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TRANSCRIPT OF PROCEEDINGS

O/N H-1063563

**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**

MELBOURNE

10.00 AM, MONDAY, 9 SEPTEMBER 2019

Continued from 8.8.19

DAY 47

**MR P. ROZEN QC, counsel assisting, appears with MS E. BERGIN, MR R.
KNOWLES and MS E. HILL
MR S. FREE SC appears with MR B. DIGHTON for the Commonwealth
DR S. PRITCHARD SC appears for the State of New South Wales**

COMMISSIONER BRIGGS: Please open the Commission. Good morning. I'd like to welcome you to the first of our hearings here in Melbourne. I'd like to start by acknowledging the Boon Wurrung and the Wurundjeri people who are the traditional custodians of the land on which we meet today. I would also like to pay
5 my respects to their elders, past and present, and to extend our respect to other Aboriginal and Torres Strait Islander people present today.

Mr Rozen, before I call on you, I should note that Commissioner Richard Tracey is unable to be with us at this hearing this week, however, you can be assured, of
10 course, that he will read the transcript. On 17 January 2019, Commissioner Tracey signed authorisations pursuant to the Royal Commissions Act 1902. The effect of those authorisations is that I may preside as the authorised member at any hearing. This is one such hearing. Yes, Mr Rozen.

15 MR ROZEN: Morning, Commissioner, I appear with Richard Knowles, Erin Hill and Eliza Bergin to assist you. Commissioner, we join you in acknowledging the traditional owners of this land and paying respect to other Aboriginal and Torres Strait Islander people who may be present here today. We pay our respects to their elders past and present. Commissioner, this week's public hearing, the
20 Commission's ninth and the first here in Melbourne, focuses on younger people receiving aged care services. The Royal Commission's terms of reference require it to examine, and I quote:

25 *How best to deliver aged care services to people with disabilities residing in aged care facilities including younger people.*

I'll return to this wording presently. Commissioner, a number of the witnesses that you will hear from this week have made public submissions to the Royal
30 Commission. We've now received 6022 submissions from the public. About 10 per cent of these raise concerns about care for younger people with disabilities. Those submissions are the life blood of our work and we encourage more members of the public and organisations to make submissions to assist us. Information about ways in which submissions can be made can be found on the Royal Commission's website.

35 Commissioner, we start by asking, how do younger people end up in aged care facilities. By definition, one would assume that aged care facilities are for the aged, and not the young. The answer is found in section 21(2) much the Aged Care Act 1997. That section provides that:

40 *A person is eligible to receive aged care services in the form of residential care if the person satisfies the criteria specified in the approval of Care Recipients Principles 2014.*

Section 6(1) of those principles provides that:

45 *A person is eligible to receive residential care only if the person satisfies three criteria. First, that they are assessed as having a condition of frailty that requires*

continuing personal care. Secondly, that they are incapable of living in the community without support.

And then relevantly for this hearing:

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If the person is not an aged person, there are no other facilities or care services more appropriate to meet the person's needs.

10 The clear intent of this provision is that residential aged care is to be, as one might expect, a last resort for younger people. In this hearing, we will examine whether in practice it is, in fact, a last resort. We will ask what efforts are made to source alternative accommodation for younger people and what alternatives are currently available. We'll investigate what training and information are provided to those charged with the very important role of applying section 6 of the principles.

15 Commissioner, despite the clear legislative intent, every week on average in Australia 42 younger Australians enter aged care, six per day or 2000 per year.

By the time we return today after the luncheon adjournment, on average one more younger person can be expected to have become a resident in an aged care facility.

20 Dr Morkham, who is the national director of an important advocacy group in relation to younger people in aged care and from whom you'll hear later this week will describe this process as a pipeline. She will say that that pipeline must be stopped. A number of witnesses we call this week, most of whom speak from their personal experience will explain very clearly why residential aged care is inappropriate for

25 younger people. They'll tell you that residential aged care facilities are inappropriate for a number of reasons.

First, the residential aged care facilities are unable to provide the support required by younger people, many of whom have profound disabilities. Secondly, there are

30 inadequate numbers of appropriately trained staff to provide that care. Thirdly, younger people in residential aged care commonly experience significant functional decline. And fourthly, the Aged Care Funding Instrument funding levels are woefully inadequate to enable the aged care providers to provide the care required by this group of people. Housing younger people with disabilities in residential aged

35 care is not just inappropriate. It can also offend fundamental human rights principles as set out in article 19 of the Convention on the Rights of Persons with Disabilities, which is concerned with the right to live independently in the community.

In the very recent submission by the Australian Human Rights Commission to the

40 United Nations Committee on the Rights of Person with Disabilities, the Human Rights Commission welcomed recent initiatives to reduce the number of younger people in aged care but called for more ambitious targets and proposed other reforms. Commissioner, we will call witnesses who will describe their experiences of life as younger people in aged care. They will tell you of the anguish caused by

45 not having people their own age with whom they can socialise. Mr James Nutt, who was to be the first witness we call today but we're hopeful will now give evidence tomorrow, will tell you he was 22 years old when he first entered aged care.

He will refer to the seven years he experienced in aged care as a prison sentence. His absence from today's witness list is a reminder of how challenging life is for younger people with disabilities in Australia. He was unable to travel to Melbourne as planned yesterday from his home in New South Wales because of the difficulty
5 getting his motorised wheelchair on the aeroplane. He told me in conference last week, Commissioner, that appearing in person here today was to be the pinnacle of his life.

10 Previous reports. Commissioner, as with so many areas that this Royal Commission has examined is and is examining, the topic of younger people in aged care has been the subject of several critical reports over many years. For example, a 2005 Senate Committee report was strongly of the view that accommodation of younger people in aged care is unacceptable in most instances. Recognising that the issue could only be
15 jurisdictions work cooperatively to provide alternative accommodation for younger people in aged care facilities and ensure that no further younger people are moved into aged care facilities in future because of a lack of accommodation options.

20 The Council of Australian Governments responded to this report in 2006 with a funded five year initiative to give effect to the recommendations. This initiative, which ran from 2006 until 2011 led to a significant drop in the number of people under 50 living in aged care but it barely affected the 50 to 65-year age group. Overall, and despite the expenditure of considerable resources, that initiative had a negligible effect on the overall numbers of younger people entering aged care.

25 You will hear from Ms Kym Peake, the secretary of the Victorian Department of Health and Human Services, that one lesson to be learnt from this experience, that is of that initiative, is that such an initiative cannot succeed unless it is a truly multidisciplinary collaboration, rather than solely a disability reform and we will ask
30 whether history is about to repeat itself with the current initiative in place only this year. After a detailed examination of the available data, the Australian Institute of Health and Welfare reported this year, and I quote:

35 *In the 15 years between 1990 and 2014 the overall number of younger people first entering permanent aged care increased by 22 per cent.*

And it's to be recalled, Commissioner, that the period of that earlier initiative, 2006 to 2011, falls squarely within that 1999 to 2014 period. The evidence will be that the Commonwealth spent in excess of \$100 million on that initiative. A further Senate
40 Committee report in 2015 decried a lack of progress in stemming the flow of younger people into residential aged care. It made a number of recommendations including that the Commonwealth compile a database of all younger people living in residential aged care, including the

45 The evidence will show that many of the recommendations, including that one, have not been implemented. We don't have such a database four years later. The

evidence will reveal that our Commonwealth Government agencies still do not have accurate and reliable data upon which to provide evidence-based policy.

5 Who are the younger people in residential aged care facilities. The Australian
Institute of Health and Welfare reported in 2019 that each year between 2009 and
2014, around 2000 under the age of 65 first entered permanent aged care. Around
half of this group were between the ages of 60 and 64 but some were considerably
younger than that. The majority were assessed under the aged care assessment
10 program in a hospital, usually by staff connected to the hospital. It was those
assessments that concluded that there were no other appropriate care facilities or care
services as required by the Approval of Care Recipients Principles. You will hear
some evidence this week that those assessments can be quite perfunctory and there is
surprisingly little oversight of this process by the Commonwealth Department of
Health.

15 It's also noteworthy that some 2500 younger people are receiving home care
packages under the aged care system, either not eligible or not engaged with more
age appropriate service options such as the National Disability Insurance Scheme,
NDIS. Commissioner, we will hear that the drivers of admission for younger people
20 into aged care are many and are longstanding. We intend to show that this situation
is the result of a number of factors, largely attributable to a policy environment that
has failed to recognise adequately the wishes and needs of younger Australians
requiring care. There's nothing inevitable about younger people ending up in
residential aged care facilities. It happens as a result of deliberate policy decisions
25 that have been made by the Commonwealth, State and Territory governments over
many years.

This group of Australians includes those with a lifelong disability, those who acquire
a disability as a result of traumatic injury, those with a progressive or life-limiting
30 illness, those with complex care needs arising from social disadvantage, and those
experiencing the early onset of age-related illness or disability. In statistics recently
released by the Australian Institute of Health and Welfare the most common health
conditions cited at the time of admission to aged care are dementia, cancer,
cerebrovascular disease and progressive neurological disorder. It's also noteworthy
35 that these data indicate that more than 20 per cent of younger people admitted to
aged care spent less than six months in that setting. This suggests that residential
care is being used as either a transitional or, more likely, a palliative care option.

Of almost 2000 younger people who exited residential aged care in 2017/18 almost
40 60 per cent exits were for those who died. Only 10 per cent of younger people
leaving aged care went either home or back to their family. They're the two
categories identified in the report. Only a small proportion moved to more
appropriate accommodation. We will be exploring this phenomenon in more detail
throughout the hearing. Central to the theme of this hearing is the notion of
45 appropriateness. Commissioner, the aged care system has been designed for people
with care and social needs that reflect their advanced age. As you heard in the first
hearing in Adelaide, the average age of a resident in an aged care home is now

approximately 82 for men and 85 for women. This reflects a two, or even three generation difference in age between the average aged care resident and some of the younger people that are forced to enter aged care.

5 Shortly, I will outline in further detail the witnesses we will hear from over the four hearing days, being today, tomorrow, Wednesday and Friday. I note the Commission will not sit on Thursday. The broad approach to the hearing. First, I would like to outline the broad approach we will be taking. We believe that to understand the issues affecting younger people in aged care settings we must hear
10 their voices. This week, we will hear directly from those who have been or continue to be stuck in aged care. We'll also hear from their families about the level of advocacy required to find alternative care for their loved ones and to ensure adequate care is provided whilst they are in aged care. Commissioner, one can only admire the selfless devotion of these families.

15 Witnesses with direct experiences will lead us to question whether the placement of younger people in aged care settings is, in fact, ever appropriate. This hearing will examine the policy settings in both State and Commonwealth Governments that influence the care options for younger people in, or those that are at risk of being
20 admitted to, aged care. We will demonstrate that nonsensical funding arrangements have perpetuated younger people entering into and remaining in aged care. Recent developments may well have made it more likely that younger people will enter aged care.

25 We'll explore the interfaces between the health, disability and aged care sectors, identifying the barriers and levers that contribute to younger people being placed in aged care. Commissioner, you'll hear of the tension that exists between these systems and the inter and intra-jurisdictional issues that drive this tension. It's a tension that is no more evident than when hospitals aim to shift patients they refer
30 disparagingly to as bed-blockers into alternative care arrangements. We will explore how the pressure on hospitals, aged care assessment teams and aged care homes influences the placement of younger people into aged care.

The hearing will highlight the importance of data and information sharing,
35 particularly at the point of these system interfaces. More than this, though, it will highlight that despite a mountain of data being collected by the key agencies involved in caring for young people in aged care and multiple reviews and inquiries calling for better understanding, there is a glaring lack of knowledge about this group, their characteristics and needs. This suggests the Professor Westbrook
40 observation in Darwin that the aged care system is data rich but information poor is especially true for this cohort. Commissioner, we plan to show that the current situation doesn't necessarily have to continue.

We will consider the way in which other schemes for those with very similar needs
45 operate, namely, the compensable insurance schemes for people with a lifelong disability arising from an accident, be it a work accident or transport accident. Representatives of the New South Wales, South Australian and Victorian

government-run injury insurance schemes will describe how their systems' processes and priorities result in extremely low numbers of people in these schemes being placed in aged care settings. There are lessons here for the Commonwealth Government and its policy makers; it's not clear, though, that those lessons are being learned.

Finally, we'll have regard to the insights of three organisations: Youngcare, the Summer Foundation and the Young People In Nursing Homes Alliance. These groups have been working tirelessly for many years to support younger people to avoid and find an alternative to aged care. We'll hear of their frustration, that despite dedicated resources and bold announcements there's been little impact made on the number of younger people being admitted to residential aged care. It's not the intention, Commissioner, of this hearing to examine the quality of aged care services delivered to younger people. Rather, the focus will be on the appropriateness of aged care for younger people in particular and how better solutions may be delivered.

Returning to your terms of reference for a moment, we will ultimately be submitting to you it is not appropriate to deliver care services to younger people with a disability in aged care facilities in most circumstances. Their important care needs must be met in care settings that are appropriate and tailored to their needs. We recognise that the special needs of those such as Aboriginal and Torres Strait Islander people or people who are homeless or at risk of homelessness may require the use of aged care before the age of 65 because of conditions associated with premature ageing, where they are unable to access other services, such as the NDIS, to deliver the kind of support most suited to their needs.

This will form part of the focus of a future hearing of the Royal Commission next month on groups with special needs and also prompts us to reflect on previous evidence about the importance of place-based solutions in rural and remote areas. Other hearings have explored and will continue to explore the quality of aged care service more broadly. And any findings relating to the overall quality of aged care in Australia will also apply in the context of younger people. I can turn, then, to the witnesses that we will hear from. As I've just indicated, this hearing will emphasise the insights of younger people with lived experience in aged care and the experiences of their families.

Commissioner, we do not propose to conduct formal case studies in this hearing. Rather, we will hear accounts of eight younger people who have spent time or continue to reside in aged care. These accounts will highlight that aged care acts as a service of last resort for many younger people and that often what was envisaged as a term placement can turn into a very lengthy stay in aged care, from a few months to a number of years. This evidence will emphasise the importance of younger people not entering aged care in the first place if it is at all avoidable. These personal stories serve to build an understanding of the effects living in aged care can have on the wellbeing and outlook of a younger person.

Some of these witnesses will also be able to describe the difference to their lives that securing alternative care and accommodation arrangements can have. The story of Mr James Nutt will bring into focus the impact that inappropriate placement in aged care can have on the psychosocial wellbeing of younger people. Mr Nutt acquired a
5 brain injury as a 19 year old. After a lengthy stay in hospital, followed by extensive rehabilitation, James found himself in a nursing home with almost every other residents there more than 60 years his senior.

10 Reflecting on his seven years in aged care, Mr Nutt will describe the lack of age-appropriate activities, social interactions, relationships and the sense of powerlessness that he felt. Mr Nutt will describe his sense of hopelessness, isolation and grief and how finding alternative care arrangements and access to specialist disability accommodation, or SDA, has made his life worth living. We'll also hear the story of Ms Kate Roche, Ms – Roche's late husband, Michael Burge, died in
15 residential aged care. Mr Burge suffered a stroke in 2014, at the age of 56. He was admitted to residential aged care in around June 2015, following a period in hospital and 10 months in a rehabilitation service. Mr Burge died in June 2017.

20 Ms Roche's story will illustrate the complex pathways into residential aged care for younger people, the hospital residential aged care interface, specifically the absence of appropriate long-term rehabilitation options, resulting in entry into aged care, and the inappropriateness of aged care for younger people, in particular, the lack of rehabilitation services, leading to a functional decline whilst in residential aged care. We'll hear the experience of Jessica Dodds' late husband, Anthony, who died in
25 residential aged care just five weeks after being admitted.

Ms Dodds' story will illustrate the pathway of a younger person who enters aged care with a cancer diagnosis, the lack of information and supports to navigate the NDIS and the aged care systems, the Aged Care Assessment Team, or ACAT,
30 process, as it applies to a younger person, and the lack of alternatives to residential aged care, particularly for those needing palliative care services. Ms Dodds' story will also highlight the lack of age-appropriate activities for younger people in residential aged care, as well as barriers to accessing full and coherent supports from both the NDIS and aged care systems.

35 We'll hear from Robyn Spicer, whose daughter, Jessie, has a chromosomal anomaly, which resulted in disability from birth. They live in a regional area. And when Jessie's needs increased and Robyn was no longer able to meet those needs at home, there was no suitable alternative other than residential aged care in her local area.
40 The only other option was to move further away, where Ms Spicer would have to travel long distances to see her daughter. Ms Spicer will tell a positive story, as she has managed to obtain aged care and disability services to cater for her daughter's care needs and to improve her quality of life.

45 While Jessie lives in an aged care facility, she spends most of each weekday at a disability day service where she engages in activities personalised to her needs and interests. The Spicer family story illustrates that even where there are no other

options it is possible for aged care and disability services to work together to provide a younger person with coherent services. Unfortunately, however, this story is not representative of the experience of many younger people in residential aged care. Lisa Corcoran's experience provides a stark contrast to that of Ms Spicer.

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Ms Corcoran, like a number of other witnesses from whom you'll hear, felt as though she had no choice when she was moved from the hospital to a residential aged care facility. She entered residential aged care in 2013, when she was 37 years old. It has been six years and she continues to live there, where she feels isolated and unsupported. Ms Corcoran feels that aged care staff at the facility are not responsive to her care needs. She has found it difficult to connect with other residents, who she says are dying all around her. She spends every day in her room alone. Ms Corcoran will tell you she hates living in residential aged care. She cannot wait to get out after her supported disability accommodation is completed, which is expected to be around December 2019.

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Commissioner, Kirby Littley and her parents, Carol and Kevin, will highlight the significant commitment and advocacy required to find appropriate accommodation for younger people with disabilities. Ms Littley was a special needs teacher who was diagnosed with a brain tumour at the age of 28. And following an operation to remove the tumour, she suffered two strokes, which left her unable to speak or move. She spent 11 months in a hospital and then 12 months in a residential aged care facility in 2014/15. She was only 28 years old at the time.

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From the time Ms Littley became unwell, her parents have been with her every step of the way, vigilantly navigating the maze of health, aged care and disability systems. This intense advocacy has resulted in Ms Littley's successful transition to live with her parents for three years and, more recently, to move into her own apartment. Commissioner, Mario Amato will tell us about being a physically-able man who lived in residential aged care for almost three and a half years between 2015 and 2019. Mr Amato was 55 years old when he had an epileptic seizure and two strokes, causing damage to his frontal lobe.

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He will talk about how hopeless he felt when he was put into a residential aged care facility and how, like Ms Littley, it took a concerted effort to exit residential aged care. He credits his successful exit to his two guardians and an advocate, who helped him fight to leave aged care. We'll also hear how the NDIS did not improve Mr Amato's quality of life while he was in the residential aged care facility. But now that he's living in a community setting, it has been NDIS funds that have been redirected to help him live a more independent life. This distinction between the way the NDIS considers people with disabilities in the community as compared to those in residential aged care will be one of the themes that we will examine this week.

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Mr Amato now lives his partner and spends his day maintaining his house. He continues to aspire to return to work as an accountant. Finally, Commissioner, we'll hear from Neale Radley, who, in early 2014, had a diving accident that left him a quadriplegic. He lives in a rural town and, like Ms Spicer's daughter, Jessie, did not

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have a meaningful choice of where he could reside. Mr Radley has lived in a residential aged care home for about four years and remains hopeful the NDIS will provide him with the support he needs. Mr Radley is optimistic that through the NDIS he will move into more appropriate disability accommodation, where he will have better social interactions. But Mr Radley is tempering his expectations, because too often the health, aged care and disability systems have disappointed him.

These accounts will illustrate how inappropriate and insensitive residential aged care environments can be for younger people and the profound impact that this environment can have on their quality of life. The accounts will also examine issues of lack of choice and connection to family and community. Commissioner, government witnesses will appear from both Commonwealth and State levels. At the Commonwealth Government level, it is clear that responsibilities for the care of younger people in aged care are shared between the Department of Social Services, the National Disability Insurance Agency and the Department of Health.

We'll hear from senior representatives of each of these agencies about the convoluted, contradictory and unequal ways in which younger people may receive care due to unclear and unwieldy policy and funding frameworks. These Commonwealth witnesses are expected to describe a lack of policy clarity and ownership, as well as limited data collection and sharing capabilities, which result in a lack of knowledge of the who, how and why of younger people being admitted to aged care.

The National Younger People in Residential Aged Care Action Plan. During the hearing we'll explore this action plan, which was announced with much fanfare by the Commonwealth Government in March of this year. The plan has three goals. Firstly, supporting those already living in aged care, under 45, to find alternative age-appropriate housing and supports by 2022, if this is their goal. Secondly, supporting those already living in aged care under 65 to find alternative age-appropriate housing and supports by 2025, if this is their goal. And, thirdly, halving the number of younger people aged under 65 years entering aged care by 2025.

We expect the Commonwealth witnesses we call will tell you that they're confident this plan will achieve what are its admittedly limited goals. We noted earlier that other plans, projects and initiatives have been implemented with limited success in recent years, in an attempt to reduce the number of younger people in residential aged care. Yet despite those earlier plans and the considerable resources that have been invested in reducing the number, we still have approximately 6000 younger people in residential aged care. This figure has remained largely unchanged since 2006, when it was 6557. The evidence will be that the most recent figure from 31 December 2018 is 5802.

Commissioner, we plan to demonstrate that the action plan will not do enough soon enough to resolve this issue. Part of the reason for that is a lack of investment in suitable alternative accommodation. The Commonwealth is placing its faith in market solutions. We will examine whether that faith is misplaced and whether a

greater intervention by government is needed. We will also examine whether the lack of any specific funding commitment underlying the action plan will be detrimental to its success. Commissioner, Ms Peake, Secretary of the Victorian Department of Health and Human Services, will reflect on the tensions involved when someone attends hospital and no longer requires acute care but cannot be safely discharged home.

As the operators of public hospitals, as well as the employers of aged care assessment teams, state health departments are at the frontline when considering the safest and most appropriate options for younger people with high care needs. For reasons that we will explore, and despite much evidence that it should have done, the Commonwealth decided not to consult with the states and territories in the development of the action plan. The contrast between a compensable insurer's emphasis on rehabilitation and promoting independence with that of the maintenance approach of the NDIS and aged care sectors will be brought into focus. This will prompt us to consider alternative approaches to care.

Youngcare, the Summer Foundation and the Younger People In Nursing Homes Alliance will tell us that despite more than a decade of dedicated focus on this issue, we are still seeing unacceptable numbers of younger people placed in aged care. They will highlight the drivers of inappropriate placement, in particular, the lack of suitable accommodation, the lack of real advocacy services and the lack of appropriate levels of care, particularly nursing and complex health care. In summary, Commissioner, we will see this week as an opportunity to cast a light on the 6000 younger Australians who are accessing residential aged care services. This is a group of largely unseen and lost Australians. They are hidden. They deserve better, and this Royal Commission provides an opportunity to deliver better outcomes for them.

For too long, Commissioner, aged care services have been seen as the last resort option, the safety net, if you will, when all else fails. We can no longer be satisfied with the aged care sector acting as a band aid for the failings of other systems. Commissioner, at this point, I would seek to tender the general tender bundle, which is a bundle of documents that will be referred to throughout the course of the hearing. I can indicate to the parties that the bundle presently has 188 documents in it. And if that could be marked as an exhibit now, please, Commissioner.

COMMISSIONER BRIGGS: Yes, Mr Rozen. The general tender bundle will be exhibit dash 1.

MR ROZEN: Should that be 9-1?

COMMISSIONER BRIGGS: Sorry, 9-1.

EXHIBIT #9-1 GENERAL TENDER BUNDLE

MR ROZEN: 9-1. Thank you, Commissioner. Commissioner, after a brief adjournment to make some arrangements for the next witness – Ms Bergin will call that witness. Before adjourning the commission, it may be appropriate now to take some appearances from – on behalf of other parties.

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MR S. FREE SC: May it please the commission, my name is Free, I appear with my learned friend, MR DIGHTON, for the Commonwealth.

COMMISSIONER BRIGGS: Mr Free.

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DR S. PRITCHARD SC: May it please, Commissioner, Pritchard. I appear for the State of New South Wales, pursuant to leave granted on 13 August 2019.

COMMISSIONER BRIGGS: Dr Pritchard. Thank you. Is this an appropriate time to take a short adjournment?

15

MR ROZEN: It is. Thank you.

20

COMMISSIONER BRIGGS: Okay. We'll take a short adjournment of five or 10 minutes.

MR ROZEN: Thank you.

25

ADJOURNED

[10.34 am]

RESUMED

[10.49 am]

30

COMMISSIONER BRIGGS: Ms Bergin.

MS BERGIN: I call Lisa Joan Corcoran and Jodie Elizabeth Chard.

35

<LISA JOAN CORCORAN, AFFIRMED

[10.50 am]

40

<JODIE ELIZABETH CHARD, AFFIRMED

[10.50 am]

MS BERGIN: Ms Chard, your full name is Jodie Elizabeth Chard.

MS CHARD: Yes.

45

MS BERGIN: You're qualified as a speech pathologist and a counsellor.

MS CHARD: That's right.

MS BERGIN: You have worked in speech pathology for 30 years and for about 12 years in counselling.

5

MS CHARD: That's right.

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

10 MS CHARD: I have.

MS BERGIN: Operator, can you please bring up WIT.1250.001.0001. Is there a copy of your statement in front of you, Ms Chard?

15 MS CHARD: There is.

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

MS CHARD: I don't.

20

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

MS CHARD: It is.

25 MS BERGIN: I tender the statement of Jodie Elizabeth Chard dated 3 September 2019.

COMMISSIONER BRIGGS: The witness statement of Jodie Elizabeth Chard dated September 2019 will be exhibit 9-2.

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**EXHIBIT #9-2 WITNESS STATEMENT OF JODIE ELIZABETH CHARD
DATED 03/09/2019 (WIT.1250.001.0001)**

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MS BERGIN: Ms Chard, you're Ms Corcoran's speech pathologist?

MS CHARD: That's right.

40 MS BERGIN: And you've known her for five years.

MS CHARD: Correct.

MS BERGIN: You usually meet with her weekly.

45

MS CHARD: Yes.

MS BERGIN: You're going to give evidence today jointly with Ms Corcoran on the basis of your knowledge and experience of Ms Corcoran over the last five years.

MS CHARD: Correct.

5

MS BERGIN: Ms Corcoran, your full name is Lisa Joan Corcoran.

MS CORCORAN: Yes.

10 MS BERGIN: You are 43 years old.

MS CORCORAN: Yes.

MS BERGIN: You currently live in residential aged care.

15

MS CORCORAN: Yes.

MS BERGIN: You've lived there for about six years.

20 MS CORCORAN: Yes.

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

MS CORCORAN: Yes.

25

MS BERGIN: Is there a copy of your statement there. Ms Chard, perhaps you can show it to Ms Corcoran. Is that your statement? Is it true and correct?

MS CORCORAN: Yes.

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MS BERGIN: I tender the statement of Lisa Joan Corcoran dated 29 August 2019.

COMMISSIONER BRIGGS: The witness statement of Lisa Joan Corcoran dated August 2019 will be witness statement 9-3.

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**EXHIBIT #9-3 WITNESS STATEMENT OF LISA JOAN CORCORAN
DATED 29/08/2019**

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MS BERGIN: Thank you, Commissioner. Ms Corcoran, you moved to a residential aged care facility from a hospital in about 2013.

MS CORCORAN: Yes.

45

MS BERGIN: And the hospital and the aged care facility were on the same site in Melbourne.

MS CORCORAN: Yes.

MS BERGIN: Is that right? You spent five weeks in intensive care.

5 MS CORCORAN: Yes.

MS BERGIN: And then you moved to hospital where you spent about eight months.

10 MS CORCORAN: Yes.

MS BERGIN: And then you moved to aged care.

MS CORCORAN: Yes.

15 MS BERGIN: You have three daughters and three grandchildren.

MS CORCORAN: Yes.

20 MS BERGIN: And you're close to your brother, Peter.

MS CORCORAN: Yes.

MS BERGIN: And Peter is here with you today in the Royal Commission.

25 MS CORCORAN: Yes.

MS BERGIN: You're lucky to have such a loving brother.

30 MS CORCORAN: Yes.

MS BERGIN: And you're also lucky to have such a supportive carer, Michelle, who is also here with you today. Ms Chard is sitting here with you here in the witness box to assist you to communicate with me and with the Commissioner and

35 with the audience today.

MS CORCORAN: Yes.

MS BERGIN: Ms Corcoran, what are your goals for the future?

40 MS CORCORAN:

MS CHARD: Okay. My number 1 goal is to get the fuck out of the nursing home. My number 2 goal is to hug my children.

45 MS CORCORAN:

MS CHARD: I don't need to tell you this, you know. My number 3 goal is to communicate better.

5 MS BERGIN: Ms Corcoran, you mention that you want to get out of residential aged care.

MS CORCORAN: Yes.

10 MS BERGIN: Tell us how you feel living there at the moment.

MS CORCORAN:

15 MS CHARD: That's okay. I'll take over. I feel all right at the moment. I have – because I have carers that come in daily for about 12 hours a day. I have an NDIA plan which initially only gave me 60 hours of therapy and not much more, but it's been reviewed and they've fixed it up.

MS CORCORAN:

20 MS CHARD: But before that, it was a nightmare.

MS CORCORAN:

25 MS CHARD: My hygiene, I had to fight for a shower every second day.

MS CORCORAN:

30 MS CHARD: I called a meeting with the manager because I wanted to be washed more than once a week.

MS CORCORAN:

35 MS CHARD: It was the commissioner into safety – she said she called in the - - -

MS BERGIN: The quality agency?

MS CHARD: - - - quality agency to have a meeting.

40 MS CORCORAN:

MS CHARD: And then after that I got a shower every two days.

MS CORCORAN:

45 MS CHARD: Instead of once a week.

MS CORCORAN:

MS CHARD: I'm a vegetarian so the food was crap.

MS CORCORAN:

5 MS CHARD: It was a nightmare.

MS CORCORAN:

10 MS CHARD: It's your worst dream ever.

MS CORCORAN: Yes.

MS BERGIN: Ms Corcoran, when something isn't right, for example, when you had problems with only being showered once a week and you organised a meeting
15 with management, how do you communicate what your needs are and what you want to change about your situation; how do you communicate that?

MS CORCORAN:

20 MS CHARD: It's pretty hard because the management have a communication problem with their staff.

MS BERGIN: You mention that things have improved since you got the NDIA plan, Ms Corcoran. How have things improved and how do you feel living in aged
25 care now?

MS CORCORAN:

30 MS CHARD: Okay. I still don't like it but I have company now. Before that, I would just sit in my room and I couldn't even twiddle my thumbs.

MS BERGIN: And your company, Ms Corcoran, is that your carer such as Michelle who is with you today?

35 MS CORCORAN: Yes.

MS BERGIN: How do you socialise in aged care with the other residents; are there people to talk to?

40 MS CORCORAN:

MS CHARD: There was one person but they passed away, so I don't like to make friends. There is one person now, Lee, who is 54.

45 MS BERGIN: How do you spend your time at the facility, Ms Corcoran?

MS CORCORAN: I used to just sit in my room.

MS CHARD: I used to just sit in my room.

MS BERGIN: You mentioned in your statement, Ms Corcoran, that recently six residents died within two weeks.

5

MS CORCORAN:

MS BERGIN: You saw one of the bodies being moved out of the facility at lunchtime, and I'll read from it:

10

I just can't get it out of my head. I heard about these people dying as the nurses told me. I saw one body being moved. I saw his head in a red bag. This was at 12 noon when everyone was eating lunch.

15 Ms Corcoran, how do you deal with events like this?

MS CORCORAN:

20 MS CHARD: You've got to deal with it. Mentally, I'm not all right. I can't move and it's emotionally draining.

MS BERGIN: In your statement you mention that at times you have not felt safe in the aged care facility.

25 MS CORCORAN: Yes.

MS BERGIN: Have you had particular issues or problems because of your age?

30 MS CORCORAN: Yes.

MS CHARD: I was sexually assaulted. I have been punched. I was pinched by staff. Did you say - - -

35 MS CORCORAN:

MS BERGIN: Ms Corcoran, you mentioned that you've secured a place in a supported disability accommodation under NDIS and that this is under construction.

40 MS CORCORAN: Yes.

MS BERGIN: How do you feel about moving out of the facility?

MS CORCORAN:

45 MS CHARD: It's fantastic.

MS CORCORAN: I can't wait

MS CHARD: I can't wait. Every day is another day for me. I'm excited.

MS BERGIN: What do you most look forward to about living independently again?

5 MS CORCORAN:

MS CHARD: So there's a few things. Mainly the quietness; no screaming or crying.

10 MS CORCORAN:

MS CHARD: That's why my grandchildren don't come and visit anymore, because it's scary for them.

15 MS CORCORAN: I told my daughter not to bring them in.

MS CHARD: I told my daughter not to bring them in.

20 MS BERGIN: You mentioned that you're looking forward to hugging your daughters. You're looking forward to hugging your grandchildren too in your new home.

MS CORCORAN:

25 MS CHARD: Of course.

MS CORCORAN: I'm halfway there.

30 MS CHARD: I'm halfway there.

MS BERGIN: Ms Corcoran, Ms Chard is here with you today. How important is it to have advocates and support people in your community?

35 MS CORCORAN:

MS CHARD: Okay. I'm lucky to have good people around me. Other people don't have that and I feel – I feel sorry for them.

40 MS CORCORAN: Water.

MS CHARD: Water. Sure.

MS CORCORAN: And I have my brother.

45 MS CHARD: And I have my brother.

MS CORCORAN:

MS CHARD: He's always got my back.

MS BERGIN: Ms Corcoran, at the start we talked about the time you spent in hospital.

5 MS CORCORAN: Yes.

MS BERGIN: And your move to residential aged care.

10 MS CORCORAN: Yes.

MS BERGIN: Why do you think your move to aged care from the hospital?

MS CORCORAN: I don't know.

15 MS CHARD: I don't know.

MS CORCORAN:

20 MS CHARD: Who knows what they were thinking.

MS CORCORAN:

MS CHARD: I was only 37 then.

25 MS BERGIN: Ms Corcoran, why was it important for you to give evidence and share your story with the Royal Commission today?

MS CORCORAN: So people understand that

30 MS CHARD: Okay. That was a long one.

MS CORCORAN:

35 MS CHARD: So people understand that there are people like me and we're all humans, and humans crave respect.

MS CORCORAN: And we're all equal

40 MS CHARD: And we're all equal.

MS CORCORAN: And we're all human.

MS CHARD: And we're all human.

45 MS CORCORAN: We all crave respect.

MS CHARD: We all crave respect. And then you said “I feel like I’ve lost that respect”.

MS CORCORAN: I have.

5

MS CHARD: I could be here with nothing on and I wouldn’t feel any different.

MS CORCORAN: Except my brother is in the courtroom.

10

MS CHARD: Except my brother is in the courtroom.

MS BERGIN: Thank you, Ms Corcoran and Ms Chard.

MS CORCORAN: Thank you.

15

MS BERGIN: Commissioner, that concludes my examination of Ms Corcoran.

MS CORCORAN: I’ve got one more thing to say.

20

MS BERGIN: One more thing to say; yes.

MS CORCORAN:

MS CHARD: Okay.

25

MS CORCORAN:

MS CHARD: Okay. So one more thing I wanted to say, that I’m not in the witness box because I couldn’t fit in the witness box. And the person before me couldn’t fit on the plane. This is everywhere. We can’t fit into shops and we can’t fit here and there because we’re on wheels.

30

MS CORCORAN: And that kind of sucks.

35

MS CHARD: That kind of sucks.

MS CORCORAN: That’s all I wanted to say.

MS CHARD: That’s all I wanted to say.

40

MS BERGIN: Thank you, Ms Corcoran.

MS CORCORAN: Thank you.

45

MS BERGIN: Thank you, Commissioner. This concludes my examination of this witness.

COMMISSIONER BRIGGS: Thank you, Ms Corcoran. It's been good to see you here again and I certainly look forward to seeing you once you've achieved your ambition of getting out of the nursing home and into your own accommodation and having the freedom that you so aspire to. I'd like to officially excuse you from
5 giving evidence and thank you for coming in this morning.

MS CORCORAN: Thank you for listening.

10 MS CHARD: Thank you for listening.

COMMISSIONER BRIGGS: Thank you.

15 <THE WITNESSES WITHDREW [11.11 am]

COMMISSIONER BRIGGS: We might, I think, take a short adjournment of about 10 minutes until 20 past 11.

20 MS BERGIN: May it please the Commission.

ADJOURNED [11.11 am]

25 RESUMED [11.26 am]

30 COMMISSIONER BRIGGS: Mr Knowles.

MR KNOWLES: Commissioner. We have Ms Roche in the witness box so perhaps if she could swear the oath.

35 <CATHERINE EILEEN ROCHE, SWORN [11.27 am]

<EXAMINATION BY MR KNOWLES

40 MR KNOWLES: Ms Roche, could you tell the Commission your full name.

MS ROCHE: Catherine Eileen Roche.

45 MR KNOWLES: And you prepared a witness statement for the Royal Commission.

MS ROCHE: I did.

MR KNOWLES: And that's dated 29 August 2019.

MS ROCHE: Correct.

5 MR KNOWLES: And it's document WIT.1238.0001.0001. Have you read your statement lately?

MS ROCHE: I have.

10 MR KNOWLES: Yes. And are there any changes that you wish to make to your statement?

MS ROCHE: Yes. I noticed in section 34 that there was an incorrect – a typo.

15 MR KNOWLES: Yes.

MS ROCHE: Basically while in the first hospital, that should actually read:

While in the rehabilitation unit.

20

MR KNOWLES: Yes. Well, subject to that change, are the contents of your statement true and correct to the best of your knowledge and belief?

MS ROCHE: Yes.

25

MR KNOWLES: I seek to tender the statement of Catherine Eileen Roche dated 29 August 2019, Commissioner.

30 COMMISSIONER BRIGGS: The witness statement of Catherine Eileen Roche dated 29 August 2019 will be exhibit number 9-4.

**EXHIBIT #9-4 WITNESS STATEMENT OF CATHERINE EILEEN ROCHE
DATED 29/08/2019 (WIT.1238.0001.0001)**

35

MR KNOWLES: Thank you, Commissioner. Ms Roche, in your statement you've described the experience of your husband Mr Michael Burge who lived in a residential aged care facility for two years while in his 50s. You met Michael in 1988.

40

MS ROCHE: I did, yes.

MR KNOWLES: Yes, and you married one another in 1999.

45

MS ROBINSON: Correct, yes.

MR KNOWLES: Yes. Can you tell the Commissioner a bit about Michael.

MS ROCHE: Michael was a big fellow. He's six foot four, heavily set. He had a heart of gold, and he was a very articulate man, kind and considerate. He had a lot of
5 very good friends, a strong circle of friends and he loved meeting them. He was a very social person and – yes.

MR KNOWLES: Now, you've referred in your statement to the fact that on 21 May 2014 Michael suffered a stroke. How old was he at that time?
10

MS ROCHE: 56.

MR KNOWLES: And can you tell the Commissioner the nature of the stroke that he had.
15

MS ROCHE: Basically, to give you some idea, he woke up on a Wednesday morning, 21st of May 2014, and he said to me "Kate, I'm suffering from a headache." I left for work and at about 12 o'clock that day when I was at lunch, I tried to get in contact with him via the mobile. There was no answer. So I tried the landline.
20 Luckily, he had sat down near the landline and when he answered the phone, I could hear immediately that his voice had changed. So I basically rushed home and immediately upon seeing him, I called the ambulance. I had a fair idea that he'd probably suffered a stroke because he was slurring his words quite badly. So basically he was brought to the hospital and at the hospital – I think we're calling it
25 the first hospital, he was diagnosed with a pontine haemorrhage, colloquially known as pons stroke which is haemorrhagic. So he was in ICU for probably about five nights. I was warned two or three times during that period that I would probably lose him, but being the fighter that he is, he pulled through.

30 MR KNOWLES: But it had changed his life, that stroke, hadn't it?

MS ROCHE: Absolutely. He went from a man of being very eloquent in his speech to having dysphasia, basically. So he couldn't swallow, he couldn't pronounce his words properly, and the biggest thing for us was probably his lack of mobility. So he
35 suffered from ataxia and hemiplegia down his left-hand side, so he was basically – he changed from a man who was able to walk, talk and do everything for himself, perfectly independent, to a man that was cut down in the prime of his life and basically was wheelchair-bound and more or less totally reliant on people for the day-to-day activities such as washing and bathing, eating. We had to retrain him
40 how to use a spoon, you know, to feed himself and lots of other different occupational therapy things that we had to redo.

MR KNOWLES: He wasn't, in terms of his cognition, affected by the stroke though; is that correct?
45

MS ROCHE: No, I don't believe so.

MR KNOWLES: Did you notice any change in his mood after the stroke?

MS ROCHE: Yes. Obviously it would have had a huge impact on him. You know, he went from being a man that was perfectly capable to a man that was reliant on
5 other people to keep him fed and, you know, to look after his day-to-day activities.

MR KNOWLES: Yes. Now, at that first hospital that you mentioned earlier, what plans were made there for Michael's discharge from hospital?

10 MS ROCHE: So the NUM, I believe she was a NUM, came up to me and said that, you know, where would I like Michael to go after hospital.

MR KNOWLES: Sorry, you said the NUM?

15 MS ROCHE: Yes, the nursing unit manager.

MR KNOWLES: Yes.

MS ROCHE: So we talked about it and she said, obviously, Michael has to go to a
20 rehabilitation unit, and I said yes. And we agreed that the nearer it would be to home the better. So upon – I think she approached that rehabilitation unit and they advised us that there wouldn't be a bed immediately so that we would have to wait until one became available, which it did approximately four weeks later.

25 MR KNOWLES: Now, did that nurse unit manager say anything to you at the time about Michael's long-term accommodation options.

MS ROCHE: No. Her job was purely to, I suppose, take us from the first hospital
30 into the next phase which was the rehabilitation unit.

MR KNOWLES: Okay. And as you say, that occurred after a month or so in the hospital.

MS ROCHE: We were moved, yes.
35

MR KNOWLES: And that rehabilitation unit, was that in another hospital or connected to another hospital?

MS ROCHE: It was connected to another hospital on the northern beaches.
40

MR KNOWLES: And how long was Michael in that rehabilitation unit?

MS ROCHE: Basically he was there for from May – sorry, June 2014 to approximately March, I think 26 March 2015. So approximately nine months.
45

MR KNOWLES: And what rehabilitation services did he receive while he was at the rehabilitation unit?

MS ROCHE: The main focus was upon mobility. So we did a lot of work in the gym trying to get him to walk again. There was speech therapy and also occupational therapy, all kind of therapies designed to try and regain his – his day-to-day activities.

5

MR KNOWLES: And what was your involvement in that rehabilitation yourself?

MS ROCHE: I suppose because I'm quite sporty, I wanted to be involved in Michael's care there and his – and to make sure that the staff were actually doing what they needed to do. I understood that Michael was a very big fellow and I also understand, I suppose, the public service, because I work with them a lot myself in my own job, and I just felt that with my presence being there, I could ensure that Michael could get the optimal care and make the best progress that he possibly could in the time we were there.

15

MR KNOWLES: And did you observe progress in relation to rehabilitation for Michael up to Christmas of 2014?

MS ROCHE: Yes, I did. Basically – so every day, or nearly every day, unless he wasn't feeling all that great, we would go to the gym and we would practice sit to stands many, many thousands of times with the physiotherapists, and we eventually got him to stand on his own. It was quite a task but he did it. And we also got him to start walking between parallel bars. That was quite an achievement and it took probably about six months or so to do. He was still very wobbly and over that kind of December/January period I noticed that his ataxia was actually getting progressively worse. So we actually brought him to – we decided that we needed to get him an MRI to see what was going on in his brain and so for – that was done.

It was a massive exercise to get him to the actual X-ray or the MRI machine but we did it and the initial diagnosis was that he actually had a brain tumour. So for about two weeks I thought, you know, we were dealing with a brain tumour. This impacted me a lot because my brother had previously passed away only about 12 months – 18 months before from a brain tumour. However, his case was presented at the first hospital and the senior consultants there diagnosed it as a condition called hypertrophic olivary degeneration, which is a very rare condition that can happen with pontine haemorrhages. So, yes, that kind of added to the trauma of everything that was happening to us at that particular time with regards to his health.

MR KNOWLES: And that was around the end of 2014, early 2015.

40

MS ROCHE: Yes. His diagnosis was probably – was given January/February of that year.

MR KNOWLES: Right. Now, in your statement you refer to there being, in your words, "a constant battle to keep Michael in the rehabilitation unit", and you say that there was enormous pressure on you to move him out. Can you tell the Commissioner just how you felt that pressure.

45

MS ROCHE: Okay. Basically probably two days after Michael moved into the rehabilitation centre, the – one of the younger doctors kind of showed me Michael's MRI scan, and as part of the conversation he made a point to me that Michael would only be there for three months. That immediately put me on my guard because it just
5 showed to me that it was all about churn rather than a patient's recovery, and I thought it was far too early for them to be telling me that Michael would be leaving within three months. That was also one of the reasons why I deliberately gave up work. I took a leave of absence because I wanted to be there. I wanted to make sure that nobody could tell me things that I didn't know myself. I wanted to see it and
10 experience it, and I also felt that by being with my husband through the rehabilitation process, it would help him.

And I was very glad I did because, you know, through – we used to have family meetings with regards to Michael's care and with the amount of pressure that I was
15 being put under I did not feel it would help Michael's rehabilitation in any way if he attended those meetings, so himself and my sister – not my sister, Michael's sister attended the family meetings. And basically from the word get-go I felt we were under pressure to leave. And, you know, so I said to the doctors, explain to me why; I never really got a suitable answer. I explained to them that I felt, given the type of
20 haemorrhage and type of stroke that he had, that he was always going to be a slow recovery patient. That's the nature of those types of strokes, having read, you know, Dr Google and, you know, and just talking to other people.

So yes, at the family meetings, the pressure, you know, gradually built up further and
25 further. They demanded that I take Michael from the – from the rehabilitation unit. I explained to them that I was a private patient, or Michael was a private patient and therefore we had certain rights. I wrote a declaration of health with regards to Michael's progress and how we were being treated. That was actually sent to the hospital management and I eventually did receive a reply from them. But all in all,
30 you know, the stress levels that they applied to me were incredible and I think if I didn't have the experience that I – I suppose I gained through my own work, I can only imagine what it would be like for somebody else. And hence one of the reasons why I'm here today because I would like to represent people who have had similar stories, for the future.

35 MR KNOWLES: You mention those family meetings; did you – thinking ahead to the future and with that pressure that you mentioned, did you request plans for Michael in terms of post-discharge?

40 MS ROCHE: Absolutely.

MR KNOWLES: And what was the response to that?

MS ROCHE: The – you know, I said to them, you know, we need to develop a
45 discharge plan outlining how – basically, after we leave the rehabilitation unit, I wanted some guarantee that his rehabilitation would continue. You know, everybody has heard stories so I felt it was my duty to ensure that, you know, we could keep

Michael's rehabilitation going afterwards. He was always – Michael's nature was always slow and methodical and I had no reason to believe it was going to be any other way. And I explained all of this to the – to the doctors and, you know, I said to them, you know, we didn't think he would get to stand on his own and he did that.
5 We didn't think he would learn to walk on his own. We nearly achieved that. We got him to the parallel bars and one assist. And I felt that he was making progress, particularly up until December, until the hypertrophic olivary kicked in.

10 And, you know, things like they would demand that I would leave the rehabilitation unit and I asked for further management and kind of area – regional directors to attend, which they did, and I explained my case to those representatives at the time. And I suppose all in all I had – I managed to keep Michael from the three months when I was told he would leave, to the nine months, and I felt, you know, the reason why we even left at that stage was I had to go back to work eventually. So I went
15 back to work in January. And one morning, I – I came back to see Michael, because I basically went and visited him every day, and I found that he'd moved – they had moved him up to the second hospital - - -

MR KNOWLES: Right.
20

MS ROCHE: - - - from the rehabilitation unit, without any consultation with me.

MR KNOWLES: And around that time, even before then, had you been looking at options outside of the rehabilitation unit, given what you say you had been hearing
25 from people - - -

MS ROCHE: Yes.

MR KNOWLES: - - - within the rehabilitation unit about Michael's future options?
30

MS ROCHE: Absolutely. Very early on, probably after a month being in the rehabilitation unit, I started to – to look at, you know, avenues for where we could put Michael. You know, I went to, kind of, various groups that are, you know – who look after patients, like the Stroke Foundation, or whatever, looking for ideas on
35 where we could put Michael afterwards. And I followed -- you know, I went to the Department of Health website, you know, and they talk about pathways that stroke patients can – can go under or go down. I followed every one of them, but never really got anything of value – where we could actually place Michael afterwards. So I suppose after about six months in, you know, investigation, I began to realise that
40 residential aged care was the only place that we could move Michael at that time.

MR KNOWLES: Was that because of a lack of available options in your - - -

MS ROCHE: There was nothing.
45

MR KNOWLES: - - - in the local area?

MS ROCHE: There was nothing. Absolutely nothing. I must have rang hundreds of places.

5 MR KNOWLES: And in terms of residential aged care, how many residential aged care facilities did you look at?

MS ROCHE: I probably went to 15 or 20. I went to other rehabilitation centres in Sydney, asking them, "Could we go there to continue Michael's rehabilitation?" And at every – I suppose I just got, you know, comments like, "You're very lucky
10 that Michael is where he is for nine months. Most patient would have been moved on after three." Comments like that. And I'm saying to them, "Well, my husband is still not rehabilitated, so what are we supposed to do with him?" And they all, kind of, came back – and the only option I eventually got to was we need to put him into an aged care facility.

15 I went down the road of working with community care, to see if we could modify our home. Unfortunately, it's a house with four levels with stairs. And, you know, that didn't work out either. It would have meant putting in an internal lift and doing other modifications. And that probably would have taken, I don't know, three to six
20 months, you know, to actually do. And what happened there was when they heard that Michael had moved into the aged care, they quietly put his file away and basically said, "We don't have to worry about him now. He's in aged care."

MR KNOWLES: Was the National Disability Insurance Scheme available in your
25 local area at that time?

MS ROCHE: No. Michael had a stroke in 2014, and the NDIS was rolled out to the Northern Beaches in – it starts in July 2016.

30 MR KNOWLES: Now - - -

MS ROCHE: Again, that was one of the – the issues that I had, because the social worker in the second hospital tried to find out if there was any funding available. And she basically said that all funding had been put on hold, pending the NDIS being
35 started in 2016. Again, I asked the question, "What happens to people like Michael, who are falling between the end of the existing funding and the start of the NDIS?" And nobody had an answer for me. So basically, I was left in a position where I had to fund Michael's rehabilitation myself, which was fine; I did that. But in the essence of this hearing, I would like to – to, you know, suggest that I shouldn't have
40 been in that position and it would have helped me greatly if there was funding available to me.

MR KNOWLES: In terms of the 15 to 20 residential aged care facilities that you went and looked at, how did you come to make the choice that you did, in terms of
45 the particular residential aged care facility that Michael eventually moved into?

MS ROCHE: I'm just going to take a – sorry, Richard. Yes.

MR KNOWLES: Yes. You say you went and looked at 15 to 20 residential aged care facilities. How did you come to choose the one that you did, that Michael eventually moved into?

5 MS ROCHE: Desperation. When – Michael had been moved up to the main hospital. And as I was, kind of, leaving there, picking up Michael’s gear, one of the nurses said to me, “Kate, get him out of there as quickly as possible.” I said, “Why?” He said, “It’s an old hospital and full of germs.” Now, Michael had, through his rehabilitation, suffered quite a lot from UTIs, urinary tract infections, and when they
10 occurred it could actually wipe him out for about a month or two, once – with regards to his rehabilitation. So I knew that I had to get him out of there as quickly as possible, or else he would go backwards.

MR KNOWLES: Were there facilities at all in the residential aged care facility that
15 could be potentially used by Michael for - - -

MS ROCHE: Yes.

MR KNOWLES: - - - rehabilitation?
20

MS ROCHE: Eventually, the residential aged care, where I went, we – there was a small gym downstairs. And that had a – kind of a baby set of walking bars and also had a stairway, where we could practice, you know, going up and down the stairs. And that would have been essential if we were to get him home. And, you know,
25 again, around that time, I went and visited three, four, five residential aged care. This particular manager, who was part of the – the nursing home that we went to, she was very kind and she was probably one of the kinder people that I had talked to in the hundreds that I had talked to prior to that. And she said that she would look after Michael and, you know, we would be able to access the physio that the facility had.
30 They wouldn’t have speech therapy; I was fine with that. I would organise myself – that myself. And also, you know, he would get involved in the activities of the nursing home.

And it was a high care facility, which was what I needed because of Michael’s
35 disabilities. So we moved in there, basically, on six weeks respite. My thought pattern at that stage was still that this was a stopgap and we would try and get Michael into somewhere. Maybe we could get into another rehabilitation centre at some stage or we could get him into a – I suppose a bigger, more competent aged care centre, because the focus in this one was actually – the vast majority of the
40 patients there were – dementia. And it was a mixed facility, in that the dementia patients were not separated from those who were, kind of, of full mind but just old and weak.

MR KNOWLES: Before going into that aged care facility, had Michael had an
45 Aged Care Assessment Team assessment conducted while at the rehabilitation unit?

MS ROCHE: Yes. He did. And he was categorised for a home care package of the highest level and also, I think, level 3/4, which, again, is high care from a care point of view.

5 MR KNOWLES: Did the assessment, so far as you could tell, consider accommodation options other than aged care?

MS ROCHE: No. Well, it - - -

10 MR KNOWLES: Other than the home care package that you mentioned.

MS ROCHE: It did offer home care – a package there. And it was either a home care or, basically, nursing home.

15 MR KNOWLES: So is it fair to say that, so far as you were concerned, the assessment seemed geared towards receipt of funding for care in the aged care system and not otherwise?

20 MS ROCHE: Yes. It was also something that the second hospital had to get us through, because I suppose part of their brief was that we need – an ACAT assessment have to be done. So we went through that gate, basically.

25 MR KNOWLES: You said that Michael went into the residential aged care facility initially as a respite resident, but it transpired that he became a permanent resident after that respite period?

MS ROCHE: Correct.

30 MR KNOWLES: And when was that?

MS ROCHE: That would have been six weeks after we transferred from the second hospital.

35 MR KNOWLES: And was that around May 2015?

MS ROCHE: Let me just check.

MR KNOWLES: You've referred to it in your statement.

40 MS ROCHE: Yes. He moved - - -

MR KNOWLES: At paragraph 46.

45 MS ROCHE: Yes. He moved in March into the residential care. So it would have been, probably, May - - -

MR KNOWLES: Yes.

MS ROCHE: - - - that he became a full-time - - -

MR KNOWLES: Yes.

5 MS ROCHE: - - - resident.

MR KNOWLES: And how long was he at the facility, all up, from then on?

10 MS ROCHE: Well, Michael passed away on 6 June 2017.

MR KNOWLES: Yes. So about two years - - -

MS ROCHE: Yes.

15 MR KNOWLES: - - - he was there. And you said earlier that the residential aged care facility had many people who are living there with dementia. How did that affect Michael, in terms of his everyday activities and - - -

20 MS ROCHE: Yes.

MR KNOWLES: - - - social engagement?

25 MS ROCHE: Well, it was a cultural thing. Because the vast majority of the patients were old and, I would think, you know, maybe 50 per cent of them had dementia, a lot of the social activities were geared towards that. So you know, playing bingo, bringing all the patients in and having, kind of, Second World War singsongs was not particularly appealing to a 56 year old man. So over – he never went to them, basically, but over time, what it meant was Michael became more and more isolated. And by that, he would just remain in his room day in, day out.

30 MR KNOWLES: Was he able to go on any excursions outside of the residential aged care facility?

35 MS ROCHE: Initially, yes. I – he was able to -- when we went there, he was able to do a car transfer. And so I would actually take him out at the weekends and – and we'd go to Dee Why Beach and grab a sandwich and a cup of coffee. He used to love doing that. But – however, the facility itself did not bring him out. They found he was too much of a liability and they couldn't cope with somebody who was two assist. So unless I brought him out, he didn't really get outside the facility. In the
40 early days, we - - -

MR KNOWLES: When you say two assist, what do you mean by that – just to explain?

45 MS ROCHE: Two assist is, basically, you're categorised as needing somebody to help you and you need two people there at all times.

MR KNOWLES: Yes. Thank you. Yes. Sorry.

MS ROCHE: Yes.

5 MR KNOWLES: I've interrupted you - - -

MS ROCHE: Yes.

10 MR KNOWLES: - - - Ms Roche. Was he able to form any bonds with other residents at all while he was there?

MS ROCHE: No. I suppose his best bond was probably with the lady, the administrator, who ran the - you know, the facility itself. He had more in common with her because she used to show him all the computer programs that she used, and
15 that interested him. He was 56; he was a man. You know, he was - you know, he hadn't given up on life, basically, and he wanted to keep his mind strong. So he tried to help her.

20 MR KNOWLES: What rehabilitation did he engage in while at the residential aged care facility?

MS ROCHE: Sorry, what?

25 MR KNOWLES: What rehabilitation activities did he engage in while at the aged care facility?

MS ROCHE: Initially, we - we - he was able to get the physiotherapy once a week that the actual nursing home provided. That finished probably after about two months or so. I asked the nursing home why and they never gave me an adequate
30 answer. I engaged a speech therapist quite early because, you know, they clearly told me that there wouldn't be speech therapy as part of the package, and that was fine. I also engaged a physiotherapist privately because my thought pattern was, I'll get one session out of the nursing home and then maybe I can fund two or three other sessions a week. So that we would be able to maintain Michael's tone - muscle tone
35 and condition, so that we could keep going with his mobility and his walking.

MR KNOWLES: And what happened to Michael's physical condition over time while he was in the aged care facility?

40 MS ROCHE: Unfortunately, it deteriorated, basically, even to the best of my attempts.

MR KNOWLES: And what do you put that down to yourself?

45 MS ROCHE: It's a combination of a number of things. The hoists that they used to use to get Michael in and out of bed were very cramped. They were not scaled for a bariatric patient, which is basically a person who is overweight and obese. It was

tiny. So – and the room that he was in was also tiny. It was basically a box room and, you know, they used to just dump Michael into the bed every night and he was a dead weight and it was one of the reasons why I went there every day, to be there to get Michael into bed. I wasn't there all the time but certainly when I could be, I
5 could. And the thing about it is, he'd get into the bed and he'd just lie there, and whereas in the kind of – the hospitals, they would turn him every night at, you know, maybe two hour intervals, none of that really happened in the nursing home. So over time his spine just basically got worse and worse, and that led to the lack of strength in his legs which he just went downhill.

10 MR KNOWLES: And you mentioned earlier that the NDIS didn't become available in your local area until around July of 2016.

MS ROCHE: Correct.
15

MR KNOWLES: When it did, did you apply for supports for Michael - - -

MS ROCHE: Absolutely.

20 MR KNOWLES: - - - in connection with his rehabilitation activities and other matters?

MS ROCHE: Yes, prior to the 2016 I went to the NDIS myself down near home and I basically was in bits and I said somebody had better help me. And so the
25 minute – so the NDIS actually got somebody out in, I think, July, and told us what I needed to do. So I put together a presentation, basically a business case on what we needed for Michael. And yes, and I engaged occupational therapists who did a review of Michael's physical situation, both from a kind of an equipment point of view and also from an accommodation point of view. So yes, I negotiated a kind of
30 three versions of the plan. One, I think, was for – the first one was for about 50K per annum and that looked after getting equipment and keeping his therapies going, and the relief of that was incredible.

And then when we got the occupational therapy report done, that also was in a – in
35 the hope of qualifying him for a special disability accommodation. And the amount of – sorry, just going to take a sip of water. That – sorry. Sorry. I'm just a bit – so what was I saying, Richard?

COMMISSIONER BRIGGS: You were talking about the package, the first
40 package.

MS ROCHE: Yes, so then by the third package we had negotiated about 100,000 per annum which would help us get him into accommodation with a disability, basically.
45

MR KNOWLES: You referred earlier to your particular work experience, without saying what it was. Can you tell the Commissioner what your work experience is?

MS ROCHE: Yes. Basically I work in the IT industry. My current job is a principal project manager.

5 MR KNOWLES: And in that role as a project manager I take it you have to present cases and apply for tenders and things of that sort.

MS ROCHE: Absolutely. Yes.

10 MR KNOWLES: How did you find the process of applying for NDIS supports, even with your experience to which you've just referred?

15 MS ROCHE: Basically, because I've written quite a, I suppose a number of documents for government departments, I was used to putting together business cases and understood the types of things that they would listen to. And I used that experience to put the collateral together, basically. And that's also a point that if I didn't have that experience, somebody who doesn't have that work experience, I think it would be very difficult for them to actually meander their way through the miasma of getting funding.

20 MR KNOWLES: Now, you mentioned that there were three plans that Michael had over time with the NDIS and you also referred to specialist disability accommodation, being an aspect of the first plan, but not – in your statement you say it wasn't of the second plan. Can you just explain to the Commissioner why there was initially provision made for that alternative accommodation, but then in the
25 second plan it reverted back to funding in connection with your residential aged care?

MS ROCHE: To be honest, I'm not 100 per cent sure, Richard.

30 MR KNOWLES: Yes.

35 MS ROCHE: Like, I just followed the bouncing ball to be honest, and the occupational therapist who I got to do our assessment told us about the special disability accommodation and, therefore, we changed, improved our business case for that. But what we found was that it was probably early days in the NDIS and they hadn't worked out a lot of the rules and regulations. My understanding was that that was only possibly finalised in 2018. I'm not too sure, but in essence it was too late for us, but we did start the bouncing ball to see if we could – could get there. And I think in recognition of the fact that they hadn't worked out the SDAs, they
40 actually started to pay for Michael's accommodation in the nursing home. And, again, I found that very, very helpful, because it took away the pressure from me of basically looking after that as well.

45 MR KNOWLES: So apart from paying for the fees in the residential aged care facility, what else did the NDIS plan cover in terms of costs for you and Michael?

MS ROCHE: Equipment. So we were able to get a wheelchair. We were able to get a commode. Yes. They were the two items that we were able to get from them.

5 MR KNOWLES: You mentioned earlier that Michael eventually passed away in June of 2017. Now, prior to that, he had had a fall at the aged care facility on 18 May 2017.

MS ROCHE: Yes.

10 MR KNOWLES: Can you just tell the Commissioner what happened between that time, and leading up to him passing away?

MS ROCHE: Yes. So basically I got – Michael took a fall. I got a phone call to say he'd taken a fall. Everything was okay, and that they had put him back into bed.
15 The following day, when I went to visit him that night, and he seemed in pain. I talked to the registered nurse on, and I said to them to look at, you know, to check him. The following day I got another phone call from the aged care facility to say that they thought Michael should be moved to hospital because he was in extreme pain. So we got an ambulance and we moved him into the second hospital again.
20 The – they basically put him on morphine to reduce his pain and to manage his break-out pain, and I found that he basically got hooked on the morphine very, very quickly.

He stayed in the hospital for about 10 days and we returned back home to the aged
25 care. At this stage he was more or less fully bedbound and he was sleeping quite extensively. And in hindsight he was probably preparing to die. I got a phone call on 4 June – maybe the Sunday, could have been the 5th – 5th of June, about 10 am to say that Michael was unresponsive and we moved him back to the second hospital. And basically they ran some tests on him and they said he was in kidney failure.

30 MR KNOWLES: How old was Michael at that time?

MS ROCHE: 58.

35 MR KNOWLES: Now, Ms Roche - - -

MS ROCHE: 59.

MR KNOWLES: - - - in your statement.
40

MS ROCHE: Yes.

MR KNOWLES: You set out some paragraphs in which you convey what you wish to say to the Royal Commission by way of a message from your experiences. That's
45 from paragraphs 91 and following. Can I ask you to read out those passages from your statement now for the Royal Commission?

MS ROCHE: Certainly. I will grab a couple okay. My message to the Royal Commission:

5 *Residential aged care was not the appropriate place for Michael. There is no doubt in my mind that Michael should never have had to enter residential aged care. There should have been other options available to us so that he could have been properly cared for in a specialised rehabilitation facility or at home with adequate supports so that I could continue working and providing financially for us. Instead, I was forced to place him in a residential aged care. This decision is not one I should have had to*
10 *make. Michael was in his 50s and even following the stroke, he should have been able to have years of meaningful life and enjoyable lifestyle in front of him.*

In aged care, Michael spent most of his time in his small room as he was wheelchair-bound and could not really leave without help from someone. There, he had had any
15 *limited remaining independence and choice stripped from him. He was in a dementia-focused setting that was not designed to provide him, as a younger person suffering from the after effects of a stroke, with the care he required to live well and continue to improve. Michael's life got worse in aged care. I believe he got increasingly depressed. He did not engage with the activities on offer as they were*
20 *not designed for a younger person. His physical condition deteriorated.*

I believe this deterioration contributed to the fall he suffered on 18 April 2017. I also believe that complications resulting from Michael's fall contributed to his passing away on 5 June 2017. In my view, if Michael had not entered residential
25 *aged care and if other options had been available, he would still be here today. In my experience, case management is fundamental to helping younger people who have a disability. The biggest challenge I faced was a lack of a road map or any pathways for Michael other than aged care.*

30 *I think that if Michael had been assigned a case manager to help determine a long-term plan for him to rebuild his life, including access to rehabilitation, it would have made all the difference. It is so important to have someone assist to navigate the various systems and advocate for a person to receive the care and supports they need. My experience with Michael illustrated that the Australian health system is not*
35 *integrated. It is made up of disparate systems that at times do not communicate with each other at all. I was constantly caught between the New South Wales health system and the Commonwealth disability and aged care systems and it always seemed like each system would not take responsibility for Michael. A case manager would have been invaluable to break down these barriers.*

40 *In Michael's case, aged care was clearly not an appropriate place for a younger person with a disability. Residential aged care facilities are seen as a place for people to be made comfortable as they prepare to die. Michael was not there to die and quite the opposite. He wanted to recover and recreate his life. The environment*
45 *of a residential aged care facility did not foster this, and does not promote in regaining abilities. Younger people with a disability should be placed in an environment with experienced and trained staff and other people they can socialise*

with. I do not believe such an environment is ordinarily found at a residential aged care facility.

5 In the short term, where there are no other options for younger people, residential aged care facilities that specialise in rehabilitation should be available more widely. The number of facilities that offer these services should reflect the percentage of patients known from historical health records to have long-term high care needs. When residential aged care facilities do offer these services, allied health care practitioners should visit the facilities on a daily basis to offer rehabilitation services. Right now, there needs to be more options available for young stroke patients who need ongoing rehabilitation and appropriate time to recover, such as slow recovery patients.

15 I could not find a facility that provided this on the Northern Beaches. My greatest nightmare was that once Michael left the rehabilitation unit, we would not get help to continue his daily regime, particularly because there would not be adequate facilities and staff to ensure he went to the gym to do his exercises. My nightmare became a reality at the residential aged care facility. My suggestions for the future: in the long term, sufficient SDA, specialised disability accommodation, must be built to accommodate the percentage of patients known from historical health records to require long-term high care combined with rehabilitation services. This will prevent these people entering residential aged care facilities.

25 All parts of the health care system must work together to ensure other young patients do not end up in dementia-focused residential aged care facilities because there is no other option available to them. These people should go to rehabilitation facilities or access special disability accommodation. Funding must be made available for this to occur. Quality assessments needs to be completed with patients who are in rehabilitation and residential aged care facilities to ensure the care being provided is meeting the patient's requirements. Greater transparency is required so that improvements can be initiated if care is not appropriate to that person.

35 If ACAT assessments are to continue being used for younger people with a disability, the ACAT assessment form should be amended so that it triggers NDIS funding early in a patient's rehabilitation journey. Many of the decisions I made would have been different if funding had been available for Michael's rehabilitation. I was completely stressed during most of the time Michael was in residential aged care as I was paying more money than I earned each month for Michael's care, our home mortgage and my own living expenses. I did this because I wanted to ensure he received rehabilitation and there was no other option but for me to pay for it myself.

45 The ACAT and the NDIA should work together to allow patients and their caregivers the opportunity to rent out suitable accommodation and receive 24 by 7 care if required. Changes need to be made so that no other family has to go through what Michael and I endured together, and what I still live with every day.

MR KNOWLES: Thank you, Ms Roche. Is there anything else that you wish to tell the Royal Commission at this time?

MS ROCHE: No.

5

MR KNOWLES: Thank you very much for your evidence. I have no further questions for Ms Roche.

10 COMMISSIONER BRIGGS: Ms Roche, you've been through a terrible, terrible time which nobody should have to. The health system should be responding appropriately in circumstances such as those of your husband. At the same time, the rehabilitation services should be rising to the occasion so that people get the slow-stream rehabilitation that they need. I was struck during your evidence and, indeed, in reading your witness statement, this question; I think you alluded to it as the lack
15 of aspiration. Unfortunately it's a lack of aspiration for older people as well as younger people, and the system as a whole needs to really grow up about people's lives and their choices and their ability to manage as best they can, and to help them improve as best they can as well.

20 But your evidence about how difficult it is for a younger person in a nursing home and how troublesome it is that they cannot communicate effectively with the older residents who are there causing isolation for those people is shocking. It's truly shocking and shouldn't be allowed to continue. So we've heard your evidence and we will do our best. I'm going to excuse you now from giving further evidence and
25 thank you for your attendance.

MS ROCHE: Thank you, Commissioner.

30 <THE WITNESS WITHDREW [12.22 pm]

MR KNOWLES: Perhaps if there might be now a luncheon adjournment.

35 COMMISSIONER BRIGGS: Yes, I propose we adjourn now for lunch and return at 1.20. Thank you.

40 ADJOURNED [12.22 pm]

RESUMED [1.24 pm]

45 COMMISSIONER BRIGGS: Ms Hill.

MS HILL: Commissioner, if the Commission please, I called Mrs Jessica Dodds.

<EXAMINATION BY MS HILL

5

MS HILL: Good afternoon.

MS DODDS: Good afternoon.

10

MS HILL: Mrs Dodds, can I ask you to please state your full name.

MS DODDS: Yes, it's Jessica Helen Dodds.

15

MS HILL: How old are you?

MS DODDS: I'm 32 years of age.

MS HILL: Where do you live?

20

MS DODDS: I live in Cooranbong, New South Wales, Australia.

MS HILL: Is Cooranbong a town of Lake Macquarie?

25

MS DODDS: Yes.

MS HILL: What do you do for work?

30

MS HILL: So I'm a social worker with the Central Coast Local Health District currently working as an ACAT assessor, so ACAT stands for the Aged Care Assessment Team. But I'm here in a personal capacity today.

35

MS HILL: You contacted the Aged Care Royal Commission in February of this year, didn't you?

MS DODDS: Yes.

40

MS HILL: And you did so because you wanted to share the experience of yourself and your late husband's time in aged care.

MS DODDS: Yes, that's correct.

MS HILL: And you made a public submission.

45

MS DODDS: Mmm.

MS HILL: And you've subsequently made a statement dated the 29th of August of this year, haven't you?

MS DODDS: Yes, I have.

5

MS HILL: Operator, could I ask you, please, to display document ID WIT.1269.0001.0001. Mrs Dodds, do you see a copy of your statement in front of you?

10 MS DODDS: Yes, I do.

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

MS DODDS: No.

15

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

MS DODDS: To the best of my knowledge, yes.

20 MS HILL: Commissioner, I tender that statement.

COMMISSIONER BRIGGS: The witness statement of Jessica Helen Dodds dated 29 August 2019 will be exhibit number 9-5.

25

**EXHIBIT #9-5 WITNESS STATEMENT OF JESSICA HELEN DODDS
DATED 29/08/2019 (WIT.1269.0001.0001)**

30 MS HILL: As the Commission pleases.

MS DODDS: Thank you.

MS HILL: Your late husband's name was Anthony Dodds, wasn't it?

35

MS DODDS: Yes, it was.

MS HILL: But he went by Tony.

40 MS DODDS: Yes.

MS HILL: How would you describe Tony's personality?

45 MS DODDS: So Tony was very much a social chameleon. He was the life of the party, very outgoing. I would actually consider myself quite an outgoing person, and felt like an introvert compared to him. He could carry a conversation with just about

anyone about anything, and it was actually his outgoingness that attracted me to him in the first place, when we first met.

5 MS HILL: And operator, could I ask you to display tab 82 of the general tender bundle. You've picked a photo of Tony to share with the Commission today.

MS DODDS: Yes.

10 MS HILL: And, in fact, you brought a copy of that along in a frame that you've got there with you as well.

MS DODDS: Yes. Sorry, you can see.

15 MS HILL: When was that photo taken?

MS DODDS: So that photo was taken on our wedding day on 31 March 2012.

MS HILL: And why did you pick that photo to share?

20 MS DODDS: So I picked this photo because this is probably the happiest day of our lives together and you can really – you can really see his smile and his joyful personality shown in this photo.

25 MS HILL: In your statement you talk about the circumstances and when you first met and what you would tell people as to how you first met. Would you like to share that?

30 MS DODDS: Yes. So our age difference was actually quite a talking conversation because we met when I was 18 and he was 48. And so naturally people would want to know how we met and we always said that we met at a party, we started talking and we never stopped talking.

MS HILL: Tony had some health conditions, didn't he?

35 MS DODDS: He did.

MS HILL: And what were they?

40 MS DODDS: So he had Type 2 diabetes. He had a number of issues with his eyesight, which is why he had an NDIS package and that was his main disability, his – to do with his vision, but he also had metastatic kidney cancer which he was diagnosed in 2017 with.

45 MS HILL: Now, you've also picked a photo of yourself and Tony to share with the Commission. Operator, could I ask you to display tab 83, please. When was that photo taken?

MS DODDS: That photo was taken a month before we got married, so it's on 25 February 2012.

MS HILL: And why did you pick that photo to share?

5

MS DODDS: I picked this photo because you can see how happy we made each other, and our love and personality really shone through this photo. It's probably one of my favourite ones that we have of us together.

10 MS HILL: You've described that Tony ultimately was diagnosed with kidney cancer.

MS DODDS: Mmm.

15 MS HILL: How old was Tony when he passed away?

MS DODDS: Tony was only 62 years of age when he died.

20 MS HILL: At that point you and Tony had been in a relationship for 13 and a half years.

MS DODDS: Yes.

25 MS HILL: How do you feel about giving evidence today?

MS DODDS: I have quite mixed feelings. I – sorry. It's very hard.

COMMISSIONER BRIGGS: Don't worry, it's nerve-wracking. Just relax.

30 MS DODDS: I brought part of Tony along with me to help me through this. Sorry, what was the question?

35 MS HILL: How did you feel about coming along and giving evidence and sharing your and Tony's story today?

40 MS DODDS: Quite nervous. But ultimately I wanted to stand up and give him a voice when he had none. I see myself as an advocate for change and I feel that his cancer diagnosis really stifled his – his vibrancy for life and towards the end of his life I felt that he wasn't able to really advocate for himself, and I wanted to be that voice for him. I was a little worried that coming here today, that I would seem quite emotionally disconnected while sharing my story, but that's how I am able to talk about it without breaking down too much.

45 MS HILL: So on the 31st of March 2012 you and Tony get married on that day.

MS DODDS: Yes.

MS HILL: What plans do you and Tony have for your future at that time?

MS DODDS: So at the time when we got married I was halfway through my Bachelor of Social Work degree, and we were looking forward to having a life
5 together where we would be able to raise a family, build a new house and just enjoy the fruits of our employment and life and love.

MS HILL: Can I take to you September 2016; have you finished your social work studies at that point?
10

MS DODDS: Yes. So I had graduated from social work in April 2015 and later at the end of that month started working for New South Wales Health, and our life was quite exciting at that point in time because it's the first time I had full-time employment and we were making plans to build a house and – and it was just before
15 September 2016 when we started building our house.

MS HILL: And what happened in September 2016?

MS DODDS: So in September 2016, I was diagnosed with endometrial cancer.
20 And – sorry, can I just have a moment?

MS HILL: Certainly.

MS DODDS: So I was diagnosed with grade 1, stage 1A endometrial cancer and it was quite a shocking diagnosis for us because I was the younger of us. The plan was for Tony to eventually retire and be a stay-at-home dad and raise our children that we would have together, and I would be the working mum. And so this diagnosis, we were quite scared that I would pass away before him. And it was a few months after that that my cancer had progressed and I had to start undergoing treatment for that.
30

MS HILL: In June 2017 what do the doctors tell you about your health?

MS DODDS: So after three months of radiation and brachytherapy in – at the beginning of 2017 I went in to have a biopsy in June of that year. And the outcome of that was that I was clear of cancer, and we were quite overjoyed because our life was on hold when I was – when I was unwell. And we felt like all our plans – we couldn't move forward with. And it was just the most amazing news that I was well again and we could move on with our lives and keep going towards our future that we wanted to have.
40

MS HILL: And how were the house plans going at that time?

MS DODDS: So at that stage in our lives, we were about a month away from having our house completed. And in July – end of July 2017, we actually moved
45 into our new house. And we felt like our lives were pretty well complete at that stage. Like, we – I'd overcome my illness. Still, I worked all the way through my

job and I hadn't lost – lost my job at that stage, which was good. So I had stable employment and things were going well for us again.

MS HILL: How was Tony's health during this time?

5 MS DODDS: So during this time I did notice a deterioration in Tony's eyesight. So he had a number of issues that impacted on his – on his vision. And it was about this time that he had to start considering giving up work, because he could no longer see well enough to drive. He could no longer see well enough to do his hobbies. So he
10 was very much into playing with radios and computers, and with his deteriorating vision he – he couldn't see, to do that anymore. So at September that year, he had to – to give up work, due to medical reasons. And he was on an NDIS package at that stage.

15 MS HILL: And that was in respect of his vision loss - - -

MS DODDS: Yes.

MS HILL: - - - connected to the glaucoma, was it?
20

MS DODDS: Yes. That's correct.

MS HILL: What happens in December 2017?

25 MS DODDS: So the week before the beginning of September is a week that I'll never forget. Tony became quite unwell. And he was just about to go in for surgery to have – to prevent further loss of vision in his eye. And the day – day before he was meant to go into hospital for that, he started having quite concerning symptoms, and we presented to emergency and – at our local hospital. And then at the end of
30 that week, he – on 1 December, he had a diagnosis of kidney cancer.

MS HILL: And had he received treatment for that?

35 MS DODDS: At that stage, no. So original scans showed that it was only small – a small tumour, and they were planning for surgery of his right kidney to remove his kidney. And then further scans at the end of that year showed that the tumour actually extended into his inferior vena cava, up to the level of his liver, but not in the liver. So his surgeons were talking about – they were quite positive that the surgery would be – would be successful, would be able to remove the kidney and
40 take the tumour that was out – that was sitting in the inferior vena cava out, and it would be a bit of a recovery after that because it's quite major surgery.

And through all of the, like, pre-op investigations to make sure he was well enough to go in for surgery, they found out that he had a heart condition as well, and so they
45 were also preparing for a coronary artery bypass graft at the same time. So the surgery that he was going to have was a radical nephrectomy with IVC thrombectomy and a coronary artery bypass graft. It required having a

cardiothoracic surgeon and a renal – urological surgeon involved. They told me that it was a nine-hour surgery and that part of the surgery involved putting him on a heart bypass machine and then cooling down his body temperature to less than 20 degrees and, effectively, taking him off that heart bypass machine.

5

And he would be clinically dead for 30 minutes while they did what they needed to do with resecting the tumour. And then, like, reverse the process, to warm his body back up slowly and bring him back to life, essentially. So Tony was quite frightened about what would happen to his soul during that time, because we're Christian and we believe in God, and he was quite frightened that he wouldn't make it through that surgery as well. So that was meant to be in March 2018 that he was to go in for there – that surgery. And that's – that's when he went in to hospital at that stage.

10

MS HILL: And does Tony have the surgery in March 2018?

15

MS DODDS: Yes. So on 19 March, he went in to have that surgery. And that was the last day that I remember him being the man that I fell in love with, because after that his – his personality changed quite significantly and – sorry. So he – he had the surgery and two hours into the surgery the surgeons rang me and told me that, "We're sorry, but he" – sorry. "Sorry, but we couldn't remove the kidney." And the tumour was grown in quite extensively into his body and he started bleeding quite extensively during the surgery. So they had to put some surgery packs behind his liver to stop him bleeding out and they kept him sedated and moved him to ICU and kept him sedated until the Wednesday.

20

25

So he had the surgery on the Monday and he was still under – under until Wednesday, when they went back in to remove the surgical packs that they put in to stop the bleeding. And that – that surgery, the second one, after that they said, "It's quite an aggressive cancer and we can't do anything for him in terms of treatment-wise. Second dose of chemotherapy probably wouldn't work. Radiation therapy wouldn't work." Essentially, they said it would be a long recovery but – like, after his surgery, with – like, from his surgical wounds. But they said, "We don't know if there's anything else we can do."

30

35

And at that stage I was told that he might not see Christmas 2019. And so they weaned him off his medications that was keeping him sedated after that second surgery on the Wednesday. And it took another two days for him to wake up. And – and when he did wake up, he was quite delirious and not making any sense and quite distressed, trying to pull, like, tubes and everything out in the ICU bed. And I had taken the week off work at that stage. So I'd used all my sick leave and my annual leave to – at work to help me get through my own cancer treatment, because I decided to work through my own cancer treatment and drop down to part-time and did that.

40

45

And then I had used all my sick leave in the lead-up to his surgery as well and taking Tony to appointments. So I was looking at taking unpaid leave at that point from work. And I was preparing to go back to work on the Monday following his – like,

after his surgery, and – and I got a call from the ICU doctor saying that, “We think he’s dying”, to, “Come in and say your goodbyes”, and, “We’ll start him on”, like, “an end-of-life pathway in hospital.” And I remember coming into the ICU at 5 in the morning and, like, me and his children were gathered around him and the ICU
5 doctors were talking about what to do next, and he woke up and he was quite lucid enough for the surgeons to tell him that “the surgery didn’t go well and that essentially you’re dying and we want to start palliative care for you”. And so he – he was understandably upset, and they gave us time to say our goodbyes and they made him comfortable with some medication and he sort of slipped into, like, being asleep
10 and I thought that was going to be it.

So because he was with – they were saying within days of dying, he got transferred to a ward within the same hospital in a private room where we could have time with him, and I spent the next eight days and eight nights in a hospital bed next to him in
15 the same room, helping the nurses care for him and – and being there, because I didn’t want him to be alone when he died. And it was probably around that time that during these eight days and eight nights that – that he was in – in that room, he did wake up periodically and was quite delirious and kept saying “I want to go home, please take me home to die, I don’t want to be here. I don’t want to die here in
20 hospital. I want to go home.”

So I started having conversations with the – with the nurses on the ward about how do I take him home, and what care would I need to bring him home with. Because at that stage I think only a month before his surgery, he had been approved for his
25 second NDIS package which was about \$30,000 that he got approved for. Most of that was for social support related to his vision loss to get him out and about while – whilst I wasn’t there during the day because I was working full time. And so I was inquiring about, like, how could I use that at home to care for him because I wanted to take him home to die. At that stage, I had had two weeks off unpaid leave, and my
30 husband had retired six months prior so we weren’t getting any income in at that stage and I realised I actually can’t take him home because I was realising he needed 24/7 care at that stage.

Like he was completely bedbound, he needed two nursing staff to attend to his –
35 sometimes up to three nursing staff to attend to his personal care and toileting needs and pressure area care where, like, to prevent pressure injuries they had to roll him, and I was very much involved in that process and wanted to be there to care for him. And so faced with the reality that I had to go back to work, the other option that was offered to me at that time was hospice care.

40

MS HILL: Was that in April 2018?

MS DODDS: Yes.

45 MS HILL: And ultimately in April 2018 Tony was transferred from the hospital to the hospice?

MS DODDS: Yes, that's correct.

MS HILL: And he – was it your experience that Tony received social support through his second NDIS package at that point in time?

5

MS DODDS: Yes.

MS HILL: And what did that mean for the – for what Tony received when he was at the hospice?

10

MS DODDS: So when Tony first went into the hospice, I don't know whether – why but for some reason they started him on antibiotic medication and he seemed to respond well to that and seemed to recover a bit while he was there. So it seemed as though he wasn't imminently dying anymore. And so because he was becoming more lucid and able to engage in conversation, I was trying to keep his NDIS care coordinator, like, in the loop with how his care was going and when we could start his package and all that sort of stuff. And she suggested "Would you like us to organise some services to come into the hospice and maybe read a book to him or read a newspaper, spend some time talking to him", because when he was awake and more lucid he was wanting me to be there 24/7 and I just couldn't because I had to work.

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And I didn't want him to feel isolated and alone and scared there, so I organised for those services – for social support to start a couple of days a week. And once they did start, Tony, later on when he was more lucid and remembered part of that time, he had actually told me that – that those visits meant the world to him, being able to have someone come in and – and talk to him and make him feel less alone while I wasn't there.

30

MS HILL: Does Tony ultimately – Tony goes to rehab at the hospital?

MS DODDS: Yes. So because he started to improve with the antibiotics and was then becoming more aware of his surroundings, two weeks after being in the hospice, the hospice staff had a conversation about, well, he's not imminently dying anymore and my understanding is that you go to the hospice when you're within days of dying, but once you're looking like you've recovered, we need to look at more long-term discharge plan options. So they talked to me about possibly getting him to rehab. So to do that, they were planning on transferring him to the hospital to have some inpatient rehab, and then hopefully go to a young person's rehabilitation centre after that. And then either look at taking him home there, or, like, reassessing where he was at that point.

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MS HILL: And if we go to May 2018 you're ultimately able to take Tony home as a result of the rehab he did receive?

45

MS DODDS: Yes. So he ended up having – about five to six weeks in the hospital ward, receiving rehab, and he managed to go from being completely bedbound and

unable to do any of his personal care or toileting to being able to go to the toilet with a toilet surround, to help him with his transfers. He was able to transfer with one person assisting him to four-wheel walker and he was able to mobilise for short distances with the four-wheel walker and in a wheelchair for long distances. He

5 went from not being able to have any core body strength to hold himself up – just – like to sit up, to being able to do that. So – and at that stage the wait list was too long to get into the young person’s rehab so they – the hospital staff talked to me about taking him home with services at that point.

10 MS HILL: And how did it go at home?

MS DODDS: So when Tony was discharged, he was originally discharged with a rehab in the – Rehab in the Home program which is six weeks of allied health therapy, in addition to a ComPacks package which is just straight service provision

15 to assist with, like, personal care, transport, etcetera, to medical appointments or, I don’t know, meal preparation and social support, that kind of thing. And the idea was that he would have that – those two running at the same time for six weeks and then you then at the end of the six weeks transitioning onto the NDIS package that he had to replicate what the rehab – yes, what they were doing.

20 And so initially he was responding quite well to that and when I brought him home I had – I had felt quite well supported with those two services running and I also had palliative care nurses involved and to help me with managing his symptoms. But ultimately towards the end of the six weeks he did start to deteriorate in his function

25 again.

MS HILL: You describe in your statement that ultimately Tony’s care needs increased.

30 MS DODDS: Yes.

MS HILL: And you’re still working full time.

MS DODDS: Mmm.

35 MS HILL: And at paragraph 57 of your statement you described that the time had come when Tony wasn’t able to safely be at home when you weren’t there.

MS DODDS: Yes.

40 MS HILL: How did you work out what to do next?

MS DODDS: Sorry, can I go to that paragraph?

45 MS HILL: Certainly.

MS DODDS: So to put in context the day – the day before this, whilst I was at work, Tony had had a fall at home, and he rang me after being on the floor for an hour and – and said “I can’t get up from the floor. Can you please help me?”. And I – I was an hour away because I was at work. And I said “Well, hang on, I’ll call the
5 ambulance and – and – and I’ll make my way home”. And he didn’t want me to call the ambulance at that stage, I think because he knew that if he did go back into hospital he probably wouldn’t come out. So I ended up calling my neighbours and they – just to come in and sit with him until I got there, and they thankfully had picked him up off the floor, cleaned up the blood that, like, because he had hit his
10 head, and was bleeding from his head, and he still refused for me to call an ambulance when I got home.

So I spent the whole night pretty well awake monitoring him for signs of concussion – and I’m not a trained nurse by the way, so I googled how do you tell if someone
15 has got a concussion, and I was also worried about him having a – what if he had a bleed on his brain when he had a fall, and so I was, like, googling, like, signs of that and what to do in this situation. And it was at that point that I started to realise I couldn’t leave him at home for too much longer. Most of the time at that point his – his days were looking like I would get up in the morning and I would get him
20 breakfast and my own breakfast and prepare myself for work. I’d give him his pain relief before I went to work. And he would then lay in bed on the days that the services weren’t coming.

So they were only coming three days a week at this stage from NDIS. So on the days
25 that NDIS were coming, he – they were getting him out of bed, having a shower. Sometimes he would refuse to have a shower, so that meant that I would have to do that when I got home. On the days where he wasn’t having services coming in, I – I would sometimes find him in the same place when I got home to when I – to when I had left for work and I would ask him “Have you been up to go to the toilet? Have
30 you eaten anything today? What’s your pain levels like? Have you had any pain relief” and he would say “No, I haven’t moved since you left” some 12 hours before.

And the day after this fall that he had I really struggled to get out of bed that next day because I had no sleep that night and just from sheer exhaustion, I managed to get
35 myself up, go to work, had several coffees just to keep myself awake and I realised I can’t – I can’t do this anymore. I can’t function like this. I – I can’t – and I needed to go to work because I was our only source of income.

MS HILL: So what did you do?
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MS DODDS: So it was at this point that I first had contact with – sorry, backtrack a bit. So I was ringing the palliative care nurses more frequently and they, I think, recognised the signs of carer stress and they suggested, “Why don’t you look at
45 having an ACAT assessment”, to consider residential respite care, just to give myself a short break, and then hopefully I could continue caring for him at home after a short break. So I had contact with My Aged Care and – and this would have been in July, late July, and – 2018.

And I explained my situation to the person on the phone when I called and they said, "I'm sorry. He's under 65. We can't refer you on to anyone. You have to go through NDIA." And I was quite frustrated at that stage. So I rang NDIA and explained my situation and said he's got terminal cancer, his care needs are
5 becoming too much, I can't – I don't think I can do this, I need a break for a little bit, what can I do about getting an ACAT assessment or some respite care? And they said, "Well, his NDIS package doesn't cover his health needs. You would need to put in a change of circumstances form," I think, "and that may take several months to go through."

10 And at that stage, I – I was at breaking point and I became quite frustrated on the phone to them and told them, "Well, I don't have months because he's dying." He was spending 20 hours a day in bed and I had googled signs of dying so many times so that I could recognise the signs when they came, to try and educate myself. And I
15 was frightened that he was coming towards the end and I – and what would I do when that happened and how would I manage that. And so I became quite frustrated. I was – I felt trapped between the aged care system and the disability system, not knowing what to do.

20 MS HILL: So what did you end up doing?

MS DODDS: So I continued to care for him at home, feeling like, well, I guess I can't get an ACAT assessment unless he goes back to hospital. So getting an ACAT assessment in the community just seemed too hard to organise, because he was under
25 65. And a few weeks later, I came in to – came in to give Tony his medication in the morning and he was not responsive and his – his body was quite cold and I was trying to shake and call his name, and I couldn't get him to wake up. And so I called an ambulance, because I thought he was dying. And when the ambulance came, they said – because he woke up at the time when the ambulance arrived, and the
30 paramedics were saying that he was – he looked – you know, we could probably keep him at home a little bit longer because he was – probably won't be able to do much acutely for him in the hospital setting, but I was saying, "I can't do this any more."

35 The weekend before I called the ambulance, Tony had started to say things like, "I can't go to the toilet. Can I just go in my incontinence pads and you just clean me up?" And he was – he was having diminished strength, to the point that just to feed him – he couldn't sit up anymore and hold himself in a sitting position. So I would get a tray table that I'd bought – like, you know, the ones in the hospitals next to the
40 bed, on wheels, and I'd put his meal in front of him. And then I'd go and lie across the bed and hold him – hold his back up, to try and get him to sit up to eat.

And that was becoming exhausting, just transferring him out of the bed to the chair to watch TV in the lounge room or out of the chair to get him to bed – was quite
45 scary that weekend, because I would get him up and he would go to fall and then I'd go to grab him. And I was worried about injuring myself, and I – that just highlighted further how isolated I felt, that I – I can't do this by myself. So

ultimately, the paramedics decided to take him to hospital, to give myself a break, but also to resolve some pain issues that he had at the time that I couldn't meet.

MS HILL: And was Tony assessed for ACAT when he was in hospital at that time?

5

MS DODDS: No. So one of the first things I did when he got to hospital was ask to see the ward social worker when he got admitted to a ward, and explained that I tried to get an ACAT assessment in the community and was told that, "We can't do anything for you, because he's understand 65. You need to go through NDIS." I said, "Is there a possibility that he could have an assessment for respite or permanent care approvals whilst he was in hospital?" And I was told by the social worker that – that you – that the ACAT only usually assesses people for those things in hospital if their discharge option is for respite, either with a view to going home afterwards or with view for going into care. And at that stage, I'd only just started working for ACAT myself, so I didn't have, like, a full grasp of what you could and couldn't do with assessments and how that all worked and stuff. So – sorry.

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MS HILL: Take your time.

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MS DODDS: So that – the doctors eventually had a discussion with me, that they felt his care needs were too high anyway for him to return home, because he was needing two nurses overnight for care and – and there was just one of me at home and I couldn't do it. So they did say that they would organise an ACAT assessment in the hospital, to give him the respite and permanent care approvals, because there were no other options in terms of care for him other than an aged care facility if I couldn't care for him. To – even the nearest hospice for him to go to – and he wasn't imminently dying, so he probably wouldn't meet that criteria anyway – I was looking at either going to Newcastle or Sydney. And I was stuck in the middle, with no options other than residential care.

And so the social worker assured me that, "Yes. We will get him an ACAT assessment", and, "We have to wait till he's medically stable and then we will put in a referral for that." Because it's my understanding – and now having worked with ACAT, that often we don't come and do assessments in the hospital until they're medically stable for discharge. And so Tony was in hospital for about two weeks. And I came in to visit him on a Sunday and I wasn't aware that he was going to be discharged the next day; no one mentioned anything to me. And then the next day the hospital rang and said, "We're moving him to a CAP hospital bed in an aged care facility." And then he ended up having his ACAT assessment at the aged care facility once he moved.

MS HILL: What's a CAP bed?

45

MS DODDS: So the CAP bed is – it stands for care whilst awaiting permanent placement. So it was explained to me as, essentially, a hospital bed within an aged care facility, and – but it's kind of like he's still in hospital, it's just – it's more for people who aren't getting anything acutely done in an acute hospital setting, but

because of bed blockages and needing to have those acute hospital beds vacant for people who needed them, they needed to move him somewhere where he could still get the care he needed but wasn't taking up an acute bed.

- 5 MS HILL: So Tony ultimately receives an ACAT assessment when he's in that CAP bed position?

MS DODDS: Yes.

- 10 MS HILL: And then at the end of August 2018, once the ACAT assessment has been approved, you decide to move Tony to another residential aged care facility?

MS DODDS: Yes.

- 15 MS HILL: And how did Tony feel about being – and going into aged care at that time?

- MS DODDS: So at that time, he – he just wanted to go home. He didn't want to be there. He told me numerous times, "I want to go home." We – we had even done
20 advanced care directive for him and went through the process of organising an enduring power of attorney, enduring guardian, and had all those advanced care planning stuff in place prior to him being unwell. And it actually even had on his advanced care directive that he didn't want to die or go into a nursing home – or, sorry, an aged care facility. So he – he didn't want to be there at all. And I think at
25 that stage he just wanted – possibly faced with this, "If this is what my life is going to be, I just want to give up." And I believe that that's what he did. He mentally threw in the towel and didn't want to fight any more. And because he thought, "Well, if this is what my life is in an aged care facility and I can't be where my wife is and live together, I don't want to be here."

- 30 MS HILL: In your statement, you make four observations of concern about Tony's time in aged care. You talk about the communication between yourself and the aged care facility, pain medication, Tony's food and eating, and Tony's social engagement.

- 35 MS DODDS: Mmm.

MS HILL: I want to ask you a question about social engagement.

- 40 MS DODDS: Mmm.

MS HILL: In respect of social engagement, what did you want for Tony when he was in aged care?

- 45 MS DODDS: So because – because I couldn't be there with him, because I had to go to work, I – I wanted him to feel like he still had a sense of purpose to life and I wanted him to not feel isolated and alone. Part of why I originally advocated so

much for him to have greater funding in his NDIS package before he became unwell was because I knew he – he had medically retired and he was probably at risk of getting depression if he stayed at home and did nothing when he's – you know, he couldn't do his hobbies anymore, he couldn't do the things that made his life
5 meaningful. So I wanted to make sure that he had someone to talk to, that he wasn't isolated, that he had that social connection, to keep him going.

MS HILL: And did he receive that type of social connection?

10 MS DODDS: I don't feel that he did, no.

MS HILL: Ms Dodds, you've provided a couple of photographs of the time that you and Tony spent some time together in the sunroom.

15 MS DODDS: Yes.

MS HILL: Operator, could I ask you to please display tab 84 and 85. Why was it important to share those photos with the commission?

20 MS DODDS: So during the five weeks that Tony was in the second aged care facility, before he died, I don't feel he got out of his room at all. And often I would go to visit him every night after work, to have my dinner with him; sometimes I'd bring my cats in to see him. And he said to me that that was the most meaningful engagement that he had. On the weekends, I would – well, like, as in – whilst he was
25 in the aged care facility. On the weekends, I would go in around midday, have lunch with him, spend six, seven hours a day with him and leave just after dinner. And every time I turned up, the – either the door was just left slightly ajar or closed and the curtains were drawn and he was just in the room by himself. And I wanted to get him out of the room just to give him a taste of sunlight, fresh air, anything. Tony and
30 I, before he became unwell, we loved going places on the weekend, even if it was just for a drive to nowhere, but just in particular, but just to get out of the house. When he retired, I found that he struggled with being housebound.

35 Because he couldn't drive anymore he – his independence was taken away from him, and so he lived for the weekends when I would not be at work and be able to take him anywhere that wasn't in the house. So for me I knew – I felt it was killing him being in that room and I wanted to get him out. And so that those photos were the day that I was able to get some of the nurses to help me get him into our waterbed chair and they wheeled him to a sunroom that was in the aged care facility where he
40 was and they placed his bed right near the window and they opened the window and he had fresh air and just sat – sat there in the warmth and we sat there for a few hours sharing a milkshake and talking and listening to his favourite music.

45 And I felt like that – that day just brought that little bit of warmth and sunshine to his life at that point. And I wanted him to have more of that.

MS HILL: You described in your evidence today about how you advocated for greater funding for Tony's NDIS package for social supports; was Tony eligible for social supports through his NDIS - - -

5 MS DODDS: Yes.

MS HILL: - - - when he was in aged care.

MS DODDS: Yes.

10

MS HILL: And was that something that you were able to use at that time?

MS DODDS: Sadly, no. So because I didn't really have a good understanding of the disabilities system at that point, I – I was of the belief that whilst he was in respite, that he wasn't able to have services going in to see him, and that they would be able to resume once he came home from respite. And I was quite surprised when one of the providers who were involved prior to him going into care contacted me a couple of weeks into his admission and – at the aged care facility and said, "Just wanting to check in and see how you're going. Were you aware that we could actually come in to provide care for him whilst he was in residential care?". And I said "Well, no, I wasn't aware. Can we make that happen?" because I knew how much the social engagement that he had whilst he was in the hospice meant to him. And so I asked if they could get those services started.

25 So that was probably about three weeks, three to three and a half weeks into his admission there of the five weeks that he was there. And they said "Yes, we could probably organise something for the following week" and then that week went by and didn't hear anything and then they rang the following week and said "We're ready to start services" and I had to tell them that he had passed away three days before.

30

MS HILL: In your evidence today and in your statement, you described to the Commissioner feeling trapped between two systems.

35 MS DODDS: Yes.

MS HILL: Looking back, what did you need at that time?

MS DODDS: Sorry. I think someone to explain how he could have used his NDIS package whilst he was at home with complex health needs that weren't related to his package. How I could have got the most out of his package to help him and also just someone even explaining, yes, we can, you know, bring services in whilst he's in care. Like, I had no idea that that was a possibility. I didn't even know that – it wasn't until I got some help from another organisation to prepare my submission that I was told that part of his package could have been used to fund his place in aged care, because I was in significant financial distress at that time trying to meet the payments and I wasn't aware of that either, that that could have been an option.

45

And I feel like the system has failed me in that I've come across health, NDIA, My Aged Care, ACAT, and no one was able to tell me that I could have used his package, even though I was very, very much telling everyone he's got an NDIS package, I want to take him home, I want to be able to care for him at home, how can I do that. No one could tell me how to – how to best use that. That would have been helpful.

MS HILL: How do you think Tony would feel about you coming along and giving evidence today?

MS DODDS: I think he'd – I think he'd be very proud of me. Tony always was proud of anything that I did and always stood behind me 100 per cent. And I guess I've always had a passion for standing up for people who don't have a voice and creating awareness and hopefully creating change from that awareness, and I think he would be extremely proud and honoured to see me giving him a voice, and putting the human experience to his story so it's not just words on a paper, but so that everyone understands that this is his life.

MS HILL: And how does it feel now, having had the opportunity to reflect on the past few years?

MS DODDS: It feels very empowering to be able to share what I've shared with you guys today. It's very empowering.

MS HILL: Commissioner, that concludes my examination.

COMMISSIONER BRIGGS: Thank you very much, Ms Dodds. You're excused from giving further evidence but before you go, I can assure you that the Royal Commission has heard what you're saying, and your evidence around your husband being trapped in the system and living quite a joyless last period of his life is quite disturbing for us, as is your evidence around the disjuncture between the health system and disability system and even the aged care system as well, all of those things coming together. But I think the thing you have done today is give him that voice, so well done and thank you very much for your evidence today.

MS DODDS: Thank you for listening.

<THE WITNESS WITHDREW

[2.24 pm]

MS HILL: Commissioner, Mr Rozen will lead the next witness.

COMMISSIONER BRIGGS: Mr Rozen.

MR ROZEN: The next witness is Dr Nicholas Hartland, who I call, please.

<EXAMINATION BY MR ROZEN

5

MR ROZEN: Good afternoon, Dr Hartland. Can you confirm for us, please, your full name is Dr Nicholas Hartland.

10 DR HARTLAND: That's right, Dr Nicholas Gerard Hartland, yes.

MR ROZEN: Sorry, middle name in there.

DR HARTLAND: Gerard.

15

MR ROZEN: Gerard. Thank you. And you hold the position of first assistant secretary in the home aged care division with the Commonwealth Department of Health.

20 DR HARTLAND: That's right.

MR ROZEN: It's a position you have held since July of this year?

DR HARTLAND: Yes, that's right.

25

MR ROZEN: Is that right? And before July of this year, had you worked in aged care policy and regulation for some years?

30 DR HARTLAND: Yes, for a period of just over a year, I believe, in aged care policy regulation. I've also worked in areas related to disability policy in the Department of Social Services.

35 MR ROZEN: All right. I'll come to the disability policy experience in a moment. Did you just say that you had worked in aged care policy and regulation for about a year before your current position?

40 DR HARTLAND: Yes. There was a gap of about a year when I was working in either – a gap of a couple of years when I was working in either hospital policy or I spent some time in Parliament working for Minister Ken Wyatt as well.

MR ROZEN: Yes. Just in relation to that we know that Mr Wyatt had aged care responsibility. I think when you were working for him, he held a different portfolio; is that right? Or no - - -

45 DR HARTLAND: No, he was Minister for Senior Australians and Aged Care so in that job I also had responsibilities for aged care.

MR ROZEN: Yes. Okay. Thank you. In terms of your formal qualifications, they are several but perhaps most importantly you hold a PhD in criminology; is that right?

5 DR HARTLAND: That's right.

MR ROZEN: Now, for the purposes of the Royal Commission you've made a witness statement dated the 23rd of August 2019. Operator, please bring up WIT.0374.0001.0001. On the screen in front of you I hope is the first page of your
10 witness statement; Dr Hartland.

DR HARTLAND: Yes, that's right.

MR ROZEN: And have you had an opportunity to read through your statement
15 before giving evidence today?

DR HARTLAND: Yes, I have.

MR ROZEN: And is there anything that you wish to change in your statement?
20

DR HARTLAND: No, there isn't.

MR ROZEN: Are the contents of your statement true and correct?

25 DR HARTLAND: Yes, they are.

MR ROZEN: I tender the statement of Dr Hartland dated 23 August 2019, Commissioner.

30 COMMISSIONER BRIGGS: The witness statement of Dr Nicholas Hartland dated 23 August 2019 will be exhibit 9-6.

35 **EXHIBIT #9-6 WITNESS STATEMENT OF DR NICHOLAS HARTLAND
DATED 23/08/2019 (WIT.0374.0001.0001)**

MR ROZEN: As the Commissioner pleases. In addition, I want to ask you briefly about another response that has been provided to the Commission by the Department
40 of Health. Operator, please bring up WIT.0001.1000.9493. Sorry, that's CTH.0001.1000.9493. Dr Hartland, do you recognise that as a response provided not so much by you personally, but by the department to a notice to give numbered 0355.

DR HARTLAND: Yes, I do.
45

MR ROZEN: And the notice was dated 14 August 2019. I don't need to have it brought up but it asked the department seven questions, each of which is set out

helpfully in the response. We can see the first two there. Was this a response that you assisted in the preparation of?

DR HARTLAND: Yes, I did.

5

MR ROZEN: But along with other officers - - -

DR HARTLAND: That's right.

10 MR ROZEN: - - - of the department as I understand it. And you can confirm for us that what you see on the screen there is, in fact, the first page of that response that was provided.

DR HARTLAND: Yes, that's right.

15

MR ROZEN: I tender that as a separate exhibit, Commissioner.

COMMISSIONER BRIGGS: Okay. The Department of Health's response to notice to give information in writing NTG-0355 will be exhibit 9-7.

20

EXHIBIT #9-7 DEPARTMENT OF HEALTH'S RESPONSE TO NOTICE TO GIVE INFORMATION IN WRITING NTG-0355 (CTH.0001.1000.9493)

25

MR ROZEN: If the Commission pleases. Dr Hartland, you answer to the secretary of the Department of Health.

30 DR HARTLAND: Through a relevant deputy secretary, but yes, but I'm ultimately accountable to the secretary. Yes.

MR ROZEN: Yes. Who's the relevant deputy secretary that you answer through?

DR HARTLAND: Mr David Hallinan.

35

MR ROZEN: And I don't have his exact job description in front of me but he is essentially responsible for aged care policy in an overall sense.

DR HARTLAND: Yes, that's right.

40

MR ROZEN: And the secretary, of course, is ultimately responsible for the administration of the Aged Care Act, is she not?

DR HARTLAND: That's right.

45

MR ROZEN: The holder of that position is responsible for the administration of the Aged Care Act.

DR HARTLAND: Yes, that's right.

MR ROZEN: And you've been present in the hearing room throughout today, I take it.

5

DR HARTLAND: Mmm.

MR ROZEN: And you've heard the evidence of the three witnesses who have given accounts, either of their own experience in residential aged care or the experience of loved ones in residential aged care, and that evidence has, I suggest, indicated in a way that's consistent with your evidence that residential aged care is no place for younger people. Do you agree with that as a general proposition?

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DR HARTLAND: Yes, I'd certainly agree with that. The witness statements brought out that fact very well.

15

MR ROZEN: Yes. And in paragraph 12 of what is now exhibit 9-7, that is the department's response to the notice to give, the response says this:

20

Residential aged care services are intended to serve the needs of older people and are not equipped to support the functional improvement of younger people with disability or to meet their social and developmental needs.

And I take it that's a statement with which you'd agree.

25

DR HARTLAND: Yes, that's right.

MR ROZEN: And it seems to run through the evidence of most of the witnesses who are giving evidence this week that that proposition seems to be generally accepted by not only the people who had experience of aged care but also the government officers who are giving evidence on behalf of the Commonwealth.

30

DR HARTLAND: Yes, I think that's fair to say.

MR ROZEN: This issue of younger people, that is, people under the age of 65 being inappropriately housed in residential aged care facilities, is not a new problem, is it, Doctor?

35

DR HARTLAND: No. For as long as I've had contact with the issue and, you know, the evidence and analysis that's done within the department shows even further back than that, it's been a somewhat intractable problem in aged care and there has remained around about 6000 young people in residential aged care, and I don't think there's anyone who would say that that's on appropriate. It's far too high a number.

40

45

MR ROZEN: In relation to your own personal experience, I think it's right, isn't it, that you were working in the disability policy area at a time that overlapped with that earlier 2006 to 2011 initiative.

5 DR HARTLAND: Yes, that's right.

MR ROZEN: Was part of your responsibility then related to that initiative?

10 DR HARTLAND: Yes, I was the general manager, equivalent to a division head in the department, that became the DSS that managed that scheme on behalf of the Commonwealth, yes.

MR ROZEN: The 2006 initiative responded to the Senate report of the year before, didn't it, the 2005 Senate report that identified, amongst other things, this problem.
15

DR HARTLAND: Mmm.

MR ROZEN: And 2005 is, of course, a long time ago, isn't it, 14 years ago?

20 DR HARTLAND: Yes, that's right.

MR ROZEN: Yes. And are you able to tell us, from your position with the experience that you've had, both in the disability area and now in relation to aged care, why it is that this Royal Commission is having to grapple with this problem in
25 2019?

DR HARTLAND: So from around about that time, so 2009/2010, I think it became evident as the YPIRAC scheme was winding up that that scheme had had some success. It had showed that it was possible to enhance the service experience of
30 young people in residential aged care and it had shown that it was possible to help divert people from going into residential aged care, but it wasn't a scheme that had been funded at a level that was meant to reduce the 6000-odd people in the scheme. Towards its end, my memory is that it had – it had in that specific program around 1400 people. So it had shown some potential but it really illustrated that the actual
35 crucial gap in the social support network, or net for these people was a well-funded disability scheme and, you know, at that time that was before the NDIS had been developed and costed and negotiated with the States.

40 And it was actually one of – I think one of the arguments and drivers for working on the NDIS and developing a scheme that was both resourced enough but administered in such a way that it could develop a flexible response that would enable us to address the needs of the people in this cohort.

MR ROZEN: I might just have to ask you to keep your voice up, not because you
45 don't have a loud voice but because you're competing with a bit of background noise in here.

DR HARTLAND: I'm sorry.

MR ROZEN: So I'll just ask you to do that. And I'll see if I can just tease out a few
5 of the things that you said there. You referred to the – YPIRAC, I think, is the word
you used.

DR HARTLAND: Yes.

MR ROZEN: Of course, there's an acronym, young people in residential aged care.
10 That was the name to that initiative we spoke about a moment ago, the 2006 to 2011
initiative.

DR HARTLAND: Yes, that's right.

MR ROZEN: And that was wound down at about 2012, is that right? Perhaps you
15 can explain to us; what happened at the conclusion?

DR HARTLAND: I would use the term "wound down". What happened at that
point in 2011 that there was a renegotiation of roles and responsibilities between the
20 Commonwealth and the States that occurred under the national health reform
agreement. So at that time there was a change whereby prior to 2011 if someone was
in residential aged care the Commonwealth – a younger person was in residential
aged care, the Commonwealth paid for their care and support. In 2011 as part of
health reform, there was an agreement that what would happen is that the States would
25 now be financially responsible for young people in residential aged care and the
Commonwealth took financial responsibility for older people in State services, both
HACC and special – specialist disability services.

And the intent of those changes at the time was to address the issue by providing the
30 States with an incentive to better fund people in – who would otherwise go into
residential aged care and to address the problem of young people being in residential
aged care.

MR ROZEN: Thank you for that. I'm not sure though that's answered my question.
35 As a specific initiative to address the - - -

DR HARTLAND: I see, sorry, excuse me.

MR ROZEN: - - - issue of younger people in residential aged care, that 2006
40 program concluded in 2011.

DR HARTLAND: So the Commonwealth funding rolled into the SPP, the disability
services.

MR ROZEN: I'll have to - - -

DR HARTLAND: And there was - - -

MR ROZEN: I have to ask you to avoid acronyms. I'm not familiar with them and others are even less than I am. SPP?

5 MR ROZEN: They're a special purpose payment that the Commonwealth made to the States to support them in their efforts to provide services for people with a disability.

MR ROZEN: That funding was quite considerable, was it not, in the - - -

10 DR HARTLAND: It was about 122 million, yes.

MR ROZEN: A bit over a \$120 million.

15 DR HARTLAND: Yes. So you were right – and excuse me if I've walked around the question the wrong way – yes, the specific program was wound down but the intent and effort of addressing the needs of that group didn't dissipate.

20 MR ROZEN: So can you help me then with the lessons to be learnt from that initiative in advance of any further initiatives. So it was one that the funding was inadequate; is that what you said a moment ago, that the money that was put in was insufficient to make a significant dent in the numbers?

25 DR HARTLAND: I – I don't – I think "inadequate" is a word that I wouldn't necessarily want to use, but the program was not intended to remove all of the 6000 people who were then in residential aged care, so the funding was adequate for the ambitions of the scheme but I think it's true to say that the ambitions of the program at that point weren't to completely ensure that there was no young person ever had to go into residential aged care, but it did show that you could address the issue whereas before that it had seemed entirely intractable.

30 MR ROZEN: I think you said a moment ago that the initiative had some effect on the numbers of younger people in residential aged care.

35 DR HARTLAND: Yes.

MR ROZEN: Is that right? There was – there were two evaluations done of the program, weren't there, one mid-term in about 2009.

40 DR HARTLAND: Yes, that's right.

45 MR ROZEN: And then ultimately at the conclusion of the program in 2012. I'll ask you about the one at the conclusion of the program. It's at tab 59 of the general tender bundle. Whilst that's coming up on the screen, Dr Hartland, that was an evaluation that was carried out by the Australian Institute of Health and Welfare; is that right?

DR HARTLAND: That's right.

MR ROZEN: And that's the front page of it that we see on the screen now; is that right?

DR HARTLAND: Yes, that's right.

5

MR ROZEN: And if we could go to page – native page 1, it's .1988. Sorry, no, it's not. It's .0542. We see there in those first three dot points the main objectives of the 2006 YPIRAC initiative. Perhaps if we could just be blown up on the screen:

10 *To move younger people with disability living in residential aged care into appropriate supported disability accommodation where it can be made available and if that is the client's choice.*

15 So that's aimed at the 6000-odd people that were in residential aged care at the time. Am I understanding that correctly; people who were living in residential aged care at the time the program was initiated?

DR HARTLAND: It was a service offer intended to help a proportion of those who were able to move and wanted to move.

20

MR ROZEN: I understand.

DR HARTLAND: It wasn't aimed at the 6000 but yes.

25 MR ROZEN: I understand that.

DR HARTLAND: Yes.

MR ROZEN: The second objective was:

30

To divert younger people with disability who are at risk of admission into residential aged care into more appropriate forms of accommodation.

35 So that clearly was aimed at stopping people going into residential aged care in the first place that might be at risk of going in.

DR HARTLAND: Yes.

40 MR ROZEN: From the evidence we've heard today that may well be people have been receiving long-term treatment in hospital, for example, might fall into that category.

DR HARTLAND: Yes.

45 MR ROZEN: And then the third objective was:

To enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care or for whom residential aged care remains the only available and suitable supported accommodation option.

5

So once again that's aimed at the cohort in residential aged care who want to stay there, and it's aimed at providing further and better supports for them. Is that - - -

DR HARTLAND: Yes.

10

MR ROZEN: Am I reading that correctly.

DR HARTLAND: Yes, you are.

15

MR ROZEN: If we can focus then on the first – the first objective of the program. There's some data in this evaluation report which I'd like to ask you about. It's on page 0544 in the form of a table; perhaps if that could be brought up. And it's set out according to numbers in each State and Territory and it's divided into three blocks, those under 50, those aged 50 to 64 and then the last is the total. Do you see that?

20

DR HARTLAND: Yes, I do. I can see it.

25

MR ROZEN: And we see from the first group of figures that the number of younger people under the age of 50 in residential aged care did, in fact, drop considerably during the five years of the program from 1007 to 658.

DR HARTLAND: Yes.

30

MR ROZEN: Do you see that? And is that what you had in mind a moment ago when you told the Commission that there was some measure of success in that initiative?

35

DR HARTLAND: Yes, it's one aspect. It's probably the aspect that had been most successful.

MR ROZEN: Yes.

40

DR HARTLAND: You know, I think there are other areas where you can point to where YPIRAC has had some success. It seems to have stabilised any increase in the cohort but it's probably the area where it's true to say there's been most success.

45

MR ROZEN: Yes. It's no coincidence that that's the area of most success because that's the area where the resources were focused; is that right?

DR HARTLAND: Yes.

MR ROZEN: Just so that we can understand this, that 120-odd million that was provided by the Commonwealth to the States and Territories was provided to them because at that time it was the States and Territories that were responsible for disability services.

5

DR HARTLAND: Yes.

MR ROZEN: Is that right? They were also responsible for housing.

10 DR HARTLAND: That's right.

MR ROZEN: They continue to be responsible for housing but disability has now been transferred to the NDIS. Is that broadly right?

15 DR HARTLAND: Yes, well – that's right. Technically, you could see that the NDIS is a joint scheme in that the States still fund it but the administrative and legislative responsibility is Commonwealth.

MR ROZEN: The Commonwealth. That's right. So we can see amongst that group
20 some considerable achievement. If we go to the next group, though, the 50 to 64 age group the numbers actually increased from 2006 to 2011, not significantly but nonetheless they increased from 5550 to 5723. Do you see that?

DR HARTLAND: Yes, that's right.
25

MR ROZEN: And then the last figures, the total, we see a similar pattern, albeit at a slight decrease which is probably no surprise because that's presumably - - -

DR HARTLAND: The addition to. Yes.
30

MR ROZEN: - - - the sum of the previous figures.

DR HARTLAND: Yes. That's right.

35 MR ROZEN: And so we see a very small decrease, from 6557 to 6381, which, I think, is something just short of a three per cent decrease. Is it too simplistic, Dr Hartland, to say that overall that's a very small decrease for the – in excess of \$120 million of Commonwealth funding? Is that too simplistic?

40 DR HARTLAND: Yes. I wouldn't like to endorse the statement in quite those terms. I mean, I think, you know, we – we need to recognise that there's been some success for the younger age group. I think the small increase in the 50 – the over 50 group needs to be seen in the context of a relative population group. So that population group is probably growing a bit quicker than that increase. So we also
45 see that, for example, when we look at this group as a percentage of aged care population, because aged care is also growing while this is happening. And so, in – over the very long term, we've seen a slight decline in the percentage of aged care

beds taken by younger people. That's resulted in, basically, a stable cohort. So no one's going to – from the Commonwealth will come and argue that we think that 6000 is appropriate and – but the fact that we've maintained it at 6000 and seen some success is, I think, is also worth noting.

5

MR ROZEN: I understand that. Are you able to put a figure on that? That is, the percentage of the overall population in residential aged care that young people constitute. As you sit there now, are you able to?

10 DR HARTLAND: So in 2005/6, it was about 3.9 per cent in residential care.

MR ROZEN: Yes.

DR HARTLAND: In 2017/18, it's 3.1 per cent.

15

MR ROZEN: Just before leaving this report, if I can take you to table 2, please, which is on the following page, from 0545. And if we just concentrate our attention on the last figures at the bottom there, under the heading Total – sorry. Just before we do that, the heading of this table is People Admitted to Permanent Residential Aged Care Aged Under 65 by Age Group and State and Territory. So that is rather

20

than the total numbers, this is the annual number that are entering residential aged care. Do you understand that?

DR HARTLAND: Yes.

25

MR ROZEN: And if we now focus in on that bottom group, please, Operator, we can see that if we – if we start our analysis in the year before that program, the number was 2018 that went in, and a conclusion it was 1940. So a very slight decrease.

30

DR HARTLAND: Yes.

MR ROZEN: But if our analysis starts at the first year of the program, 2006, then we can see that there is actually a small increase in the total number going in each

35

year. Do you see that? So if we start the analysis – sorry, just one line, or - - -

DR HARTLAND: I see.

MR ROZEN: Either one - - -

40

DR HARTLAND: Yes. Sure.

MR ROZEN: It's gone up a bit, hasn't it?

45 DR HARTLAND: It's gone up, but - - -

MR ROZEN: Yes.

DR HARTLAND: - - - you know, again, it needs – look, I don’t want to give you the impression that I think that that’s a fantastic result.

MR ROZEN: Yes.

5

DR HARTLAND: You know, everybody would want that to be smaller. But it does need to be seen in the context of the relative population growth. So over a five-year period, given the way the population’s changing, given the way that aged care is increasing, a small – you know, a small increase is something to have – to have some hope for.

10

MR ROZEN: Dr Hartland, it’s not that it’s not a fantastic result. This was an initiative by all Australian Governments, with considerable resources invested in it. And I accept your point about the general increase in population during the period, but it’s a very poor outcome, isn’t it, for such a program? If that’s the best we can do as a nation with all our governments combined and significant resources being thrown at this problem, it’s not a good outcome at all, is it?

15

DR HARTLAND: Well, I said at the start that, you know, this is – I recognise this being an intractable problem and one where progress hasn’t been as quick as anyone would have wished. I think the fact that that specific program, while indicating there’s some potential for work in this area – remember, this is development – you know, a program that wasn’t intended to cover everyone in that cohort, was part of the experience that led me to conclude around that time that the best path forward was to have a disability system that was properly and adequately resourced. And I remember at that time we were dealing with state disability service systems that were chronically underfunded and struggling to meet demand.

20

25

MR ROZEN: Yes.

30

DR HARTLAND: So it seems to me that the policy lesson out of this, which is still relevant for today, is how do you make sure that these people that would otherwise – or where residential aged care appears to be the only community option, how do you make sure that you can get them into a well-resourced and properly functioning disability system. And I think that lesson, if you listen to the testimony of the witnesses today, is still relevant – is still relevant.

35

MR ROZEN: I’ll ask you a bit more about the NDIS in a moment, but before leaving the history lesson, are there any other – are there any other lessons from your point of view to be learnt from the 2006 YPIRAC initiative?

40

DR HARTLAND: No. I think we’ve covered – we’ve covered them.

MR ROZEN: You see, what I’m struggling with, Doctor, is despite 2005 Senate report and extensive recommendations – and we know, more recently, 2015 Senate report, further recommendations, which I’ll ask you specifically about in a moment –

45

we still seem to be grappling with the same interface problems: health, disability, aged care, Commonwealth and State.

DR HARTLAND: Mmm.

5

MR ROZEN: Is it beyond our wit to address these problems in relation to this relatively small group of young people, who we've heard eloquently today, are clearly suffering as a result of these problems? Not academic issues, are they, doctor?

10

DR HARTLAND: No, no. I agree. Well, it – well, it isn't beyond our wit. I mean, I think my personal view formed by being around this policy area, as I've said before, is that the crucial gap is the – has been the lack of suitable alternative options to aged care. So it's the Department of Health's view that aged care, as we said at 15 the start, isn't an appropriate destination for young people. I guess I'd elaborate that with two points. One is that it has been a provider of last resort in the past and it may – it continues in that role today.

And where it is a provider of last resort, it does need – and that is the only option for 20 a young person, we need to make sure that the administrative arrangements is such that it can be reasonably available. But it seems to me that the crucial issue, no matter which way you turn it, is the availability of community options, which requires, you know, a national system, a disability support that has the ability to invest in those options. And that's the capacity that we see developing through the 25 NDIS.

MR ROZEN: Now, we know, Doctor, that the government announced in March of this year a new initiative, this time badged as an action plan aimed at reducing the numbers of younger people in residential aged care and also at producing the 30 numbers going into aged care; is that right?

DR HARTLAND: Yes.

MR ROZEN: I'll ask you a bit more about the detail of that in a moment, but I want 35 to understand, firstly, why it took eight years for a further initiative to be announced by the Commonwealth after the conclusion of the 2006 to 2011 initiative. Why the gap?

DR HARTLAND: So I think there's a number of phases to the roles and 40 responsibilities in this area. So after the conclusion of the YPIRAC program, as I said before, we had a national health reform. And the Commonwealth's assumption then was that by working with the States to change the funding roles and responsibilities it would create an incentive for States to develop community-based options for people with disability, because they were now financially responsible for 45 them when they were in residential aged care. And the hope was that that incentive would lead to better options in the community.

I think it's fair to say that that didn't dramatically change the situation. And around about 2009/10, really, the policy attention shifted to developing the NDIS. And I think, as I said before, my view has been – since that time and remains, that having – supporting that system, making sure it can operate and making sure that it can work
5 with aged care is the best policy solution to get a – long-term better options for people that would otherwise go to residential aged care.

MR ROZEN: Once again, Doctor, I don't want to be constantly the wet blanket here, but, really, there was very little by way of specific initiative between 2011 and
10 this year in this country in relation to reducing the numbers of younger people going into residential aged care. That's a correct statement, isn't it?

DR HARTLAND: Well, they've always been recognised as a group that should benefit from the NDIS. I think what the most recent action plan shows is that there
15 was a need for special attention for that group, so I would agree with – you know, I would agree with that. Yes.

MR ROZEN: Now, we know this Royal Commission was announced in September of last year, don't we, and we know that one of the terms of reference that this Royal
20 Commission has is an examination of this cohort. That is, younger people in residential aged care. That's right as well, is it not?

DR HARTLAND: Yes.

25 MR ROZEN: Is it just a coincidence that the – that Minister Fletcher asked his department to turn their attention to younger people in residential aged care in October 2018, one month after the Royal Commission was announced?

DR HARTLAND: I'm sorry, I've not worked for the Department of Social
30 Services, so I - - -

MR ROZEN: But - - -

DR HARTLAND: - - - would be entirely speculating as to what was made about –
35 in the Minister's timing.

MR ROZEN: Won't ask you to do that. Do you think that's a question better addressed to the Department of Social Services?

40 DR HARTLAND: I think that's right. Yes.

MR ROZEN: All right. In any event, we had the announcement in March of this year. And I want to ask you a little bit about that. Perhaps if tab 9 in the general tender bundle could be brought up. Now, before I ask you about this, I know that the
45 Department of Health is playing a subsidiary role in relation to the implementation of this plan. Is that a fair description of your department's role?

DR HARTLAND: A supporting role would be - - -

MR ROZEN: I supporting role.

5 DR HARTLAND: - - - another way of putting it. But, yes, we're not the lead.

MR ROZEN: All right. This has been driven by the Department of Social Services and the NDIA?

10 DR HARTLAND: That's right.

MR ROZEN: As you indicate in your statement, the Department of Health's role is a supportive one - - -

15 DR HARTLAND: Yes.

MR ROZEN: - - - in a couple of specific areas, which I will ask you about. But I wonder if I can ask you about the goals, because the Department of Health, of course, supports this initiative, does it not?

20

DR HARTLAND: Yes.

MR ROZEN: Yes. And the first goal that we can see there in the box, if – perhaps if that could just be blown up a little:

25

Supporting those already living in aged care aged under 45 to find alternative age-appropriate housing and supports by 2022, if this is their goal.

DR HARTLAND: Yes. I see that.

30

MR ROZEN: What are we to understand about that, in terms of a measurable initiative, Dr Hartland? How are we going to know in 2022 whether the plan has achieved that goal?

35 DR HARTLAND: Well, this is, again, an area where you will probably benefit from the expertise of the Department of Social Services.

MR ROZEN: They will get their turn tomorrow, Doctor. Don't worry.

40 DR HARTLAND: I'm sure they will. We would look for the numbers of people that had successfully moved - - -

MR ROZEN: Yes.

45 DR HARTLAND: - - - and how that measured up against the numbers of people that had an NDIS plan where they'd indicated in that plan that that was their goal.

MR ROZEN: There's no target there, is there, Dr Hartland?

DR HARTLAND: Not in that goal as worded, no.

5 MR ROZEN: No. And why is that? Is the government concerned that if a target was there, you might not meet it? Is that the concern that's underlying a lack of a measurable target?

10 DR HARTLAND: Well, I haven't been involved in the – in detailed discussions that have led to that goal.

MR ROZEN: Yes.

15 DR HARTLAND: So if you want a personal view about why that might be the case, you know, I can give you a view on my knowledge of the way in which government processes these issues, if that would assist you.

MR ROZEN: I think it might.

20 DR HARTLAND: So my guess is that – sorry, “guess” is the wrong term, but in many of these cases – and we'll find it, I think, if you go through some of the things that the health is responsible for, what you're able to commit to is really dependent on your knowledge of this group and I'd accept that this is an area where it would be fair to say our knowledge is evolving. And so I suspect they haven't committed to a
25 specific target because the actual choices of young – young people in these situations is not known at this stage. And the capacity of industry to respond with supported accommodation is also still being tested. So I – my suspicion would be that it would be very hard to put a precise number on it in the absence of information about those two.

30 MR ROZEN: Did I just understand you to say, Doctor, that the department's knowledge is evolving in relation to the numbers of younger people in residential aged care and their wishes and the like? Is that – did I understand you correctly a moment ago?

35 DR HARTLAND: Yes. Yes.

MR ROZEN: That seems perplexing from the outside, that the department that is administering the Aged Care Act and under which an assessment has to be made of
40 every person before they can go into residential aged care, we know that, that an ACAT has to be completed. How is it that the department's knowledge is evolving about this cohort? Why doesn't the department know more about the younger people that are in residential aged care?

45 DR HARTLAND: So our assessment process is designed to be a comprehensive needs assessment for aged care services. So it doesn't go to the goals and aspirations of young people in residential aged care to move out of it, and what would need to be

done to support them. And the reason for that, which – to go back a couple of steps, is because the Department of Health, as we've said, doesn't regard residential aged care as an appropriate point of contact, an appropriate support option for young people. It is only ever, in our view, appropriate as an option of last resort and we've

5 always looked to the disability system, whether that be run by the States or now by the NDIS as the organisation that's best placed to engage with those young people, understand their circumstances, understand their goals and to support them in their goals, if they have that, to move into the community.

10 COMMISSIONER BRIGGS: It's a point well made, Dr Hartland, but it seems that because the numbers of young people with disabilities are pretty much stable around 6000 with a flow in each year of around 2000 that there's not been a lot of will within the system to try and stem that flow or, indeed, to try and help people move out to other more appropriate arrangements. Do you think they've been forgotten?

15 DR HARTLAND: No, I don't. I think progress has certainly been slower than everybody would have wished for, but I think the policy response of creating an agency such as the NDIS that has the resources and the infrastructure set-up to fully engage with young people is the right response, and we now – which we are now in

20 quite a different situation, I think, than we've ever been in before in that we do actually have the institutional underpinnings to address this problem, whereas before that was created, either relying on a bespoke program that was not going to cover the full cohort or State and Territory disability systems that were chronically underfunded, I don't think we ever had the building blocks to be able to address

25 them.

So I think it's fair to say to say that the 6000 is not acceptable and is a stubbornly high figure but I don't think it's – I don't think I would say that young people in residential aged care have been forgotten or left out of policy debates but it is going

30 slower than we would have liked.

COMMISSIONER BRIGGS: But it would be true to say, wouldn't it, on the basis of some of the evidence we've heard this morning, that young people with disabilities have been somewhat neglected if not left isolated, not given rehabilitation

35 that might enable them to live a more fruitful life than they can in a institution fundamentally designed for people many years older than themselves.

DR HARTLAND: No. Well, I certainly agree with that, and the – the cases today were very confronting for the people that have worked in the system and what they

40 show is while, you know, my last answer to you talked about 6000 being stubbornly high and progress being slower than what people liked, of course, what the cases this morning show is that that's a real human, that has an effect on people that are trying to live the life that they're entitled to. So those cases illustrate the importance of this area and the effect of the fact that it's going slower than would be desirable. But I

45 don't – they show why this is an important area, but I don't think they show that the basic building blocks that we're trying to create with the new arrangements are fundamentally flawed.

MR ROZEN: Thank you, Commissioner. Go back to the question of knowledge and what is known about the cohort that we are examining, their aspirations and goals and the like. Can I ask, operator, please for tab 116 to be brought up on the screen. I'm sorry, 115. As you can see from the screen there, Dr Hartland, this is the

5 government's response to the Senate Community Affairs References Committee report, and I won't read out the entire title, but that was a report about residential care for young people in 2015 that I asked you about a short while ago. Do you recall those questions that I asked you?

10 DR HARTLAND: Well, I recall – sorry, I can't recall the questions in detail, so - - -

MR ROZEN: That's all right. But this is the report - - -

DR HARTLAND: You know, I'm sure you'll have an opportunity to ask them

15 again.

MR ROZEN: I'll try not to do that. We discussed this report a moment ago - - -

DR HARTLAND: Yes.

20 MR ROZEN: - - - and I want to ask you about one recommendation that the Senate Committee made. It's recommendation 1. Unfortunately I don't have a page number at my - - -

25 DR HARTLAND: Page 3.

MR ROZEN: If you just scroll through. There it is. Thank you. So if recommendation 1 in the block could just be blown up, please:

30 *The Senate Committee recommended in 2015 that the Australian Government compile a database of all the young people under the age of 65 years living in residential aged care facilities using the data held by the Aged Care Assessment Team program. This list should be provided in a regularly updated*

35 *form to the National Disability Insurance Agency and to State and Territory governments. This data should include the following information: name, age, age of entry, diagnosis, length of time spent in the aged care system and the factors that need to be addressed for the person to move out of the aged care facility.*

40 Do you see that was recommendation 1 that was made - - -

DR HARTLAND: That's right.

MR ROZEN: - - - by the Senate.

45 DR HARTLAND: Yes.

MR ROZEN: And that recommendation, I suggest to you, for any government that is serious about addressing the issue that this Royal Commission is concerned with, that is, the over-representation of younger people in residential aged care, that's a pretty obvious base level of information that you would need to make evidence-based policy decisions; do you agree with that, Doctor?

DR HARTLAND: Yes, I think that's a fair point, yes.

MR ROZEN: Yes. If we can just scroll down the page, please, to the government's response to recommendation 1: "It was noted", that's government speak for something other than accepted, is it not, Dr Hartland?

DR HARTLAND: That's right, yes.

MR ROZEN: It's not rejected, but it's not accepted either; is that where it fits?

DR HARTLAND: So in reviewing that and thinking about where we are today with the data exchange with the NDIA - - -

MR ROZEN: Yes.

DR HARTLAND: - - - Health is – Health has been providing the NDIA with a quarterly dataset.

MR ROZEN: Yes.

DR HARTLAND: And that's gone some way to helping this situation but what Health doesn't have to hand, we don't have an easy way of understanding diagnosis from the information that we have together in our systems. And we don't have an easy way of customer by customer understanding the factors that need to be addressed to have the person move out of the aged care facility. So I think in that – this context, "Noted" means that we're able to provide part of that data but we weren't at that stage, and are not able currently to provide all of it.

MR ROZEN: Well, that's precisely the point, isn't it? The Senate Committee was noting in 2015 that that data wasn't available and they were recommending a means by which it could be made available, were they not, by setting up this database?

DR HARTLAND: Yes, well, I think that's right. They were recommending that the database be established and the response from the government effectively is we are doing some of – we are able to do some of this, but not all of it at this point, yes.

MR ROZEN: Well, it's not so much that you weren't able to do it, or the government wasn't able to do it, rather, but the government wasn't prepared to do it. I won't read through that response because A, it's long, and B, with the greatest of respect to its author, it's difficult to follow. But the upshot of it seems to be this, that we're not going to set up such a database; that's essentially the government's

response, wasn't it? Take a moment to read through it in its entirety, if you need to, Doctor.

5 DR HARTLAND: It's fair to say reading the response – and I haven't read it word for word, I have reviewed it as we've been speaking and just before this, that yes, the government did not set up the database. I think this overall response to this recommendation and some of the others reflect that at the time the aim was – and remains to facilitate the NDIA to get in contact with these young people in residential aged care, get them into the scheme and work with them to either improve
10 their lives or provide options for them to move out.

MR ROZEN: Indeed. But it's your data, isn't it, it's the Department of Health's data because they're in aged care facilities that are funded by the department, regulated by the department and overseen by the department, aren't they?
15

DR HARTLAND: Well, I'm not sure that we would say that the factors that need to be addressed is health data but if your point to me was that if we had thrown every resource at it we could have developed a questionnaire and done it, so I think the judgment on that issue is that we saw the NDIA as better placed to understand young
20 people and were addressing this issue by supporting them in their efforts, rather than creating a dataset in Health.

MR ROZEN: The project board, which I know you're not a member of, but there's a project board that's overseeing the implementation of the action plan, isn't there?
25

DR HARTLAND: That's right.

MR ROZEN: Yes. And if one reads the minutes of those project board meetings – and I won't take you to them for the moment but I'll ask you to accept that a lack of data along the very lines of the first recommendation the Senate Committee made in
30 2015 has been a topic of concern by those charged with implementing the action plan. Are you aware of that?

DR HARTLAND: No, I'm sorry, I haven't reviewed the minutes so I couldn't
35 comment on that.

MR ROZEN: Okay. But you would agree with me, wouldn't you, that a database along the lines of that recommended by the Senate Committee back in 2015 would be a helpful factual foundation for the implementation of the action plan now in
40 2019?

DR HARTLAND: Yes, I would, but I think that that last dot point which we've been discussing would be most helpful if it arose out of the NDIA's planning process and their understanding of the goals and aspirations of the young people affected,
45 and if that's right, then the strategy that we have at the moment which is Health playing a supporting role by providing the data that it has to hand to others might not be such a bad outcome.

MR ROZEN: I suggest to you that the government's response, which is there for all of us to see on the screen, back in early 2016 to this, what I suggest was a sensible recommendation about compiling a database, is entirely consistent with Commissioner Briggs' question to you a moment ago of there being too little
5 attention paid to younger people in residential aged care. I think it was put to you that they've been ignored. You took issue with that then, but I suggest to you that this sort of response that we see here is consistent with too little attention being paid to younger people in residential aged care. What do you say to that, Doctor?

10 DR HARTLAND: I think that would be an entirely fair conclusion if nothing else was happening, and I don't think that's the case. I – I think nothing else was happening, and I don't think that's the case. I – I think that what we are seeing is agencies working together to attempt to get the pathways and the administrative underpinnings of the NDIS better in place in order to address this problem. So while
15 I can certainly see the logic of a dataset facilitating the NDIA's work, that's not the only pathway towards assisting young people in residential aged care and other work has been going on to assist this group. Having said that, I do accept that progress is slower than it ought to have been.

20 MR ROZEN: I don't mean to be rude, Dr Hartland, but this attempt to, what looks like deflect responsibility to the NDIA in terms of the data collection is problematic, I suggest, in at least one respect and that is not all younger people in residential aged care are eligible for the National Disability Insurance Scheme, are they?

25 DR HARTLAND: No, that's right, yes.

MR ROZEN: Ultimately it's only Health that had a complete picture or should have a complete picture of all of the younger people in residential aged care, isn't it?

30 DR HARTLAND: We will – that's true, we will have a picture of everybody under the age of 65 in residential aged care. I think it's important to keep in mind that that group of people who are not eligible for the NDIS looks like a small group at this stage. But it's also true that we need to understand more about that group.

35 MR ROZEN: I started this period of my questioning of you with a discussion of the first objective of the 2019 action plan, and if I can take – if we can go back to that, please. It's tab 9, the first page of tab 9, and I've asked you about goal 1. I want to turn to goal 2:

40 *Supporting those already living in aged care aged under 65 to find alternative age appropriate housing and supports by 2025 if this is their goal.*

We see there that the difference between that objective and the first one is that it's aimed at a broader – a far broader group, that is, those aged under 65, all younger
45 people in residential aged care. That's the case, it not?

DR HARTLAND: Yes. That's right. It's got two differences.

MR ROZEN: Secondly, there's a more generous timeframe been given which is three years beyond the timeframe for the first objective. Once again, I suggest to you that measuring the success of such an objective in 2025 is not going to be particularly easy, is it? Once again there's no target there; that's the case, isn't it?

5

DR HARTLAND: No, so the conversation that we had about the first objective applies to this one. There's no specific target in terms of numbers but you would expect it to be analysed and understood in relation – to develop such a target you would need to have an analysis of and understanding of what young people's goals are and the capacity of the market to respond, yes.

10

MR ROZEN: And once again they're quests that we're presently on, are we not, as part of the implementation of the action plan, that is - - -

15

DR HARTLAND: I'm sorry, I missed that. I just – sorry.

MR ROZEN: That understanding of the goals is something that is part of the implementation of the action plan, is it not? There are surveys that are being conducted to try and ascertain the goals of younger people.

20

DR HARTLAND: I'm sorry, I think you have to ask someone who is closer to the action plan.

MR ROZEN: All right.

25

DR HARTLAND: If it's a very specific question about – you know, I'm happy to use my background as a public servant to kind of help you understand the broad things that would be in movement but as to a specific approach to understanding that, I'd have to defer on that.

30

MR ROZEN: No, a fair point, Dr Hartland. We are going to be hearing from your colleague, Mr Carlile, tomorrow. He's actually on the project board, is he not - - -

DR HARTLAND: That's right.

35

MR ROZEN: - - - and would be better placed to answer those questions.

DR HARTLAND: I think that's right. Yes.

40

MR ROZEN: All right. I accept that. That distinction that we see in those first two goals between the relatively small group of those under 45, are we in danger of falling into the trap that we fell into with the previous initiative of putting all our focus and energy into that relatively small group of young – younger young people, if I can put it that way? Isn't that part of the lesson from the previous initiative, that all of the resources and energy went into that smaller group under 50 but the overall effect was minimal?

45

DR HARTLAND: Look, it certainly – I think I'd agree that the experience of the specific program is that gains were easier to find in the younger group and, you know, I think it's also true that the resources were concentrated on that group because of the obvious dynamic that if you were treating someone in residential aged care to prevent or get them out of residential aged care, if you're looking at a 30 year old, there's a much longer period in which you've had a success. So it's certainly a risk and there are some – it's also true that if there's a group that may wish to continue in residential aged care, then they're more likely to be in the older – the older category. So I agree there's a risk. You know, I think one of the things that we need to keep in mind in discussing these goals is that for many people we will have had a great effect on their lives if we're able to enhance the services they get in residential aged care through their NDIS plan.

So the solutions and ways to improve people's lives, and I think that comes out from a couple of the case studies that have been presented to the Commission, is not only getting people out of residential aged care but it can be enhancing the services and supports that they have while they're in there.

MR ROZEN: A cynic, Dr Hartland, might observe that if you pick a relatively small group and put all your resources into that small group; it used to be under 50, it's now under 45s, we're talking about a few hundred people, if you put all your resources in there then you're going to be able to claim a bigger percentage reduction in that cohort at the end of the relevant period. Isn't that the motivation for focusing the energy on the smaller group under 50 or now under 45?

DR HARTLAND: Look, I think clearly when you're working with resources and market response capacities, you're drawn to wanting to get the best outcome for resources, but I'd be very surprised if the motivation was that cynical.

COMMISSIONER BRIGGS: You keep referring to market-based responses. Wouldn't you agree there's a clear case of market failure here because if there wasn't the accommodation services to support these young people with disabilities in the community would already be there?

DR HARTLAND: So, you know, there's a lot of things that need to be improved in aged care, Commissioner, but I mean, aged care does show that you can build facilities. So I'd be surprised if the constraint was a classic market failure of there being enough money but no response. It seems to me that the – it is slower than we'd hoped to get support accommodation up in the community. But I don't know that I'd say that it's a failure in that it's impossible. It looks to me that it's just proving more difficult than I think anyone would have hoped.

COMMISSIONER BRIGGS: And are you so confident that that's the case for rural and remote areas as well?

DR HARTLAND: No, I wouldn't be confident of that. I think that in a couple of my answers I've talked about aged care being a provider of last resort and that's been

prefaced with the statement aged care is not appropriate for young people, but I think if you'd asked me the question directly, will aged care continue to remain a provider of last resort in some areas, including rural and remote, I think the honest answer would be I think that's likely and that's a – when we come through this transitional
5 phase that's an arrangement that we will have to reflect on and see how that can be done in a way that best supports the young person, recognising that I don't think that it's going to be easy to have supported disability accommodation in every area of Australia.

10 COMMISSIONER BRIGGS: That's something that I think most people in rural Australia would find very disturbing. Mr Rozen.

MR ROZEN: Thank you, Commissioner. Just focusing our attention on that second group there, that is, those aged under 65 which necessarily must mean over 45 and
15 under 65 presumably, would you agree with that, Doctor, in the context of the goals here?

DR HARTLAND: Yes, I think that's right, yes.

20 MR ROZEN: So that group – and we know from the data and I won't take you to the specific figures but we know there's a considerable proportion of those, the younger people, as we're referring to them, under 65 who are actually, you know, between 55 and 65, that's a significant proportion of the overall number of younger people, is it not.

25 DR HARTLAND: Yes, that's right, yes.

MR ROZEN: By 2025 half of them will have, by definition, aged out of this category, will they not? Anyone who's 60 and over now will be over 65 and no
30 longer a younger person by 2025.

DR HARTLAND: Yes, that's right.

MR ROZEN: Sadly, we also know a significant proportion will probably have died
35 by then, based on the statistical evidence, don't we?

DR HARTLAND: That's right.

MR ROZEN: Yes. So given that, I suggest to you that the second goal there is
40 particularly meaningless and particularly difficult to measure, isn't it?

DR HARTLAND: Well, I'm not close enough to know exactly how they were intending to measure it, but I'd be surprised if they were intending to take a metric of people under 65 now and applying what happened to that cohort in 2025. My
45 suspicion is that the metric would be the cohort under 65 at 2025. So I don't think that would be flawed by the problem of people ageing out of the scheme. It would still be a relevant metric.

MR ROZEN: I suggest to you, Dr Hartland, that without a target, without something measurable, it's a meaningless commitment, isn't it? What do you say to that? And it might be a laudable goal to support people, but what does it mean given the seriousness of the issues that we're concerned with?

5

DR HARTLAND: Well, I wouldn't say it's meaningless but it would certainly be supported by metrics around actual numbers of people supported to leave residential aged care and – and an understanding of what people's goals were, but I don't accept that it's meaningless.

10

MR ROZEN: Now, before leaving these goals, is the third goal to be understood as getting that figure which is variously referred to as 2000 per year or even as much as 2500 per year, it's halving that number so that by 2025 if we reconstitute, we would be hoping to find that the figure is 1000 or less; is that right?

15

DR HARTLAND: Yes, that would be my understanding of that goal, yes.

MR ROZEN: Commissioner, I'm about to go on to a different topic. I wasn't sure whether you intended to have an afternoon break. I'm in your hands, I'm happy to proceed or - - -

20

COMMISSIONER BRIGGS: I'm happy to proceed if you are.

MR ROZEN: I am. Dr Hartland, I'm not sure - - -

25

DR HARTLAND: I'm fine. Yes.

MR ROZEN: He's fine, too. Well, we'll press on.

30

COMMISSIONER BRIGGS: Let us know if you want a break.

MR ROZEN: Dr Hartland, I want to ask you about one specific area of the Department of Health's responsibility under the action plan and it's something that you refer to in your statement, that is, the supplementary assessment guidelines for younger people with disability. You discuss these supplementary guidelines at paragraph 14 on page .0002 of your statement. And just to provide a bit of context here, the question that you're answering is set out in that box we see on that page:

35

40

Provide an overview of any internal departmental guidelines that currently apply to the assessment of people under the age of 65 into residential aged care under the Aged Care Act 1997.

And then you're asked whether the guidelines have been changed or withdrawn in the last five years. Do you see that?

45

DR HARTLAND: Yes.

MR ROZEN: You draw the Commission's attention, helpfully, to a set of guidelines produced in July of this year, the supplementary assessment guidelines which are then attached to your statement. Before taking you to those, I want to just ask you a little bit about once again a little bit of history and context for that
5 document. They are supplementary assessment guidelines in the sense that they are not intended to be a complete guide to the operation of the ACAT process.

DR HARTLAND: That's right.

10 MR ROZEN: Is that right?

DR HARTLAND: Yes.

MR ROZEN: There is a separate manual - - -
15

DR HARTLAND: Yes.

MR ROZEN: - - - that deals with ACAT assessments generally, that is, aged care assessment team assessments generally.
20

DR HARTLAND: That's right.

MR ROZEN: And these are supplementary, as their name suggests, dealing with the particular cohort of younger people that the Commission is presently concerned with;
25 is that right?

DR HARTLAND: That's right.

MR ROZEN: There was a previous set of guidelines of similar scope which were
30 published in 2017 that are also attached - - -

DR HARTLAND: That's right.

MR ROZEN: - - - to your statement. And was that 2017 supplementary guideline
35 document the first time that the Department of Health had published a set of guidelines specifically for dealings with younger people entering residential aged care? If you're not sure, I won't ask it of you.

DR HARTLAND: I'm actually not sure.
40

MR ROZEN: Okay.

DR HARTLAND: They'd certainly been covered by the Aged Care Assessment Team manuals - - -
45

MR ROZEN: Yes.

DR HARTLAND: - - - for – since the manuals – as I understand it, since the manuals have been in operation.

MR ROZEN: Yes.

5

DR HARTLAND: The two supplementary guidelines were created in the context of the transition to the NDIS, but I don't know whether in the past – I'm sorry, Counsel, I haven't reviewed whether in the past we've had anything else that's been supplementary to the main manual.

10

MR ROZEN: All right. As you indicated at the start of that answer, the general guidelines prior to 2017 certainly addressed the application of the ACAT process to younger people.

15

DR HARTLAND: That's right.

MR ROZEN: That's right. So those I would like you to you to briefly now. They're behind tab 186 in the general tender bundle. And we can see the front page there. These are the general guidelines that were published in January 2014; is that right?

20

DR HARTLAND: That's correct.

MR ROZEN: And have you had an opportunity to have a look at the part of these guidelines that deals with younger people before giving your evidence now, Dr Hartland?

25

DR HARTLAND: Yes. I have.

30

MR ROZEN: All right.

DR HARTLAND: Yes. Yes.

MR ROZEN: It's to that, then, I will take you. It's at page .8198. And whilst that's coming up on the screen, can we just clarify that these are guidelines which are aimed at Aged Care Assessment Teams? Is that right?

35

DR HARTLAND: Yes. That's right.

MR ROZEN: And Aged Care Assessment Teams, in general terms, perform a function under the Aged Care Act as the gatekeeper for residential aged care, amongst other forms of aged care; is that right?

40

DR HARTLAND: That's right. Yes.

45

MR ROZEN: Yes. As is the wont in our federation, they have a slightly different name in Victoria, don't they? Aren't they called - - -

DR HARTLAND: Aged Care Assessment - - -

MR ROZEN: - - - ACASs, rather - - -

5 DR HARTLAND: - - - Services.

MR ROZEN: - - - ACATs?

DR HARTLAND: Yes.

10

MR ROZEN: But they're the same thing, effectively.

DR HARTLAND: Exactly. Yes.

15 MR ROZEN: And the evidence the commission has heard about this is that the Secretary of the Department of Health's role, in carrying out these assessments, has been delegated to the states and territories who carried out these assessments on the Secretary's behalf.

20 DR HARTLAND: Yes. That's right.

MR ROZEN: That's the case, isn't it? And we've heard previous evidence that these ACAT teams, or ACATs, receive referrals from My Aged Care and carry out assessments to see if people are, in fact, eligible to receive aged care services under the Aged Care Act; is that right?

25

DR HARTLAND: That's the main pathway through - - -

MR ROZEN: Yes.

30

DR HARTLAND: - - - the system. There are some other ways of entering the system, but - - -

MR ROZEN: Yes.

35

DR HARTLAND: - - - that's certainly the main pathway.

MR ROZEN: Yes.

40 DR HARTLAND: Yes.

MR ROZEN: And we've heard that there are some 80 teams, I think, in the various states and territories. I won't ask you to - - -

45 DR HARTLAND: I'm sorry. Can see I've - - -

MR ROZEN: - - - confirm the number.

DR HARTLAND: Yes. I - - -

MR ROZEN: It's probably not - - -

5 DR HARTLAND: It sounds about right. I don't - - -

MR ROZEN: It sounds about - - -

DR HARTLAND: I realise I don't have that number in my head, but - - -

10 MR ROZEN: I understand that.

DR HARTLAND: - - - yes, that's about right.

15 MR ROZEN: But you are generally familiar with the operation of - - -

DR HARTLAND: Yes.

MR ROZEN: - - - the ACAT team. Is it part of your area of responsibility - - -

20 DR HARTLAND: That's right.

MR ROZEN: - - - at the department? Are you able to tell the commission in general terms the backgrounds of the people that carry out these assessments?

25 Professional backgrounds?

DR HARTLAND: So in general, we would be looking for someone with some capacity to exercise clinical judgment. So many of them are nurses. And, I understand, some are Allied Health professionals.

30 MR ROZEN: Yes. Are some of them also social workers, such as - - -

DR HARTLAND: Yes. That'd be right.

35 MR ROZEN: - - - Ms Dodd, who we heard - - -

DR HARTLAND: Yes.

MR ROZEN: - - - from just a moment ago?

40 DR HARTLAND: Yes.

MR ROZEN: And in general terms, are you able to indicate to the commission what sort of training they get from the department - - -

45 DR HARTLAND: Well, in - - -

MR ROZEN: - - - to perform their role?

DR HARTLAND: In addition to any professional qualification, the department provides online training through My Aged Care.

5

MR ROZEN: Okay.

DR HARTLAND: And that will take them through how the ACAT -- how the systems work, and it takes them through their responsibilities in filling out the national screening and assessment form.

10

MR ROZEN: Now, without taking you to it, unless you need me to, the provision of the Aged Care Act that governs eligibility is section 21-2. Is that your understanding?

15

DR HARTLAND: Yes. That's right. Yes.

MR ROZEN: Yes.

20 DR HARTLAND: But the Act itself is quite high-level in relation - - -

MR ROZEN: It is.

DR HARTLAND: - - - to eligibility.

25

MR ROZEN: You're right. And we can see that on the screen - - -

DR HARTLAND: Yes.

30 MR ROZEN: - - - in front of us, can't we?

DR HARTLAND: Yes. That's right.

MR ROZEN: Someone's anticipating my next request - - -

35

DR HARTLAND: Yes.

MR ROZEN: - - - which is always - - -

40 DR HARTLAND: Have been very helpful.

MR ROZEN: - - - impressive but slightly scary. We see section 21(2) set out. And then, at the bottom of the page, we see the previous approval of care recipient principles from 1997. Do you see that?

45

DR HARTLAND: Yes. That's right.

MR ROZEN: The current principles, which I'll take you to in a moment, are actually a document dated 2014, the current approval of care recipient principles.

DR HARTLAND: Yes.

5

MR ROZEN: Do you agree with that, Doctor?

DR HARTLAND: Yes. That's right. These aren't the current, because I don't - - -

10 MR ROZEN: They're not the - - -

DR HARTLAND: - - - recognise the numbering. But I think - - -

MR ROZEN: Yes.

15

DR HARTLAND: - - - the effect is very similar.

MR ROZEN: Content is very similar - - -

20 DR HARTLAND: Yes.

MR ROZEN: - - - isn't it? As far as we're concerned now, we can see that a person at this time was eligible for residential care:

25 *If the person is assessed –*

I'm reading 1 (a) –

30 *as having a condition of frailty or disability requiring at least low-level continuing personal care, being incapable of living in the community without support; meeting any other eligibility criteria for the level of care assessed for that person, as set out in the classification principles.*

And then, importantly for our purposes, (b):

35

For a person who is not an aged care person, there are no other care facilities more appropriate to meet the person's needs.

Do you see that there?

40

DR HARTLAND: Yes.

MR ROZEN: It's satisfying that criterion that gets a younger people into aged care. I'll put it another way. Unless you're satisfy that criterion, you're not eligible for aged care.

45

DR HARTLAND: Yes. That's a better way of putting it. Yes.

MR ROZEN: All right. And even though the numbering's changed, the wording in the current approval of care principles is, word for word, the same as that requirement.

5 DR HARTLAND: Yes.

MR ROZEN: Do you agree with that?

10 DR HARTLAND: Yes. I agree with that.

MR ROZEN: All right. Now, the purpose of these guidelines that we're looking at presently, the 2014 guidelines, was to provide guidance to a person doing an aged care assessment and, for our particular purposes, to provide guidance for the operation of this particular part of the approval of care principles. Do you agree with that?

15 DR HARTLAND: That's right. Yes.

MR ROZEN: Yes. And if we can go then, please, to the page where that is dealt with – just excuse me a moment – .8193, please, Operator. Do you see there's a heading in the middle of the page Other Groups with Significant Needs?

DR HARTLAND: Yes.

25 MR ROZEN: And then a subheading, Younger People with Disabilities?

DR HARTLAND: Yes. Yes. I can see that.

MR ROZEN: Now, we can see from 12.1 – it says:

30 *States and territories will have developed protocols consistent with the national guiding principles for the referral on assessment of younger people with disability.*

35 And it goes on:

40 *The national guiding principles were developed between the Commonwealth and the states for the referral of younger people with disability for assessment and coordination of their specialist disability accommodation and support services.*

Concluding the reading there, the position back in 2014, this is – the NDIS is in its very early stages, is it not, just starting to be roll out?

45 DR HARTLAND: That's right. It would have been in existence in a couple of trial areas. Yes.

MR ROZEN: Yes. So disability services were primarily the role of the states - - -

DR HARTLAND: The states and territories. That's right.

5 MR ROZEN: - - - and Territories still at this time - - -

DR HARTLAND: Yes.

10 MR ROZEN: - - - were they not? And if we can just scroll down the page to 12.2, please, Operator. Sorry, 12.1.1. There's a reference to the approval of care principle that I've just taken you to. We needn't go over those again. But as we've seen, they're requiring assessment that there are no other care facilities or care services more appropriate. And then if we go to 12.1.2, please. We see there's a reference to the role of ACATs. And then it's the second sentence I want to ask you about in that
15 first paragraph:

ACATs may not have the skills or experience to assess younger people with disability or have an understanding of the range of specialist disability accommodation and support services available.

20

That remains the case, does it not, Dr Hartland, in 2019, that ACATs with the sort of professional background you described a moment ago, which is primarily clinical, may not have the skills or experience to assess younger people with disability or have an understanding of specialist disability accommodation and support services?
25 Do you agree with that?

DR HARTLAND: No, that's correct. We wouldn't normally expect them to have, personally, a deep understanding of either of those issues, no.

30 MR ROZEN: No. Are they provided with any training specifically in relation to that or is it just what's from the guideline that they get?

DR HARTLAND: No, the training doesn't go specifically to that. The way of solving that issue has been both under these guidelines and under the arrangements
35 that we're developing at the moment to find a way of getting them to interact with organisations, and people who are expert in disability and accommodation options.

MR ROZEN: All right. I'll come to the present arrangements in a moment. I just want to dwell on this, if I could, for a moment. We see in the third paragraph there,
40 at the bottom of the box that's been highlighted:

It is the responsibility of the relevant State or Territory disability services agency to assess younger people with disability and ensure they are referred to the most appropriate care service available.

45

So the position then was that it wasn't the ACAT assessor that was making that assessment, it was the State or Territory disability service. Is that – am I reading that correctly?

5 DR HARTLAND: If you mean that it's the responsibility of the State and Territory disability agency to assess and refer to disability services, yes. It would always have been under these arrangements in the past and the present that – to be referred to an aged care facility, it – that would have to be an ACAT decision. Drawing on
10 information from others, but it would be their responsibility.

MR ROZEN: Well, can we go to the next paragraph, please, over the page. Perhaps if the top four paragraphs on that page could please be highlighted. You see that what the guidelines said at the time was:

15 *All options for specialist disability accommodation and support services should be fully explored and utilised prior to acceptance by an ACAT of a referral for assessment and approval of aged care services.*

And then it's the next paragraph that I particularly want to draw your attention to:
20

*Where following an assessment by a State or Territory disability services agency or authorised assessment provider and discussion with the younger people with disability and their family it is determined through a disability assessment that there are no other care facilities or care services more
25 appropriate to meet the needs of the younger people with disability, referral to an ACAT may be considered.*

So I suggest to you that these guidelines made it clear that there was a two-step process for a younger people with disability. Firstly - - -
30

DR HARTLAND: Ye.

MR ROZEN: - - - they would be assessed by the specialist State disability service to determine if there were alternative care arrangements, facilities or services that were
35 more appropriate, and it was only if that service concluded, "No, there's nothing more appropriate", that ACAT came into the picture.

DR HARTLAND: Yes.

40 MR ROZEN: That's what it says, isn't it?

DR HARTLAND: Yes. That's – that's right.

MR ROZEN: Yes.

45 DR HARTLAND: Yes.

MR ROZEN: And it went on, we see in the last line of that paragraph:

5 *There must be documentation from the State or Territory disability agency of
the assessment and that there are no disability care options appropriate to meet
the person's needs.*

10 So in other words, there needs to be some sort of paper trail which sets out what
inquiries have been made that led to the conclusion that there was nothing more
appropriate. Is that how we're to - - -

DR HARTLAND: Yes. That's - - -

MR ROZEN: - - - understand that guidance?

15 DR HARTLAND: - - - right.

MR ROZEN: Now, I suggest to you that in the current guidelines, which we'll go to
in a moment, it's a very different process, is it not? In particular, there's no
requirement for any documentation of the assessment that there are no disability care
20 options appropriate?

DR HARTLAND: So I think – I'll just review, as we're talking the '19 guidelines.
So I think the current process still envisages that the pathway for a younger person
would be to first approach the relevant disability agency, which is now the NDIS,
25 and explore all their options for support through that agency. And only if there were
no reasonably available options to then approach – or to be directed towards an
ACAT, and that an ACAT ought to have in front of them information that would
allow them to make that judgment. I think you're going to take me to the next set of
guidelines, I suspect.

30 MR ROZEN: You guessed correctly.

DR HARTLAND: And when we see that, we'll look at what has dropped out. And
it may well be – I haven't reviewed them with the questions that you're raising in
35 mind, so to anticipate where we might get to, it may well be that the formal
requirement for documentation has dropped out, yes, but let's have a look at the
guidelines - - -

MR ROZEN: All right. We'll - - -
40

DR HARTLAND: - - - when you're ready and - - -

MR ROZEN: Let's do that.

45 DR HARTLAND: - - - we'll see if that's happened.

MR ROZEN: Before we do that, and this is not an exercise in testing your knowledge of the documents but more try to understand, from the commission's perspective, the processes, I suggest to you that what we see in 2014 might not be perfect but there was at least a recognition that the ACAT assessors were perhaps not
5 equipped to be making the assessment or whether there are alternative accommodation or care facilities available for the person with a disability. Do you agree that's what the guidelines suggest?

10 DR HARTLAND: Yes. That's certainly what the guidelines suggest.

MR ROZEN: Yes. And there was also a recognition that – given the importance of this assessment, that some sort of evidentiary documentation ought be compiled to provide some transparency to the decision-making. Do you agree that's also - - -

15 DR HARTLAND: Yes.

MR ROZEN: - - - part of it? And the reason I say this is such an important decision is this, Dr Hartland, we know, just from the three cases that we've heard evidence of today, just how significant it is when a decision is made that a younger person is
20 eligible to go into residential aged care, don't we?

DR HARTLAND: Certainly, the decision to enter, yes, can be life changing.

25 MR ROZEN: Yes.

DR HARTLAND: And we've seen in some of the cases today that it's changed people's lives for of the worse.

30 MR ROZEN: Yes.

DR HARTLAND: The intent is still that the aged care assessment is only undertaken when there's been a satisfactory exploration of whether there are alternatives available.

35 MR ROZEN: Yes.

DR HARTLAND: So I think the intent still applies. I guess the question that -- well, we'll go – you'll ask me about the guidelines and, of course, I'll have to look at them, we'll see how we're going, but I think what we are trying to do through the
40 two sets of additional guidelines is draw the NDIS as a new entity into an aged care decision-making process and enable aged care decision-makers to benefit from it. That's still evolving. And if there are areas where it needs to be improved, then, of course, we would be open to and ought to be open to addressing that issue.

45 MR ROZEN: As you have anticipated, I do want to ask you about the 2019 guidelines. They're behind tab 89, please, Operator. And it's quite a lengthy document. If I can take you to page .8332, please, which, on my reading, seems to

be the relevant part that guides an ACAT assessor in relation to that principle; that is, determining whether or not there are appropriate alternative accommodation arrangements. If there's other aspects of the document, Doctor, that you'd like to draw the Commissioner's attention to, then please do that. But for the moment
5 you'll see halfway down the page there's a paragraph that starts with the word, "Before". Do you see that:

10 *Before the ACAT refuses to approve a person who is not an aged person for care types under the Aged Care Act, aged care legislation requires that they investigate if more appropriate care facilities or care services are available to meet the person's needs.*

And there's then a reference to the current approval of care recipient principles, do you see, 2014?

15 DR HARTLAND: Yes. That's right.

MR ROZEN: And it says:

20 *This includes exploring all options for age-appropriate accommodation and supports and, in rollout areas, whether the younger people is eligible for the NDIS.*

DR HARTLAND: Yes.
25

MR ROZEN: Now, in relation to that first dot point, you've noted that in the 2017 supplementary guidelines – that is, the one that preceded this, the equivalent sentence read:

30 *This includes fully exploring all options for age-appropriate accommodation and supports.*

Do you recall pointing that out to the commission in your statement, Dr Hartland?

35 DR HARTLAND: Yes.

MR ROZEN: Why was the word "fully" removed from the first sentence?

40 DR HARTLAND: I – actually, I don't have information on that specific edit. My guess would be that it was seen as redundant and that "exploring" was seen as equivalent to "fully".

MR ROZEN: I - - -

45 DR HARTLAND: But, I'm sorry, if there's – I'd have to explore why that change was made. I – it's not been - - -

MR ROZEN: Yes. I won't ask you to guess. I will ask you, though, to, if you're able to - - -

DR HARTLAND: Make - - -

5

MR ROZEN: - - - make some inquiries - - -

DR HARTLAND: Yes. Of course. Yes.

10 MR ROZEN: - - - of the relevant officers - - -

DR HARTLAND: Yes.

15 MR ROZEN: - - - and inform the commission, because I suggest to you, on its face, it's sending the wrong message, isn't it, to the ACAT assessor? It seems to be suggesting a lesser form of exploration - - -

DR HARTLAND: I see. Interesting.

20 MR ROZEN: - - - is required under these guidelines than was previously the case. What do you say to that?

DR HARTLAND: Well, I think it's worth pointing out at this stage that – so we do need to explore the word “fully”, but it is worth pointing out that one of the reasons
25 why we changed the guidelines from the November 2017 version to the July 2019 version was that we'd actually found that there had been an unintended consequence of a too restrictive approach to access to residential aged care and that had been pointed out by some of our key stakeholders. And what had been happening was that people that would normally get access to residential aged care because they were
30 homeless and – premature frail ageing were being refused by ACATs, and so it was put to the department, with some evidence of case studies, that that needed to be addressed because it was leaving people without support who would otherwise have been receiving support from aged care facilities developed specifically to help homeless people.

35

So that accounts for the change, before the ACAT refuses, which in the previous guidelines had been different. They'd been, I think, before the ACAT agrees, and it may well – it may well account for why the word “fully” was dropped. But I'd want to check on the “fully”.

40

MR ROZEN: Please do that. There's no guidance provided at all to this ACAT assessor who has this responsibility of applying the principles. There's no guidance at all about what they're to do other than they explore all options. Am I reading it correctly?

45

DR HARTLAND: No. I don't believe that that's the case. But I would accept that there these guidelines could be clearer. If you turn to page 8, 2.2.1 - - -

MR ROZEN: I'm sorry, what's the page in the bottom right-hand corner perhaps might be the easiest way to get there. Do you see it's got – the document itself has a page in the bottom right-hand corner.

5 DR HARTLAND: Yes, page 8.

MR ROZEN: I see, 2.1.1.

10 DR HARTLAND: There is reference there, and I'd certainly accept that this might be an area where greater clarity could be needed but there's a reference there to the NDIA support coordinator so I think if you read through these guidelines as a whole an ACAT should have formed the conclusion that the relevant process was to talk to the NDIA support coordinator to confirm whether or not the – there was other alternatives available to a young person.

15 MR ROZEN: You mentioned a moment ago that the change from the 2017 guidelines to the 2019 guidelines, the effect of which was to make it easier for younger people to get into aged care. Did I understand that to be your evidence? Is it the response to the stakeholder concerns that you spoke of?

20 DR HARTLAND: Yes, it was to address an unintended consequence that we seemed to have been precluding from aged care, people who would actually need – actually needed it.

25 MR ROZEN: Who are those stakeholders; are you able to tell Commission?

DR HARTLAND: They were the aged care providers with responsibility for homeless people.

30 MR ROZEN: I see.

DR HARTLAND: So this is a component of the aged care system. In my view, it's actually a component that we do very well. There are very few other social support systems that can look at their service footprint and say that they help the homeless as well and there are some really excellent homelessness services. And the thing about the homelessness services is that the people that they literally pick up off the street and give accommodation to, are often younger because of the fact that living on the street with low income and no shelter makes – produces a frail ageing effect that you would see in people otherwise much later. So the idea that there was some evidence that the way in which the new system was operating and people were understanding their roles and applying the rules was not – was preventing access to aged care was something that needed to be addressed.

45 MR ROZEN: The Commission has heard evidence of Wintringham, for example.

DR HARTLAND: That's exactly right. That's one of the services - - -

MR ROZEN: Is that the sort of organisation you have in mind?

DR HARTLAND: That's right. Yes.

5 MR ROZEN: Isn't the risk there, though, that in addressing that concern, you are facilitating the entry of the group of younger people with disabilities in greater numbers into aged care?

10 DR HARTLAND: Yes, of course. That's right. And these guidelines need to be seen in the context of other processes that are developing at the time such as the streaming processes from My Aged Care, but at the moment this is a balancing act, yes, I agree.

15 MR ROZEN: Now, you've told us in your witness statement that it's the insertion of the urgent circumstances category in the 2019 guidelines, that's the major change from the predecessor guidelines.

DR HARTLAND: Yes.

20 MR ROZEN: Is that right? If I can ask you to look at those, please, on .8337; the heading is 2.3.2. You see just more than halfway down that page. This is the section that was inserted in response to those stakeholder concerns that you mentioned a moment ago.

25 DR HARTLAND: Yes, that's right.

MR ROZEN: And we see the first dot point concerns people who are homeless or at risk of homelessness.

30 DR HARTLAND: Yes.

MR ROZEN: And if we can scroll over to the following page, please, do you see at the bottom of the page there's a heading Referral Management:

35 *The entry point for people seeking access to aged care services through the My Aged Care contact centre. As aged care is the option of last resort for a younger person most younger people who contact the contact centre will be required to provide evidence that they've tested their eligibility via the NDIS or*
40 *via a State or Territory in a non-NDIS area before they have been referred for an ACAT assessment.*

Do you see that there?

45 DR HARTLAND: That's right.

MR ROZEN: That's consistent with the evidence you gave a moment ago about the involvement of the NDIS in the assessment process.

DR HARTLAND: That's right.

MR ROZEN: Is that what you were referring to us earlier.

5 DR HARTLAND: Yes.

MR ROZEN: The Commission has received a letter from the solicitors for the Commonwealth that I want to ask you about in this context. It's tab 119. It's a letter from the Commonwealth solicitors, Gilbert + Tobin, dated 5 September 2019. Now,
10 if you look at page 2 of the letter, if that could please be brought up on the screen; do you see the question that was asked by the Commission was:

What steps is the NDIA taking –

15 this is the top of the page –

...to ensure that it identifies younger people in hospital pathways who are at risk of entering residential aged care.

20 And then the third paragraph there, there's a reference to the supplementary guidelines that we've just been talking about; do you see that?

DR HARTLAND: Yes.

25 MR ROZEN: And the response was provided that:

The guidelines were published and the updated guidelines now include a process whereby the aged care assessment teams will liaise with the NDIA prior to recommending that a younger people is assessed to enter residential aged care.
30

And then the next sentence is the one I want to ask you about, if that could please be blown up:

35 *This process –*

that is the process of referral to the NDIA –

...only applies to a younger people experiencing urgent circumstances.
40

And then:

Situations of urgent circumstances may including but are not limited to –

45 and it's the list that we just looked at, homelessness and so on. Is the Gilbert + Tobin letter right, that the referral to the NDIA by the ACAT only applies in this relatively narrow range of special circumstances?

DR HARTLAND: I think the context has become slightly misleading, so the urgent circumstances have a special process for expedited contact between ACATs and the NDIA where we've developed a form to deal with that so that communication can be clear and performance expectations around how quickly the NDIA will respond and that's because of the nature of a person facing these extreme circumstances that, you know, you really, if someone is on the streets and has no form of accommodation, you don't want to be kind of waiting for someone just to mail you back when they think that it's appropriate. So that's what this process applies to.

My understanding is that it references – I'd have to see the letter again in context, the special process that we developed for the urgent circumstances. In addition, if you look at the guidelines we have here, and the rules that we've developed around the flow for customer streaming in My Aged Care irrespective of whether – if someone is not in the urgent circumstances category then ACAT should also contact the NDIA.

MR ROZEN: So what's in the letter is not right. The referral to the NDIA is not limited to urgent circumstances cases.

DR HARTLAND: It may still be right as drafted. You'd have to show me the whole letter again in the sense that this is referring to a particular sub-process rather than the general process. But the situation is that anyone who is being assessed by an ACAT, the ACAT should contact the NDIA if they're an NDIA participant and find out from them what the options are for the person. In addition when someone is in a special stream that we created to address the unintended consequences that I talked about before, there is a particular administrative arrangements to make sure that that can happen quickly, but it may well be that the drafting is not perfect either, I believe, so I - - -

MR ROZEN: Well, this is not some exercise in statutory drafting or anything else, Dr Hartland. This is a vital bit of guidance, isn't it, for the ACAT teams? These guideline are all they get, aren't they, in terms of informing their application of section 6 of the Approval of Care Recipients Principles. This is the guidance, isn't it, provided by the department?

DR HARTLAND: Well, that and along with the manual. There is a form and a fact sheet for the urgent circumstances as well, but this is the primary guidance, yes.

MR ROZEN: And it's got to be clear, doesn't it, as you've told us, these social workers, nurses, physios and the like are not trained in relation to the assessment of disability services and accommodation. That's right, isn't it?

DR HARTLAND: Yes, that's right.

MR ROZEN: They need specialist input to inform the assessment of whether or not there are appropriate alternative care and accommodation services; do you accept that?

DR HARTLAND: Yes, I accept that.

MR ROZEN: Yes. Under the previous guidelines it was pretty clear, wasn't it? It was the responsibility of the States through their disability services to make that
5 initial assessment and it was only if they decided that there wasn't an alternative, that you even got to an ACAT; is that right?

DR HARTLAND: I'd have to have a look at the – yes, that's certainly the intent.

10 MR ROZEN: Yes.

DR HARTLAND: So I think if you reflect on these guidelines, the intent is still that there be a close connection with ACATs, and the NDIA. The situation becomes slightly more complex because we evolved a new process to deal with urgent
15 circumstances. But I think when you look at the guidelines as a whole and I do accept, if you were to say to me, could they be written more clearly, I'd accept that. But I think if you look at them as a whole and the other customer flows that we have around I think it's fair to say that it is still reasonably clear that ACATs ought to avail themselves of the knowledge of the NDIA in making these decisions.

20

MR ROZEN: Does the department do any auditing of ACATs to satisfy itself that the assessors understand their role in relation to section 6 of the Approval of Care Principles?

25 DR HARTLAND: We don't have a formal third party auditing process at this stage. We do have a quality assurance process for ACAT decisions but we haven't yet – and that does have a place for third party auditing in it, but that framework is still relatively new and it's still a developing capacity, so the short answer is no, we don't do audits.

30

MR ROZEN: That's not really acceptable, is it, Dr Hartland?

DR HARTLAND: Well, its this is an area where the department's practice across the board could improve. But I'm not convinced at this point that this fundamental
35 issue that we face with ACATs and their assessment decisions is that they've decided to admit people to aged care where there was actually, on the face of it, a reasonably available alternative. But I accept the point that it would be prudent for the department to look into this issue further.

40 MR ROZEN: Don't you think it would be helpful for the department to provide some guidance to the ACATs in very clear terms, step by step, what it is that they're to do when there's an application by a younger person who may be eligible for the NDIS?

45 DR HARTLAND: Well, I think that's what we've attempted to do with the July 2019 guidelines.

MR ROZEN: Now, the Commission has been provided with some examples of ACAT assessments conducted for younger people and I want to ask you about two of those. I would ask you to accept, before I take you to the documents, that they are complete records of the ACAT assessments that were carried out in relation to the

5 two particular people, and they were both conducted in hospitals. I ask you also to accept that. They've been quite heavily redacted because the personal information is not of particular relevance to the questions that I want to ask you, but just so that you can understand what the documents are. The first is at tab - - -

10 DR HARTLAND: Well, are you about to show me the document? So are you about to show me the document? So that's fine.

MR ROZEN: I take it - - -

15 DR HARTLAND: I certainly accept the second point you make about the redactions. I'd like to see the documents before I accept the first.

MR ROZEN: Well, I mean, perhaps in fairness to you, Dr Hartland, maybe you can assist us in relation to the first point. Perhaps if you can point out to us if there's

20 anything obvious that's missing from the documentation.

DR HARTLAND: Yes, of course.

MR ROZEN: I will tell you the first is at tab 142. Sorry, my apology. If we can

25 start with tab 141, please. And if we can go to page .0007. Can you confirm for us, please, Dr Hartland, that this is an application for care under the Aged Care Act 1997 as it appears at the top right-hand corner of the document there.

DR HARTLAND: Yes, that's right.

30 MR ROZEN: And the date of the application, we see about halfway down the page on the right, 23 August 2018. So it's quite recent. Do you see that?

DR HARTLAND: Yes.

35 MR ROZEN: And looking further up the page, top right-hand corner, we see the date of birth of the applicant, and the date is redacted but we see the year is 1956 and if we do the sums, we can see that that person was under 65 at the date of making the application.

40 DR HARTLAND: That's right.

MR ROZEN: Do you see that?

45 DR HARTLAND: Yes.

MR ROZEN: All right. Now, if you go to page 0004 we see in the top left hand corner, this is ACAT inpatient assessment referral. Can you assist us with understanding what this – the person who's completed this page is doing, what part of the exercise?

5

DR HARTLAND: Let me just make sure that I've got the right document.

MR ROZEN: The number in the top right-hand corner should be .0004, ACAT - - -

10 DR HARTLAND: So this is a referral from a social – appears to be a referral from a social worker in a hospital - - -

MR ROZEN: Yes. I see.

15 DR HARTLAND: - - - in order for an ACAT to be conducted.

MR ROZEN: Right. And I want to draw your attention to the last box at the bottom of the page. Do you see the section B:

20 *Complete for all residential aged care placement referrals.*

You see that's been highlighted on the screen, if that helps you.

DR HARTLAND: Yes.

25

MR ROZEN: Then there's a series of boxes down the left-hand side with some words next to them and the first line is:

All other options have been explored, e.g. home with services.

30

Do you see that?

DR HARTLAND: Yes, I do.

35 MR ROZEN: Is that the point at which, in the ACAT assessment process, there's an assessment made that the particular younger person has no alternative accommodation that's appropriate?

DR HARTLAND: No, it isn't.

40

MR ROZEN: It's not?

DR HARTLAND: No.

45 MR ROZEN: I see. Looking through – so I withdraw that. So that's a decision that's made at a later stage in the process; is that right?

DR HARTLAND: That's right. This is just a form to get a patient in contact with an ACAT.

5 MR ROZEN: I see. And so if you look at page 0005, you'll see that that's a letter prepared by the delegate of the Secretary of the Department of Health. Do you see in the bottom left-hand corner? And it's informing the person although I'd ask you to accept is the applicant for aged care services that they had an assessment on 23 August 2018 and the assessment was successful. They've been approved as eligible to receive - - -

10 DR HARTLAND: That's right, yes.

MR ROZEN: - - - care and the specific care is residential care.

15 DR HARTLAND: That's right.

MR ROZEN: So the date of this letter is 24 August 2018 and if we go back to the previous page that I asked you about, which was .0004, the inpatient assessment referral, there's a date on that just under that heading, date of referral, 22 August '18. Do you see that.

DR HARTLAND: Yes, I do.

MR ROZEN: Just highlighted there for you now. 22 August '18.

25 DR HARTLAND: Yes.

MR ROZEN: From the social worker at the hospital, presumably. Is that how we're to understand that.

30 DR HARTLAND: Yes, that's right.

MR ROZEN: So we can understand this, there's a referral made by the social worker to the ACAT team; is that right? Which, on the face of it, appears to be on 22 August.

DR HARTLAND: Yes.

MR ROZEN: Then and they we've got - - -

40 DR HARTLAND: On 24 August.

MR ROZEN: - - - a letter signed on 24 August - - -

45 DR HARTLAND: That's right.

MR ROZEN: - - - saying "you're eligible."

DR HARTLAND: Yes.

MR ROZEN: What are we to understand has happened in between those two? Is there a further assessment that's been conducted.

5

DR HARTLAND: Yes. So there's an assessment that is conducted with the national screening and assessment form.

MR ROZEN: Yes.

10

DR HARTLAND: That is the – effectively the needs test – the needs assessment as to whether this person would be eligible for aged care services and so that occurred on 23.08.

15 MR ROZEN: Yes.

DR HARTLAND: On the information available to me, and then the letter was signed by the delegate the next day.

20 MR ROZEN: Can I ask, Dr Hartland, what it is you're reading from in relation to - - -

DR HARTLAND: I'm sorry?

25 MR ROZEN: Can I ask what you're reading from to answer my questions?

DR HARTLAND: A form that we've been able to locate that relates the outcomes of the ACAT assessment.

30 MR ROZEN: I see.

DR HARTLAND: Do you mean in terms of the folder or - - -

MR ROZEN: Yes.

35

DR HARTLAND: Yes. So I've got some notes on the cases because it had been indicated that you were interested in them.

MR ROZEN: Yes.

40

DR HARTLAND: And we've looked at the cases and what document we could find to try to assist you.

45 MR ROZEN: I'm not suggesting you you've done anything improper, Doctor. The course of events the world can know. I spoke to senior counsel representing - - -

DR HARTLAND: Yes.

MR ROZEN: - - - the Commonwealth, drew your attention to these two documents and asked you that familiarise yourself with them.

DR HARTLAND: Yes. Yes. Yes.

5

MR ROZEN: You've done that. But in addition are you telling the Commission that you found some additional documents that help you understand better the process in these two cases?

10 DR HARTLAND: Yes, that's right.

MR ROZEN: Okay. Can we please have a copy of those.

15 DR HARTLAND: Yes, I understand that they've been provided but your – they've been provided in the bundle of - - -

MR ROZEN: I see.

20 DR HARTLAND: - - - material that's been provided and they happen to come up in your quote, but you're more than welcome to have them. There's no - - -

MR ROZEN: Yes. No, no. You may - - -

25 DR HARTLAND: There's no problem at all and, in fact, it's not really my decision to say "no, you can't have them", so it doesn't matter, does it?

MR ROZEN: Yes. No. That's very true. You may well be right that they've been provided and as I say, I'm not suggesting you're doing anything - - -

30 DR HARTLAND: No.

35 MR ROZEN: - - - incorrect or inappropriate but it may be most appropriate, Commissioner if – perhaps if I had the benefit of seeing those documents and given that it's now quarter past 4 and I'm probably not going to finish with Dr Hartland anytime soon, it might be an appropriate time to adjourn and I'll be able to look at those documents overnight and hopefully that will truncate my examination of Dr Hartland. I think the expectation was always that he may need to come back tomorrow anyway.

40 COMMISSIONER BRIGGS: What time do you want to start tomorrow?

MR ROZEN: I'm in your hands. I think the scheduled time – I've got into trouble guessing these things in the past so I'm very wary now. I'm looking to my right.

45 COMMISSIONER BRIGGS: Okay. The scheduled time I'm told is 10 o'clock. In that discussion tomorrow, I wouldn't mind hearing from you as well about the differentials in the funding that can be provided when you're an NDIS recipient in

the community versus when you're in residential aged care. We believe there's a differential there and I'd like to have a look at that tomorrow, if I could, please. With that, we will adjourn the hearing until tomorrow morning at 10 am.

5

<THE WITNESS WITHDREW

MATTER ADJOURNED at 4.15 pm UNTIL TUESDAY, 10 SEPTEMBER 2019

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