someone's care. Who do you think is responsible for that process?

5 ASSOC PROF MACFARLANE: Who is responsible and/or who should be responsible?

MS HUTCHINS: Who should be responsible in an aged care facility?

10 ASSOC PROF MACFARLANE: I think the staff within the aged care facility regardless of their grade or their level need to take responsibility for that. And if you talk to providers and staff within providers about their model of care, they will say that it's person-centric and holistic, but when you dig down there seems to be very little understanding of what that means and it's more something that's paid lip-  
15 service to, rather than implemented, and to be honest, I'm not sure that the staff have the time necessarily, nor certainly the skills to implement it fully, by virtue of their poor training.

MS HUTCHINS: Yes. And do you think there should be greater involvement by general practitioners in that process?  
20

ASSOC PROF MACFARLANE: Around the process of behaviour management in particular?

MS HUTCHINS: Yes, and feed into the, I guess, holistic approach of someone's case management if you want to use that term.  
25

ASSOC PROF MACFARLANE: Ideally, yes, it should be a multidisciplinary team approach with regular case conferences between GPs and staff and other specialists who are involved. We've heard for various reasons why that doesn't occur, the various disincentives around it. I don't think GPs are the answer to adequate  
30 behaviour management in residential care either. I mentioned the deficits in the aged care training curriculum and alluded to those in the nurse training curriculum. The same deficits apply to the medical training curriculum. Most doctors, by the point of graduation from medical school might have had three or four lectures on dementia, if they're lucky. Those lectures are often focused around medication management.  
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Those people who complete the Royal Australian College of General Practitioners specialist training program do very little over and above what is taught in medical school so consequently if GPs are only provided with the prescription pad as a tool to  
40 use in managing behavioural disturbance in dementia, they tend to use the tool that they have. So if all they have is a hammer everything looks like a nail because a hammer is all you know how to use. I don't think doctors do behavioural assessments well at all, and I'm not criticising general practitioners here, I don't think specialist doctors do it well at all as well. My own experience in having to do  
45 these assessments when I was going into aged care facilities, I don't have the time nor has my training provided me with the expertise to do as good a job as the DSA consultants who are a multidisciplinary team. It requires specific training, a lot of

time to do a proper assessment. That's time that doctors don't have typically and it's expensive time and a lot of expertise.

5 MS HUTCHINS: So what do you think is the most important thing to concentrate on to raise the standard of care in aged care facilities?

10 ASSOC PROF MACFARLANE: In relation to behaviour management in particular, I would refer you back to the Brodaty triangle. If you look at the shape of the Brodaty triangle by far the majority of behaviours that might occur, occur at those lower behavioural tiers. The very extreme and severe behaviours are significantly more rare. Therefore, you're going to do more people more good if you focus on upskilling residential aged care staff in their basic qualification to enable them to manage the lower tiers of behavioural disturbance. You will probably prevent for inappropriate psychotropic prescription if you target your interventions at that level than if you set the bar too high and expect everybody to be an expert in the management of severe to extreme behaviours. That's never going to happen, but I do think that upskilling staff to manage lower tier behaviours is a desirable and an attainable goal if the necessary changes are made to training requirements for staff.

20 MS HUTCHINS: Thank you.

25 COMMISSIONER BRIGGS: Can I intervene and ask what those necessary changes to training requirements might be? I listened to we've got a deficit at GP level, we've got a deficit at nursing level, we've got a deficit at personal care, because the existing training really doesn't cover this area adequately at all. What is needed?

30 ASSOC PROF MACFARLANE: Well, if the majority of staff in a facility are PCAs who have completed a six week course and within that course they have to learn about a variety of medical conditions, a variety care approaches, and in addition to that learn all about dementia, that's doomed to fail just in terms of the quantum of education and training that can be provided in that period of time. I think there should be specific modules with an educative focus on how to manage problem behaviours from a psychological, environmental and social perspective rather than perhaps education that reinforces behavioural problems as being something that it's the doctor's responsibility to sort out, because most doctors will then only have the tool of a prescription pad available to them. I think behavioural modification modules as a mandatory part of aged care training would go a long way, Commissioner.

40 MS HUTCHINS: Moving on, do you think that the current accreditation system promotes quality aged care services?

45 ASSOC PROF MACFARLANE: No, I don't. The current accreditation system, as I understand it, tends to focus much more on the documentation of care, or a review of documentation regarding care that may or may not have actually been provided, but it has been documented, and staff are very conscious of this and the staff that I talk to tell me that a large proportion of their time is spent documenting what they

should have done or have done rather than actually doing it. And that satisfies the requirements of the accreditation standards agency but isn't indicative of the provision of quality or safe care to residents. I think if accreditors were to focus more on observing the care that was actually provided by staff to residents, that  
5 would force providers to focus on upskilling their staff in the actual provision of care rather than devoting resources to the documentation of care. And that to me would drive quality care as well as safety as well, because as a result of that staff would have more time to provide this hands-on care. So it would be nice if the accreditors were to change emphasis perhaps.

10 I also perhaps raise the issue at this point that safety does not necessarily reflect quality. Somebody made the point to me a couple of weeks ago that you can have a perfectly safe flight from Melbourne to Sydney on particular airlines but that could not be a quality experience at all, and I do think that the current accreditation  
15 standards overemphasise safety at the expense of quality and don't allow for that dignity of risk. The acceptance of reasonable risk with the trade-off that acceptance of such risks maximises quality of life and has some meaning for the person and gives them pleasure. An example might be around food standards in facilities which emphasise safety to the extent that, for example, you couldn't eat a soft cheese in an  
20 aged care facility because theoretically there's a risk of listeriosis.

We accept those risks every day in our own home and eat soft cheeses. We accept the risk is there, it's low, we don't aim to eliminate it completely in our daily lives. We accept that some things that we do that give us pleasure might have a degree of  
25 risk, and that's dignity of risk, and the current standards currently emphasise safety, I think, at the expense of the quality aged care experience, allowing residents to take reasonable controlled risks that are manageable in the name of maximising their quality of life.

30 MS HUTCHINS: Yes. And do you think that providers are reluctant to afford residents opportunities which might give them the ability to exercise that dignity of risk because they're concerned about potential consequences if, you know, a resident falls or something else goes wrong?

35 ASSOC PROF MACFARLANE: Yes, that's a good example. A lot of facilities will have beautiful outdoor areas in courtyards that are surrounded by glass doors which are kept locked because if the residents go out and ambulate in these areas they might fall, with the result that residents see these beautiful outdoor areas and continually try the handles to try to get out and access these beautiful outdoor areas,  
40 at which point they get labelled as behaviourally disturbed and potentially medicated. So you can exercise appropriate risk management and allow residents access to outdoor areas as long as those outdoor areas follow good dementia design principles and are tailored to the needs of people with dementia. Currently we don't see that.

45 MS HUTCHINS: If you could encourage reform to one part in particular of the current system what would be the area that you would recommend focus is put on.

ASSOC PROF MACFARLANE: Staff training. If you focus on that, I think you get the most bang for your buck in terms of appropriate behaviour management and decreasing inappropriate psychotropic polypharmacy. I think that the new accreditation standards around behaviour that are coming in in July will to some extent help influence that change. The current standard around behaviour is simply quote, unquote, that behaviours are effectively managed with no comment about quality or safety. The new standards will require that providers' behaviour management practices follow best practice, and best practice is clearly not psychotropic medication prescription. It's holistic tailored suite of individualised psychological, environmental, social interventions aimed at determining the cause of the behaviour and addressing that, rather than focusing just on symptom management. So it's really going to come down to the rigor with which the accreditation standards body interprets that best practice clause within the behaviour standard.

MS HUTCHINS: Yes. Because in your opinion, do you think providers are currently capable of implementing best practice?

ASSOC PROF MACFARLANE: I think some providers are very well prepared to do that. DSA has only been into 60 per cent of facilities in Australia. I'm assuming that at least, in some of the remaining 40 per cent, they're managing things really well and don't need us. And I would love to see the situation where a need for our service is eliminated. So I think there's certain islands of excellence in behaviour management, but I don't think the majority of providers are well positioned to meet that standard at all.

MS HUTCHINS: I have no further questions, Commissioners.

COMMISSIONER TRACEY: Thank you. Professor, it has been put to us that one way of attracting empathetic and skilled nurses to the system might be a placement arrangement in the course of their training, similarly to the way doctors do periods of residential placement in hospitals in the course of their degree training. I wonder if you have a view as to whether that might work, provided that the facility where the training was provided is at the top of the benchmark, not the bottom.

ASSOC PROF MACFARLANE: I do think that would be a good idea, and I can speak to my own personal experience in that regard. I certainly didn't enter medical school with a burning ambition to become a geriatric psychiatrist. I had no idea what the speciality involved for – and no interest in it until I did a rotation in aged psychiatry during my training as a psychiatrist. At that point I fell in love with it. And I'm sure that unless nurses get exposed to the possibility of working within aged care, unless they get that exposure they're not going to consider it as being on the radar for their career. It's something that you only determine a love for or find a love for, in many cases, once you've actually done it. And if you can provide more opportunities for that exposure, then I suspect that will have flow-on effects for recruiting passionate, qualified nurses into the sector.

COMMISSIONER TRACEY: And my second question is – I’m not sure that you’ve expressed a concluded view – you may not have one – as to whether there is merit in having standalone facilities for elderly people with dementia separate from aged care facilities where the frail and otherwise – I’ve perhaps not put this as clearly  
5 as I may, but what I’m getting at is there a case for discrete aged care facilities for patients with dementia?

ASSOC PROF MACFARLANE: I guess arguably, Commissioner, you have that situation already because you have dementia specific units, so called, within larger  
10 generic facilities. I would go back to the point I made earlier though about not all residents with dementia being created equal, because if you simply segregate people on the basis of diagnosis that doesn’t cater to their individual needs. I think that somebody who has a mild degree of dementia is quite capable of living a fulfilling life within a generic facility.

15 COMMISSIONER TRACEY: It may be a good thing they are in a generic facility.

ASSOC PROF MACFARLANE: That’s right. I would hate to see, though, a diagnosis-based segregation where you have people with wildly divergent needs and  
20 wildly divergent patterns of behaviour – the example of the young physically aggressive robust male with frontotemporal being housed in a unit with a frail 95 year old lady living with dementia who just sits in a chair all day. That’s nonsense to me. I think that standalone facilities for people with particular types of behavioural disturbance and particular degrees of behavioural disturbance is good, and we are  
25 seeing that with the Commonwealth’s move towards implementing specialist dementia care programs for those, you know, tier 6 behaviours that we see. That move, I think, will create expertise within the sector which hopefully will flow on to the broader sector, because all of these special dementia care programs are going to be housed within generic residential aged care facilities as they currently exist. So I  
30 think that way of proceeding is a lot better than segregation on the basis of diagnosis. Diagnosis doesn’t predict individual needs.

COMMISSIONER BRIGGS: When you get – when we get to tier 7, what do you see as the appropriate facilities, if you like, or housing arrangements and care  
35 arrangements for that group?

ASSOC PROF MACFARLANE: Currently, I don’t feel, Commissioner, that there is an appropriate setting for that group of people. Even the specialist dementia care programs are targeting tiers 5 and mainly 6 of the Brodaty Triangle. People with  
40 those very extreme behaviours – which, fortunately, are very rare, are really exhibiting degrees of disturbance that are too great to reasonably expect any provider to adequately care for them. They might often require, for example, constant one-to-one supervision or the availability of security staff. Such individuals do exist in the system currently, but they’re housed, really, according to the availability of long  
45 stay, often psychiatric services within State hospital network facilities rather than the aged care environment.

COMMISSIONER BRIGGS: And is that where you think the appropriate arrangement is?

ASSOC PROF MACFARLANE: Sorry?

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COMMISSIONER BRIGGS: So do you think long stay psychiatric facilities is the best place for those people to be?

ASSOC PROF MACFARLANE: Not at all, because again, in that environment, you have a mixed group. You have people with long-term psychiatric illness, which is the appropriate group. But people with extreme behaviours in the setting of dementia will often be shoehorned into such settings because there's really no alternative within the State system. So it's far from ideal. I mentioned that the skill set that's required to care for one group of people with behaviours arising from psychiatric illness is quite different to that which might be required for somebody with severe behaviours in dementia. And I guess it's that colocation of resident mix that led to such disasters as Oakden, for example, not best practice care.

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COMMISSIONER TRACEY: Anything arising from that?

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MS HUTCHINS: No, Commissioners.

COMMISSIONER TRACEY: Professor, thank you very much for sharing your considerable expertise with us. And we will certainly take on board your recommendations when we come to deciding what we're going to recommend to government in relation to this very vexed area. Thank you very much for your assistance.

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ASSOC PROF MACFARLANE: Thank you, Commissioners for your time.

30

**<THE WITNESS WITHDREW**

**[4.05 pm]**

COMMISSIONER TRACEY: The Commission will adjourn until 10 am tomorrow morning.

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**MATTER ADJOURNED at 4.05 pm UNTIL THURSDAY, 16 MAY 2019**

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